Untangling and Addressing Cancer-Related Fatigue Guidelines Implementation Gaps: A Knowledge Translation Perspective

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Preface

This thesis is manuscript-based, containing a general introduction, two studies, and a general discussion/conclusion. The core research team of this dissertation research includes Dr. Sophie Lebel, Dr. Jennifer Brunet, and myself. In both studies, I was primarily responsible for conducting a thorough literature review; preparing all study documents (ethics review board applications, consent forms and information sheets, etc.); liaising with team members; data collection, entry, and analysis; conference presentations; and writing the manuscripts. The role of each co-author is summarized below.

Dr. Sophie Lebel, Professor at the University of Ottawa and my research supervisor, guided all of my research activities and contributed to the aforementioned responsibilities in our weekly supervision meetings. More specifically, she assisted me with study design, ethics review board applications, selection of measures, data collection, analysis and interpretation, dissemination of research findings, and manuscript preparation.

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The following research ethics boards approved these studies: The Ottawa Health Science Network Research Ethics Board (Protocol # 20170704-01H), the Montfort Hospital Research Ethics Office (Protocol # GJ-06-08-15), and the University of Ottawa Office of Research Ethics and Integrity (File #H12-15-26). One of these two studies has been accepted for publication peer-reviewed journal. The pilot study entitled "Translating Guidelines to Practice: A Training Session on Cancer-Related Fatigue" had been published as an original research article in *Current Oncology* (Jones, Rutkowski, Trudel, St-Gelais, Ladouceur, Brunet, Lebel, accepted November 2019). The study 1 article, entitled "*A Perfect Storm and Patient-Provider Break Down in Communication: Two Mechanisms Underlying Practice Gaps in Cancer-Related Fatigue Guidelines Implementation*", has been accepted for publication in the *Journal of Supportive Care in Cancer*.

General Abstract

Cancer-related fatigue (CRF) as a distressing, persistent, subjective sense of physical, emotional, and/or cognitive tiredness or exhaustion related to cancer and cancer treatment that is not proportional to recent activity, such as physical activity, that interferes with usual functioning (Howell et al., 2015; National Comprehensive Cancer Network, 2020). CRF is one of the most common symptoms experienced by cancer patients at all stages of the cancer trajectory which significantly impacts patient's quality of life, return to work, mental health, and can lead to disability (Bower, 2014b; Jones et al., 2016). Much research has focused on the development of CRF assessment and intervention strategies which have promoted the development of comprehensive evidence-based guidelines (Howell et al., 2015; National Comprehensive Cancer Network, 2020). However, previous research has identified many practice gaps in their implementation (Berger et al., 2015; Borneman et al., 2007; Pearson et al., 2015a, 2017b). This thesis' objectives were to gain a deeper understanding of potential barriers to CRF clinical guideline implementation to identify potential knowledge translation strategies of CRF guidelines into practice following a Knowledge-To-Action (KTA) framework perspective (Graham et al., 2006; Straus et al., 2013).

In Study 1, a qualitative research design was used to recruit a total of 62 participants—16 patients, 32 healthcare providers (HCPs), and 15 community support providers (CSPs). Drawing on the KTA model, the goal of the study was to explore key stakeholders' (patients, HCPs, CSPs) experiences and opinions on CRF assessment and management and to explore underlying causes of CRF treatment gaps. No specific hypothesis were determined given the exploratory nature of the study. The results of this study highlight CRF guideline implementation gaps, patient dissatisfaction with CRF care, and challenges contributing to CRF assessment and

management gaps. The results also suggested the presence of two underlying mechanisms contributing to treatment gaps: *A Perfect Storm* and *Patient-Provider Communication Gaps.* Understanding these mechanisms provides clarity on the potential causes maintaining CRF treatment gaps and can help direct targeted knowledge translation strategies to improve the implementation of CAPO CRF guidelines into practice. Consistent with a recent Delphi study (Pearson et al., 2017b), the results supported the need for professionals' training on CRF guidelines to fill knowledge gaps.

In Study 2, a mixed-methods pilot study with 18 HCPs and CSPs was used to develop and evaluate the acceptability and feasibility of a one-time training session for HCPs and CSPs on CAPO CRF guidelines, once again flowing the KTA framework (Graham et al., 2006; Straus, 2011). A secondary objective was to evaluate the learning outcomes of the training session including CAPO CRF guidelines knowledge, self-efficacy, and intent to apply CAPO CRF guidelines in practice. Overall, results suggest that offering a brief one-time training for HCPs and CSPs on CRF guidelines may be effective in increasing knowledge, self-efficacy, and intent to apply guidelines into practice. Similarly, that KT tools are appreciated by HCPs/CSPs and may be used in practice to supplement and sustain the knowledge and skills gained in training.

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General Introduction

Cancer is defined as a “large group of diseases that can start in almost any organ or tissue of the body when abnormal cells grow uncontrollably, go beyond their usual boundaries to invade adjoining parts of the body, and/or spread to other organs” (World Health Organization, 2020). Cancer’s progression is described in terms of staging from I to IV; stage 0 is also described as carcinoma in situ, a pre-cancerous change, stage I regroups small cancers contained in their original location, stages II and III represent cancers in which the tumour is larger or has grown outside of the organ of origin to nearby tissue, and stage IV represents cancers that have spread through the blood or lymphatic system to a distant site in the body (metastatic spread) (Canadian Cancer Society, 2020).

Cancer remains the leading cause of death in Canada. Nearly one in two Canadians will develop cancer in their lifetime and about one in four will die from cancer (Brenner et al., 2020). Canadian cancer statistics predict a total of 225 800 new cases of cancer to be diagnosed in Canada in 2020 (Brenner et al., 2020). Lung and bronchus, breast, colorectal, and prostate cancer are projected to be the most commonly diagnosed in Canada and are expected to account for about half (48%) of all cancers diagnosed in 2020 (Brenner et al., 2020).The Canadian Cancer Society projects an 80% increase in cancer diagnosis rates from 2005 to 2030 (Canadian Cancer Statistics Advisory Committee, 2018). With improvements in treatment methods, 75% of these patients are expected to survive up to 5 years post-diagnosis (Canadian Cancer Statistics Advisory Committee, 2018). Hence, more and more Canadians will be living with cancer for longer periods of time, which will lead to a higher demand for survivorship care. Survivorship psychosocial care has been identified as critical to ensure the quality of life and wellbeing of

cancer survivors in a report by the National Research Council which provided recommendations on strategies to improve survivorship care (National Research Council, 2006). A recent review of the implementation of survivorship care revealed that gaps remain over a decade after the release of the original report (Nekhlyudov et al., 2017). Indeed, recent studies show high levels of survivors' unmet information needs, low satisfaction with information received, and unmet psychological support needs (Faller et al., 2016), which impacts their quality of life (Cheng et al., 2016). Cancer-related fatigue (CRF) is a common symptom which has been identified as a frequently unmet need by cancer patients (Wang et al., 2018).

Cancer-Related Fatigue

Definition and Diagnostic Criteria

The National Comprehensive Cancer Network (NCCN)'s definition of cancer-related fatigue (CRF) is the most commonly used definition for CRF and is also adopted by the Canadian Association of Psychosocial Oncology (CAPO). It defines CRF as a distressing, persistent, subjective sense of physical, emotional, and/or cognitive tiredness or exhaustion related to cancer and cancer treatment that is not proportional to recent activity, such as physical activity, that interferes with usual functioning (Howell et al., 2015; National Comprehensive Cancer Network, 2020). Diagnostic criteria for clinically significant CRF have been developed and proposed for inclusion in the ICD-10. Such criteria suggest that clinically significant CRF is present if six (or more) of 11 key symptoms have been manifest every day or nearly every day over a two-week period in the past month, and at least one of the symptoms is significant fatigue. Key symptoms include: 1) significant fatigue, diminished energy, or increased need to rest, disproportionate to any recent change in activity level, 2) complaints of generalized weakness or

limb heaviness, 3) diminished concentration or attention, 4) decreased motivation or interest to engage in usual activities, 5) insomnia or hypersomnia, 6) experience of sleep as unrefreshing or nonrestorative, 7) perceived need to struggle to overcome inactivity, 8) marked emotional reactivity (e.g., sadness, frustration, irritability) to feeling fatigued, 9) difficulty completing daily tasks attributed to feeling fatigued, 10) perceived problems with short-term memory, and 11) post-exertional malaise lasting several hours. It is also specified that a) the symptoms must cause clinically significant distress or impairment in social, occupational, or other important areas of functioning, b) that symptoms are related to cancer or its treatment as evidenced by the patient's history, physical examination, or laboratory findings, and c) the symptoms are not primarily a consequence of comorbid psychiatric disorders such as major depression, somatization disorder, somatoform disorder, or delirium (Mitchell, 2010). Cancer agencies have adopted classification systems for CRF severity ranging from mild, moderate, to severe CRF. Mild levels of CRF represent the presence of minimal fatigue symptoms with minimal impact on functioning and can be classified from 0-3 on a 0-10 scale, moderate CRF consists of moderate to severe distress caused by CRF and moderate impact on functioning with limitations in daily activities and can be classified from 4-6 on a 0-10 scale, severe fatigue is described as significant fatigue with severe impact on functioning with a significant need to rest and are classified as 7-10 on a 0-10 scale (Howell et al., 2015). Severe fatigue can also be accompanied with sudden onset of shortness of breath at rest, rapid heart rate, and blood loss (Howell et al., 2015).

Prevalence

CRF is the highest unmet need reported by cancer patients (Hall et al., 2013). Indeed, a large majority of cancer patients will report some level of CRF throughout their cancer trajectory. Prevalence rates of mild to severe CRF vary from 59-100% (Cella, 1997; Hoffman et al., 2007; Howell et al., 2015; Karthikeyan et al., 2012; Reinertsen et al., 2010; Weis, 2011) in

samples collected in the United States, Norway, and India. Further, research has identified that large proportions of patients also report moderate to severe or clinically relevant levels of CRF. An American multicenter study identified that 45% of patients reported moderate to severe CRF levels (Wang et al., 2014), a cross-sectional study identified severe levels of CRF in 40%, 33%, and 17% across breast, colorectal, and prostate survivors respectively (Jones et al., 2012) in a Canadian sample, and a meta-analysis identified a total prevalence of severe CRF of 26.9% (Abrahams et al., 2016). CRF affects patients who have received diverse treatment regimens including surgery, chemotherapy, hormonal therapy, and/or radiation therapy (Ahlberg et al., 2003; Hoffman et al., 2007; Karthikeyan et al., 2012; Reinertsen et al., 2010). It has been shown to be present across age, gender, cancer type, and cancer severity with trends indicating higher prevalence of CRF in younger female patients and those with stage IV cancer (Singer et al., 2011). CRF can develop from diagnosis onward (Lawrence et al., 2004) and can persist for several years after the completion of treatment, with approximately 30% of cancer survivors continuing to report moderate to severe CRF post-treatment (Jones et al., 2016; Reinertsen et al., 2010; Wang et al., 2014). A meta-analysis showed that most studies used the standards adopted by CAPO (i.e.,0-10 scale with classification of mild (0-3), moderate (4-6), and severe (7-10) levels of CRF), however some studies used multi-item scales (Brief Fatigue Scale, Piper Fatigue Scale, EORTC-QOL-C30 fatigue subscale) with various cut points for moderate and severe levels of CRF (Abrahams et al., 2016), this may contribute to discrepancies in the prevalence rates of CRF rates.

Impact

CRF has severe consequences on patients' wellbeing, quality of life, and ability to function. Indeed, CRF interferes with usual daily function and can lead to weakness, limb

heaviness, inactivity, deconditioning, inability to function, disability, and being too tired to eat (Bower et al., 2014a). Cognitive functioning can also be affected by CRF—attention, problem solving, and decision-making capacities are often affected (Bower et al., 2014a). Left untreated, CRF can lead to significant healthcare and societal costs due to increased healthcare utilization and lost opportunities for patients affected by this symptom (Borneman, 2013; Jones et al., 2016; Wu & Harden, 2015). Indeed, CRF may lead to the inability to work, missed work, quitting work early or retiring (Given, 2008), and disability (Jones et al., 2016) which cause significant financial burden on patients. CRF itself can also lead to lower cancer treatment adherence (Bower, 2014b) and increased healthcare usage due to comorbid conditions such as depression and anxiety (Bower et al., 2014a). In summary, CRF is a common and debilitating symptom associated with cancer and its treatment. Its management is necessary given the predicted increase in cancer diagnoses in the next decades (Canadian Cancer Statistics Advisory Committee, 2018).

CRF Etiology

Biological factors. CRF is a complex symptom which can develop pre cancer diagnosis and persist post-treatment into survivorship (Jones et al., 2016; Lawrence et al., 2004; Reinertsen et al., 2010; Wang et al., 2014). A central hypothesis to the etiology of CRF is the increased release of proinflammatory cytokines (Bower, 2014b; O'Higgins et al., 2018; Saligan et al., 2015). Proinflammatory cytokines are released by immune cells due to the cancer tumour itself or to regulate immunity and inflammation and hematopoiesis functions as a result of tissue damage from surgery, radiation, or chemotherapy (O'Higgins et al., 2018; Saligan et al., 2015). Their release promotes inflammation, which produces a cascade of dysregulations of important biological systems which contribute to both biological and psychological symptoms of CRF. Increased proinflammatory cytokines cause alterations within the central nervous system,

including hypothalamic-pituitary-adrenal (HPA) axis dysfunction, circadian-rhythm dysregulation, serotonin dysregulation, vagal afferent activities, neuroendocrine impairments, and induce feelings of sickness and sickness behaviors (i.e., adaptive behavioral changes, like depression, fatigue, lethargy, and loss of appetite) (O'Higgins et al., 2018; Saligan et al., 2015). These systemic functions are highly interconnected and interact in the maintenance of CRF. Indeed, proinflammatory cytokines may lead to both an abnormally high or low level of serotonin (5-HT), which in turn lowers cortisol output and interacts with the HPA axis loop, which results in lower cortisol levels and stress response and reduces energy levels (O'Higgins et al., 2018). Further, cancer patients often report poor sleep quality and insomnia leading to altered rest-activity patterns. Alterations in the circadian rhythm leads to lower diurnal cortisol secretion and disrupted circadian rhythms, which in turn cause HPA axis dysfunction (O'Higgins et al., 2018). Finally, vagal nerve afferents (activated by proinflammatory cytokines or 5-HT) cause reflex inhibition of somato-motor activity in muscles, which contributes to CRF and subjective weakness and sickness behaviours (O'Higgins et al., 2018). Alterations to the peripheral nervous system including degeneration of muscle function, impaired adenosine triphosphate (ATP) contraction properties, and impaired physical function also appear to contribute to CRF (O'Higgins et al., 2018). The ATP dysregulation hypothesis proposes that cancer or its treatment impairs mechanisms for regeneration of skeletal muscle, thereby compromising the cells from replenishing their energy source (ATP) contributing to increased muscle fatigue and limb heaviness (O'Higgins et al., 2018). Other biological factors including genetic factors, cancer stage, cancer treatment, comorbidities, and concomitant medications may also interact to contribute to increased CRF (O'Higgins et al., 2018; Saligan et al., 2015).

Interactions between psychological and biological factors. Psychological and biobehavioural factors that interact with biological markers of CRF have been identified. Mental health status, in particular the presence of pre-diagnosis depression and anxiety and elevated distress in acute phase of cancer are associated to increased CRF in later stages of the cancer trajectory (Bower, 2014b; Bower et al., 2019). A history of childhood neglect and abuse has also been identified as a predictor of increased CRF (Bower et al., 2019). Depression and childhood trauma may influence CRF via alterations in neural, neuroendocrine, immune, and behavioural processes. Further, both have been linked to increased inflammation which may explain in part their association with increased CRF (Bower et al., 2019). Preexisting sleep impairments also predict increased CRF and are related to increased inflammation (Bower, 2014b). Behavioural and patient factors such as body mass index (BMI) and physical inactivity also appear to influence CRF (Bower, 2014b; Donovan et al., 2007). These factors are associated to physical deconditioning and lower cardio-respiratory fitness which contributes to the development and persistence of fatigue (Bower, 2014b). Thus, psychological processes (i.e., cognitions, emotions, and behaviors) and biological processes appear to bi-directionally interact to increase patients' vulnerability to CRF.

Psychological and social factors. Psychological factors including unhelpful coping and appraisal strategies, in particular, the tendency to catastrophize, or engage in negative self-statements and thoughts regarding fatigue, is associated with higher CRF post-treatment (Bower, 2014b; Donovan et al., 2007) and may also act and perpetuating factors. Demographic factors including younger age, children living in the home, lower income, lower education, and being unmarried are also associated to increased post-treatment CRF (Bower, 2014b; Bower et al., 2019; Donovan et al., 2007). Such patients may be less prepared for the demands of diagnosis,

treatment preparation, have fewer financial and social support resources with which to meet those demands, and experience higher stress levels. In sum, CRF's etiology is complex and multi-facetted. Its complex etiology may lead to gaps in HCPs' understanding of CRF. Further, its assessment and management thus involve the coordination of complex multidisciplinary interventions, which are difficult to implement. This thesis will explore HCPs' understanding of CRF and their experience and barriers with CRF assessment and management.

CRF Differential Diagnosis

Depression

CRF and depressive disorders such as major depressive disorder and persistent depressive disorder have overlapping symptoms including difficulty concentrating, low energy, less interest in activities, hypersomnolence and insomnia and psychomotor retardation and agitation (American Psychiatric Association, 2013). Some symptoms of depressive disorders are distinct from CRF such as excessive guilt or worthlessness, suicidal thoughts, and changes in appetite (Cella, Davis, Breitbart, & Curt, 2001). Further, CRF and depressive disorders are highly interconnected and may entertain a bi-directional relationship—fatigue is a symptom of depression and CRF may also contribute to depression due to interference with social, occupational, and leisure activities, which can lead to the development of depressive disorders (Bower, 2014b).This bi-directional relationship highlights the importance of adequate assessment for CRF and differential diagnosis between depressive disorders and CRF. Further, the International Classification of Diseases (ICD) proposed diagnostic criteria for CRF described above specify that the symptoms of CRF must not be better explained by comorbid psychiatric disorders including depressive disorders (Mitchell, 2010), which highlights the importance of an

appropriate assessment of CRF in order to differentiate CRF from depressive disorders and develop appropriate treatment recommendations to patients

Cancer-related Cognitive Impairments

The cognitive impairments related to CRF also resemble the phenomenon of " brain fog" which represents deficits in cognitive abilities, processing, and organizational skills which can affect language ability, memory, concentration, attention, and executive function (Staat & Segatore, 2005). However, the physical and emotional aspects of CRF are not as present within the phenomenon of "brain fog" (Staat & Segatore, 2005) and, as described above, CRF can be present across all treatment modalities including radiation therapy, surgery, and hormonal therapy and can be related to the cancer itself (Bower, 2014b).

CRF Guidelines

The Institute of Medicine defines clinical practice guidelines as "statements that include recommendations intended to optimize patient care, that are informed by a systematic review of evidence, and an assessment of the benefits and harms of alternative care options" (Institute of Medicine, 2011). Clinical practice guidelines translate evidence into practice recommendations which help assist providers and patients in making decisions about their care (Straus et al., 2013). When implemented, clinical practice guidelines can reduce practice variations and improve healthcare quality and safety (Institute of Medicine, 2011). The use of clinical practice guidelines also provide a basis for measuring, evaluating, and improving provider performance and quality of care, contribute to the development of clinical decision support systems and other decision aids, assist in educating patients, caregivers, and the media regarding best healthcare practices, and aid policy makers in the allocation of healthcare resources (Institute of Medicine, 2011).

Interventions for CRF have been thoroughly researched over the past decades leading to the recent development of clinical practice guidelines for CRF by multiple cancer agencies. The most comprehensive guidelines have been developed by the American Society of Clinical Oncology (ASCO), the National Comprehensive Cancer Network (NCCN), the Oncology Nursing Society (ONS), and the Canadian Association of Psychosocial Oncology (CAPO). The CAPO CRF guidelines were developed in 2011 based on systematic reviews of literature and existing clinical guidelines by an expert panel and were updated in 2015. The CAPO CRF guidelines have been independently evaluated as the most suitable available guidelines for clinical practice among interdisciplinary teams to use following the Appraisal of Guideline Research and Evaluation (AGREE II) tool (Brouwers et al., 2010; Pearson et al., 2016). CAPO's CRF guidelines provide an overview of evidence-based screening methods, comprehensive assessment recommendations, and intervention strategies for patients reporting mild to severe levels of CRF as well as a care pathway algorithm (Howell et al., 2015).

Screening

CAPO guidelines recommend that all health care providers (HCPs) routinely screen for the presence of CRF from the point of diagnosis onward and that screening should be performed and documented using a quantitative or semi-quantitative assessment, for example a rating on a scale of 0 to 10, in order to monitor the severity of CRF overtime (Howell et al., 2015). The Edmonton Symptom Severity Assessment System-revised (ESAS-r) is a 10 item visual analogue scale assessing common symptoms for cancer patients including tiredness (Watanabe et al., 2012). CAPO guidelines recommended rating patients' level of CRF and to classify the severity of CRF from Mild (1-3), Moderate (4-6), to Severe (7-10) using the ESAS-r (Howell et al.,

2015). Initial screening and classification of CRF severity (mild, moderate, severe) is used to determine appropriate care pathways for both CRF assessment and intervention.

Assessment

If moderate to severe levels of CRF are found, further assessment is required. The CAPO CRF recommend performing a focused and comprehensive assessment of CRF. The assessment should review CRF onset and duration, perpetuating or provoking factors, the quality of the CRF (i.e., physical, emotional, cognitive), comorbid symptoms of CRF, strategies that patients are using to manage their CRF, patients' level of physical activity, patients' understanding of CRF and its management, the functional impact of CRF on the patient, and the patient's goals to improve this symptom. Next, laboratory tests and physical exams are recommended in order to assess for physical causes of CRF. Treatment complications, anemia, infection, fever, nutritional deficiencies, fluid and electrolyte imbalances, medication side effects, alcohol and recreational drug use, comorbid conditions, pain, depression, anxiety, and sleep disturbances should be assessed for and ruled out via laboratory tests and physical examinations before proceeding to treatment recommendations for CRF (Howell et al., 2015).

Intervention

The CAPO guidelines recommend offering education on CRF to all patients reporting mild to severe CRF. CRF education should include information on the difference between normal fatigue and CRF, oncology treatment-related fatigue patterns, the persistence of CRF, contributing factors of CRF, consequences of CRF, the effectiveness of physical activity for CRF management, and signs and symptoms of worsening CRF to report to HCPs. Counselling on energy conservation strategies and encouragement of the use of a CRF log to monitor CRF

patterns and levels are also recommended in addition to CRF education for patients reporting all levels of CRF (Howell et al., 2015).

For patients reporting moderate to severe levels of CRF, the intervention demonstrating the highest empirical support for effectiveness in CRF management is physical activity. In fact, physical activity has been demonstrated to moderately reduce CRF among various cancer diagnoses across all cancer stages (Howell et al., 2015). The CAPO CRF guidelines recommend that all cancer patients follow the Canadian recommendation in terms of physical activity (150 minutes of moderate-to-vigorous intensity aerobic physical activity per week and 2 strength training sessions per week) (Canadian Society for Exercise Physiology [CSEP], 2019; (Howell et al., 2015). Lower intensity physical activity such as walking and yoga are also recommended and evidence suggests that these activities are likely to improve CRF (Howell et al., 2015).

Psychosocial interventions also have demonstrated a good level of evidence of effectiveness in CRF management. CAPO CRF guidelines recommend that cancer treatment centres should promote access to multi-component, group psycho-education programs targeted to the self-management of CRF for patients and survivors. Components likely to be beneficial in such groups include information on coping with emotions, understanding of fatigue, healthy sleep, include opportunities for positive peer reinforcement, overcoming barriers, and opportunity to share experiences (Howell et al., 2015). Cognitive behavioral therapy (CBT) targeted to CRF has been demonstrated to be effective in reducing CRF and the treatment effect has been shown to be maintained for longer periods of follow-up with small effect sizes (Howell et al., 2015; Kangas et al., 2008; National Comprehensive Cancer Network, 2020). Meta-analysis findings demonstrate effectiveness of CBT protocols ranging between six sessions to eight or more sessions (Kangas et al., 2008) and a systematic review demonstrated positive

improvements of 6-12 week CBT treatment on quality of life in breast cancer survivors (Fors et al., 2011). CBT was also shown to have greatest impact on CRF, quality of life, and mood in cancer patients (Wu et al., 2019). The CAPO CRF guidelines also recommend that patients reporting moderate to severe levels of CRF receive a nutritional consultation, receive services to optimize their sleep quality, receive information on stress reduction strategies including progressive muscle relaxation, yoga, mindfulness, relaxation guided imagery, massage therapy, and healing touch therapy, and attention restoring therapy such as reading, games, music, gardening, and experiences in nature since risks to these interventions are low (Howell et al., 2015).

CAPO identified insufficient evidence to draw conclusions regarding the effectiveness of acupuncture for CRF (Howell et al., 2015). Chinese herbal medicine and natural supplements were not determined as effective in managing CRF either (Howell et al., 2015). In terms of pharmacotherapy, CAPO CRF guidelines identified evidence of harmful impacts of methylphenidate, insufficient evidence for Paullinia cupana and certain types of ginseng products for reducing fatigue, and no evidence for supplementation with Coenzyme Q10 (CoQ10) for reducing CRF (Howell et al., 2015).

Implementation Gaps

Although clinical guidelines highlighting evidence-based CRF assessment and intervention strategies are available (Howell et al., 2015; National Comprehensive Cancer Network, 2020), limited research has investigated the implementation of CRF guidelines. Surveys of HCPs and patients indicate that CRF is under assessed and treated (Hilarius et al., 2011; Pearson et al., 2015b, 2017a). Indeed, studies demonstrate low uptake of recommended assessment and intervention strategies for CRF (Berger et al., 2015; Given, 2008; Hilarius et al.,

2011; Pearson et al., 2015). Rather, HCPs often recommend strategies that lack empirical support (e.g., resting) (Stone et al., 2003). Further, discrepancies in beliefs about effective CRF interventions appear to exist among types of HCPs leading to inconsistent CRF service delivery. A study reported that 12.5% of allied HCPs and 24% of physicians agreed that people with cancer should rest when they experienced fatigue compared to 59% of nurses and 66% of radiation therapists (Nadler et al., 2017). CSPs may also offer such strategies to the detriment of patients. Implementation rates of CAPO CRF guidelines in Australia ranged from 33-46% among diverse HCPs (i.e. allied health professionals, nurses, doctors, managers) (Pearson et al., 2017), with similar levels reported in samples of nurses in Jordan and in the United States (Abdalrahim et al., 2014; Given, 2008). Such difficulties in implementing CRF clinical guidelines to tailor and coordinate care for cancer survivors exist leaving this symptom largely under assessed and treated. Diverse patient, provider, and systemic barriers have been identified as potential causes for the low implementation of the CRF clinical guidelines (Borneman et al., 2007, 2010; Pearson et al., 2015b, 2017; Piper et al., 2008).

Provider barriers include a lack of information on the causes of CRF and its management, which in turn prevents adequate assessment and intervention (Borneman et al., 2007a). Indeed, 52% of HCPs reported lack of expertise in assessment and intervention of CRF and 63% a lack of awareness of intervention strategies for CRF (Pearson et al., 2015). Knowledge of evidence-based guidelines in HCPs is also low. Indeed, a survey of nurses' knowledge of National Comprehensive Cancer Network (NCCN) CRF guidelines indicated that 50% of nurses were somewhat familiar with the guidelines and 41% were not at all familiar with the guidelines (Given, 2008). Studies have reported on HCPs' desire for further education on CRF assessment and management strategies (Pearson et al., 2015b, 2017a). A recent study identified that 80% of

oncology HPC were unaware of physical activity recommendations in cancer and felt the need to be further educated and training in providing physical activity recommendations to patients (Nadler et al., 2017). Thus, HCPs may not feel equipped with the necessary knowledge to intervene for CRF management in general and to provide specific recommendations, such as physical activity, for CRF management

Patient-provider communication gaps have been highlighted in qualitative studies demonstrating that patients do not disclose CRF symptoms to HCPs because they assume nothing can be done to help (Fitch et al., 2008; Pertl et al., 2014; Stone et al., 2003) or because they do not want to burden HCPs (Carter, Miller, et al., 2014). One potential barrier may be the disparity between patient and HCPs' views on the prevalence and adverse effects of CRF, and whose role it is to manage CRF (Vingerhoets & Breed, 2008;; Efficace et al., 2012; Oechsle, Goerth, Bokemeyer, & Mehnert, 2013; Hockenberry et al., 2003). HCPs were found to underestimate the severity of patients' CRF following a questionnaire assessment with patients reporting prevalence levels of moderate to severe CRF of 71% a vs. HCPs at 54% (Laugsand et al., 2010). A recent focus group study exploring patient and oncology HCPs' perspectives on physical activity and cancer revealed that a majority of patients did not receive physical activity recommendations from their oncology care team and that HCPs' opinions diverged on whom, how, and where to disseminate physical activity recommendations (Smaradottir et al., 2017). Discussions with stakeholders are necessary to provide some answers to these questions by identifying barriers leading to communication gaps HCPs, patients, and CSPs experience in managing CRF.

Systemic issues include lack of time, limited access to assessment tools, lack of knowledge of resources available, difficulty making and following-up on referrals, and absence

of an accessible format for documenting CRF in medical records to properly assess and intervene for CRF (Borneman et al., 2007, 2010; Given, 2008; Pearson et al., 2015). Further research is necessary to gain understanding on contributing factors of patient, provider, and systemic gaps in CAPO CRF guidelines implementation.

Closing the Implementation Gap: Knowledge Translation Strategies

Many components of CRF guidelines for screening, assessment, and management of guidelines are ready for implementation (Berger et al., 2015). Education and systemic efforts to disseminate and implement evidence-based guidelines via researcher-clinician partnerships are needed (Berger et al., 2015). Systemic efforts to evaluate the feasibility of CRF interventions', effectiveness, acceptability, and cost are also needed in order to effectively implement evidence-based guidelines into practice (Berger et al., 2015). Knowledge translation (KT) is defined by the Canadian Institutes of Health Research (CIHR) as a dynamic and iterative process that includes the synthesis, dissemination, exchange and ethically sound application of knowledge to improve the health of populations, provide more effective health services and products and to strengthen the health care system (Canadian Institutes of Health Research, 2005). KT strategies are commonly applied in public health settings in order to promote evidence-based practices (Grimshaw et al., 2012; LaRocca et al., 2012; Scott et al., 2012; Straus, 2011).

According to the UK Medical Research Council parameters (Craig et al., 2008), the CAPO CRF guideline is a "complex intervention". Its implementation requires the coordination of multidisciplinary healthcare and community support providers to perform the screening, comprehensive assessment, and offer a multitude of evidence based CRF management interventions. Complex interventions such as clinical guidelines require pilot testing to determine the feasibility of delivery within a given health care context (Craig et al., 2008). A recent Delphi

survey conducted with patients and HCPs (i.e., allied health professionals, nurses, doctors, managers) which revealed the need to promote CRF guidelines uptake via modifications to the guideline presentation, health professional education, and integration of screening, assessment, and intervention strategies with existing practices could further enhance implementation (Pearson et al., 2017).

Many implementation theories and models have been established in the scientific literature. Such models can be classified across wider categories of process models, determinant frameworks, classic theories, implementation theories, and evaluation frameworks (Nilsen, 2015). The Normalization Process Theory (NPT) (May & Finch, 2009a, 2009b) represents an implementation theory with a sociological perspective of implementation into routine practice via individual and collective action. The NPT provides insights on the implementation of practices within a social organization, of embedding practicing into routine elements of everyday life, and of integrating practices in their social contexts. The Theoretical Domains Framework (TDF) (Atkins et al., 2017; Cane et al., 2012) is a theoretical framework that provides a theoretical lens through which to view the cognitive, affective, social, and environmental influences on behaviour, including in healthcare services. The TDF is therefore a behavioural determinant framework that guides the promotion of behavioural change. Such theories can be helpful in guiding the implementation of CAPO CRF guidelines into practice. This thesis aimed to understand CAPO CRF implementation gaps and to investigate the development of a knowledge translation strategy to fill these gaps. Thus, a process-focused theory to guide the design of these steps.

Knowledge-to-action framework

The Knowledge-to-Action (KTA) framework is a dynamic and fluid process-based model divided in two different stages: 1) knowledge creation; and, 2) action cycle (Graham et al., 2006; Straus et al., 2013) and is depicted in Figure 1 below. It theorizes that the development of knowledge is an iterative process of knowledge inquiry, knowledge synthesis, and the development of knowledge tools (Straus, 2011). The KTA model has been adopted by the Canadian Institutes of Health Research (CIHR) (Government of Canada, 2014) and has been widely applied in diverse health care and academic settings targeting patients, the public, nursing, and allied health professionals (Field et al., 2014).

The KTA's knowledge creation phase comprises three steps in order to tailor knowledge to a specific problem: knowledge inquiry, knowledge synthesis, and the development of knowledge tools. As described above, researchers and agencies have inquired, synthesized, and developed knowledge tools (i.e., clinical guidelines) for CRF screening, assessment, and management. In terms of implementation, the KTA's action cycle is based on planned action theories and focuses on creating change in health care systems and groups. The action cycle regroups a series of seven interactive steps in order to promote and sustain knowledge implementation. The first step is the identification of a specific problem and the identification, review, and selection the knowledge needed to be implemented. Next, the knowledge or knowledge tools must be adapted to the context and setting in which the implementation will take place. Identifying barriers to the knowledge use is a key step prior to the selection, tailoring, implementation of a KT intervention strategy. Following the intervention's implementation, it is crucial to monitor the use of the intervention, evaluate its outcomes, and determine strategies for the sustainability of the KT (Straus, 2011). Due to the iterative nature of the model, the action

cycle may be repeated in its entirety or steps may be repeated in order to achieve implementation and sustainability. Moreover, stakeholders that are part of the KT strategy and that are end users of the KT should be consulted and included throughout the knowledge-action process (Straus, 2011). As previously described, in terms of CRF guidelines implementation, KT strategies are needed in order to close the practice gaps (Berger & Mooney, 2016; Pearson et al., 2017a).

Qualitative methods

Qualitative research methods are used to answer a wide range of research questions. Qualitative methods are used to explore problems and issues to gain understanding on participants' experience, meaning, and perspectives. Qualitative methods can also assist in providing rich and detailed descriptions of complex phenomena by talking directly to the people experiencing the issue. Qualitative research can also complement quantitative studies to help explain mechanisms and linkages in theories and models. Further, qualitative methods are also used in theory development and to generate new research hypotheses (Creswell, 2012). The best qualitative research is systematic and rigorous, and it seeks to reduce bias and error and to identify evidence that disconfirms initial or emergent hypotheses. Qualitative research techniques include focus groups, individual interviews, semi-structured interviews, in depth-interviews, and analysis of texts and documents (Hammarberg et al., 2016). Qualitative research helps illuminate the experience and interpretation of events by participants with widely differing stakes and roles and well as giving voice to those whose views are rarely heard (Creswell, 2012). Common qualitative research approaches include narrative research, phenomenology, grounded theory, ethnography, and case study (Creswell, 2012). The phenomenological approach focuses on understanding the essence of a lived phenomenon by studying individuals with a shared experience by employing primarily interviews with individuals involved in the phenomenon and

identifying significant statements and descriptions of the phenomenon at study (Creswell, 2012). Such an approach may be helpful in exploring practice gaps in CRF guideline implementation and mechanisms underlying these gaps in order to identify appropriate knowledge translation strategies to address these gaps. Indeed, this thesis applied principals of the phenomenological approach to guide participant selection to include participants most concerned by CRF guideline implementation and the interview guide to explore participants experience with CRF assessment and management and barriers to CRF guideline implementation.

Healthcare Provider Cancer-Related Fatigue Training

As described above, HCPs appear to lack knowledge of CRF and of CRF clinical practice guidelines (Abdalrahim et al., 2014; Hilarius et al., 2011; Pearson et al., 2015b). Studies have also called for increased HCP training and education surrounding CRF to improve CRF guidelines implementation (Berger & Mooney, 2016; Pearson et al., 2017a). The World Health Organization (WHO) published a recent report describing gaps in the current training of HCPs and recommended guidelines for HCP training (World Health Organization, 2013). The report states the need for continuous learning programmes for HCPs that are applicable to the changing needs of the communities being served. This could be achieved using community-based clinicians and HCPs as training facilitators. Moreover, training methods that are reported as favorable by the WHO include simulation methods, inter-professional education (IPE), continuous professional development, and in-service training of HCPs (World Health Organization, 2013). The report stressed the important need for IPE to allow different professionals to learn together in order to increase collaboration, team work, patient-centred care (World Health Organization, 2013). HCP training can lead to different levels of knowledge use including conceptual and instrumental use of knowledge. Conceptual knowledge use involves

changes in knowledge level, understanding, and attitudes whereas instrumental knowledge use involves changes in behaviour or practice (Straus et al., 2013). Knowledge use interventions such as HCP training can be measured on the provider (e.g., satisfaction, efficiency), patient (e.g., health outcomes, quality of life), and systemic level (e.g., cost, waiting times) (Hakkennes & Green, 2006; S. Straus et al., 2013). Similarly, continuing education outcomes in the professional development of physicians have been classified as ranging from participant participation or attendance, participant satisfaction, learning leading to changes in knowledge, attitudes, and skills, performance leading to changes in practice performance, patient health, and population health outcomes (Moore, 2003).

To date, no training protocol on CRF guidelines has been developed. A recent study investigated the efficacy of a 30 minute in-person didactic training on fear of cancer recurrence among interdisciplinary HCPs which led to improved knowledge, self-efficacy, and anticipated practice behaviours for fear of cancer recurrence management (Berrett-Abebe et al., 2019). Similar HCP training protocols could also be assessed for efficacy in interdisciplinary HCPs and CSPs to help bridge CRF knowledge gaps. Indeed, didactic training methods have been shown to increase participants conceptual knowledge use, which may be useful to increase HCPs and CSPs' knowledge of CRF guidelines. Practical training methods could also be helpful to assist HCPs and CSP in making practical implementations towards CAPO CRF guideline implementation. HCP and CSP training outcomes including efficacy, satisfaction, CRF knowledge, behavioural intentions, and self-efficacy may be possible outcomes to such a training protocol.

Behavioural Intentions

Many behavioral models have been developed in order to predict behavioural changes including the Theory of Planned Behaviour (Ajzen, 1985), the Stages of Change Model (Prochaska & Diclemente, 1982), and the Precaution Adoption Process Model (Weinstein & Sandman, 1992). The Theory of Planned Behaviour developed by Ajzen, (1985) describes that attitudes toward the behavior, subjective norms, and perception of behavioral control lead to the formation of a behavioural intention and that behavioural intentions lead to behavior given a sufficient amount of control on the behavior. The theory stipulates that behavioural intentions represent motivational factors that influence behaviour adoption and thus that the stronger the intention to engage in a behavior, the more probable the behaviour is to occur (Ajzen, 1991). Systematic reviews and meta-analyses have supported the relationship between behavioural intentions and actual behaviour across a wide range of behaviours including alcohol consumption, organic food consumption, and physical activity (Brooks et al., 2017; Cooke et al., 2016; Scalco et al., 2017; Steinmetz et al., 2016). However, the relationship between behavioural intentions and behaviour uptake has been criticized in the literature and has been demonstrated to vary in its predictive value (Ajzen, 2011; Sniehotta et al., 2014). Notwithstanding this limitation, other behavioural models include a similar intention component that predicts action or behaviour including Prochaska and Diclemente's Preparation stage that is defined as the intent of taking action to address the problem (Prochaska & Diclemente, 1982) and Weinstein and Sandman (1992) also describe a Decided to Act stage that represents the initial motivation phase during which people develop an intention to act, based on beliefs about risk, outcomes, and self-efficacy (Weinstein & Sandman, 1992). Thus, behavioural intentions to adopt CRF best practice guidelines can represent an indicator of future adoption of these recommendations amongst

HCPs and CSPs and will represent an outcome measure of the training module proposed in this thesis. The Theory of Planned Behaviour stipulates that behavioural intentions are predicted by attitudes, subjective norms, and perceived behavioural control (or self-efficacy). Attitudes refer to an individual's positive or negative disposition when performing a particular behaviour. Subjective norms refer to perceptions about how others would judge a person for performing a specified behaviour. The third predictor—perceived behavioural control refers to self-assessment of one's capability or skill and the actual opportunity to perform the desired behaviour. A systematic review suggested that perceived behavioural capacity and attitudes predicted behavioural intentions to a higher degree than social norms amongst HCPs (Godin et al., 2008). A recent focus group study with allied HCPs suggests that HCPs have positive attitudes towards evidence-based practices, however experience low perceived control to perform such behaviours and that organizational-specific factors, including social norms towards evidence-based guidelines at the organizational level, can moderate the relationship between behavioural intention and behaviours (Klaic et al., 2019). The present thesis will draw on the Theory of Planned Behaviour's components in exploring HCPs and CSPs' experience with the application of CAPO CRF guidelines into practice and evaluating outcomes of a training session on CAPO CRF guidelines. Components that will be measured are behavioural intentions and self-efficacy. Given that this thesis represents a first pilot study to assess a CRF training protocol's self-efficacy, behavioural intentions were selected as a preliminary outcome prior to conducting further research assessing behavioural outcomes. Self-efficacy was selected given its key role in Bandura's Social Cognitive Theory (Bandura, 1989) and its application in many behavioural change models such as the TPB model.

Healthcare Provider (HCP) Self-Efficacy

Perceived self-efficacy is defined as a person's belief about their capabilities to exercise control over their own level of functioning and over events that affect their lives by believing in one's capability to organize and execute the necessary behaviours to achieve a selected outcome (Bandura, 1986). It can therefore be operationalized as the probabilistic estimate of one's ability to perform a specific task (Bandura, 1984). Self-efficacy beliefs have been demonstrated to be a significant predictor of motivational changes, development of cognitive skills, athletic accomplishments, career choice and pursuits (Bandura, 1986), and improvements in alcohol abuse, cigarette smoking, birth contraception usage, physical activity, and weight control (Strecher et al., 1986). Self-efficacy has been demonstrated to influence the acquisition of new behaviors, the inhibition of existing behaviors, and the disinhibition of behaviors (Bandura, 1977) and has been positively associated to behavioural intentions (Maddux & Rogers, 1983).

Self-efficacy can be achieved via performance accomplishments, vicarious experience, verbal persuasion, and via physiological states. Performance accomplishments represent experiences in which one achieves mastery over a difficult or previously feared task. This type of learning experience represents the most potent source of self-efficacy. Vicarious experience represents learning through observation of events and/or other people. Verbal persuasion constitutes receiving encouragement from others to persevere in changing behaviour. Finally, our physiological states can also provide information that can influence self-efficacy expectations as signs of physical inefficacy or efficacy to perform a certain task (Bandura, 1977). The training session outlined in the present thesis will aim to increase HCPs and CSPs' self-efficacy in CRF assessment and management. Activities that promote self-efficacy such as performance accomplishments via role plays and vicarious learning via modeling will be promoted in the

training module. The training module will aim to increase HCPs and CSPs' intentions to engage in CRF best-practice guidelines by bolstering their self-efficacy about their ability to assess and provide recommendations for CRF management to patients.

Patient-Provider Communication

A meta-analysis on physician communication skills revealed that effective physician communication leads to 19% better patient adherence to treatment and that communication skill training helps to improve patient adherence to treatment by 12% (Zolnierek & DiMatteo, 2009). Effective communication skills are also associated with increased patient satisfaction and physical health (Charlton et al., 2008). Effective communication skills aim to increase the transmission and retrieval of important clinical and psychosocial information, facilitate patient involvement in decision making, allow open discussion of benefits, risks, and barriers to adherence, build rapport and trust, and offer patients verbal and nonverbal support and encouragement (Zolnierek & DiMatteo, 2009). Effective communication is thought to function as a mean to exchange information, respond to emotions, manage uncertainty, foster therapeutic relationships, make decisions, and promote self-management (Street et al., 2009). These factors can influence health outcomes directly by promoting well-being and indirectly by promoting access to care, commitment to treatment, effective medical decision-making, trust in the healthcare system, social support, self-care strategies, and emotional management (Street et al., 2009).

Oncology HCPs are faced with difficult communication tasks such as breaking bad news and discussing unanticipated adverse events, discussing prognosis, reaching a shared treatment decision, responding to difficult emotions, coping with survivorship, running a family meeting, and transitioning to palliative care and end of life. (Banerjee et al., 2017; Bos – van den Hoek et

al., 2019; Kissane et al., 2012; Wittenberg et al., 2019). In fact, many factors can influence HCP communication effectiveness including level of self-efficacy, knowledge of the topic discussed and of communication skills, attitudes and beliefs about communicating with patients, perceived support from the workplace and colleagues, and outcome expectancy (Bumb et al., 2017; Parle et al., 1997).

Training programs have been developed in order to increase HCPs effectiveness in communicating with cancer patients. Literature reviews and meta-analyses demonstrated that HCP effective communication strategies can be taught successfully to HCPs with moderate effect sizes (d = .54; .15-2.0) (Barth & Lannen, 2011; Gysels et al., 2004). Communication training for HCPs can lead to outcomes including raising self-awareness, confidence in addressing sensitive issues with patients in palliative care, self-efficacy, communication skills (empathy, clarification), and practice changes (Banerjee et al., 2017; Gysels et al., 2004; Kissane et al., 2012). In terms of communication training modalities, research suggests that basic skill training in itself is not sufficient to increase nurses' awareness of patient concerns. This suggests the need for behavioural components, such as role plays, in training programs to help implement skills into practice and increase self-efficacy and awareness of outcome expectancy. Similar training strategies could be developed and evaluated in the context of the assessment and management of CRF in order to meet the communication training needs of HCPs and CSPs. Such training could be beneficial in order to improve HCPs and CSPs' self-efficacy in assessing and managing CRF, as previously suggested by others (Banerjee et al., 2017; Bos – van den Hoek et al., 2019; Gysels et al., 2004; Kissane et al., 2012).

Current Studies

This dissertation consists of two studies. The objectives of the first study, a qualitative exploratory study, were to: explore key stakeholders' (patients, healthcare providers [HCPs], community support providers [CSPs]) experiences and opinions on CRF assessment and management and to explore underlying causes of CRF treatment gaps drawing on the Knowledge-to-Action framework to guide the development of knowledge translation strategies to increase the implementation of CAPO CRF guidelines. The results of Study 1 served as a guide for the development of Study 2 by highlighting knowledge and practice gaps in HCPs and CSPs'implementation of CAPO CRF guidelines. The objective of the second study, a pilot-test study, was to develop and evaluate the acceptability and feasibility of a one-time training session for HCPs and CSPs on CAPO CRF guidelines. A secondary objective was to evaluate the learning outcomes of the training session including CAPO CRF guidelines knowledge, self-efficacy, and intent to apply CAPO CRF guidelines in practice. The current studies were conducted with the support and assistance of members of the Montfort Hospital, the Ottawa Regional Cancer Foundation, and Psychosocial Oncology Program at The Ottawa Hospital, General Campus. As previously mentioned, approval was obtained from the Institutional Research Ethics Boards of all affiliated investigators: The Montfort Hospital, The University of Ottawa, and The Ottawa Hospital

Rationale for current studies

Cancer-related fatigue (CRF) is a distressing and debilitating symptom experienced by many cancer patients. Although several guidelines provide evidence-based recommendations for screening, assessing, and managing CRF, there is limited evidence of their implementation in

practice. Patient, healthcare provider (HCP), and systemic barriers have been identified in previous research impeding CRF guidelines implementation. Knowledge translation strategies can assist in the understanding of implementation gaps and systematic evaluation of effectiveness of knowledge tools and implementation strategies. Research must be completed in order to explore and understand CRF practice gaps and systematically evaluate implementation strategies to fill such gaps.

Study 1

The manuscript entitled "A Perfect Storm and Patient-Provider Break Down in Communication: Two Mechanisms Underlying Practice Gaps in Cancer-Related Fatigue Guidelines Implementation." illustrates the results of a qualitative study with 62 participants—16 patients, 32 HCPs, and 145 CSPs HCPs and CSPs. The goal of the study was to explore key stakeholders' (patients, healthcare providers [HCPs], community support providers [CSPs]) experiences and opinions on CRF assessment and management and to explore underlying causes of CRF treatment gaps. This study was published in the Journal of Supportive Care in Cancer, the full reference is a follows: Jones, G., Gollish, M., Trudel, G., Rutkowski, N., Brunet, J., & Lebel, S. (2020). A perfect storm and patient-provider breakdown in communication: two mechanisms underlying practice gaps in cancer-related fatigue guidelines implementation. Supportive Care in Cancer, 1-9.

Study 2

One barrier to the implementation of CAPO CRF guidelines identified in Study 1 was lack of professionals' (HCPs and CSPs) knowledge of the guidelines. The manuscript entitled "Translating Guidelines to Practice: A Training Session on Cancer-Related Fatigue" illustrates the results of a mixed-methods pilot study with 18 HCPs and CSPs. The goal of the study was to

develop and evaluate the acceptability and feasibility of a one-time training session for HCPs and CSPs on CAPO CRF guidelines to address the knowledge gap identified in Study 1. A secondary objective was to evaluate the learning outcomes of the training session including CAPO CRF guidelines knowledge, self-efficacy, and intent to apply CAPO CRF guidelines in practice. The research hypotheses were that the training session would: 1) increase HCPs and CSPs' knowledge of CRF and of CAPO CRF guidelines; 2) increase HCPs and CSPs' self-efficacy to assess and intervene on CRF; 3) increase HCPs and CSPs' intention to apply CAPO CRF guidelines in practice; and 4) be acceptable (as evidenced by high HCPs and CSPs satisfaction) and feasible (as evidenced by acceptable recruitment time, participation rate, and post-training interviews). This study was published in Current Oncology, the full reference is as follows: Jones, G., Rutkowski, N., Trudel, G., St-Gelais, C., Ladouceur, M., Brunet, J., & Lebel, S. (2020). Translating guidelines to practice: a training session about cancer-related fatigue. *Current Oncology*, 27(2).

Study 1

A Perfect Storm and Patient-Provider Break Down in Communication: Two Mechanisms Underlying Practice Gaps in Cancer-Related Fatigue Guidelines Implementation

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Abstract

Purpose: Cancer-related fatigue (CRF) is a debilitating symptom experienced by many cancer patients. Although guidelines provide evidence-based recommendations for screening, assessing, and managing CRF, there is limited evidence of their implementation in practice. This study aimed to explore patients', healthcare providers' [HCPs], community support providers' [CSPs] experiences and opinions on CRF guidelines and the underlying causes of CRF treatment gaps following the Knowledge-to-Action model. *Methods:* A total of 62 participants were recruited—16 patients, 32 HCPs, and 14 CSPs—for a total of 9 focus groups and 4 individual interviews. Sessions were recorded and transcribed verbatim. Transcripts were analyzed using thematic analysis. *Results:* There were gaps in the application of CRF guidelines and patient dissatisfaction with care. Two underlying mechanisms may contribute to these gaps. First, professionals' lack of knowledge and resources paired with systemic obstacles created difficult conditions to adequately address CRF—*A Perfect Storm*. Further, patient-provider communication gaps lead to patients feeling discouraged to report issues to their healthcare teams and turning to community services for help—*A Breakdown in Communication*. *Conclusions:* There is little indication that CRF guidelines are routinely implemented in clinical practice. This study provides insights from various perspectives to aid understanding of the critical issues that require consideration to increase implementation of CRF guidelines by HCPs. As patients are currently dissatisfied with CRF-related care, implementation of CRF guidelines is needed.

Keywords: Cancer-related fatigue, Clinical guidelines, Healthcare research, Knowledge translation, Qualitative Methods

A Perfect Storm and Patient-Provider Break Down in Communication: Two Mechanisms Underlying Practice Gaps in Cancer-Related Fatigue Guidelines Implementation

Yearly, an estimated 14.1 million new cancer cases develop worldwide (International Agency for Research on Cancer, 2014). Further, one in three Americans and one in two Canadians will be diagnosed with cancer by 2030 (Canadian Cancer Statistics Advisory Committee, 2018; Siegel et al., 2019). Treatment and prevention efforts have led to improvements in survival rates. Approximately 75% of adults diagnosed with cancer are expected to survive up to 5 years post-diagnosis (Canadian Cancer Statistics Advisory Committee, 2018; Siegel et al., 2019). Therefore, more patients will need survivorship support in the upcoming years. Cancer-related fatigue (CRF) is the most frequently reported side effect by cancer patients (Hall et al., 2013). Its prevalence ranges between 45-99% and it is present from diagnosis onwards (Karthikeyan et al., 2012; Reinertsen et al., 2010; X. S. Wang et al., 2014). CRF is defined as a distressing, persistent, subjective sense of physical, emotional, and/or cognitive tiredness or exhaustion related to cancer and cancer treatment that is not proportional to recent activity, such as exercise, that interferes with usual functioning (Howell et al., 2015; National Comprehensive Cancer Network, 2020). CRF is linked to the activation of the pro-inflammatory cytokine network by the cancer itself and by treatment regimens, neuroendocrine alterations of the hypothalamic–pituitary–adrenal axis, and autonomous nervous system dysregulations (Bower, 2014a; Saligan et al., 2015) .

CRF has severe consequences on patients' wellbeing and functioning. It can limit participation in social events and result in poor adherence to cancer treatments (Bower et al., 2014b; J. Jones et al., 2016). Left untreated, CRF can lead to significant healthcare and societal costs due to increased rates of depression, anxiety, and disability (Jones et al., 2016). In addition,

CRF may impair patients' ability to work, cause them to miss (or quit) work or retire prematurely (Bower et al., 2014b).

Treatment Gaps

Evidence-based assessment and treatment strategies for CRF have been identified. The Canadian Association of Psychosocial Oncology (CAPO) has developed comprehensive guidelines of evidence-based screening, assessment, and intervention strategies for mild to severe levels of CRF (Howell et al., 2015). The CAPO CRF guidelines have been independently evaluated as most suitable for clinical practice among interdisciplinary teams to use (Pearson et al., 2016). However, difficulties implementing CRF clinical guidelines (CAPO's and otherwise) in cancer survivorship care leave this symptom largely under assessed and treated. Patient, provider, and systemic barriers contribute to low guideline implementation (Abdalrahim et al., 2014; Borneman et al., 2010; Hilarius et al., 2011; Pearson et al., 2015; Piper et al., 2008). Consequently, calls for the implementation of CRF clinical guidelines into practice have been launched (Berger et al., 2015; Berger & Mooney, 2016; Pearson et al., 2017). The need for further collaborations between relevant stakeholders to promote the implementation of CRF clinical guidelines has been identified as a key mechanism to achieve this goal (Berger et al., 2015; Berger & Mooney, 2016).

The Knowledge-to-Action model highlights stages to both create knowledge and apply knowledge in practice (Graham et al., 2006; S. Straus et al., 2013). The first stages of the action cycle involve identifying the problem, assessing barriers to knowledge use, and adapting the knowledge to the local context (Graham et al., 2006; S. Straus et al., 2013). Such strategies are necessary to understand the underlying mechanisms preventing the implementation of CRF guidelines and to direct the development of knowledge translation strategies to fill these gaps.

Incorporating local and organizational factors is essential to ensure the applicability of knowledge to the local context.

Current Study

Drawing on the Knowledge-to-Action model, this study aimed to explore challenges to CRF guideline implementation to understand the mechanisms underlying CRF practice gaps as a first step prior to evaluating their implementation in clinical practice. This study aimed to explore key stakeholders' (patients, healthcare providers [HCPs], community support providers [CSPs]) experiences and opinions on CRF assessment and management with the objective to understand what factors influence the implementation of the CAPO CRF guidelines.

Method

Participants

Phenomenological research favors the inclusion of participants involved in the phenomenon at study to explore and understand their experience with the phenomenon and draw common themes (Creswell, 2012). Purposeful sampling methods were thus used to guide participant recruitment in order to include participants most affected by CRF and CRF guideline implementation (Palinkas et al., 2015) and to select participants that are especially knowledgeable about or experienced with a phenomenon of interest (Cresswell & Plano Clark, 2011) and to communicate experiences and opinions in an articulate, expressive, and reflective manner. These included patients, multidisciplinary HCPs, and CSPs who were willing to discuss their experiences and opinions on receiving care or providing care for CRF. These stakeholder groups were selected based on the importance of seeking the experience of patients who are affected by CRF and professionals who work to screen, assess, and intervene for CRF both

within the healthcare system (multidisciplinary HCPs) and in the community (CSPs). Within the Ottawa context, CSPs play an important role in the management of psychosocial symptoms for cancer patients and survivors, including CRF, via cancer coaching programs, educational sessions, support groups, and complementary and alternative medicine services. Inclusion criteria for patients were to: (a) speak English or French; (b) be aged 18-85 years; and (c) be diagnosed with cancer. Inclusion criteria for HCPs and CSPs were to: (a) speak English or French; (b) be aged 18-85 years; and (c) have experience working with cancer patients. Criterion-I, convenience, and snowball recruitment strategies were used to recruit participants (Palinkas et al., 2015). Patients were recruited in hospital and community settings via flyers, HCPs/CSPs sharing information about the study to their patients, and recruitment ads sent through community centres' patient email lists. HCPs were recruited from local hospitals via email invitations shared by clinical managers and profession leaders, presentations during clinical and educational rounds. CSPs were recruited via managers of cancer community centres in Ottawa, Canada.

Protocol

This study aimed to respect the Standards for Reporting Qualitative Research (O'Brien et al., 2014). A qualitative research design utilizing focus groups and one-on-one interviews, was selected to allow for the exploration and understanding of participants' lived experience with challenges of CRF guideline implementation following interpretive phenomenological principals (Creswell, 2012; Smith & Shinebourne, 2012). This approach was selected to allow the deeper understanding of mechanisms underlying the CRF practice gaps previously identified in the literature. Participants were divided by stakeholder group for the focus groups, such that 3 were conducted for patients, 4 for HCPs, and 2 for CSPs. Physicians were interviewed individually

due to schedule constraints. Physician interviews were conducted in-person or by phone depending on their availability. Recruitment began in July 2016 and was completed in May 2019 once data saturation was met, data was considered saturated once no new themes emerged within the coding hierarchy (Braun & Clarke, 2006). Research Ethics certificates were received from all institutions where participants were recruited from (protocol numbers: # GJ-06-08-15 and #20170704-01H). Participants provided informed consent and completed a questionnaire before the beginning of the focus groups or interviews. Each focus group was facilitated by two investigators experienced in psycho-social oncology (G.J., S.L., J.B. and N.R.); interviews were conducted by G.J. Focus groups were video and audio recorded, whereas interviews were audio recorded only. All were transcribed verbatim for analyses.

Measures

Quantitative measures. A questionnaire was administered to all participants. Patient questionnaires collected basic socio-demographic including age, gender, income, employment status, ethnicity, immigration status (born in Canada: yes or no), mother tongue, and information and medical information including diagnosis, date of diagnosis, treatments received, date of treatment termination, and presence of other medical conditions. HCP and CSP questionnaires collected data on years of experience working in oncology, frequency of working with oncology patients, location of work (urban, rural), profession, and type of employer (hospital, outpatient clinic, community centre), and basic socio-demographic information including age and gender.

Qualitative interview. Following phenomenological principals, a semi-structured guide was developed to facilitate the focus groups and interviews. The guide differed for patients and professionals (HCPs, CSPs) and aimed to capture participants' experience and opinions on CRF and CRF guideline implementation. Interview and focus group guides were identical. Following

interpretive phenomenological principals, the prompts and specific follow-up questions were added to the interview guide after conducting first interviews with patients and professionals to capture further themes emerging from these focus groups. The patient guide contained nine questions with follow-up questions that aimed to: (a) explore what CRF represents for them; (b) ask about their experiences with CRF; (c) identify what recommendations they received to manage CRF; and (d) identify the barriers that prevented them from receiving adequate CRF care. The HCP and CSP guide contained eight questions with follow-up questions that aimed to: (a) explore their knowledge and experience with assessing and managing CRF; (b) identify how CRF should be managed; (c) identify barriers to CRF management; (d) identify their level of knowledge with CRF clinical guidelines. The semi-structured guides for professionals can be found in Jones et al., 2020.

Analyses

Qualitative analyses. Transcripts from individual interviews and focus groups were analysed with NVivo12 software (QSR International Pty Ltd., 2018) using thematic analysis following Braun and Clarke's methods (Braun & Clarke, 2006). Data analysis consisted of the identification of initial codes via a first reading of all transcripts to ensure an understanding of the whole experience of participants' accounts. Notes of tentative potential themes were taken based on the statements in the transcripts and the author's experience of the interviews themselves. Next each transcript was read and codes were extracted and collated across transcripts, codes were then collated into preliminary themes which gathered all data relevant to the theme, themes were reviewed and discussed with the main research team. Coding maps were created to reflect interactions and inter-relations between themes and subthemes, and finally the themes were defined and named. Themes were conceptually regrouped together to reflect

mechanisms precipitating and perpetuating implementation gaps in CAPO CRF guidelines, reflecting links between sub-themes observed in the data. These two main themes were conceptually represented in figures. Following the interpretive nature of this study, the author's perspective on the need to improve CRF symptom management, their understanding practice gaps previously identified in the literature, and favorable view of CAPO CRF guidelines shaped the interpretation of the data. Further, the author's training as a scientist-practitioner also influenced the data interpretation in favor of a bi-directional relationship between scientific evidence and clinical practice. Across each step of the coding process, codes and themes were discussed amongst the research team to increase credibility and consistency of results. Data source triangulation was used to compare themes across stakeholder type for the interpretation and reporting of the results to identify commonalities and differences between patients, HCPs, and CSPs' perspectives within themes to make sense of participants' experience in the context of understanding CRF guideline implementation gaps (Carter, Bryant-Lukosius, et al., 2014). Meaningful transcript extracts were selected to represent the themes to help readers assess the credibility and rigor of authors' interpretations of participants' accounts. Names were replaced with participant groups in text to ensure participant confidentiality. To achieve higher internal validity of the coding scheme, 20% of the interviews were double coded by a second coder (G.T. (French) and N.R. (English)) and discrepancies were discussed until agreement was achieved. The average inter-rater agreements were of 99.58% (French) and 97.89% (English). Following interpretive phenomenological analysis principles, the themes were related to the existing literature in the discussion section (Smith & Osborn, 2015; Smith & Shinebourne, 2012). Overall, the study aimed to demonstrate rigor by following the Standards for Reporting Qualitative Research (O'Brien et al., 2014), by insuring credibility of codes via the use of

citations, promoting the transferability of methods to other topics of healthcare settings, describing the methods to permit replication, and by discussing limitations to promote the neutrality and confirmability of the results (Thomas & Magilvy, 2011).

Quantitative analyses. Analyses were performed using SPSS 25 statistical software (IBM Corp., 2017). Frequencies, means, and standard deviations were calculated to report participant socio-demographic, medical, and work experience-related data. Independent sample t-tests and Mann-Whitney U-tests were performed to analyse mean differences in age and years of work experience between CSP and HCP groups. *P* values of 0.05 were set to determine significance.

Results

Participants

Sixty-two participants were recruited—16 patients, 32 HCPs, and 14 CSPs. Patients took part in one of three focus groups: two in English, one in French. Twenty-eight HCPs took part in one of four focus groups: one with members of an interdisciplinary breast cancer team (French), one with members of an interdisciplinary psychosocial oncology team, one group of oncology nurses, and one group of radiation technicians. Four HCPs were interviewed one-on-one in person or by phone. CSPs took part in one of two groups. Patients were on average 55.6 years of age (SD = 10.3), female (56.3%), French speaking (62.5%), and no longer working (62.5%). Furthermore, over one third had a family income of 100 000-150 000$ (37.5%) and all patients were born in Canada and Caucasian (100%). Most patients were diagnosed with breast cancer (62.5%) and received radiation therapy (62.5%) or surgery (62.5%). HCPs and CSPs were mostly female (84.4% and 87.5%, respectively), were on average 42.1 (SD = 9.8) and 43.9 (SD =

11.2) years old, and had 11.1 (SD= 8.2) and 3.9 (SD=3.1) of work experience, respectively. Most HCPs were registered nurses (31.3%) and radiation technologists (31.3%) and most CSPs were cancer coaches (50%). No differences existed in terms of the age of HCPs (*M*=42.1, *SD*=9.8) vs. CSPs (*M*=43.9, *SD*=11.2) (*t(44)* = .55, *p* =.59); however, CSPs had significantly less work experience than HCPs (*U*= 80.0, *p* =.001) (*Mnd* = 13.2; *Mdn* = 28.0, respectively). See Table 1 for complete patient sociodemographic and medical information and HCPs and CSPs sociodemographic and work-related information.

Overview of Themes

Many practice gaps in CRF screening, assessment, and intervention were identified. Two underlying themes seemed to give rise to gaps in practice: *"A Perfect Storm"* and *"A Break Down in Communication"*. Results will be presented in three main sections. To provide further context, a code representing participants' description of CRF will first be briefly presented. Next, the two underlying causes maintaining practice gaps will be presented, see Figures 1 and 2 for an overview of each underlying cause.

Description of CRF

All stakeholders described CRF that CRF is a different beast altogether compared to normal fatigue experienced following physical activity or sleep deprivation and is multidimensional, including physical, psychological, cognitive, and emotional fatigue. A patient described her fatigue as follows: *"It's not that you want to sleep, it's like every cell in your body doesn't have energy, it feels completely different than staying up until midnight and being sleepy. It's not the same feeling at all"*. **Frequency**. Professionals (HCPs and CSPs) described CRF as a common symptom they see in their practice. A radiation technician reported: *"I'm tired" that's like probably 90% of our patients or higher."* **Impact.** Participants recognized that CRF has a

large impact on patients' functioning in diverse domains and impairs their ability to return to work after cancer. A CSP explained: *"Just the energy to eat well, to do all of the good things that they want to do, and they have fear of recurrence and know they should be doing all of this healthy stuff, but they don't have the energy to go to the store and buy the healthy groceries."*

Trajectory. Participants had diverse opinions on CRF's progression throughout the cancer trajectory. Patients experienced fatigue at diagnosis, during treatment, and post-treatment, whereas professionals felt that CRF appears mostly during treatment and post-treatment. A CSP described this as follows: *"People [experience CRF] while they are in treatments, and many who have completed treatment but are now living with this exhaustion in their daily lives."*

Contributing factors. Participants identified many factors contributing to CRF including psychosocial aspects (e.g., stress, anxiety, depression, sleep disorders), physical aspects (e.g., certain diagnoses, radiation therapy, anemia), people's expectations to be back to normal, and lack of social support. A CSP explained: *"Such an abundance of stress; not knowing physically what's going to happen, the fear of all those things, the worry about your kids and your family, and finances. That anxiety, or any mild depression would relate to that fatigue as well. "*

Mechanism 1: A Perfect Storm

As can be seen in Figure 1, professionals' low knowledge of CRF guidelines paired with organizational obstacles within a context of limited funding and real-world constraints prevents professionals from offering optimal services to patients. Indeed, the subtheme *Knowledge of Guidelines* reflects professionals' level of knowledge with diverse CRF guidelines. Although professionals applied evidence-based interventions and guidelines in their general practice, both HCPs and CSPs were unaware of CRF-specific guidelines or were aware they exist but not familiar with the content and used them infrequently. A physician stated: "*I am blissfully*

unaware of any specific recommendations" and a CSP stated: *"I know I've read it, but it's been a long time."* Only one team consulted expressed being familiar with guidelines for CRF: "*Well for the CCO guidelines, we review and provide it; I would say we're probably familiar with that iteration tool 8 or 9 out of 10" – radiation technician.*

Professionals' low and inconsistent level of knowledge of CRF guidelines was also reflected by a second subtheme labeled *Lack of Education and Resources*, which reflects professionals' level of understanding of CRF and its assessment and management. Professionals' lack of knowledge of CRF interventions differed however, whereby HCPs reported low knowledge of psychosocial interventions and CSPs reported low knowledge of medical rule-outs (e.g., anemia, electrolyte imbalances) and associated interventions, as reflected in Table 2. HCPs also reported difficulty making recommendations for interventions outside of their specialty (e.g., a psychologist recommending exercise). Patients received few recommendations from their healthcare teams to help them manage CRF and feeling that CRF was underdressed in their care. A patient stated: "*They [healthcare providers] need to be more aware of how the fatigue affects us. I think they take it too lightly or they take it for kind of like I said it's a ball floating, and no one really grabs it."* These knowledge gaps appear to maintain CRF implementation gaps. A HCP explained: *"Pain, I know what to do, nausea I know what to do, fatigue I do not know what to do. I see it as if there is nothing I can do."*

Difficulties related to professionals' low knowledge is exacerbated with organizational obstacles including systemic difficulties for HCPs to follow-up on referrals, difficulty reviewing past notes in electronic systems, inter-professional communication gaps, and a reactive approach to symptom management. A nurse explained difficulties related to note taking and revision as follows: "*There isn't really like a quick snapshot of the issues and this what has been done today.*

There isn't really an easy way without you going back and reading a bunch of notes and trying to figure it out." Further a physician stated: *"I refer them, I lose them"*, and a CSP explained: "*Well I just think that we're all fighting for the same thing, and we don't work collaboratively, you know?".* Patients agreed with this and expressed needing to follow-up on their cases and fearing falling through the cracks. A patient explained: "*When you enter the healthcare system, you have to become aware that you need to keep track of your own file, that you don't lose sight of it, because they [healthcare providers] can lose sight of it quickly*." Systemic costs and limited funding were identified as an obstacle limiting the availability of symptom management and psychosocial services within the healthcare system. A HCP explained: *"The issue becomes in the health care system right now there's limited funding and unfortunately things like managing fatigue is considered a luxury"* and a CSP stated: "*It's a competitive market out there, certainly Health Canada and the Government are not going to bring up any money and make that a standard of care any time soon.*". Whereas patients also highlighted funding issues related to general practitioners involved in their survivorship care: "*The problem with the GPs is the way they're funded. They don't have the time to talk to you at length"*.Coupled with knowledge gaps, these systemic obstacles leave professionals with little resources to provide optimal services to patients. Professionals' work is further complicated by patient variability which represent patient factors influencing CRF service delivery. Professionals reported difficulty adjusting their recommendations based on patients' characteristics, needs, living situation, physical condition, life stressors, and familiarity with technology. They also reported that some patients need more support and motivation to implement strategies whereas others need to be told to slow down. A HCP explained: *"People who sometimes need a little more and other people whose expectations are high, and they are constantly feeling that they're failing because they're not meeting those*

expectations. So, it's two very different populations, and of course everybody in between. " A CSP also stated: "*It's not just about individuals, but changing a whole family diet, how everybody interacts, and eats, and exercises. I think there's a lot of home barriers, and it's just a different type of care that people are used to, there's not a pill that can fix CRF*." In sum, these factors contribute to creating "*A Perfect Storm"* preventing professionals from offering optimal services to patients.

Mechanism 2: A Break Down in Communication

The second underlying cause reflects the inconsistencies in screening and assessment strategies used by professionals, professionals' attempts to normalize patients' CRF without provision of specific management strategies, and patients' perception of limited face-to-face time due to professionals' heavy workload. These leave patients feeling dismissed and discouraged to rely on their healthcare team for CRF management (see Figure 2 for a diagram of this mechanism).

Assessment strategies applied by professionals and patients' report of the type(s) of assessments they received for CRF were captured in the subtheme *If They Don't Bring It up, I Don't Ask*. Patients were seldom asked about their levels of fatigue and thus felt discouraged from reporting it to their HCPs. Patients were asked to complete the Edmonton Symptom Assessment Scale (ESAS) at their follow-up appointments; however, they received limited follow-up on their scores. A patient stated: *"When you go into the cancer center, they give you this little piece of paper, you do it on the machine. One day I put on 10… And you know what? Nobody took notice of that. I went home with it. Because she never asked, the doctor never asked me."* Professionals used diverse methods to assess for CRF, typically using general open-ended questions such as 'how are you feeling' and only assessing further if patients reported CRF. The

ESAS was used in one hospital surveyed, but professionals did not follow with a comprehensive CRF assessment as recommended by CAPO CRF guidelines. Further, professionals also reported assessing for CRF if patients expressed barriers to health behaviour changes rather that assessing systematically for CRF. A CSP explained: *"I do bring it up in terms of when they're saying: I want to lose weight, or I want to get healthier, or I want to exercise. When we're talking why is that not happening?"*. Other CAPO CRF assessment guidelines were used; however, they were not used systematically in each group. HCPs expressed assessing for medical factors, sleep disorders, psychological disorders, reviewing survivorship care plans, monitoring CRF over time, assessing overall functioning, and stated that patients often do not report their CRF. CSPs expressed using an intake questionnaire, assessing overall functioning, and assessing for CRF when presented as a secondary symptom or barrier to one of their treatment goals. See table 2 for a review of assessment strategies per stakeholder group.

Intervention strategies applied by professionals and interventions patients received from professionals for CRF are represented in the subtheme *We Do What We Can, but It's Not Enough*. Patients were dissatisfied with the information and recommendations they received from their HCPs. They explained that they often received messages of normalization (i.e., CRF is a normal side effect), with little recommendations to manage CRF which left them feeling invalidated and discouraged or no intervention at all. A patient stated: "*I've seen all 5 oncologists…each one on the oncology side were: "well that's normal", "that's the side effect. It'll go away. Give it a couple of years, it'll go away". No solution, no remedy*". A CSP expressed using normalization in their practice combined with recommendations for sleep and energy conservation as follows: "*We talk about a new normal, tell them to take time for themselves, and nap, don't plan so much in a day.".* HCPs recommended strategies supported by the CAPO CRF

guidelines such as exercise and psychoeducation, however recommendations varied per type of HCP and were not offered systematically. HCPs reported using medical interventions and referrals more frequently than CSPs. They also recommended strategies that lacked evidence, including pharmacotherapy and acupuncture. Psychosocial interventions were more frequently applied by CSPs such as stress management interventions. Patients reported turning to services outside the healthcare system including complementary and alternative medicine, exercise classes, self-monitoring of their CRF, and volunteering. See Table 2 for a checklist of intervention strategies adopted by each participant group. Systemic challenges leading to *Lack of Time and Heavy Workloads for HCPs* allowed them little time to address CRF with their patients. Patients expressed feeling pressed by their healthcare professionals which left them thinking that their CRF was not a priority. A HCP explained: *"We have most time, 15 minutes with our patients; 2 minutes getting the patient from the waiting room; then setting up the patient is another 5 minutes and then we have 7 to 8 minutes of treatment time and that doesn't leave a lot left for discussion".* These factors cumulate to important *Patient-Provider Communication* gaps. Indeed, HCPs' attempts to normalize patients' CRF led them feeling dissuaded to raise this issue with them. Patients also withhold information from their healthcare teams when they seemed rushed. A patient reported: *"I went in and I thought "Why am I here?" because she stood with her hand on the doorknob for the whole 5-minute interview. " and another expressed: "It's just one of those things you're just like "why bother?*""". HCPs were aware that they may not always appear open to listening to their patients' concerns. A Physician explained: "*I think that patients might be afraid to ask; they think they've already used up enough time of the health care professional or the system etc. And, and, some may think that they can deal with it themselves.".* See Figure 2. for a diagram of this theme.

Discussion

The results highlight challenges contributing to CRF guidelines implementation gaps. Consistent with previous research (Borneman et al., 2010; Hilarius et al., 2011; Pearson et al., 2015; Piper et al., 2008), the results demonstrated that HCPs and CSPs applied both evidence-based and non-evidence-based CRF assessment management strategies in their practice and strategies were applied inconsistently across professional groups. Specific challenges identified were 1) professionals' lack CRF knowledge, systemic challenges related to the healthcare system and the interdisciplinary nature of CRF guidelines, and time and funding constraints (A Perfect Storm); and 2) Patient-Provider Communication Gaps leading to patients under-reporting their CRF and looking outside of the healthcare system for support.

The Consolidated Framework for Implementation Research (CFIR) is a model that is composed of five major domains: intervention characteristics, outer setting, inner setting, characteristics of the individuals involved, and the process of implementation (Damschroder et al., 2009). The results of the present study identify challenges to CRF guideline implementation which can be classified into the CFIR's domains and potential knowledge translation strategies can be identified to address these gaps. In terms of intervention characteristics, the level of complexity of the CAPO CRF guidelines and the lack of provider-specific recommendations leads to role confusion and inter-professional communication challenges. The development of behavioural tasks specific to each profession and streamlined versions of the guidelines may alleviate this challenge. Further, professionals should be informed of and equipped with psychoeducational material on CRF to facilitate CRF communication with patients, many organization have developed such tools (Alberta Helath Services, 2017; American Cancer Society, 2020; Cancer Care Ontario, 2016; Cancer Council Victoria, 2019; Memorial Sloan

Kettering Cancer Center, 2018; National Cancer Institute, 2020; National Comprehensive Cancer Network, n.d.). In terms of the outer setting, our results highlight the important patient need for CRF services and a lack of funding for psychosocial services which leads to service gaps. Time and cost-effective strategies such as stepped-care models, education sessions, and web-based self-management CRF interventions may help address these challenges. Inner setting obstacles also contributed to systemic challenges to CRF assessment and management including the lack of time, lack of inter-professional communication and documentation. Setting-specific strategies to improve electronic medical record documentation of CRF and psychosocial symptoms should be piloted and evaluated. Individual level obstacles including lack of knowledge of CRF and CRF guidelines represents a significant barrier to CRF guideline implementation. The implementation of electronic behavioral prompts and reminder systems integrated into electronic medical records to assist professionals to screen, assess, and manage CRF following the CAPO CRF algorithm should be investigated. Further, professional education sessions and training on CRF guidelines should be considered (Jones et al., 2020; Pearson et al., 2017).

Limitations

Whilst the patient sample was well distributed in terms of gender, diagnosis, and treatments received, all were Caucasian. Non-Caucasians may have had different experiences and opinions. Moreover, a large majority of the sample (41.7%) had an income over 100,000$, which is not representative of the general population. This could indicate that participants may have had greater access to private services to help manage their CRF compared to the overall Canadian patient population. Geographical and cultural factors may also influence the generalizability of the results as the data was collected within a Canadian cultural and healthcare system context. Policy makers and healthcare management are key stakeholders which were not

included in the present study. Further, this study represents a retrospective subjective report of participants' experience of CRF, therefore self-report biases may be present. Finally, researchers' characteristics including professional domain (psychology) and female gender may have influenced interactions between researchers and participants during interviews.

Conclusions and Future Recommendations

This study identified CRF guideline implementation challenges including lack of knowledge of CRF guidelines, systemic and organizational challenges, and patient-provider communication gaps. Further research is needed to investigate the feasibility and efficacy of the application of CAPO CRF guidelines into clinical practice with multidisciplinary HCP teams across diverse sites. The efficacy and effectiveness of knowledge translation strategies to promote the implementation of the CAPO CRF guidelines should also be investigated according to the CFIR model.

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Table 1.

Participant descriptive statistics		
Patients *n* = 16		
	M	SD
Age	55.56	10.30
Time since diagnosis (years)	5.31	2.55
Time since treatment completion (years)	3.13	1.92
	n (%)	
Gender		
Female	9 (56.3)	
Language		
French	10 (62.5)	
Employment		
Full-time	3 (18.8)	
Part-time	3 (18.8)	
No	10 (62.5)	
Born in Canada		
Yes	16 (100)	
Ethnicity		
Caucasian	16 (100)	
Diagnosis		
Prostate	2 (12.5)	
Breast	8 (50)	
Colorectal	1 (6.3)	
Stomach	1 (6.3)	
Multiple	3 (18.8)	

Colon	1 (6.3)
Chemotherapy	
Yes	8 (50)
Radiation	
Yes	10 (62.5)
Surgery	
Yes	10 (62.5)
Income ($ CAD)	
<40,000	4 (25)
40 000 – 59 999	2 (12.5)
60 000-79 999	1 (6.3)
80 000 – 99 999	1 (6.3)
100 000 – 150 000	6 (37.5)
> 150 000	1 (6.3)
Don't know	1 (6.3)

Healthcare providers *n* = 32

	M	SD
Age	42.06	9.75
Work experience (years)	11.05	8.21
	n (%)	
Gender		
Female	27 (84.4)	
Title		
Radiation technician	10 (31.3)	
Registered nurse	10 (31.3)	
Social worker	4 (12.5)	
Psychologist	2 (6.3)	

Radiation oncologist	2 (6.3)
Dietician	1 (3.1)
Surgeon	1 (3.1)
Palliative care physician	1 (3.1)
Physiotherapist	1 (3.1)

Community support providers *n* = 14

	M	SD
Age	43.86	11.20
Work experience (years)	3.93	3.13
	n (%)	
Gender		
Female	12 (85.7)	
Title		
Cancer coach	7 (50)	
Hypnotherapist	1 (7.1)	
Chinese medicine practitioner	1 (7.1)	
Registered massage therapist	1 (7.1)	
Naturopathic doctor	1 (7.1)	
Yoga therapist	1 (7.1)	
Manager	1 (7.1)	
Research fellow	1 (7.1)	

Table 2.

Reported Assessment and Intervention Strategies per Stakeholder Group

	Patients	Healthcare providers	Community Support Providers
		Assessment strategies	
Medical	X	X	
ESAS/VAS 0-10	X	X	X
Other questionnaire		X	X
Fatigue as secondary symptom		X	X
Survivorship Care plan		X	
Functioning	X	X	X
Sleep		X	
Psychosocial		X	
Monitoring	X	X	
General open question	X	X	X
Patient not reporting	X	X	
Lack of follow-up	X		
		Intervention strategies	
Normalization	X	X	X
Pharmacotherapy	X	X	
Information/education	X	X	X
Energy conservation	X	X	X
Physical activity	X	X	X
Cognitive-behavioural therapy		X	

Psychosocial support/stress management		X	X
Complementary and alternative therapies		X	X
Medical	X	X	
Referral	X	X	
Healthy habits		X	
Social/pleasurable activities		X	
Rest/sleep		X	
No intervention	X		

Figure 1. A Perfect Storm Diagram

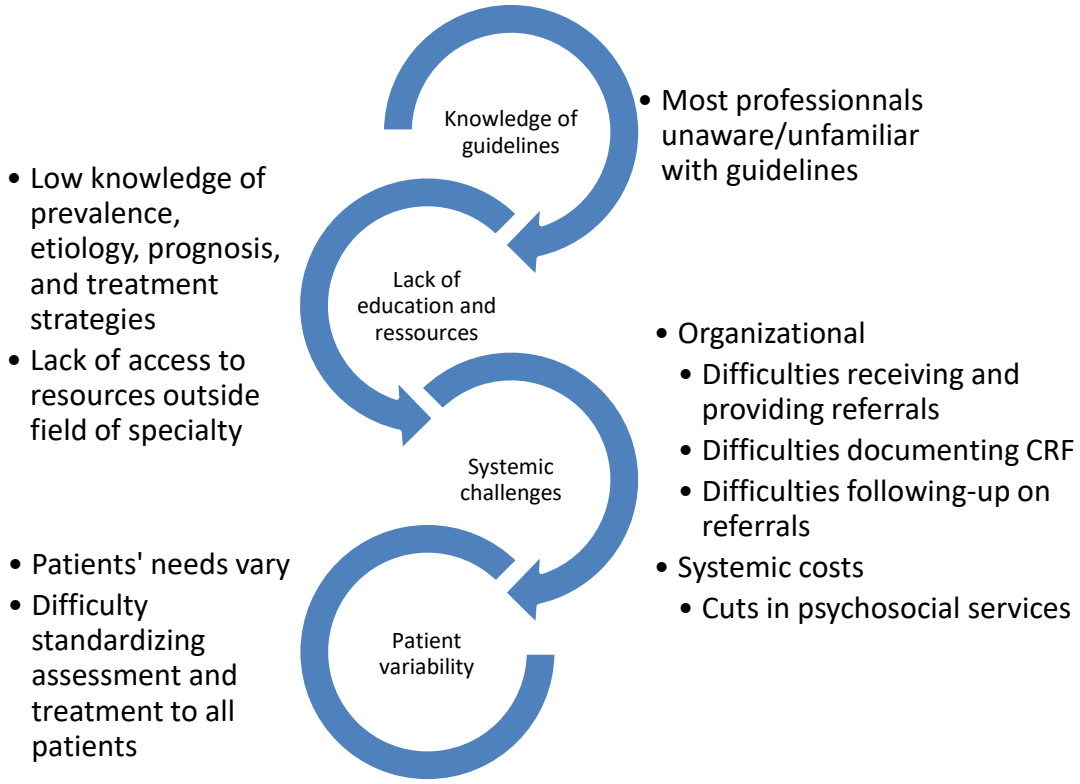
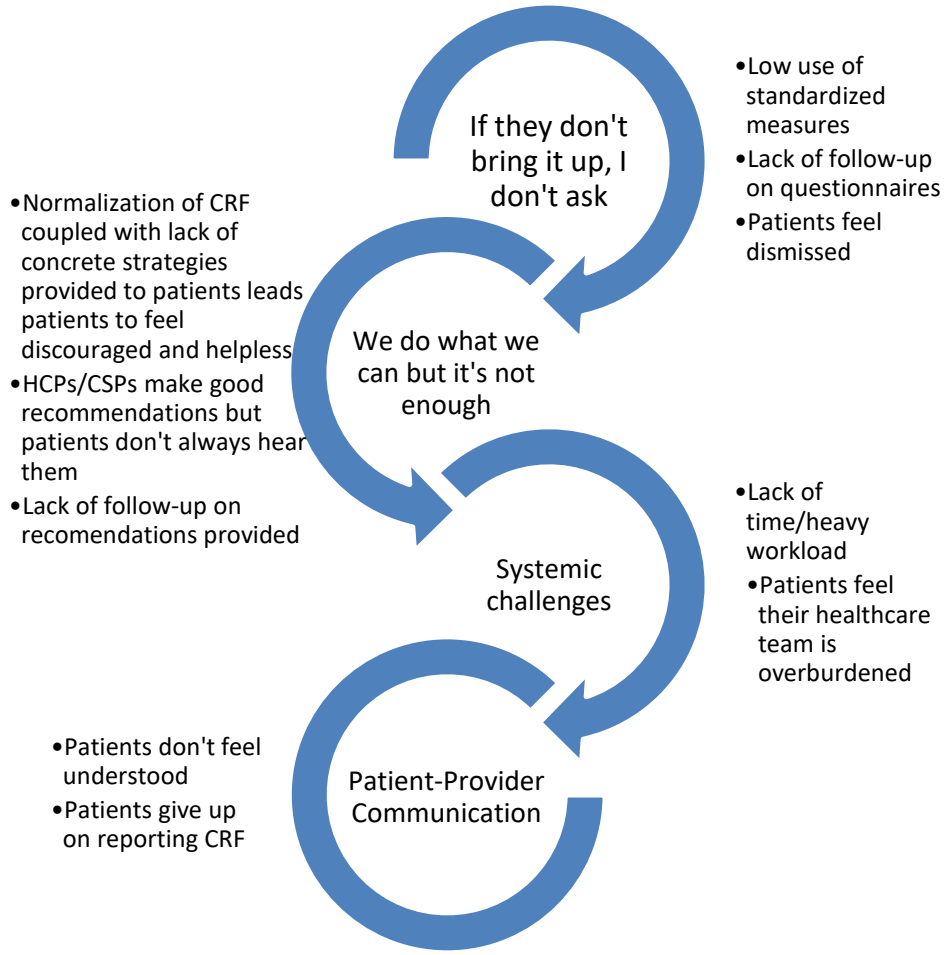


Figure 2. A Break Down in Communication Diagram



Study 2

Translating Guidelines to Practice: A Training Session on Cancer-Related Fatigue

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Abstract

Background. Cancer-related fatigue (CRF) is the highest unmet need amongst cancer survivors. The Canadian Association of Psychosocial Oncology (CAPO) has developed guidelines to guide screening, assessment, and intervention of CRF; however, they are not consistently applied in practice due to patient, healthcare provider (HCP), and systemic barriers. Notably, previous studies identify lack of knowledge of CRF guidelines as an impediment to their implementation. Methods. This pilot study tested preliminary outcomes, the acceptability, and the feasibility of a training session and a knowledge-translation (KT) tool designed to increase HCP and community support providers' (CSP) knowledge of CAPO CRF guidelines. A one-time in-person training session was offered to a diverse sample of HCPs and CSPs (n = 18). Outcomes (i.e., CAPO CRF guidelines knowledge, intentions and self-efficacy to apply guidelines in practice) were assessed pre- and post-training. Acceptability and feasibility were also assessed post-training to guide future testing and/or implementation of the training. Results. At post-training, participants reported increased CAPO CRF guidelines knowledge, self-efficacy, and intent to apply guidelines in practice. Participant satisfaction with the training session and the KT tool was high and recruitment time, participation, and retention rates indicate that the training was acceptable and feasible. Conclusions. The provided training is both acceptable to HCPs/CSPs and feasible. It may increase knowledge of CAPO CRF guidelines and participants' intentions and self-efficacy to implement evidence-based recommendations. Future studies should investigate actual changes in practice and how to optimize follow-up assessments. KT strategies should be paired with guideline development to promote practice uptake.

Keywords: Cancer-related fatigue, Guidelines, Knowledge Translation, Healthcare provider training

Translating Guidelines to Practice: A Training Session on Cancer-Related Fatigue

The Canadian Psychosocial Oncology Association (CAPO) and the National Comprehensive Cancer Network (NCCN) guidelines define cancer-related fatigue (CRF) as a "distressing, persistent, subjective sense of tiredness or exhaustion related to cancer or cancer treatment that is not proportional to recent activity and interferes with usual functioning" (Howell et al., 2015; National Comprehensive Cancer Network, 2020). Its symptoms vary from generalized weakness, diminished concentration or attention, exhaustion preventing participation in usual activities, and emotional liability (Bower, 2014a; Cella et al., 2001; Schmidt et al., 2012). CRF is a multidimensional symptom that manifests physically, psychologically, and emotionally (Bower, 2014a; Cella et al., 2001; Schmidt et al., 2012). Increased CRF is associated with lower quality of life (Borneman, 2013), disability (Borneman, 2013), increased healthcare utilization (H.-S. Wu & Harden, 2015), and distress (J. Jones et al., 2016). Reported CRF prevalence rates range between 45-99% (Cella, 1997; Hoffman et al., 2007; Karthikeyan et al., 2012). Furthermore, CRF has been reported as the most frequent unmet need in both Canadian and Australian samples (Hall et al., 2013). CRF affects patients who have received diverse treatment regimens that include surgery, chemotherapy, hormonal therapy, and/or radiation therapy (Ahlberg et al., 2003; Hoffman et al., 2007; Karthikeyan et al., 2012; Reinertsen et al., 2010). It can develop from diagnosis onward (Lawrence et al., 2004) and persist for several years after the completion of treatment (J. Jones et al., 2016; Reinertsen et al., 2010; Wang et al., 2014).

CAPO CRF Guidelines

CAPO has developed a set of comprehensive guidelines for the screening, assessment, and intervention of CRF (Howell et al., 2015), which have been independently evaluated as the

most suitable available guidelines for clinical practice among interdisciplinary teams to use (Pearson et al., 2016). CAPO guidelines include an overview of evidence-based screening methods, comprehensive assessment recommendations, and intervention strategies for patients reporting mild to severe levels of CRF. As a first step, CAPO guidelines recommend that all healthcare providers (HCPs) routinely screen for the presence of CRF from the point of diagnosis onward using a validated numerical rating scale such as the Edmonton Symptom Assessment Scale (ESAS) (Chang et al., 2000). Supportive care interventions (e.g., psychoeducation, physical activity, counselling on energy conservation strategies), and monitoring of CRF levels are recommended for all patients reporting mild (ESAS scores: 1-3), moderate (ESAS scores: 4-6), and severe CRF (ESAS scores: 7-10). Further, CAPO guidelines recommend pursuing a comprehensive assessment including an investigation of biological, psychological, and social factors contributing to CRF, ruling-out potential comorbid diagnoses (e.g., insomnia, anemia), and providing more specific non-pharmacological interventions (e.g., cognitive-behavioural therapy, physical activity, stress management) for patients reporting moderate to severe CRF (Howell et al., 2015). Whilst CAPO offers these guidelines for HCPs, other professionals such as community support providers (CSPs) also play an important role in assisting patients presenting with CRF in the community.

Knowledge-to-Practice Gap

Although clinical guidelines highlighting evidence-based CRF assessment and intervention strategies are available (Howell et al., 2015; National Comprehensive Cancer Network, 2020), important practice gaps exist in their implementation. Indeed, studies demonstrate low uptake of recommended assessment and intervention strategies for CRF (Berger et al., 2015; Given, 2008; Hilarius et al., 2011; Pearson et al., 2015b). Rather, HCPs often

recommend strategies that lack empirical support (e.g., resting) (Stone et al., 2003). CSPs may also offer such strategies to the detriment of patients.

Previous studies have classified barriers to the implementation of evidence-based CRF assessment and intervention strategies into patient, provider, and systemic barriers (Borneman et al., 2007a, 2010; Piper et al., 2008). Patient-provider communication gaps have been highlighted in qualitative studies demonstrating that patients do not disclose CRF symptoms to HCPs because they assume nothing can be done to help (Fitch et al., 2008; Pertl et al., 2014; Stone et al., 2003) or because they do not want to burden HCPs (Carter, Miller, et al., 2014). Provider barriers include a lack of information on the causes of CRF and its management, which in turn prevents adequate assessment and intervention (Borneman et al., 2007a). Indeed, 52% of HCPs reported lack of expertise in assessment and intervention of CRF and 63% a lack of awareness of intervention strategies for CRF (Pearson et al., 2015b). Implementation rates of CAPO CRF guidelines in Australia ranged from 33-46% among diverse HCPs (i.e., allied health professionals, nurses, doctors, managers) (Pearson et al., 2017b), with similar levels reported in samples of nurses in Jordan and in the United States (Abdalrahim et al., 2014; Given, 2008). Systemic issues include lack of time, limited access to assessment tools, lack of knowledge of resources available, difficulty making and following-up on referrals, and absence of an accessible format for documenting CRF in medical records to properly assess and intervene for CRF (Borneman et al., 2007a, 2010; Given, 2008; Pearson et al., 2015b). Finally, this thesis' Study 1 used a qualitative design to explore implementation gaps and barriers to CAPO CRF guideline implementation. The results indicated a lack of knowledge of CAPO CRF guidelines and inconsistent application of screening, assessment, and intervention recommendations for CRF.

CRF guidelines for screening, assessment, and management are ready for implementation (Berger et al., 2015). Education and systemic efforts to disseminate and implement evidence-based guidelines are needed (Berger et al., 2015). Further education and practical training related to CRF that is designed to accommodate HCPs' busy schedules may enhance HCPs and other professionals' (e.g., CSPs) knowledge of CRF guidelines and practice uptake (Abdalrahim et al., 2014; Magnusson et al., 1997; Pearson et al., 2015b). This is supported by a recent Delphi survey conducted with patients and HCPs (i.e., allied health professionals, nurses, doctors, managers) that revealed the need to promote CRF guidelines uptake via HCP training and develop tools to facilitate the Knowledge Translation (KT) of the guidelines into practice (Pearson et al., 2017b). The first step to move towards CRF guideline implementation and adoption represents developing and testing the effectiveness of such dissemination and implementation strategies (Berger & Mooney, 2016).

Knowledge-to-Action KT Model

KT strategies are commonly used in the field of healthcare and represent a vital process to ensure the use of scientific knowledge and clinical guidelines in practice (LaRocca et al., 2012; Scott et al., 2012; S. Straus et al., 2013; S. E. Straus, 2011a). The development and availability of educational interventions, tools, and resources are essential to ensure guideline implementation (Gagliardi, 2012). The current pilot study applied the Knowledge-to-Action model (Graham et al., 2006; S. Straus et al., 2013) to promote the KT of CAPO CRF guidelines into practice. The Knowledge-to-Action Model is a dynamic and fluid model divided in two different stages: 1) knowledge creation; and, 2) action cycle. This study focused on the action cycle stage, which is comprised of seven steps (Graham et al., 2006; S. Straus et al., 2013) (see Figure 1 for an overview of the model). The present study will report on 4 of the 7 steps, namely:

a) identification of the problem and knowledge selection, b) selection, tailoring, and implementation of a KT intervention, c) monitoring of knowledge use, and d) outcome evaluation to describe the development and evaluation of a CAPO CRF guideline training for HCPs and CSPs, which is the focus of this study. Data on the remaining three steps (i.e., adaptation of knowledge to the local context, identification of barriers to knowledge use steps) will be presented in a separate publication. To the authors' knowledge, no research has evaluated KT strategies in relation to training HCPs and CSPs on CAPO CRF guidelines.

Objectives

Educational interventions in healthcare settings yield outcomes on different levels including participation, satisfaction, learning, performance, patient health, and population levels (Straus et al., 2013). This thesis' Study 1 findings combined with previous research led to the development of the present study's objectives and design. Indeed, Study 1 results highlighted many obstacles leading to the maintenance of CRF guidelines implementation gaps including patient-provider communication gaps, systemic gaps, and HCP and CSP's lack of knowledge of CRF guidelines. Following the KTA model, the research team wished to develop a KT intervention to help address these gaps. The research team consulted with a consultation committee to review potential interventions to address these gaps. A HCP and CSP training session was identified as a KT intervention that may help bridge CRF guidelines knowledge gaps and assist professionals to communicate regarding CRF with their patients. Specific barriers to CAPO CRF guideline implementation targeted by the present study were professionals' lack of knowledge of CRF guidelines and patient-provider communication gaps. Didactic and practical training methods were selected to address both the lack of conceptual knowledge of CRF

guidelines and to provide professionals the opportunity to practice skills related to assessing and providing recommendations for CRF management.

This study was developed as a first step to pilot test and evaluate the acceptability and feasibility of a one-time training session for HCPs and CSPs on CAPO CRF guidelines. A secondary objective was to evaluate the learning outcomes of the training session including CAPO CRF guidelines knowledge, self-efficacy, and intent to apply CAPO CRF guidelines in practice. The research hypotheses were that the training session would: 1) increase HCPs and CSPs' knowledge of CRF and of CAPO CRF guidelines; 2) increase HCPs and CSPs' self-efficacy to assess and intervene on CRF; 3) increase HCPs and CSPs' intention to apply CAPO CRF guidelines in practice; and 4) be acceptable (as evidenced by high HCPs and CSPs satisfaction) and feasible (as evidenced by acceptable recruitment time, participation rate, and post-training interviews).

Methods

Participants

This pilot study consisted of a small-scale evaluation of a CRF training session offered to an interdisciplinary group consisting of HCPs and CSPs who were recruited from two local hospitals and one community support centre for cancer patients in Ottawa, Canada. Participants were recruited using convenience and snowball sampling methods from the HCP and CSP samples in Study 1. Approval was obtained from the Institutional Research Ethics Boards of all affiliated investigators. Inclusion criteria were as follows: a) be aged 18 years old or older; b) be fluent in English or French; and, c) have experience working with cancer patients.

Description of Training Session

The first phase of this project involved focus group interviews with stakeholder groups—patients, HCPs, and CSPs—to fulfill the a) adaptation of knowledge to the local context, and b) identification of barriers to knowledge use steps of the Knowledge-to-Action Model described above. These focus groups highlighted a lack of knowledge of CRF guidelines and inconsistent application of recommended screening, assessment, and intervention strategies in practice. These practice gaps additionally appeared to be linked to patient-professional communication challenges (i.e., patients feeling misunderstood, lack of knowledge and tools for professionals to assess CRF) which resulted in patients no longer reporting their symptoms to their healthcare team and turning to community resources for support. A complete description of focus group results will be presented in a separate publication, see Table 1 for the focus group semi-structured interview questions. These practice gaps and consequences revealed a need to provide further education for HCPs and CSPs on CRF and evidence-based strategies for its screening, assessment, and intervention. Thus, the researchers selected to provide training to HCPs and CSPs on CAPO CRF guidelines and adapt CAPO CRF guidelines to the Ottawa context by developing a KT tool to assist professionals in implementing the guidelines into practice. Specific barriers to CAPO CRF guideline implementation targeted by this training session were lack of knowledge of CAPO CRF guidelines, inconsistent application of screening, assessment, and intervention strategies, and patient-provider communication gaps. The aim of the training session was to provide professionals with knowledge and practical communication skills to discuss CRF with their patients and follow evidence-based recommendations for CRF screening, assessment, and intervention following the CAPO CRF guidelines.

The researchers consulted with an advisory committee of one CSP (cancer coach, M.L.) and one HCP (nurse, C.S.-G.) as well as a pedagogy expert to develop the content and format of the training session and KT tool—an erasable flipchart. A total of 3 consultations with the advisory committee which aimed to ensure that the training content, format, delivery method, and length corresponded to the realities of HCPs and CSPs working in oncology were conducted. The consultations with the pedagogy expert aimed to refine the training's learning objectives and ensure that the training offered could reach these objectives. The pedagogy expert met with the researchers in person on 3 occasions, reviewed all the training material, and provided pedagogy coaching to the training facilitators.

The training session was divided into two one-hour parts, for a total of 2 hours per training session. The first part consisted of a presentation to provide participants an overview of knowledge and practice gaps reported in the literature, CAPO CRF guidelines, effective patient-practitioner communication skills, and motivational interviewing principals lasting approximately 45 minutes followed by a 15-minute break. The second part was interactive and involved role-playing and group discussions lasting approximately 1 hour. Participants were also provided with the flipchart that was bilingual (English and French), erasable, and reusable and presented a summary of CAPO CRF guidelines' screening, assessment, and intervention algorithm in a checklist format. During the session, participants had an opportunity to role play using CRF assessment and intervention vignettes using the flipchart and received feedback from the trainers and other participants. The training session was facilitated by a 5th-year graduate student in clinical psychology (G.J.) and a clinical psychologist with 15 years of experience in psychosocial oncology (S.L.).

Measures

A mixed method pilot study design was selected to evaluate the training sessions' learning outcomes and feasibility indicators. Participants completed quantitative measures within 1 week prior to the training (pre-training assessment) and again within 1 week following the training (post-training assessment). A 3-month post-training interview was also conducted to complement the quantitative measures of feasibility, acceptability and learning outcomes as well as to review participant feedback on areas of improvement of the training session.

Cancer-Related Fatigue Knowledge

CRF knowledge was assessed using a questionnaire developed in Australia (Pearson et al., 2015b) that was adapted to reflect healthcare terminology and locations within the Canadian context . It assesses participants' work experience in oncology, frequency of contact with cancer patients, level of knowledge of the causes of CRF, assessment and intervention strategies for CRF in practice, and barriers faced to implementing CRF assessment and intervention strategies. Self-assessment of CRF knowledge (1 item) and clinical experience (1 item) were also included using a numerical visual analog scale ranging from 0-100 whereby 0 represents low knowledge and experience and 100 represents high knowledge and experience.

Self-Efficacy

Participants' self-efficacy to assess and intervene for CRF was measured using two items developed for this study following Bandura's ability probabilistic estimate concept (Bandura, 1984). One item related to participants' estimation of success in assessing for CRF and one item related to providing recommendations for CRF were developed. Items were rated on a 5-point Likert-type scale. Responses were averaged, and higher scores reflected higher self-efficacy.

Behavioural Intentions

Participants' intentions to implement CRF assessment and intervention strategies in practice was assessed via 18 items developed for this study based on previous studies that measured behavioural intentions to adopt a new behaviour which had good fidelity coefficients (α = .84; .97) (Rise et al., 2008; Wong & Cappella, 2009). Specifically, participants were asked to rate their level of intent of performing each of the 18 CRF assessment and intervention recommendations presented in the CAPO CRF guidelines (Howell et al., 2015). Each item was rated on a 7-point Likert-type scale. Responses were averaged whereby higher scores reflected higher intentions to apply the recommendations. The Cronbach's alpha for these items in the present sample was 0.93 at the pre-training measure and 0.92 at post-training indicating good reliability (Cronbach, 1951; Tavakol & Dennick, 2011).

Feasibility

Recruitment time, training session participation rate, and rate of participation in the post-training interviews were documented by the research team to report on the feasibility of the implementation of the training session and data collection methods.

Satisfaction with Training

Satisfaction with the training session was assessed post-training using a questionnaire measuring three aspects of the participants' satisfaction: 1) the objectives and the content; 2) the methodology and the context, and; 3) the relevance of the training to their practice. The reliability of this questionnaire has been demonstrated with a Cronbach's alpha of 0.88 (Holgado Tello et al., 2006). The Cronbach's alpha in the present sample was 0.97. Responses were averaged, and higher scores reflected higher satisfaction.

Qualitative Post-Training Interviews

A semi-structured interview guide was developed for this study to assess CRF knowledge, CAPO guideline knowledge, intentions to implement guidelines, changes in practice, use of the flipchart, obstacles, areas for improvement, and training satisfaction. Telephone interviews were conducted by two independent interviewers, an undergraduate student and a 2nd year graduate student (G.T (French) and N.K (English)), with participants who had indicated an interest in sharing their impressions of the training at a 3-month follow-up.

Analyses

Quantitative analyses

Statistical analyses were performed using SPSS version 23 and statistical significance was set at $p \leq .05$. Frequencies, means, and paired sample *t*-tests were used to describe and compare scores on the knowledge, behavioural intentions, and self-efficacy scales pre- and post-training. Cohen's standardized effect sizes (Cohen's *d*) were calculated and interpreted for pre- and post-mean differences as follows: small ($\leq$.20), medium ($\approx$.50), large ($\geq$.80)(Cohen, 1992).

Qualitative analyses

Qualitative analyses were performed by G.J. using summative content analysis methods (Hsieh & Shannon, 2005) in which participants' responses to the interview questions were categorized by key themes and quantified. Analyses were conducted by post-interview question in order to review all participants responses to the question (e.g., What are your thoughts on the length of the training?). Next, responses were coded into themes based on the content and context of the responses (e.g., timing just right, too long, too short, etc.) and responses were summed to reflect the frequency of opinions reported by participants.

Results

Participants

A total of 18 females completed the training. Participants were on average 43.06 years of age (SD = 12.44), had diverse professional backgrounds, and had on average 18.53 years (SD = 13.09) of working experience in their respective fields. All participants reported working in Ontario, most participants described their work place as metropolitan, working in a hospital setting ,and working with cancer patients daily or weekly. See Table 2 for the complete sociodemographic and professional descriptive statistics of the sample.

Quantitative Outcomes

Pre-post training comparisons

Descriptive statistics: In terms of the first primary outcome—CRF knowledge— at post-training, participants were more familiar with CAPO CRF guidelines, better able to correctly identify the prevalence of CRF, more familiar with the use of a 0-10 numerical scale and of the ESAS to screen for CRF compared to pre-training. Participants also identified more CAPO assessment guidelines as being appropriate to assess for CRF post-training and more CAPO intervention guidelines as being appropriate to intervene for CRF post-training . Similarly, participants also identified both acupuncture and use of pharmacotherapy (not recommended by CAPO) as appropriate intervention strategies less frequently post-training. Finally, participants identified three CAPO intervention guidelines: 1) sleep optimization; 2) use of complementary and alternative medicines, and; 3) stress reduction as appropriate intervention strategies less frequently post-training than pre-training suggesting a possible misunderstanding of these interventions. See Table 3 for pre- and post-training descriptive statistics.

Mean comparisons: Pre-post comparisons revealed significant increase in participants': (1) perceived level of CRF-related knowledge (t = -3.959(14), p = .001) with a large effect size

(d = 0.98), (2)self-efficacy in assessing CRF (t = 2.621(13), p = .021) with a large effect size (d = 0.88), and (3) self-efficacy to intervene for CRF (t = 2.924(13), p = .012) with a large effect size (d = 1.13), and (4) intent to apply CAPO CRF guidelines in practice (t = 4.786(13), p = .000) with a large effect size (d = 1.35),.. No change was observed for participants' perceived level of clinical experience in assessing and managing CRF (t = -.427(14), p = .676) with a small effect size (d = 0.09). See Table 4 for descriptive statistics and comparisons pre- and post-training.

Feasibility indicators

The recruitment time for the sample of 18 participants was less than 1 month. The participation rate was 90%: two participants were recruited and cancelled prior to the session (one breast cancer surgeon and one nurse). All participants participated in the presentation part of the training (participation rate 100%), but two left for the interactive part (reasons cited: needed to leave early) (participation rate 88.89%). Finally, the mean satisfaction score was high (M= 52.27, SD=6.97) out of a maximum of 60 points.

Follow-up Qualitative Outcomes

Out of the total of 18 participants, seven accepted the invitation to participate in post-training interviews (38.89%) at 3 months post-training. All participants (n = 7) reported being satisfied with the training. All participants reported that the content and length was appropriate, having enjoyed the combination of didactic presentation and practical session (role playing), and reported they would recommend the training to their peers. Further, the all participants reported having learned new information about CRF and CAPO CRF guidelines. Two participants reported that the training offered a refresher on the CAPO CRF guidelines. Two participants reported that it was their first time learning about the guidelines. All participants reported that they incorporated changes in their practice that aligned with the guidelines.

Five out of seven participants reported having used the flipchart since the training, six out of seven participants reported feeling sufficiently trained to use the flipchart, and all participants reported having appreciated the flipchart's format and content. Participants reported feeling more confident in their ability to assess and intervene for CRF since their participation in the training. Obstacles to apply the guidelines into practice and to use the flipchart include lack of time, other acute patient needs to address prior to fatigue, patient barriers, and systemic medical team barriers (e.g., unsure of their role in the assessment of CRF).

Areas of improvement of the training session included: having more role-playing practice, hosting a 3-6-month review session to address any questions and review the content, and integrating the flipchart more throughout the training. Areas of improvement for the flipchart included condensing the tool into a shorter format and developing a patient-friendly version of the flipchart.

Discussion

This study applied elements of the Knowledge-to-Action cycle (i.e., implementation of a KT intervention, monitoring of knowledge use, and outcome evaluation (Graham et al., 2006; Straus et al., 2013)) to pilot test the implementation of a training session for HCPs and CSPs aiming to fill the HCPs/CSPs knowledge, resources, and patient-provider communication gaps previously identified in our focus groups (Jones et al., 2020) and the literature (Abdalrahim et al., 2014; Borneman et al., 2007a, 2010; Carter et al., 2014; Fitch et al., 2008; Given, 2008; Hilarius et al., 2011; Magnusson et al., 1997; Pearson et al., 2015a; Pertl et al., 2014; Piper et al., 2008; Stone et al., 2003). Following the Knowledge-to-Action framework, the study's principal objective was to evaluate the implementation of the training session by first evaluating is acceptability and feasibility. The study's primary hypothesis was confirmed by demonstrating

acceptability (as evidenced by high HCPs and CSPs satisfaction) and feasibility (as evidenced by acceptable recruitment time, participation rate, and post-training interview data) of the training session. Next, in line with monitoring of knowledge use and outcome evaluation of the KT intervention implementation steps of the Knowledge-to-Action framework, secondary objectives to this pilot study were established to evaluate knowledge use and learning outcomes of the training session. All secondary hypotheses were supported as results suggested that offering a brief one-time training for HCPs and CSPs on CRF guidelines may improve knowledge, self-efficacy, and intent to apply guidelines into practice. Similarly, the post-training qualitative results demonstrate that KT tools are appreciated by HCPs/CSPs and may be used in practice to supplement and sustain the knowledge and skills gained in training. Therefore, guideline developers should consider developing HCP/CSP training strategies and KT tools to help them translate clinical guidelines into practice (Gagliardi, 2012).

A recent report highlighted the need to equip HCPs to implement CRF guidelines into practice by promoting education and systemic knowledge dissemination and implementation strategies (Berger et al., 2015). A Delphi survey highlighted areas of improvement of CAPO CRF guidelines including streamlining the guidelines' format and content to a user-friendly format for HCPs, to identify roles and tasks specific to each healthcare profession which integrates referral pathways, to develop a pilot test HCP training sessions, and to develop decision support systems for HCPs which are endorsed by local and statutory bodies and integrated into current practice and consumer's needs (Pearson et al., 2017b). The development and pilot testing of this training session and KT tool represents a first step in evaluating the feasibility and acceptability of a user-friendly summary of CAPO CRF guidelines and promoting discussion of roles amongst interdisciplinary HCPs/CSPs via practical role plays. The results of

this study also corroborate those of the Australian team (Pearson et al., 2017b) by indicating that HCPs want even more streamlined tools (1 page summaries) with clear steps to implement in their practice. Strategies to increase inter-professional communication in the assessment and intervention of CRF are needed to ensure the effective CAPO CRF guidelines implementation. Further, CRF training should be delivered systematically to HCPs in order to ensure optimal knowledge dissemination and implementation (Berger et al., 2015).

Limitations

This study has limitations that should be taken into account when interpreting results. These include the use of self-report measures, which in some cases were developed or adapted by the researchers and whose validity and fidelity have not been evaluated. Changes overtime are limited to immediate pre- and post-training measurements and a 3-month post- follow-up with a subsample of participants which did not measure behavioural changes. However, behavioural intentions have shown to be indicative of future behaviors (Ajzen, 1985). Interpretation standards of feasibility indicators (i.e., recruitment time, participation rate) were not set a priori which renders their interpretation subjective. Cost-effectiveness of the training session was not evaluated in this study. In terms of the sampling method, the nature of the convenience sampling limits generalizability to the whole population and male HCPs and CSPs were not represented. Furthermore, specific professions were not represented in our sample including oncologists, family physicians, radiation oncologists, surgeons, and occupational therapists. It is also possible that the results of the study were influenced by geographical or cultural components given the selection of participants working exclusively in the Ottawa region and therefore should be assessed in other jurisdictions in Canada.

Future directions and Sustainability

Future research should assess for performance, patient health, and population health outcomes of HCP and CSP training on CAPO CRF guidelines. This can be done by measuring the practice-level changes associated with training and maintenance of skills learned in training via observational methods. The assessment of cost-effectiveness of the training using indicators such as number of patient follow-ups, duration of appointment times, and overall healthcare usage (Straus et al., 2013) should also be performed.

The development of methods to sustain the training of HCPs and CSPs on CAPO CRF guidelines and the use of a KT tool to promote a more user-friendly format of the guidelines is essential. The sustainability of the training session should be sought via integrating the session to regular training activities in hospitals, health centres, and community organizations (e.g., rounds, continuing education, staff meetings). Moreover, a self-directed online training session format could help promote sustainability of the training and increase its accessibility (Straus et al., 2013).

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Conflict of interest

The authors declare that they have no conflict of interest.

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Table 1.

Focus group semi-structured interview for healthcare professionals and community support providers

1. What is your understanding of the components of CRF or how would you define CRF?
   Probe: What is your understanding of the impact of CRF?
2. In your experience, how often and at what point do patients report CRF?

   Probe: When do you feel CRF is more prevalent?
3. How often do you actively assess patients for CRF in your practice and how do you do this?

   Probe: Do you ask questions? Do you run specific tests? Which ones?
4. What do you want to rule out in patients with CRF before you recommend self-care strategies?
5. What treatment(s) for CRF do you recommend to your patients?

   Probe: Why do you recommend these? What informs your recommendations?

   Probe: Do you recommend physical activity, CBT, energy conservation strategies?
6. Can you describe your level of familiarity with the CAPO/NCCN/CCO/COSTAR guidelines on CRF?
7. What barriers do you experience in practice for the assessment and intervention for CRF? What barriers to you think patients experience? How could they be avoided?
8. What could be done to ensure the assessment and management of CRF is sustainably done in the future?

Table 2.

Sociodemographic characteristics and professional experience

		M	SD
Age		43.06	12.44
Years of practice		18.53	13.09
Gender			*n* (%)
	Female		18 (100)
Profession			
	Nursing		9 (50)
	Social work		2 (11.1)
	Dietician		1 (5.6)
	Kinesiology		1 (5.6)
	Psychology		1 (5.6)
	Cancer coach		1 (5.6)
	Other		1 (5.6)
Province			
	Ontario		18 (100)
Work location			
	Metropolitan		17 (94.4)
	Rural		1 (5.6)

	Hospital	12 (66.7)
	Community	4 (22.2)
	Palliative Care	1 (5.6)
	Rehabilitation Center	1 (5.6)
Frequency of contact with cancer patients		
	Daily	10 (55.6)
	Weekly	5 (27.8)
	Monthly	1 (5.6)
	Occasionally	1 (5.6)
	Rarely	1 (5.6)

Table 3.

Pre and Post-training CRF-knowledge comparisons

		Pre	Post[1]
Knowledge of guidelines			
	Yes	6 (33.3%)	15 (93.8%)
	No	12 (66.7%)	1 (6.3%)
	Professional guidelines	1 (5.6%)	4 (25%)
	Cancer Care Ontario	4 (22.2%)	12 (75%)
	Canadian Association of Psychosocial Oncology	4 (22.2%)	8 (50%)
	National Comprehensive Cancer Network	1 (5.6%)	3 (18.8%)
	Other	2 (11.1%)	1 (6.3%)
Prevalence			
	Incorrect	2 (11.1%)	1 (6.3%)
	Correct	12 (66.7%)	13 (81.3%)
	No answer	4 (22.2%)	2 (12.5%)
Systematically assess patients			
	Yes	18 (100%)	16 (100%)
Knowledge assessment measures			
	Numerical scale (0-10)	4 (22.2%)	7 (43.8%)

	Edmonton Symptom Assessment Scale	6 (33.3%)	8 (50%)
	Brief Fatigue Inventory	2 (11.1%)	1 (6.3%)
	Multi-Symptom Inventory	0 (0%)	1 (6.3%)
	Quality of Life Scale	2 (11.1%)	2 (12.5%)
	Visual Analog Scale	1 (5.6%)	0 (0%)
	Other	0 (0%)	2 (12.5%)
	Not applicable	7 (38.9%)	3 (18.8%)
Assessment strategies to be used			
	Informal interview	7 (38.9%)	10 (55.6%)
	Edmonton Symptom Assessment Scale	9 (50%)	11 (68.8%)
	Comprehensive fatigue assessment	10 (55.6%)	11 (68.8%)
	Medical exam	5 (27.8%)	7 (43.8%)
	Functional exam	6 (33.3%)	7 (43.8%)
	Referral	2 (11.1%)	5 (31.3%)
Systematically provide recommendations			
	Yes	16 (88.9%)	16 (100%)
	No	2 (11.1%)	0 (0%)
Recommendations offered			
	Psychoeducation	10 (55.6%)	13 (81.3%)

Energy conservation	14 (77.8%)	14 (87.5%)
Distractions	3 (16.7%)	9 (56.3%)
Monitoring of fatigue	11 (61.1%)	12 (75%)
Physical activity	16 (88.9%)	15 (93.8%)
CBT	6 (33.3%)	10 (62.5%)
Sleep optimization	14 (77.8%)	11 (68.8%)
CAM	15 (83.3%)	12 (75%)
Stress reduction	16 (88.9%)	13 (81.3%)
Pharmacotherapy	4 (22.2%)	3 (18.8%)
Acupuncture	4 (22.2%)	2 (12.5%)

Note. 1. N = 16, 2 missing

Table 4.

Pre and Post-training t-test comparisons

Variable	Pre-training (M, (SD))	Post-training (M, (SD))	T value	Significant p < .05 (Y/N)
Perceived knowledge	53.93 (23.89)	72.40 (11.84)	*t* (df)= -3.959(14)	Y
Perceived clinical experience	60.07 (22.02)	62.07 (20.35)	*t* (df) = -.427(14),	N
Self-efficacy assessment	3.57 (1.16)	4.36 (.50)	*t* (df)= 2.621(13)	Y
Self-efficacy intervention	3.64 (.75)	4.36 (.50)	*t(df)* = 2.924(13)	Y
Intentions	72 (16.89)	93 (14.04)	*t* (df)= 4.786(13)	Y

General Discussion

Thesis rationale

CRF is the most prevalent symptom experienced by cancer patients throughout all stages in the cancer trajectory and has an important impact on patient's quality of life, mental health, and level of functioning (Bower et al., 2014b; Jones et al., 2016). Much research has focused on the development of CRF assessment and intervention strategies which have promoted the development of comprehensive evidence-based guidelines (Howell et al., 2015; National Comprehensive Cancer Network, 2020). However, implementation gaps in the application of guidelines into practice are present (Berger et al., 2015; Borneman et al., 2007; Pearson et al., 2015a, 2017b). To date, little research has focused on understanding, untangling, and addressing these practice gaps. This thesis' manuscripts explored practice gaps and obstacles to CRF management and evaluated the efficacy and outcomes of a KT strategy aiming to improve the implementation of CAPO CRF guidelines into practice. The first study employed a qualitative approach to explore patients, HCPs, and CSPs' (n = 62) experience and opinions regarding CRF management to identify obstacles contributing to practice gaps. The second study aimed to address one practice gap, professionals' (HCPs and CSPs) lack of knowledge of CRF and CRF clinical practice guidelines, by developing and piloting a CRF training session for professionals (n = 18). This general discussion will report on the findings of these two studies, integrate these findings in accordance to relevant theoretical models and previous literature, and detail the studies' limitations, strengths, clinical implications, and future research directions.

Study 1: Review of objectives and hypotheses

The manuscript entitled "A Perfect Storm and Patient-Provider Break Down in Communication: Two Mechanisms Underlying Practice Gaps in Cancer-Related Fatigue

Guidelines Implementation." illustrates the results of a qualitative study of 62 participants—16 patients, 32 HCPs, and 15 CSPs HCPs and CSPs. Drawing on elements of the KTA model (i.e., assess barriers to knowledge use), the goal of the study was to explore key stakeholders' (patients, HCPs, CSPs) experiences and opinions on CRF assessment and management and to explore underlying causes of CRF treatment gaps. No specific hypotheses were determined given the exploratory nature of the study.

Study 1: Main Findings

The results of this study highlight CRF guideline implementation gaps, patient dissatisfaction with CRF care, and challenges contributing to CRF assessment and management gaps. HCPs and CSPs applied both evidence-based and non-evidence-based CRF assessment management strategies in their practice and strategies were applied inconsistently. These results are consistent with previous research suggesting that HCPs do not systematically assess for CRF, that they lack knowledge of clinical guidelines to assess and manage CRF (Borneman et al., 2010; Hilarius et al., 2011; Pearson et al., 2015b; Piper et al., 2008), and that stakeholders' hold diverse perspectives on CRF management (Pearson et al., 2017b). Although previous literature has identified barriers to CRF management, this study was the first to gain a qualitative multi-informant perspective on barriers to CAPO CRF guideline implementation. These results demonstrate that patients and providers share similar perspectives on CRF guideline implementation barriers. Specifically, the results of this study identified potential mechanisms precipitating and perpetuating current implementation gaps in CRF management. First, HCPs and CSPs' lack CRF knowledge, are faced with systemic obstacles to manage CRF within the healthcare system and while attempting to work within multidisciplinary teams, and they experience time and funding constraints, which creates difficult conditions to adequately address

CRF (*A Perfect Storm*). Second, *Patient-Provider Communication Gaps* including professional's attempts to normalize patients' CRF without the provision of specific management strategies, the lack of follow-up on assessment measures, and lack of time lead to patients feeling discouraged to report issues to their healthcare teams and leave them turning to alternative services for help. Understanding these mechanisms provides clarity on the potential causes maintaining CRF treatment gaps and can help direct targeted knowledge translation strategies to improve the implementation of CAPO CRF guidelines into practice. Consistent with a recent Delphi study (Pearson et al., 2017b), the results supported the need for professionals' training on CRF guidelines to fill knowledge gaps.

Study 2: Review of objectives and hypotheses

The manuscript entitled "Translating Guidelines to Practice: A Training Session on Cancer-Related Fatigue" illustrates the results of a mixed-methods pilot study with 18 HCPs and CSPs. The goal of the study was to develop and evaluate the acceptability and feasibility of a one-time training session for HCPs and CSPs on CAPO CRF guidelines, once again following the KTA framework (Graham et al., 2006; Straus, 2011). A secondary objective was to evaluate the learning outcomes of the training session including CAPO CRF guidelines knowledge, self-efficacy, and intent to apply CAPO CRF guidelines in practice. The research hypotheses were that the training session would: 1) increase HCPs and CSPs' knowledge of CRF and of CAPO CRF guidelines; 2) increase HCPs and CSPs' self-efficacy to assess and intervene on CRF; 3) increase HCPs and CSPs' intention to apply CAPO CRF guidelines in practice; and 4) be acceptable (as evidenced by high HCPs and CSPs satisfaction) and feasible (as evidenced by acceptable recruitment time, participation rate, and post-training interviews).

Study 2: Main Findings

This study applied elements of the Knowledge-to-Action cycle (i.e. implementation of a KT intervention, monitoring of knowledge use, and outcome evaluation (Graham et al., 2006; Straus et al., 2013)) to pilot test the implementation of a training session and KT tool for HCPs and CSPs aiming to fill the HCPs/CSPs knowledge, resources, and patient-provider communication obstacles contributing to CRF practice gaps identified in Study 1 and the literature. Overall, results suggest that offering a brief one-time training for HCPs and CSPs on CRF guidelines appears acceptable and may also lead to improvement in CRF knowledge, self-efficacy, and intent to apply guidelines into practice. Similarly, that KT tools are appreciated by HCPs/CSPs and may be used in practice to supplement and sustain the knowledge and skills gained in training.

Integration of Findings

Conjointly, these two studies highlighted the possibility of further understanding, untangling, and addressing clinical practice guideline implementation gaps using mixed methods designs. Further, this thesis showcased the possibility of applying the KTA action cycle to gain a comprehensive understanding of CRF guideline implementation barriers, to adapt knowledge to the context, and implement KT strategies to address CRF clinical guideline implementation gaps. KT in health care is a complex process that involves the coordination and planning of many steps involving multiple stakeholders (e.g., policy makers, healthcare providers, patients). The KTA framework provides a comprehensive, systematic, and iterative approach that builds on the commonalities found in planned action theories to promote the transfer of scientific knowledge to action (Graham et al., 2006; Straus et al., 2013; Straus, 2011a; Straus et al., 2009). It differentiates KT, knowledge transfer, and knowledge exchange from action or knowledge use

which involves the use of knowledge in practice. Further, the KTA model integrates diverse subtasks and steps (e.g., identifying the problem, implementation) to provide a comprehensive guide of the KTA process that begins with knowledge creation and ends in action (knowledge use) (Graham et al., 2006). Adopting systematic and planned methods to foster the KTA process is essential to increase the likelihood of knowledge use (Straus, 2011b). Indeed, many barriers to knowledge use in health care exist, including systemic (e.g., financing), health care centers (e.g., lack of resources), health care teams (e.g., communication), individual health care professionals (e.g., variations in knowledge, attitudes and skills in critically appraising and using evidence from clinical literature), and patient (e.g., low adherence to recommendations) levels. Therefore, models to systematically evaluate the process of knowledge use such as the KTA framework are essential to orient the complex navigation involved in translating research into practice. The utilization of the KTA framework in this thesis provided a model to systematically guide, plan, and assess the process of translating the CAPO CRF guidelines into practice use.

CRF Practice Gaps

Previous research has demonstrated that evidence-based research recommendations take too long to be implemented into clinical practice leading to limited access to the best available evidence-based interventions, the provision of harmful or obsolete treatments to patients, and lower treatment outcomes (Graham et al., 2006; Straus, 2011b). This suggests that health care policy and systems fail to optimally use evidence with resulting treatment inefficiencies and reduced quality of life. A recent update on the status of the Institute of Medicine's report on cancer survivorship published in 2006 care indicated that much progress was made in the management of cancer survivors' needs over the past decade, however that many gaps remain to optimize the care of the growing population of cancer survivors (National Research Council,

2006; Nekhlyudov et al., 2017). The results of this thesis indicate that practice gaps remain present in CRF care despite significant research contributions to in the epidemiology and treatment of CRF (Berger et al., 2015; Bower et al., 2014b) as well as the availability of clinical practice guidelines (Howell et al., 2015; National Comprehensive Cancer Network, 2020).

The results of this thesis corroborate previous research identifying patient, provider, and systemic barriers to CRF guideline implementation (Borneman et al., 2007; Pearson et al., 2017b). Patient-provider communication gaps were identified in the interviews conducted, and the qualitative analyses revealed mechanisms underlying these gaps. Specifically, this thesis revealed that patients and providers appeared to misunderstand each other such that patients perceived providers' attempts to normalize their CRF as dismissive and invalidating whereas providers identified normalization of CRF as helpful intervention. Further, although providers expressed recommending CRF management strategies to their patients, patients, on their end, did not appear to receive and understand the provider's recommendations. Finally, consistent with previous research (Carter, Miller, et al., 2014; Fitch et al., 2008; Pertl et al., 2014), patients also expressed feeling uncomfortable to report their CRF to their oncology team due to perceived lack of time or interest of their providers and worries of burdening their provider with their psychosocial needs. These results highlight the importance of 1) HCPs and CSPs directly addressing CRF with their patients in order to open a dialogue surrounding this symptom and 2) of accompanying normalization and education strategies with specific recommendations for CRF management, potentially by providing tangible materials and resources (e.g., handouts, websites, referrals). This thesis piloted and evaluated the efficacy of a training session and KT tool on CRF CAPO guidelines, the first to date to evaluate the efficacy and feasibility of training methods for HCPs and CSPs on CRF. Study 2 provided a first effort to address patient-provider

communication gaps, via the HCP and CSP training on the CAPO CRF guidelines and role plays to practice assessment and intervention skills. Further KT strategies should be evaluated to improve patient provider communication surrounding CRF and other psychosocial symptoms. Some strategies may include the use of patient information booklets, increased accessibility to web-based and stepped care interventions for CRF for HCPs to refer patients to, and increased integration of medical and psychosocial HCPs in work teams to ensure the screening, assessment, and intervention for CRF across all stages of the cancer trajectory. Finally, future research should investigate the effectiveness of providers' communication of recommendations for CRF, based on clinical guidelines, using observational and behavioural measures.

This thesis also highlighted provider gaps including low levels of knowledge of CRF and CRF guidelines as previously reported in past literature (Abdalrahim et al., 2014; Given, 2008; Hilarius et al., 2011; Pearson et al., 2015a). These results corroborate with recent studies identifying HCPs education and training on CRF and CRF guidelines as an essential step to ensure the implementation of CRF guidelines into practice (Berger et al., 2015; Pearson et al., 2017b). Study 2's training session suggested that a brief training session can help address HCPs and CSPs knowledge gaps. Future research should evaluate the effectiveness of similar training methods via larger systematic studies and randomized controlled trials. Further, efforts to ensure provider training sustainability should also be investigated including online training systems.

Finally, systemic and organisational factors were also found to impact the implementation of CRF guidelines. As identified in past research, professionals' heavy workloads, lack of time, lack of systems to document CRF and other psychosocial symptoms, interprofessional communication, and lack of funding for psychosocial support were highlighted as important systemic obstacles (Berger & Mooney, 2016; Borneman et al., 2010; Pearson et al.,

2017b). Further, previous authors have identified the importance of integrating CRF and psychosocial screening, assessment, and intervention into routine care. This thesis provided a first evaluation of the efficacy of provider training and the use of a clinician KT tool (i.e., erasable flipchart checklist) to promote the use of CAPO CRF guidelines into routine care. Much efforts are needed to continue to investigate strategies to promote the implementation of CAPO CRF guidelines into routine practice. Future research should investigate strategies to incorporate similar KT tools into routine care such as built-in checklist and cues for CRF care pathway decision support to help clinicians evaluate and manage patients with moderate to severe CRF (Berger & Mooney, 2016; Pearson et al., 2017b).

***Two Underlying Mechanisms of CRF Practice Gaps*.** The results of this thesis also provide further perspective on potential interactions between previously established CRF practice gaps, which may provide a base to develop models illustrating these processes as well as identify key intervention targets to fill these gaps. Indeed, qualitative methods often lead to the development and quantitative testing of models (Braun & Clarke, 2006; Creswell, 2012). The two mechanisms developed in this thesis, *A Perfect Storm* and *Patient-Provider Communication Gaps*, following thematic analysis methods (Braun & Clarke, 2006), provide insights into potential predictors, correlates, and interactions between obstacles to guideline implementation, which could be further investigated using quantitative analyses. In terms of the *Patient-Provider Communication Gaps* mechanism, practice gaps such as lack of follow-up on ESAS scores and providers attempts to normalize patients' CRF without providing specific recommendations for CRF appeared to be related to patients' feeling dismissed. Further, systemic factors may interact and exacerbate patient-provider communication difficulties by limiting professionals face-to-face time with patients, which appeared to dissuade patients from reporting their CRF and perceive

their care teams to be closed to their psychosocial needs. Such interactions between non-verbal communication cues (e.g., hand on doorknob, provider remaining standing) and patients' perception of providers' openness to their psychosocial needs could be further investigated via quantitative methods. Identifying key relationships between practice gaps can help target specific KT interventions to fill these gaps and improve CRF guideline implementation.

Within the *A Perfect Storm* mechanism, HCPs and CSPs' lack of knowledge of CRF guidelines and resources for CRF management appeared to interact with system and organisational level obstacles by widening the communication gap amongst professionals regarding CRF and leaving professionals feeling ill equipped to address CRF within their own professions, their multidisciplinary teams, and organisations. Lack of funding and resources for psychosocial support also appeared to be a factor which contributed to professionals feeling under-equipped to manage their patients' CRF needs. Further, these struggles appeared to be complicated by the lack of profession-specific guideline recommendations which contribute to role confusion in the context of CRF management (Pearson et al., 2017b) as well as inter-patient variability in CRF presentation and need for support. Quantitative methods could be used to test the significance of such predictors on the efficacy of CRF guideline implementation, which may help predict and identify health centres or teams which may be at greater risk for lower guideline implementation.

Knowledge-To-Action Framework

As above described, this thesis' studies integrated many steps of the KTA framework's action cycle (Graham et al., 2006; Straus et al., 2013). In study 1, the individual and focus group interviews provided insight into strategies to *Adapt knowledge to local context* and allowed to *Assess barriers to knowledge use*. Its results supported previous research identifying patient,

provider, and systemic barriers in the implementation of evidence-based practice for CRF (Borneman et al., 2007b; Hilarius et al., 2011; Pearson et al., 2015b) and barriers to clinical practice guideline implementation identified in the Clinical Practice Guidelines Framework for Improvement (Cabana et al., 1999; Straus et al., 2013) such as lack of awareness and familiarity with CRF guidelines and systemic obstacles. Strategies to adapt the CAPO CRF guidelines to the local context were also identified including the need for bilingual resources to serve the francophone community of Ottawa, which was addressed by offering the CRF training in both English and French and developing a bilingual KT tool, and communication skills training to assist professionals in effectively communicating recommendations to their patients within limited time frames.

In study 2, the integration of findings from the interview and focus groups as well as consultations with our advisory committee led to the *Selection, tailoring, and implementation of a KT intervention*, the CRF training session for HCPs and CSPs and KT tool. Consultations with the advisory committee and the pedagogical expert allowed to further tailor the training to HCPs and CSPs' needs. Finally, pre and post measures as well as 3-month post training interviews allowed for the *Monitoring of knowledge use* and *Evaluation of outcomes* of the training session (Graham et al., 2006; Straus et al., 2013). Overall, this thesis' design demonstrates the possibility to adapt the KTA framework to develop, implement, and evaluate KT strategies in the context of CRF clinical guideline implementation.

Throughout this application of the KTA framework, the iterative nature of the model was helpful in order to navigate through the identification of barriers, adapting knowledge to the local context, and the selection, tailoring, and implementation of the KT intervention steps of the action cycle (Graham et al., 2006; Straus et al., 2013). This was accomplished throughout the

coding process and via multiple meetings with the consultation committee and pedogeological experts. As previously stated in the literature, limited research has been conducted on the sustainability of KT strategies (Straus et al., 2013). This may be related to the intricate complexity required to coordinate KT interventions at multiple outcome levels with diverse stakeholders each coming with their own set of barriers and challenges (Straus, 2011b). Researchers must continue their efforts to tailor scientific evidence to healthcare policy and policy makers should also favor the integration of research into policy development and decision-making. Future research should focus on the investigation of effective methods to promote KT sustainability to better equip researchers, clinicians, and decision-makers to incorporate this step in their work. Overall, the KTA framework provided a comprehensive model to pilot a locally based KT strategy to promote the translation of CAPO CRF clinical guidelines into practice.

Qualitative methods

This thesis applied phenomenological approach to gain a rich understanding of the phenomenon of CRF guideline implementation gaps. Phenomenological principals were used to guide the participant selection to include the participants most affected by the phenomenon at study (Creswell, 2012), which included both patients and professionals (HCPs and CSPs) working within the Ottawa region. Further, efforts were made to include professionals and patients in both official languages (English and French). Phenomenological principals were also used to develop Study 1's interview guide to explore participants' experience with CRF guideline implementation from each stakeholder's perspective. Thematic analysis methods were used to guide the coding of Study 1's data, which allowed the elaboration of two models of mechanisms contributing to and maintaining implementation gaps in CAPO CRF guidelines

which stem from the data collected (Braun & Clarke, 2006). Developing models from the data itself following a bottom-up method is a key component of thematic analysis and represents a significant contribution of this thesis by suggesting first models of possible interactions between patient, provider, and systemic barriers which maintain gaps in CRF guideline implementation.

HCP and CSP training

This thesis was the first study to our knowledge to evaluate the effectiveness and feasibility of a training session on CRF guidelines for HCPs and CSPs. Training strategies demonstrating effectiveness in HCP communication training were applied, such as the combination of lectures (i.e., power point presentation) and didactic training (i.e., role play) activities (Barth & Lannen, 2011; Bos – van den Hoek et al., 2019; Gysels et al., 2004). The results from this pilot study on the acceptability and preliminary efficacy of the CRF training session contributes to the literature on continuing education in health care and demonstrates that HCPs and CSPs can benefit from one-time training sessions. These results also suggest that one-time training sessions can lead to conceptual and instrumental knowledge use (Straus et al., 2013). Indeed, these results showed increased knowledge levels and understanding of CAPO CRF guidelines post-training and intentions to adjust behaviour to follow CRF guideline recommendations demonstrating positive changes in levels of conceptual CRF knowledge use (Straus et al., 2013). Further, post-training interviews revealed instrumental changes in practice including the use of the KT tool in practice and self-reported changes in practice in accordance to CRF guidelines presented (Straus et al., 2013). Previous research suggests that HCP training and continuing education can lead to diverse outcomes including provider, patient, and society level changes (Straus et al., 2013). This thesis limited its outcome evaluation to provider outcomes including feasibility indicators such as attendance and participation rates and participant

satisfaction as well as learning outcomes including knowledge, self-efficacy, and intentions to apply learning into practice. Further research should be conducted in order to evaluate the potential outcomes of HCP CRF guideline training on patient outcomes and satisfaction with care.

Training Outcomes: Behavioural intentions, self-efficacy. This thesis drew on components of the Theory of Planned Behaviour to guide the selection of outcome measures for the CRF training session including behavioural intentions and self-efficacy (Ajzen, 1985). The results indicate an increase in behavioural intentions to apply the CAPO CRF guidelines into practice from pre to post-training. Although behavioural intentions may be an imperfect predictor of behavioural change (Ajzen, 2011; Sniehotta et al., 2014), these results indicate that a short one-time training session may be effective in increasing professionals' intentions to apply evidence-based guidelines. The results also demonstrated increased self-efficacy to implement CAPO CRF guidelines into practice from pre- to post-training. These results suggest that the training session developed offered sufficient information and practical skills to help professionals feel more confident in their abilities to screen, assess, and intervene for CRF and want to use guidelines to direct their work. Although other components of the TPB model were not directly measured, the qualitative data collected provides insights into the potential influence of social norms and attitudes towards evidence-based guidelines for CRF and interdisciplinary interventions for cancer care. Indeed, this thesis' results highlight the lack of social norms to manage CRF and other psychosocial needs as an interdisciplinary team. Oncology care and survivorship care appear to work in silos of professional expertise rather than offering comprehensive programs to patients as evident for other chronic illnesses (e.g., cardiac rehabilitation). This appears to be a significant barrier to the adequate implementation of CAPO

CRF guidelines which require the collaboration of multiple healthcare disciplines. Finally, professionals' personal attitudes towards evidence-based guidelines and their perceptions of social norms towards the implementation of evidence-based guidelines within their work teams and organizations should be investigated as potential barriers to CAPO CRF guideline implementation in future research.

Thesis Limitations

It is important to note some limitations of this thesis' aforementioned studies. Study 2 had a relatively small sample sizes (n=18), therefore the results should be interpreted with caution. Furthermore, a convenience sampling method was used, which may have led to the recruitment of a sample with more favorable attitudes towards CRF guideline implementation compared to the general population. Therefore, results from both studies should be interpreted with caution. In terms of sampling representation, although both studies sought to recruit diverse samples of patients, HCPs, and CSPs, some important stakeholders were not successfully recruited. General practitioners play an important role in the provision of care in coordinating cancer care, managing comorbidities, and providing psychosocial care to patients and their families (Easley et al., 2017). Although efforts were made to recruit general practitioners to participate in these studies (i.e., emails), none were successfully recruited. This may be indicative of general practitioner's busy schedules or the need to engage them in research participation via different methods (e.g., in-person meetings, recruitment via a research champion with similar professional title (MD)). Further, hospital administrators also represent an important stakeholder group involved in healthcare management, decision-making and policy implementation. Although healthcare managers provided their support for these studies by allowing their employees time during their shifts to participate in focus groups and the training sessions and by providing rooms

for these meetings, only one administrator (of a community psychosocial oncology organization) participated in the focus group interviews. Approaching hospital managers and administrators individually and offering them individual interview times may have lifted barriers to their participation.

For Study 1, social desirability biases may have influenced professionals' report of their knowledge and experience with CRF management in relation to fear of judgement on behalf of the interview facilitators, given their status as researchers/psychologists, as well as their colleagues participating in their focus groups. Further patients self-report during the focus groups may also have been influenced by social desirability factors and interactions between their fellow focus group participants as well as with the group facilitators. In particular, the facilitators' statuses of researchers/psychologists may have influenced participants report of their opinions and experiences with healthcare teams. Further, although individual interviews with physicians provided a shorter time commitment allowing them to participate in Study 1, due to their nature, discussions and exchanges amongst participants did not occur which impacts the richness of results and themes collected within this subgroup.

For Study 2, the pre-post training outcomes should be interpreted with caution given that the fidelity and validity of most of the outcome measures were not previously assessed. Indeed, the self-efficacy, CRF knowledge, and behavioural intentions questionnaires were developed by the authors or modified from previous research on similar outcome measures. Further, all measures used in this study are self-report questionnaires. Therefore, data is susceptible to the respondent's ability to recall and social desirability. In addition, no observational methods were used to test participants' application of learning into practice and evaluate actual change in behaviour and the study was limited in its cross-sectional design, which only allowed to measure outcomes within 2

weeks after the training session. Finally, the study's original aim was to include a patient representative on the consultation committee to ensure the representation of patients' concerns and needs throughout the development of the training session, however patient recruitment efforts were unsuccessful for participation in this role.

Thesis Strengths

This thesis' studies pose an original contribution to research by investigating CRF guideline implementation gaps and was the first to pilot a HCP and CSP training session and KT tool on CRF guidelines. The findings in both study 1 and study 2 bring awareness to the understudied topic of CRF guideline implementation gaps and KT strategies and illustrate how present this concern is for patients, HCPs, and CSPs. Given the absence of previous literature that aims to address CRF guideline implementation gaps, this thesis not only addresses the gaps in the literature, but also has the potential to impact patient services for survivors living with CRF. Further, this thesis was anchored in the KTA framework which guided the developed of its research design following its action-cycle steps (Graham et al., 2006; Straus et al., 2013). The results demonstrated the efficacy of use of the KTA cycle to find a locally based KT strategy to promote the translation of CAPO CRF clinical guidelines into practice. Indeed, the implementation of the KTA model led to the development of an acceptable training session and KT tool that can be tested in larger studies. Overall findings from these studies indicate that although many practice gaps exist in CRF management, that they can be addressed effectively via simple interventions such as HCP and CSP education and training.

Noteworthy strengths of this thesis' studies are the use of qualitative analyses which provided an in-depth understanding of underlying mechanisms maintaining CRF guideline implementation gaps. Further this thesis sought multi-informant perspectives in order to gain a

complete and comprehensive understanding of the phenomenon at study following an interpretive phenomenological research approach (Creswell, 2012; Smith & Shinebourne, 2012). Finally, this thesis used a pilot study design to assess the acceptability and feasibility outcomes of a training session on CRF guidelines using both quantitative measures and qualitative interviews to assess training outcomes and to gain a rich understanding of participants' experience during and post-training.

Clinical Implications

This thesis was one of the first studies to investigate CRF practice gaps from a multi-informant perspective (Pearson et al., 2017b). Specifically, this thesis captured the experience and opinions of several stakeholder groups affected by CRF. This research provided a voice for patients to express the burden of CRF on patients' quality of life and functioning demonstrating the importance to improve the management of this symptom. The results also provided clarify on barriers that HCPs and CSPs face in their routine practice which impede their ability to manage CRF. These results stress the importance of ensuring that CRF is screened for, monitored, and comprehensively assessed following CAPO CRF care pathways (Howell et al., 2015) and is at the forefront of symptom monitoring in all cancer clinics and survivorship services. Further, that HCPs and CSP receive support from their organizations to be able to implement CRF clinical guidelines into their practice.

Furthermore, currently, there is limited research literature investigating the dissemination of CRF guidelines into practice (Berger et al., 2015; Berger & Mooney, 2016; Pearson et al., 2015a, 2017b). KT strategies are essential to promote the application of evidence-based practices into clinical care to improve patient's health, provide more effective health services and products and strengthen health care system (Government of Canada, 2010). This thesis was one of the first to

investigate HCPs and CSPs' knowledge of CRF guidelines and CRF guideline implementation gaps and was the first to develop and evaluate a KT strategy to promote the implementation of CRF guidelines into practice. These results suggest that short-term in-person training can lead to improved knowledge, self-efficacy, and intentions to apply new knowledge into practice. Specifically, pre and post-training results suggest increased HCP and CSP knowledge of CRF screening, assessment, and management guidelines which may lead to changes in professional's approach to managing this symptom and ultimately increased implementation of CAPO CRF guidelines into practice. Longer-term outcomes of systematic implementation of CAPO CRF guidelines include patient satisfaction with care, improved patient health and mental health outcomes, and lower healthcare utilization (Borneman, 2013; Bower et al., 2014b; Wu & Harden, 2015). Although further clinical implications of this thesis' studies are premature, this thesis provides preliminary evidence for the continued investigation on how the CAPO CRF training module can be widely implemented if shown to be effective in a sufficiently powered randomized controlled trial in future research.

Future Directions

Because this thesis represented a first pilot study evaluating the efficacy of this novel CRF training session, further systematic research should be conducted in order to assess the training's effectiveness in increasing HCPs and CSPs' knowledge of CRF guidelines, self-efficacy, and intentions of adopting practice guidelines via a randomized controlled trial (RCT). Further, instrumental learning outcomes associated to CRF training such as practice uptake, should be evaluated in future research (Straus et al., 2013). Methods to assess practice changes should include self-report measures, observational methods, and medical chart reviews. Common factors influencing HCPs' intent to apply CRF clinical guidelines into practice, such as their

attitudes and skills in critically appraising and using evidence from clinical literature, should also be evaluated as potential predictors of guideline implementation (Straus, 2011b). As above described, the results if this thesis demonstrated how the KTA model can be applied to identify barriers to clinical CRF guideline implementation, adapt knowledge tools to the local context, develop and implement a KT strategy to address implementation gaps, and evaluate its outcomes KTA. However, this thesis did not evaluate the sustainability of the training session and longitudinal outcomes. Future research should focus on evaluating strategies to ensure the sustainability of HCPs and CSPs CRF training methods. The efficacy and effectiveness of the provision of this training strategy via web-based platforms should be considered to achieve sustainable training methods. Providing in-person training to professionals at psychosocial oncology professional and research conventions as part of continuing professional education programs and workshops could also be investigated as methods to promote the delivery of effective training to wide-spread groups of psychosocial oncology professionals in a sustainable fashion.

Study 1 identified various factors contributing to the maintenance of CRF practice gaps. Study 2 results suggest that a brief training session for HCPs and CSPs can address practice gaps related to lack of HCP and CSP's knowledge of guidelines and improve their self-efficacy to assess and intervene for CRF. Many practice gaps identified remain to be further investigated and KT strategies to address these remaining gaps should be investigated. Indeed, many gaps related to systemic barriers, patient-provider communication, and related to the guidelines themselves in particular the integration of interdisciplinary care into routine CRF care. As previously reported by Berger (2015), these results suggest the need for tools and clinical protocols to integrate CRF guideline recommendations into usual practice. Indeed, although

many HCPs worked at institutions which implemented systematic ESAS screening for CRF and other symptoms, scores were not documented or systematically reviewed with patients. Future research should investigate the efficacy of systems to integrate the CRF CAPO care pathways into routine care. Promising strategies may include the use of electronic algorithms, prompts integrated into electronic charts, and the systematic use of electronic screening measures (Berger & Mooney, 2016). The digitalization of the KT tool (clinical checklist) piloted in this thesis could also be piloted and evaluated as a next step towards maintaining the sustainability and integration of guidelines into routine care. Authors have also expressed the need to improve access to services by disseminating evidence-based interventions in patient-focused online intervention tools. Web-based psychoeducational materials and intervention platforms following stepped care intervention principals for CRF warrant investigation. Such interventions may help alleviate pressures on the already oversaturated healthcare system as well as provide a much-needed resource for patients struggling with CRF. Further, Pearson et al. (2017) s' Delphi study revealed gaps in inter-professional management of CRF and highlighted the need for profession-specific summaries of CAPO CRF clinical guideline pathways. Although a strength of the CAPO CRF guidelines is that they are interdisciplinary, this also leads to difficulties coordinating CRF care and leads to role confusion amongst professionals, these issues were also demonstrated in this thesis' results. Indeed, the implementation of CAPO CRF guidelines require the coordination of multidisciplinary healthcare and community support providers to perform the screening, comprehensive assessment, and offer a multitude of evidence based CRF management interventions (Howell et al., 2015). Therefore, the development of practice guidelines which translate to each profession's role in the screening, assessment, and management of CRF should be a priority for future research. Further, research should investigate the systematic application

of guidelines into clinical practice in order to adequately assess their implementation feasibility with multidisciplinary HCP teams across diverse sites. Such implementation and dissemination strategies may help fill many practice gaps, increase the application of CRF clinical guidelines into practice and ultimately improve patient satisfaction with care and quality of life.

Overall, the results from these studies demonstrate that CRF practice gaps remain present and that KT strategies can be effective in improving the application of clinical guidelines into practice. It is hoped that future research efforts will build on these results and continue to promote the implementation of CRF guidelines into practice to ultimately improve patient care and quality of life.

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Appendices

Appendix I. Supplementary Table

Code Citation Table by Participant Group			
	Patients	Healthcare providers	Community Support Providers
		Description of CRF	
Code			
Description of CRF	*It's not that you want to sleep, it's like every cell in your body doesn't have energy, it feels completely different than staying up until midnight and being sleepy. It's not the same feeling at all.*	*It can be physical, or it can also mental, so people talk about cognitive fatigue as well as physical fatigue.* - Nurse	*It's different from previous kinds of fatigue where you might gradually get slower. It's huge, It's a cluster.*
Frequency	*I could have a nap all the time. Like right now I could lie down on this table and have a nap.*	*"I'm tired" that's like probably 90% of our patients or higher.* – Radiation technician	*It often comes up in a conversation, but it becomes so much a part of their experience that they don't always name it as such*

Trajectory	*I'd say after about 8 treatments [radiation] and then the fatigue hit me and I've never come back since*	*After they finish all the treatments it becomes more obvious because they are expected to get back to a more normal life. But there's work, family, at home etc. and they say "Oh my Gosh, I can't"* – Radiation oncologist	*Both people while they are in treatments, and many which have completed treatment but are now living with this exhaustion in their daily lives*
Impact	*Before I had cancer, I was active; I had two jobs. I could do both no problem. Suddenly, I had to lie down before the two meetings. I would come home and if I had the choice of lying down or eating I would lie down because that was the only way I could go to the meeting.*	*That inability not to be normal and active in the way that they were prior to the cancer diagnosis and treatment* – Psychosocial oncology team	*Just the energy to eat well, to do all of the good things that they want to do, and they have fear of recurrence and know they should be doing all of this healthy stuff, but they don't have the energy to go to the store and buy the healthy groceries*
Contributing factors			
Psychological	*Its the anxiety about it coming back, stress at work, it's just I can't stay up as late... Sometimes I feel like I have an 80-year-old body in a 58-year-old body.*	*So they're feeling anxious about their diagnosis, they're feeling anxious about their future whether they have supports or not. And all those things combined.* – Radiation technician	*Such an abundance of stress; not knowing physically what's going to happen, the fear of all those things, the worry about your kids and your family, and finances. That anxiety, or any mild depression would relate to that fatigue as well.*

Physical	*I didn't have chemotherapy, but I found the radiation therapy exhausted me.*	*Usually it depends on the kind of cancer, there some cancers where people are more tired than others. It depends too a lot on therapy, and if there's concurrent [rads] and chemo, the length of their protocol.* - Nurse	*It depends on which stage they come.*
Expectations to be back to normal	*They think that you go to the hospital, that you have surgery, that you go out of there, then go to work! You feel rejected, if you feel that you do not have the same strength, you know that you do not have the strength.*	*Not being a burden on their family. "Oh my gosh another thing. I got through my treatment, my family helped me, and they took time off etc. And now I'm feeling tired they'll need to bring me to other appointments and things"*- Radiation Oncologist	*Expectations that family has that you should be normal, you should be back to normal– it's draining for people*
Social support	*It was hard when I went through cancer treatment, but I was lucky in the sense that my mom and sister just pushed themselves in there and supported me mentally and my husband.*	*"Do you have family coming with you? Do you have children to drive you?" I had one woman take 3 buses to get here for treatment. It took her 2 hours to get here everyday on top of terrible treatment to begin with. –* Radiation technician	*You see the difference between a cancer survivor, who has had that support, whether it's been through a group session or just had that family support. Versus someone who has struggled with that all on their own.*

Perfect Strom

Knowledge of guidelines		*I am blissfully unaware of any specific recommendations.* – Radiation oncologist *Well for the CCO guidelines, we review and provide it; I would say we're probably familiar with that iteration tool 8 or 9 out of 10.* - Radiation technician	*I know I've read it, but it's been a long time.*
Lack of education and resources	*They need to be more aware of how the fatigue affects us. I think they take it too lightly or they take it for kind of like I said it's a ball floating, and no one really grabs it.*	*Pain, I know what to do, nausea I know what to do, fatigue I do not know what to do. I see it as if there is nothing I can do-* Physician	*They don't seem to have the information on the other side either, you know they're not well-educated on how they can make it easier, how they can discuss this with you in terms of coming up with a successful solution. Like they see you in this slot.*
Challenges to the Assessment and Management of CRF			
Systemic Costs	*The problem with the GPs is the way they're funded. They don't have the time to talk to you at length.*	*The issue becomes in the health care system right now there's limited funding and unfortunately things like managing fatigue is considered a luxury.* – Radiation oncologist	*It's a competitive market out there, um, certainly Health Canada and the Government are not going to bring up any money and make that a standard of care any time soon.*

Organizational	*They go on and on about the psychosocial centre, and they have physiotherapists, and they have all this other kind of stuff. But no one tells you, like, how to get an appointment there*	*I refer them, I lose them* - Surgeon *There isn't really like a quick snapshot of the issues and this what has been done today. There isn't really an easy way without you going back and reading a bunch of notes and trying to figure it out.* - Nurse	*Well I just think that we're all fighting for the same thing, and we don't work collaboratively, you know?*
Patient variability	*When I come home from work and I'm lying down on the couch it's hard to get off that couch. Especially when it's dark. When I'm on that couch and I'm watching whatever I'm watching and thinking "do I really want to go for a walk" and the answer is no.*	*People who sometimes need a little more and other people whose expectations are high, and they are constantly feeling that they're failing because they're not meeting those expectations. So, it's two very different populations, and of course everybody in between.* – Psychosocial oncology team	I*t's not just about individuals, but changing a whole family diet,; how everybody interacts, and eats, and exercises. I think there's a lot of home barriers, and it's just a different type of care that people are used to, there's not a pill that can fix CRF.*
Patient costs	*It would be nice to not have to pay because some of us don't have the money.*	*The problem with private providers is that people have to pay and some people may be willing and able to pay and some people may not be able.* – Radiation oncologist	*just offering it somewhere that is accessible - like free parking and all that.*

A breakdown in communication

If they don't report it, I don't ask	*When you go into the cancer center, they give you this little piece of paper, you do it on the machine. One day I put on 10… And you know what? Nobody took notice of that. I went home with it. Because she never asked, the doctor never asked me*	*We ask everyday, "how are you today, how are you doing?" –* Radiation technician	*"I do bring it up in terms of when they're saying: I want to lose weight, or I want to get healthier, or I want to exercise. When we're talking why is that not happening?"*
We do what we can, but it's not enough	*I've seen all 5 oncologists…each one on the oncology side were: "well that's normal", "that's the side effect. It'll go away. Give it a couple of years, it'll go away". No solution, no remedy*	*The more exercise you do, and the things that you chose in the time of day, and how to break it up. Making it custom is really the takeaway so that they don't get scared.* - Psychosocial oncology team	*We talk about a new normal, tell them to take time for themselves, and nap, don't plan so much in a day.*
Lack of time/heavy workload	*They have their timeslots and if you're in their office and you take too much of their time then everyone else gets backed up. My GP is nice, but they only have so much time...*	*We have most times, 15 minutes with our patients; 2 minutes getting the patient from the waiting room; then setting up the patient is another 5 minutes and then we have 7 to 8 minutes of treatment time and that doesn't leave a lot left for discussion. –* Radiation technician	

Patients don’t report	*It's just one of those things you're just like "why bother?"*	*I think that patients might be afraid to ask; they think they've already used up enough time of the health care professional or the system etc. And, and, some may think that they can deal with it themselves.*
Patients don’t feel understood	*I went in and I thought "Why am I here?" because she stood with her hand on the doorknob for the whole 5-minute interview*	*It’s quite um, demoralizing for, for the patients because they feel not heard.* - Psychosocial oncology team

Appendix II. HCP and CSP Consent Form Study 1

Minimal Risk Informed Consent Form for Participation in a Research Study

Study Title: An Intervention for the Management of Cancer Related Fatigue: What do Patients, Health Care Providers, and Community Partners Have to Say?

OHSN-REB Number: **#20170704-01H**

Researchers:

Principal Investigator: Dr. Cheryl Harris

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Funder: The Institut du savoir Montfort (ISM)

INTRODUCTION

You are being invited to participate in a research study. You are invited to participate in this study because you are a professional who has experience working with patients diagnosed with cancer. This consent form provides you with information to help you make an informed choice. Please read this document carefully and ask any questions you may have. All your questions should be answered to your satisfaction before you decide whether to participate in this research study.

Please take your time in making your decision. You may find it helpful to discuss it with your friends and family.

Taking part in this study is voluntary. Deciding not to take part or deciding to leave the study later will not result in any penalty or affect current or future health care or employment.

IS THERE A CONFLICT OF INTEREST?

There are no conflicts of interest to declare related to this study.

WHY IS THIS STUDY BEING DONE?

The purpose of this study is to determine the current opinions of patients, healthcare professionals (HCPs), and community support providers on cancer-related fatigue (CRF). CRF affects between 60 and 90% of cancer patients. Despite the Canadian Association of Psychosocial Oncology (CAPO)

recommending exercise as a treatment for CRF, no guidelines exist for such a treatment. We are seeking the opinions of the three groups we feel are most connected to CRF; patients, HCPs, and community support providers. These opinions will help create a plan to treat CRF effectively and sustainably.

HOW MANY PEOPLE WILL TAKE PART IN THIS STUDY?

It is anticipated that about 56 people will take part in this study, from The Ottawa Hospital.

WHAT WILL HAPPEN DURING THIS STUDY?

You will be asked to attend one focus group if possible or an individual interview. A focus group is a small group of representative people who are asked to speak about their opinions as part of the research. A moderator will organize the focus group. The focus group discussion will be about 30-60 minutes in length and will take place at The Ottawa General Hospital. If you are unable to participate in the focus group, you may participate in an individual interview that will take approximately 20-30 minutes of your time. You will be asked to speak about your professional opinion on issues surrounding cancer-related fatigue.

You will be provided with a questionnaire before you begin the study. The purpose of the questionnaire is to collect basic socio-demographics and information about your experience working with patients diagnosed with cancer. The questionnaire will take about 10 minutes to complete.

The information you provide is for research purposes only. Some of the questions are personal. You can choose not to answer questions if you wish. If you become uncomfortable during the focus group, you may leave at any time with no impact on your ability to offer services or your job and you will receive proper debriefing during which the purpose of the study will be provided as well as support resources and the investigators' contact information.

You will be audio/video recorded during the focus group.

At the conclusion of the focus group you will be asked if you are interested in participating in Part 2 of this study. If you are interested and agree, you will be given the opportunity to provide your contact information to the research team. Your contact information will remain secure on a Master list. You will be contacted prior to the commencement of Part 2 of this study, at which point you have the option to decline participation.

WHAT ARE THE RESPONSIBILITIES OF STUDY PARTICIPANTS?

If you choose to participate in this study, you will be expected to:

- Ask any of the investigators if you have any questions or concerns.
- Not discuss any information you learn in the focus group with others. This includes information about and opinions from other members.

HOW LONG WILL PARTICIPANTS BE IN THE STUDY?

Your participation on this study will last for no longer than 60 minutes.

CAN PARTICIPANTS CHOOSE TO LEAVE THE STUDY?

You can choose to end your participation in the focus group at any time without having to provide a reason.

If you decide to leave the study, you can ask that the information that was collected about you not be used for the study. Let the research team know if you choose this.

WHAT ARE THE RISKS OR HARMS OF PARTICIPATING IN THIS STUDY?

There are no medical risks to you from participating in this study, but taking part in this study may make you feel uncomfortable. You may become uncomfortable while discussing your experiences. You may choose not to answer questions or leave the group at any time if you experience any discomfort. While the study team will take precautions to protect your confidentiality we cannot guarantee that other members of the focus group will respect your privacy or keep the discussions of the group confidential.

WHAT ARE THE BENEFITS OF PARTICIPATING IN THIS STUDY?

There are no benefits to you for taking part in this study. However, we hope the information learned from this study will help researchers develop an intervention for cancer-related fatigue. Your participation will help ensure that the intervention created will reflect the needs of the patients.

HOW WILL PARTICIPANT INFORMATION BE KEPT CONFIDENTIAL?

If you decide to participate in this study, the research team will only collect the information they need for this study. Records identifying you at this centre will be kept confidential and, to the extent permitted by the applicable laws, will not be disclosed or made publicly available, except as described in this consent document. Participants' names will be replaced with random numbers when analysing the data and will be kept under password protected files in Dr. Lebel's locked lab at the University of Ottawa's main campus.

Authorized representatives of the following organizations may look at your original (identifiable) records at the site where these records are held, to check that the information collected for the study is correct and follows proper laws and guidelines.

- The Ottawa Health Science Network Research Ethics Board who oversees the ethical conduct of this study in Ontario

During the discussions, participants will be encouraged to refrain from using names. If names or other identifying information is shared during the discussion, it will not be included in the written records.

The video/audio recordings will be stored in a secure location and viewed only by members of the research team. The recordings will be kept until they have been transcribed (turned into written records), and then they will be destroyed.

If the results of this study are published, your identity will remain confidential. It is expected that the information collected during this study will be used in analyses and will be published/ presented to the scientific community at meetings and in journals.

Even though the likelihood that someone may identify you from the study data is very small, it can never be completely eliminated.

WHAT IS THE COST TO PARTICIPANTS?

Taking part in this study may result in added costs to you. For example:

- You may miss work as a result of participation in this study.

ARE STUDY PARTICIPANTS PAID TO BE IN THIS STUDY?

If you decide to participate in this study, you will be offered a light snack during your participation in the focus group.

WHAT ARE THE RIGHTS OF PARTICIPANTS IN A RESEARCH STUDY?

You will be told, in a timely manner, about new information that may be relevant to your willingness to stay in this study.

You have the right to be informed of the results of this study once the entire study is complete. If you would like to be informed of the results of this study, please tick the appropriate box.

Would you like to receive a summary of research results?

□ Yes □ No

Contact: _____

Your rights to privacy are legally protected by federal and provincial laws that require safeguards to ensure that your privacy is respected.

By signing this form, you do not give up any of your legal rights against the researcher or involved institutions for compensation, nor does this form relieve the researcher or their agents of their legal and professional responsibilities.

You will be given a copy of this signed and dated consent form prior to participating in this study.

WHOM DO PARTICIPANTS CONTACT FOR QUESTIONS?

If you have questions about taking part in this study, you can talk to your study doctor, or the doctor who oversees the study at this institution. That person is:

Dr. Cheryl Harris	613-737-8899 ext.79533
Principal Investigator	Telephone

If you have questions about your rights as a participant or about ethical issues related to this study, you can talk to someone who is not involved in the study at all. Please contact The

Ottawa Health Science Network Research Ethics Board, Chairperson at 613-798-5555 extension 16719.

Study Title: An Intervention for the Management of Cancer Related Fatigue: What do Patients, Health Care Providers, and Community Partners Have to Say?

SIGNATURES

- All my questions have been answered,
- I understand the information within this informed consent form,
- I have read, or someone has read to me, each page of this participant informed consent form,
- I do not give up any of my legal rights by signing this consent form,
- I agree to take part in this study.

Signature of Participant	Printed Name	Date

Investigator or Delegate Statement

I have carefully explained the study to the study participant. To the best of my knowledge, the participant understands the nature, demands, risks and benefits involved in taking part in this study.

Signature of Person Conducting the Consent Discussion	Printed Name and Role	Date

Appendix III. Patient Consent Form Study 1

Minimal Risk Informed Consent Form for Participation in a Research Study

Study Title: An Intervention for the Management of Cancer Related Fatigue: What do Patients, Health Care Providers, and Community Partners Have to Say?

OHSN-REB Number: **#20170704-01H**

Researchers:

Principal Investigator: Dr. Cheryl Harris

Clinical, Health, and Rehabilitation Psychologist, Psychosocial Oncology, The Ottawa Hospital

501 Smyth Road – Box 918, Ottawa, ON, K1H 8L6

Email: charris@toh.ca, phone: 613-737-8899 x 79533

Co-Investigator: Dr. Sophie Lebel

School of Psychology, Faculty of Social Sciences, University of Ottawa

Email: sophie.lebel@uottawa.ca, phone: (613) 562-5800 ext. 4811

Funder: The Institut du savoir Montfort (ISM)

INTRODUCTION

You are being invited to participate in a research study. You are invited to participate in this study because you have experienced cancer-related fatigue. This consent form provides you with information to help you make an informed choice. Please read this document carefully and ask any questions you may have. All your questions should be answered to your satisfaction before you decide whether to participate in this research study.

Please take your time in making your decision. You may find it helpful to discuss it with your friends and family.

Taking part in this study is voluntary. Deciding not to take part or deciding to leave the study later will not result in any penalty or affect current or future health care or employment.

IS THERE A CONFLICT OF INTEREST?

There are no conflicts of interest to declare related to this study.

WHY IS THIS STUDY BEING DONE?

The purpose of this study is to to determine the current opinions of patients, healthcare professionals (HCPs), and community support providers on cancer-related fatigue (CRF). CRF affects between 60 and 90% of cancer patients. Despite the Canadian Association of Psychosocial Oncology (CAPO)

recommending exercise as a treatment for CRF, no guidelines exist for such a treatment. We are seeking the opinions of the three groups we feel are most connected to CRF; patients, HCPs, and community support providers. These opinions will help create a plan to treat CRF effectively and sustainably.

HOW MANY PEOPLE WILL TAKE PART IN THIS STUDY?

It is anticipated that about 56 people will take part in this study, from The Ottawa Hospital.

WHAT WILL HAPPEN DURING THIS STUDY?

You will be asked to attend one focus group. A focus group is a small group of representative people who are asked to speak about their opinions as part of the research. A moderator will organize the focus group. The focus group discussion will be about 60 minutes in length and will take place at The Ottawa General Hospital. You will be asked to speak about your personal experience living with cancer-related fatigue.

You will be provided with a questionnaire before you begin the study. The purpose of the questionnaire is to collect basic socio-demographics. The questionnaire will take about 10 minutes to complete.

The information you provide is for research purposes only. Some of the questions are personal. You can choose not to answer questions if you wish. If you become uncomfortable during the focus group, you may leave at any time with no penalty or impact on your current or future health care and you will receive proper debriefing during which the purpose of the study will be provided, as well as support resources and the investigators' contact information.

You will be audio/video recorded during the focus group.

At the conclusion of the focus group you will be asked if you are interested in participating in Part 2 of this study. If you are interested and agree, you will be given the opportunity to provide your contact information to the research team. Your contact information will remain secure on a Master list. You will be contacted prior to the commencement of Part 2 of this study, at which point you have the option to decline participation.

WHAT ARE THE RESPONSIBILITIES OF STUDY PARTICIPANTS?

If you choose to participate in this study, you will be expected to:

- Ask any of the investigators if you have any questions or concerns.
- Not discuss any information you learn in the focus group with others. This includes information about and opinions from other members.

HOW LONG WILL PARTICIPANTS BE IN THE STUDY?

Your participation on this study will last for about 60 minutes.

CAN PARTICIPANTS CHOOSE TO LEAVE THE STUDY?

You can choose to end your participation in the focus group at any time without having to provide a reason.

If you decide to leave the study, you can ask that the information that was collected about you not be used for the study. Let the research team know if you choose this.

WHAT ARE THE RISKS OR HARMS OF PARTICIPATING IN THIS STUDY?

There are no medical risks to you from participating in this study, but taking part in this study may make you feel uncomfortable. You may become uncomfortable while discussing your experiences. You may choose not to answer questions or leave the group at any time if you experience any discomfort. While the study team will take precautions to protect your confidentiality we cannot guarantee that other members of the focus group will respect your privacy or keep the discussions of the group confidential.

WHAT ARE THE BENEFITS OF PARTICIPATING IN THIS STUDY?

There are no benefits to you for taking part in this study. However, we hope the information learned from this study will help researchers develop an intervention for cancer-related fatigue. Your participation will help ensure that the intervention created will reflect the needs of the patients.

HOW WILL PARTICIPANT INFORMATION BE KEPT CONFIDENTIAL?

If you decide to participate in this study, the research team will only collect the information they need for this study. Records identifying you at this centre will be kept confidential and, to the extent permitted by the applicable laws, will not be disclosed or made publicly available, except as described in this consent document. Participants' names will be replaced with random numbers when analysing the data and will be kept under password protected files in Dr. Lebel's locked lab at the University of Ottawa's main campus.

Authorized representatives of the following organizations may look at your original (identifiable) records at the site where these records are held, to check that the information collected for the study is correct and follows proper laws and guidelines.

- The Ottawa Health Science Network Research Ethics Board who oversees the ethical conduct of this study in Ontario.

During the discussions, participants will be encouraged to refrain from using names. If names or other identifying information is shared during the discussion, it will not be included in the written records.

The video/audio recordings will be stored in a secure location and viewed only by members of the research team. The recordings will be kept until they have been transcribed (turned into written records), and then they will be destroyed.

If the results of this study are published, your identity will remain confidential. It is expected that the information collected during this study will be used in analyses and will be published/ presented to the scientific community at meetings and in journals.

Even though the likelihood that someone may identify you from the study data is very small, it can never be completely eliminated.

WHAT IS THE COST TO PARTICIPANTS?

Taking part in this study may result in added costs to you. For example:

- You may miss work as a result of participation in this study.

ARE STUDY PARTICIPANTS PAID TO BE IN THIS STUDY?

If you decide to participate in this study, you will be reimbursed upwards of $ 13 for some study related expenses such as parking. You will need to provide your receipts for parking to the research staff in order to be reimbursed. You will be offered a light snack during your participation in the focus group.

WHAT ARE THE RIGHTS OF PARTICIPANTS IN A RESEARCH STUDY?

You will be told, in a timely manner, about new information that may be relevant to your willingness to stay in this study.

You have the right to be informed of the results of this study once the entire study is complete. If you would like to be informed of the results of this study, please tick the appropriate box.

Would you like to receive a summary of research results?

☐ Yes ☐ No

Contact: _____

Your rights to privacy are legally protected by federal and provincial laws that require safeguards to ensure that your privacy is respected.

By signing this form, you do not give up any of your legal rights against the researcher or involved institutions for compensation, nor does this form relieve the researcher or their agents of their legal and professional responsibilities.

You will be given a copy of this signed and dated consent form prior to participating in this study.

WHOM DO PARTICIPANTS CONTACT FOR QUESTIONS?

If you have questions about taking part in this study, you can talk to your study doctor, or the doctor who oversees the study at this institution. That person is:

Dr. Cheryl Harris	613-737-8899 x 79533
Principal Investigator	Telephone

If you have questions about your rights as a participant or about ethical issues related to this study, you can talk to someone who is not involved in the study at all. Please contact The Ottawa Health Science Network Research Ethics Board, Chairperson at 613-798-5555 extension 16719.

Study Title: An Intervention for the Management of Cancer related Fatigue: What do Patients, Health Care Providers, and Community Partners Have to Say?

SIGNATURES

- All my questions have been answered,
- I understand the information within this informed consent form,
- I have read, or someone has read to me, each page of this participant informed consent form,
- I do not give up any of my legal rights by signing this consent form,
- I agree to take part in this study.

Signature of Participant	Printed Name	Date

Investigator or Delegate Statement

I have carefully explained the study to the study participant. To the best of my knowledge, the participant understands the nature, demands, risks and benefits involved in taking part in this study.

Signature of Person Conducting the Consent Discussion	Printed Name and Role	Date

Appendix IV. HCP and CSP Interview Guide Study 1

Opening word:

- The group leaders will present themselves and will present the objective of the focus group
- The group leaders will ensure that all participants still consent to participating in the study and to being filmed
- Group leaders will explain that they are responsible for the confidentiality and the anonymity of the participants and will ask the participants to ensure the confidentiality of the others in the group

CRF questions for HCPs:

1. What is your understanding of the components of CRF or how would you define CRF?
    - What is your understanding of the impact of CRF?
2. In your experience, how often and at what point do patients report CRF?
    - Probe: When do you feel CRF is more prevalent?
3. How often do you actively assess patients for CRF in your practice and how do you do this?
    - *Probe: Do you ask questions? Do you run specific tests? Which ones?*
4. What do you want to rule out in patients with CRF before you recommend self-care strategies?
5. What treatment(s) for CRF do you recommend to your patients?
    - *Probe: Why do you recommend these? What informs your recommendations?*
    - *Probe: Do you vary your recommendations based on the patient's trajectory in their cancer journey (i.e. active treatment, end of life, survivorship)? What do you recommend for patients newly diagnosed with cancer? What about those on treatment? What about for pts who have just completed tx? And finally what do you suggest in patients who are in well-follow-up/survivorship?*

- *Probe: Do you recommend physical activity, CBT, energy conservation strategies?*

6. Can you describe your level of familiarity with the CAPO/NCCN/CCO/COSTAR guidelines on CRF?
7. If we wanted to improve the way we manage CRF, what would be an ideal assessment and intervention plan?
    - *Probe: Who do you think should provide patients with this assistance?*
    - *Probe: Where should patients receive this assistance?*
    - *Probe: How should patients receive this assistance? (e.g., face-to-face, online)*
8. What barriers do you experience in practice for the assessment and intervention for CRF? What barriers to you think patients experience? How could they be avoided?
9. What could be done to ensure the assessment and management of CRF is sustainably done in the future?
10. Do you have any further comments or suggestions about CRF?

Appendix V. Patient Interview Guide Study 1

Opening word:

- The group leaders will introduce themselves and will present the objective of the focus group: To explore patients' experiences with cancer-related fatigue (CRF)
- The group leaders will ensure that all participants still consent to participate in the study and to being voice-recorded and to be filmed
- Group leaders will explain that they are responsible for the confidentiality and the anonymity of the participants and will ask the participants to ensure the confidentiality of the others in the group

CRF questions for patients:

1. Can you briefly describe your experience with CRF?

2. Can you explain what motivated you to report or withhold your CRF from any or all of your health care providers?

3. Has your health care provider assessed your CRF?
    - *Probe: How did they do this?*
    - *Probe: Did they ask you questions about your CRF? Like what?*
    - *Probe: Did they do blood tests? Do you recall discussing the results of these blood tests?*
    - *When did this happen?*
4. Have you ever received information to manage your CRF?
    - *Probe: Who provided you with this information?*
    - *Probe: When did they do this?*
    - *Probe: How helpful was this to you?*
5. Have you ever received strategies to manage your CRF?
    - *Probe: Who provided you with these strategies?*
    - *Probe: When did they do this?*

- *Probe: How helpful was this to you?*

6. How and when would you have liked information and strategies to be given to you?
7. What do you do to manage your CRF?
8. What would an ideal approach to help manage your CRF look like?
    - *Probe: We know that some things like physical activity, energy conservation (i.e., pacing yourself with periods of relaxation between periods of activity) as well as psychotherapy that can help you change unhelpful thoughts about feeling fatigued are useful to help manage CRF. Would you see yourself doing any of these things?*
9. What might get in the way of continuing with the recommendations for the management of CRF after the treatment ends?
    - *Probe: What might make it easier?*
10. Who do you think should be responsible for helping your manage your CRF? Where should you receive assistance to manage your CRF? And at what point in the cancer journey would you have liked to first receive assistance?
11. Is there anything you would like to add about CRF and your experience with it?

Appendix VI. HCP and CSP Questionnaire Study 1

What is your gender? _____ male _____ female

What is your age? _____ years

Which institution are you from?

What is your position there?

How many years have you been working in that position?

Appendix VII. Patient Questionnaire Study 1

What is your gender? _____ male _____ female

What is your age? _____ years

What is your mother tongue? _____

Are you currently employed? _____

	Yes, full time and I am working approximately __ hours/week _____
	Yes, part time and I am working approximately __ hours/week _____
	No, I am either temporarily or permanently not working

5. Which statement best applies to you?

	I was born in Canada
	I was NOT born in Canada and I have lived in Canada for ___ years _____

6. Please select the ethnicity with which you most strongly identify:

	Aboriginal (e.g., Inuit, Metis, First Nations, etc.)
	Arab / West Asian (e.g., Egyptian, Iranian, Lebanese, Moroccan, etc.)
	Black (e.g., African, Haitian, Jamaican, etc.)
	East Asian (e.g., Chinese, Filipino, Japanese, Korean, Vietnamese, etc.)
	Latin / Central American (e.g., Mexican, Columbian, Brazilian, Cuban, etc.)
	South Asian (e.g., Indian, Sri Lankan, etc.)

	White (Caucasian, European, etc.)
	Other, please specify _____

7. What is your <u>estimated annual family</u> income?

Less than $40,000

$40,000-$59,999

$60,000-$79,999

$80,000-$99,999

$100,000-$150,000

Greater than $150,000

I do not know

88

8. What is your cancer diagnosis? _____

9. When did you receive this diagnosis (MM/YYYY)? _____

10. What kind of treatment did you receive? _____

11. When did you complete treatment (MM/YYYY)? _____

12. Have you been diagnosed with other diseases? If so, which ones and when?

Appendix VIII. Debriefing Form Study 1

Debriefing Form

Thank you for your participation in our study! Your participation is greatly appreciated.

We previously informed you that the purpose of the study was to discover the opinions of patients, healthcare professionals, and community support providers on cancer-related fatigue and treatment for it. The goal of our research is to use these opinions to create a feasible and sustainable intervention for cancer-related fatigue.

We realize that some of the questions asked may have provoked strong emotional reactions. As researchers, we do not provide mental health services and we will not be following up with you after the study. However, we want to provide every participant in this study with a comprehensive and accurate list of clinical resources that are available, should you decide you need assistance at any time. Please see information pertaining to local resources at the end of this form.

Confidentiality:

You may decide that you do not want your data used in this research. If you would like your data removed from the study and permanently deleted please let us know immediately, or via email, or via phone. You can find the ways to reach us at the bottom of this form.

Final Report:

If you have selected that you would like to receive a copy of the final report of this study, we will contact you once it is available.

Furthermore, the next step after the dissemination of the results of this study will be to create an intervention for CRF. We are seeking out several cancer patients to aid in the creation of the intervention. This is due to a desire to perform Participatory Action Research, where the object of the study is also the researcher. As a part of this research, you will drive the direction of the intervention, and be a full member of the research team. As such, your opinions and ideas will be solicited. If you would like to participate in the creation of the CRF intervention, please contact our research assistant, Nicole Rutkowski.

Useful Contact Information:

For information regarding the Canadian Association for Psycho-social Oncology's guidelines for the assessment and treatment of CRF, please consult this document:
http://www.capo.ca/Fatigue_Guideline.pdf

If you have any questions or concerns regarding this study, its purpose or procedures, or if you have a research-related problem, please feel free to contact the researcher, Sophie Lebel, Ph.D.

Sophie Lebel:
Email: sophie.lebel@uottawa.ca
Phone number: (613) 562-5800 ext. 4811

If you have any questions concerning your rights as a research subject, you may contact:
Protocol Officer for Ethics in Research, University of Ottawa, Tabaret Hall, 550 Cumberland Street, Room 154, Ottawa, ON K1N 6N5
Tel.: (613) 562-5387
Email: ethics@uottawa.ca

Research Ethics Board of the Montfort Hospital, 745-A ch. Montréal Rd, suite 102, Ottawa, ON K1K 0T1 Tél. / Tel.: 613-746-4621, poste/ext. 2221
Téléc. / Fax: 613-746-4111
Email : ethique@montfort.on.ca

The Ottawa Health Science Network Research Ethics Board, Civic Box 675 725 Parkdale Avenue, Ottawa, Ontario K1Y 4E9
Tél. / Tel. : 613-798-5555 poste/ext. 16719.
Email: REBAdministration@toh.ca

If you feel upset after having completed the study or find that some questions or aspects of the study triggered distress, talking with a qualified clinician may help. If you feel you would like assistance please contact:
In the case of an emergency, please call 911.

Resources:

Cancer Care Ontario Fatigue Patient Guide: https://www.cancercareontario.ca/en/symptom-management/3991

Online Chronic Disease Self-management Program: https://www.selfmanagementontario.ca/

Living Healthy Champlain: https://www.livinghealthychamplain.ca/en/home

Canadian Cancer Society: http://www.cancer.ca/en/cancer-information/diagnosis-and-treatment/managing-side-effects/fatigue/?region=nl

Information Video Dr. Mike Evans : https://www.youtube.com/watch?v=YTFPMYGe86s

Smartphone Application : https://untire.me/

Cancer Control Alberta (anglais) videos with self-management tools : https://www.youtube.com/playlist?list=PLi1tOF1I5ZoUFt61X8KxkCGE4PYl92wNB

Breast Cancer Action Group Ottawa

Website: http://bcaott.ca
Email: info@bcaott.ca

Ottawa Regional Cancer Foundation
Website: http://www.ottawacancer.ca
Email: info@ottawacancer.ca

Young Adult Cancer Canada – Localife (Ottawa)
Website: http://www.youngadultcancer.ca
Email: connect@youngadultcancer.ca or Email: shali@youngadultcancer.ca

Maplesoft Centre for Cancer Survivorship
NOTE: Several cancer support groups meet here (e.g., Adult Brain Tumour Support Group, Colorectal Cancer Association of Canada – Ottawa Support Group)
Website: https://survivorship.ottawacancer.ca/main.jsf
Email: swoodard@ottawacancer.ca (Stephanie Woodard – Survivorship Care Program Coordinator)

Ottawa Hospital Cancer Program Support Groups
Website:
https://www.ottawahospital.on.ca/wps/portal/Base/TheHospital/PatientsAndVisitors/SupportAndFollowUp/SupportGroups
Email: N/A
Phone: (613) 737-7700 ext. (varies on support group – see website)

Look Good…Feel Better Program
Website: http://www.lgfb.ca/en/
Email: lgfb@lgfb.ca

Lymphoma Support Group of Ottawa
Website: http://www.lsgo.ca/aboutus.html
Email: Fillable email form on website

Lymphomaniacs
Website: http://www.youngadultcancer.ca/what-are-the-lymphomaniacs/
Email: lymphomaniacs@gmail.com

Prostate Cancer Canada Network Ottawa
Website: www.pccnottawa.ca
Email: info@pccnottawa.ca

The Mental Health Crisis Line
Phone: within Ottawa at 613-722-6914, or across Canada at 1-866-996-0991.
Both are available 24 hours a day, 7 days a week.
Website: http://www.crisisline.ca/

The Ottawa Hospital Mental Health Unit
Phone: (613) 798-5555, tell the operator which program you want to reach.

Ottawa Academy of Psychologists
Phone: (613) 235-2529

University of Ottawa Centre for Psychological Services and Research
Phone: (613) 562-5289

Mental Health Resources Website
Website: http://www.ementalhealth.ca/

*****Please keep a copy of this form for your future reference. Once again, thank you for your participation in this study!*****

Appendix IX. Consent Form Study 2

Appendix I (a) - Consent form
Title of the study: An Intervention for the Management of Cancer related Fatigue: What do Patients, Health Care Providers and Community Partners Have to Say?

Principal Investigator: Sophie Lebel
Department of Psychology, Faculty of Social Sciences, University of Ottawa
Email: sophie.lebel@uottawa.ca, phone: (613) 562-5800 ext. 4811

Invitation to Participate: I am invited to participate in the abovementioned research study conducted by Georden Jones, supervised by Sophie Lebel, PhD.

Purpose of the Study: The purpose of the study is to develop, implement, and evaluate a training module for healthcare professionals and community support providers on cancer-related fatigue guidelines.

Inclusion and Exclusion criteria: Healthcare professionals who have experience working with patients diagnosed with cancer are eligible to participate in this study.

Participation: My participation will consist of attending one (1) in person 150 minute training session during which I will be presented information on cancer-related fatigue assessment and management strategies. I will also be asked to participate in learning tasks including role plays and vignette presentations. I will be asked to participate in group discussions concerning the content of the training module. The other attendees will be other professionals and could be my colleagues. The training module has been scheduled for [insert date and time]. I will also be asked to fill out a sociodemographic questionnaire, a questionnaire on my knowledge of cancer-related fatigue, self-efficacy, and my intentions to apply cancer-related fatigue guidelines into my practice, and on my satisfaction with the training before and after the training.

Alternatives to participation: I have the choice to participate in this study or not and I am allowed leave at all times with no impact on my abilities to offer services I am receiving or will be receiving and I will receive proper debriefing in which the purpose of the study will be provided as well as support resources and the investigators' contact information. After the focus group, I can decide that I do not want my data used in this research. If you would like your data removed from the study and permanently deleted please let us know immediately, or via email, or phone. You can find the ways to reach us at the bottom of this form.

Risks: My participation in this study will entail that I volunteer my professional experience with cancer-related fatigue. This may cause me to feel uncomfortable or upset, or may bring back unpleasant memories. I have received assurance from the researcher that every effort will be made to minimize these risks. The training will be led by Dr. Sophie Lebel who is a licenced psychologist who will ensure that difficult emotions that arise during the training are addressed. Moreover, the research team will ensure that anyone made uncomfortable or who is in any way upset by the discussion will be allowed to leave with no impact my ability to provide services

and will receive proper debriefing in which the purpose of the study will be provided as well as support resources and the investigators' contact information.

Benefits: My participation in this study will help the researchers develop a training module for cancer-related fatigue. This chronic illness affects a large number of people, and a proper treatment for it is needed. My participation will help ensure that healthcare providers receive adequate training on how to implement cancer-related fatigue guidelines into practice.

Confidentiality and anonymity: I have received assurance from the researcher that the information I will share will remain strictly confidential except in case of a legal obligation. I understand that the contents of the training will be used only for the purposes of this research and that my confidentiality will be protected by ensuring the information collected will be stored securely at the site of the focus group, or will be transferred to a secure location at the University of Ottawa. I understand that the research team is not able to ensure confidentiality on behalf of the other participants taking part in the training. I am responsible for maintaining the confidentiality and security of my data in this context.

Anonymity will be protected in the following manner: Participants' names will be replaced with random numbers when analysing the data and will be kept under password protected files in Professor Lebel's locked lab. Although not anonymous, the discussions occurring during the training will be confidential. In any publications based on this research, the participants will not be named nor personal information that would allow identification of individuals be provided. The participants will thus be anonymous to anyone but the participants of the discussion group and the researchers.

Conservation of data: The data collected will be kept in a secure manner. Paper questionnaires will be identified by a number and stored in a locked filing cabinet in the PI's lab (located on the University of Ottawa campus). Consent forms will be kept separately, also in a locked filing cabinet in the PI's lab. The master list that links the participants ID numbers to their identifying info will be kept in a separate folder in a locked filing cabinet in the PI's lab. Electronic data collected via online survey will be stored on on secure Qualtrics servers located in Canada. Qualtrics uses Transport Layer Security (TLS) encryption, and their secure servers are independently audited to meet the industry standard SSAE-16 method. The data will be destroyed from the servers after the completion of the study. Your email address will be collected and stored with your data on the server.

De-identified statistical databases will be password protected and stored on a password protected computer in the locked lab of the PI on the University of Ottawa campus. However, it is possible that research records that identify me be inspected for the presence of the researcher by the Research Ethics Committee for Research inspection. That said, I have been assured that no records identifying me, eg. with my name and initials will be allowed to leave the University of Ottawa. The all data will be conserved for 10 years in the PI's lab until destroyed.

Reimbursement: You will be compensated by a meal during the training module for the time you dedicate to this study and your parking expenses will be reimbursed if necessary.

Civil Liability: My consent to participate in this study does not affect my right to seek legal recourse in any manner whatsoever. If my participation causes me any prejudice, I reserve the right to take any available legal recourse against the various research partners.

Voluntary Participation: I am under no obligation to participate and if I choose to participate, I can withdraw from the study at any time and/or refuse to answer any questions, without suffering any negative consequences. If I choose to withdraw, all data gathered until the time of withdrawal will be erased. My decision to participate or withdraw from the study will not affect the exercise of my role within the clinical team or the quality of services available to others and to myself, now or in the future at the Montfort Hospital.

Would you like to receive a summary of research results (please tick the appropriate box)?
☐ Yes ☐ No

Contact: _____

Acceptance: I,_____ , agree to participate in the above research study conducted by Sophie Lebel, PhD. of the Department of Psychology at the University of Ottawa. If I have any questions about the study, I may contact the researcher.

If I have any questions regarding the ethical conduct of this study, I may contact the Protocol Officer for Ethics in Research, University of Ottawa, Tabaret Hall, 550 Cumberland Street, Room 154, Ottawa, ON K1N 6N5, Tel.: (613) 562-5387, Email: ethics@uottawa.ca or to the Research Ethics Board of the Montfort Hospital, 745-A Montréal Rd, suite 102, Ottawa, ON K1K 0T1, Tél. / Tel.: 613-746-4621, ext. 2221
Téléc. / Fax: 613-746-4111, Email : ethique@montfort.on.ca

There are two copies of the consent form, one of which is mine to keep.

Participant's signature: Date:

Researcher's signature: Date:

Appendix X. Cancer-Related Fatigue Knowledge Questionnaire Study 2

This first section is about you.

What is your age in years? _____

Your gender: Male Female

To which professional discipline do you belong?

Dietician

Exercise physiologist

Medical Practitioner

Nurse

Occupational Therapist

Physiotherapist

Psychologist

Other _____

1) Approximately how many years have you practiced either part time or full time in your profession? _____
   [Please do not count periods not practicing or on family or other special leave]

2) In which Province do you currently practice?

   Quebec

   Ontario

3) Do you describe your location as?

   Metropolitan

Rural

Remote

The questions in this section refer to your practice setting.

4) How would you best describe your practice setting?

   Acute hospital

   Community health

   Domiciliary service

   Palliative care centre

   Primary health care

   Private practice

   Rehabilitation centre

   Specialist oncology unit or centre

   Other _____

5) How often do you see clients with a cancer diagnosis in your own practice?

   Daily

   Weekly

   Monthly

   Occasionally (e.g. once every 2-6 months)

   Rarely (e.g. once a year)

   Never

6) Your professional discipline receives a referral for ‘Brad’, a 54-year-old man who completed surgery and chemotherapy for cancer about 4 months ago. He is able to walk at a slow pace for about 5 minutes before needing to sit down. ‘Brad’ is independent in self-care but has low mood and limited energy for other tasks and needs to return soon to his job as a salesman. He identifies his usual fatigue as 6/10.

a) Would this sort of referral (including self-referral) be made in your setting?
Yes/No

b) What services would be offered to this client? Mark all that apply.

Reassurance and/or education

Medical referral

Screening for needs

In-depth CRF assessment

Initial assessment

Referral on to other service/s

Individual therapy

Group program

Other _____

No services

7) Does your professional discipline have a priority system in place for client referrals where you currently practice?

No – what is your current waiting time for first appointment?

_____ weeks

Yes - What priority is given to referrals like 'Brad'?

Not accepted – Reason _____

Low

Medium

High

8) What is the target waiting time for that priority level?

No set time ii ____ weeks

This section concerns your knowledge and practice about cancer-related fatigue (CRF).

1) Are clients routinely asked specifically about their experience of CRF in your setting?

No

Yes ...by

Medical staff – direct question

Nursing staff – direct question

Nursing staff – screening tool (specify)

Responding to client/family initiated concern

Other staff (specify direct question, part of a quality of life screening tool, etc.)

2) Which of the following best describes your level of knowledge about cancer-related fatigue?

I don't know anything about CRF

I have heard of CRF

I have read about CRF

I have limited clinical experience with people with CRF

I have moderate expertise in CRF in my own discipline

I have a high level of expertise in CRF in my own discipline

3) Do you use any guidelines for assessment and management of CRF in your practice?

No

Yes

Facility specific guidelines

Discipline guidelines

National Cancer Action Team

Canadian Association of Psychosocial Oncology

National Comprehensive Cancer Network

Other _____

4) How do you screen for or assess CRF in your role? (Mark all that apply)

I do not screen for or assess CRF

I do not screen for or assess CRF but others in my organization do

Informal interview (no specific assessment)

Standardised patient reported outcome or validated instrument

Discipline pro-forma – generic initial assessment

Discipline pro-forma – specific for CRF

Functional assessment

Exercise test

Work or home assessment

Other (comment) _____

5) What outcome measure/s or standardised assessments do you use for CRF? (Mark all that apply)

Numeric rating scale (e.g. 0 to 10)

Edmonton Symptom Assessment Scale

Brief Fatigue Inventory

Multi-symptom inventory

Quality of life questionnaire

Visual Analogue Scale

Other (please specify) _____

Not applicable

6) What interventions are you aware of for CRF and which of these do you implement? Please list up to 5.

	Intervention	Implemented
1		
2		
3		
4		
5		

7) What do you think are the barriers in your workplace to assessment and management of CRF? Mark all that apply.

Patient expectations that doctor will raise important issues

Lack of routine screening for fatigue

Lack of documentation about fatigue

Referrals are not made

Lack of knowledge about possible interventions (referrers)

Lack of expertise in assessment or interventions (disciplines)

CRF is not considered a priority

Please add your comments (Free text) _____

8) Do you think that most clients with CRF within your facility have this symptom identified and managed?

Yes/No

Comment _____

9) Do you have any suggestions about how to improve assessment or management of CRF? Please share your opinions.

_____

_____

_____

_____

_____

Appendix XI. Self-Efficacy Questionnaire Study 2

1) I feel confident in my ability to assess my patients for cancer-related fatigue symptoms.

Strongly agree Agree Neutral Disagree Strongly Disagree

2) I feel confident in my ability to provide recommendations to my patients for the management of their cancer-related fatigue symptoms.

Strongly agree Agree Neutral Disagree Strongly Disagree

Appendix XII. Behavioural Intentions Questionnaire Study 2

How likely is it that in the next 3 months you will:

1) Screen for fatigue at entry to system and periodically throughout your care of the patient using the ESAS.
   - Very likely
   - Likely
   - Somewhat Likely
   - Neutral
   - Somewhat Unlikely
   - Unlikely
   - Very Unlikely

2) Review the scores with your patient.
   - Very likely
   - Likely
   - Somewhat Likely
   - Neutral
   - Somewhat Unlikely
   - Unlikely
   - Very Unlikely

3) Complete an in-depth assessment of cancer-related fatigue to assess for onset, perpetuating or provoking Factors, quality of Fatigue, severity of fatigue, strategies used to manage fatigue, patient's level of understanding of their fatigue, interference in functioning, and the patient's goal in the management of this symptom.
   - Very likely
   - Likely
   - Somewhat Likely
   - Neutral
   - Somewhat Unlikely
   - Unlikely
   - Very Unlikely

4) Complete or refer for a comprehensive physical assessment of fatigue
   - Very likely
   - Likely
   - Somewhat Likely
   - Neutral
   - Somewhat Unlikely
   - Unlikely
   - Very Unlikely

5) Provide psycho-education to patients on cancer-related fatigue
   - Very likely
   - Likely
   - Somewhat Likely
   - Neutral
   - Somewhat Unlikely
   - Unlikely
   - Very Unlikely

6) Provide counselling to patients on:
   Energy conservation
   - Very likely
   - Likely
   - Somewhat Likely
   - Neutral
   - Somewhat Unlikely
   - Unlikely
   - Very Unlikely

   Pacing of activities

   - Very likely
   - Likely
   - Somewhat Likely
   - Neutral
   - Somewhat Unlikely
   - Unlikely
   - Very Unlikely

   Use of distraction strategies

   - Very likely
   - Likely
   - Somewhat Likely
   - Neutral
   - Somewhat Unlikely
   - Unlikely
   - Very Unlikely

   Monitoring of their energy levels

   - Very likely
   - Likely
   - Somewhat Likely
   - Neutral

- Somewhat Unlikely
- Unlikely
- Very Unlikely

7) Offer or refer patients to the following non-pharmacological interventions:

Advise patients to engage in moderate intensity of physical activity (e.g. fast walking, cycling, swimming, resistive exercise) during and after cancer treatment unless contraindicated/previous sedentary (30 minutes per day, 5 days per week as tolerated)

- Very likely
- Likely
- Somewhat Likely
- Neutral
- Somewhat Unlikely
- Unlikely
- Very Unlikely

Psycho-education for self-management of fatigue (individual or group class)

- Very likely
- Likely
- Somewhat Likely
- Neutral
- Somewhat Unlikely
- Unlikely
- Very Unlikely

Coaching in self-management and problem-solving to manage fatigue

- Very likely
- Likely
- Somewhat Likely
- Neutral
- Somewhat Unlikely
- Unlikely
- Very Unlikely

Cognitive Behavioural Therapy

- Very likely
- Likely
- Somewhat Likely
- Neutral
- Somewhat Unlikely
- Unlikely
- Very Unlikely

Complementary therapies (Yoga, Mindfulness)

- Very likely
- Likely
- Somewhat Likely
- Neutral
- Somewhat Unlikely
- Unlikely
- Very Unlikely

Rehabilitation Specialist if functioning impaired or need for supervised exercise

- Very likely
- Likely
- Somewhat Likely
- Neutral
- Somewhat Unlikely
- Unlikely
- Very Unlikely

Optimize sleep quality

- Very likely
- Likely
- Somewhat Likely
- Neutral
- Somewhat Unlikely
- Unlikely
- Very Unlikely

Stress reduction strategies (yoga, mindfulness programs)

- Very likely
- Likely
- Somewhat Likely
- Neutral
- Somewhat Unlikely
- Unlikely
- Very Unlikely

Advise patients there is insufficient evidence for pharmacological treatment, herbal medicines, or acupuncture

- Very likely
- Likely
- Somewhat Likely
- Neutral

- Somewhat Unlikely
- Unlikely
- Very Unlikely

Appendix XIII. Training Satisfaction Rating Scale Study 2

	Totally disagree	Disagree	Neutral	Agree	Totally agree
Objectives and content	1	2	3	4	5
1. In my opinion the planned objectives were met					
2. The issues were dealt with in as much in depth as the length of the module allowed					
3. The length of the course was adequate for the objectives and content					
Method and training context					
4. The method was well suited to the objectives and content					
5. The method used enabled us to take an active part in training					
6. The training enabled me to share professional experiences with colleagues					
7. The training was realistic and practical					
8. The documentation given out was of good quality					
9. The training context was well suited to the training process					
Usefulness and overall rating					
10. The training received is useful for my specific job					
11. The training received is useful for my personal development					
12. The training merits a good overall rating					

Appendix XIV. Training Vignettes for Role Plays Study 2

Describe your approach to assessment of cancer-related fatigue for each of these patients. Describe how you would provide psychoeducation on cancer-related fatigue to each of these patients. Describe what recommendations you would provide to each patient to help them manage their cancer-related fatigue.

Vignette 1

Jean is a 53 year old colorectal cancer patient. He received surgery and radiation therapy and terminated treatment 8 months ago. He is concerned about returning to work. He reports difficulty accomplishing chores at home since he has terminated his treatment. For example, he describes having to take many breaks when vacuuming the house, whereas before he was able to vacuum the whole house easily without any breaks. He reports feeling less worthy and is concerned that his wife and kids will think he is a failure and is useless if he is not able to return to work. His financial situation has also suffered since his diagnosis, forcing his wife to take on a second job to support the family. Jean reports that he has always been the provider for the family and that this should be his role, not his wife's, and that without working he has no purpose. Jean spends most of his day working around the house until he cannot stand anymore; he then normally has a nap to recuperate and has trouble getting back up for the rest of the day. He is looking for help retuning to work as he cannot bear to stay at home anymore.

Vignette 2

Lucy is a 67 year old breast cancer patient diagnosed 3 months ago and currently receiving hormonal therapy. She has a history of depression having been diagnosed with post-partum depression following her 3 pregnancies and following her divorce. She received psychotherapy to help her manage her symptoms of low mood in the past. She reports knowing what is helpful for her to increase her mood like calling friends, walking, going to support group, but she feels too tired to do anything. In fact, she has difficulty preparing meals for herself and finds herself staying in bed for most of the day watching television and sleeping. She reports wanting to go out to do things, but having difficulty finding the energy to even think about planning a day out. Her daughter currently brings her groceries and cleans her house as she is not able to do it her own. She is looking to receive help to get back on track and be able to take care of herself on her own.

Vignette 3

Melissa is a 38 year old woman diagnosed with breast cancer 1 year ago. She received surgery and radiation which ended a few months ago. She reports having communicated her difficulties with fatigue to her health care team many times. She reports that all her doctors have told her is that fatigue is normal and that she needs to rest. She has followed these recommendations with no improvement in her fatigue. She reports feeling like the healthcare system is letting her down and feeling very frustrated that her fatigue is not improving. She reports being very irritable with her husband and young children and having difficulty concentrating, multitasking, and making decisions. She was employed as a manager in the federal government before her diagnosis and is used to being able to concentrate on work and multitask at work. She reports finding it frustrating to not even be able to respond to an email without distractions. She is hoping that

services in the community will be better than the public healthcare system in providing her with recommendations for her fatigue.

Appendix XV. Post-Training Interview Guide Study 2

Post-training interview guide
Cancer-related fatigue assessment and intervention training

Preamble

- Introduction of the person conducting the interview (name, designation, study name).
- I would like to take this opportunity to thank you once again for your continued participation in our study.
- We are conducting an interview to learn about your experience of participating in this study and to receive suggestions on how to improve the training for future studies.
- Your input as a participant who completed the study is critical to understanding what activities are most suited to equip healthcare professionals to assess and manage cancer-related fatigue. We hope that this interview will help evaluate the efficacy of the training and assists us in the development of future services.
- This study is funded by the Institut du Savoir Montfort under the researchers Dr. Sophie Lebel, PhD, Department of Psychology, University of Ottawa and Dr. Jennifer Brunet, PhD, Department of Kinesiology, University of Ottawa.
- Ethics approval to conduct the interview was obtained from Research Ethics Boards of the Montfort Hospital.

Interview Format

- The interview should take about 30 minutes and primarily involves open-ended questions regarding your experience with participating in our study and suggestions for future sessions.

Permission/Consent to Record Interview

- All information exchanged in this interview will remain confidential, reported only at aggregate levels, as indicated on the informed consent form that you have previously signed. Only the research team will have access to the collected data. You will not be named in any reports or publications that may be generated from this study.
- To improve the accuracy of my notes and to facilitate the follow-up work, analysis and overall value of this work, I would like to record this interview if this is acceptable to you. Any identifiers such as your name will be removed from the typed versions of the interviews. We will also keep all tapes in a password protected file on a desktop computer situated in

locked area at the University of Ottawa until data analysis is complete, when we will destroy the tapes.

- Do you agree to participate in this interview that will be recorded?

  □ Yes □ No

Participant must provide verbal informed consent.

Mark date _____ and time_____ of verbal consent by participant.

For reference:

Training objectives

- Become familiar with the CAPO guidelines on cancer-related fatigue
- Empower professionals to apply CAPO guidelines in their practice
- Foster confidence in the ability to apply CAPO guidelines independently
- Use the CAPO guidelines' knowledge translation tool
- Raise awareness of effective patient-professional communication strategies

Satisfaction

1. What can you tell me about your experience in participating in the cancer-related fatigue training study?

   a. What are your thoughts on the content of the training?

   b. What are your thoughts on the format of the training? (lecture, readings, role plays)

   c. What are your thoughts on the length of the training?

2. What was most helpful part of this training?

3. What was least helpful (in terms activities, new skills learned)?

4. If you could do the training again, what would you change, what would you improve?

5. If you could do the training again, what would you keep the same?

6. Would you recommend this training to your colleagues?

Practice

1. Since you participated in the training, have you changed your approach to the assessment of cancer-related fatigue? What did you change?
    a. Have you applied any components of the CCO/CAPO guidelines into your approach to assessment?

2. Since you participated in the training, have you changed your approach to the management/intervention of cancer-related fatigue? What did you change?
    a. Have you applied any components of the CCO/CAPO guidelines into your approach to intervention?

3. What obstacles do you face in applying the cancer-related fatigue guidelines in your practice?

4. Have you used the knowledge transfer tool (the calendar flip chart of CAPO/CCO guidelines) in your practice?
    a. What do you think of the tool?
    b. Do you feel that you have received enough training to use the tool?

Intentions

1. Do you intend to continue to implement changes in your practice in the assessment or management / intervention of cancer-related fatigue?
    a. If yes, which ones
    b. If not why?

2. Do you intend to make further changes in your practice?

Self-efficacy

1. Did the training have an impact on your feeling of confidence in your ability to assess cancer fatigue? Please elaborate

2. Did the training have an impact on your feeling of confidence in your ability to intervene for cancer-related fatigue? Please elaborate

Probe/optional: Some of our training objectives were to provide you with knowledge and strategies to apply them with your patients. I would now like to ask you some more specific questions about these objectives

Knowledge

1. What new aspects did you learn about cancer-related fatigue?

2. Did you find that the training was helpful in increasing your knowledge of cancer-related fatigue?

3. Did you find that the training was helpful in increasing your knowledge of CAPO/CCO cancer-related fatigue guidelines?

Communication

1. Have you adopted any new communication strategies in your practice? What did you change?

2. What communication strategies did you find the most useful?

3. What communication strategies did you find the less useful?

This wraps up the questions I wanted to ask. Do you have any additional comments or questions?

_____

_____

_____

_____

_____

Thank you very much for participating in this interview. If you have any further questions, you can contact me directly, or contact Dr. Sophie Lebel, the principal investigator on the project at 613-562-5200 ext. 4018 or by email at sophie.lebel@uottawa.ca.

Thank you

Appendix XVI. Debriefing Form Study 2

Thank you for your participation in our study! Your participation is greatly appreciated.

Purpose of the Study:
We previously informed you that the purpose of the study is to develop, implement, and evaluate a training module for healthcare professionals and community support providers on cancer-related fatigue guidelines.

We realize that some of the tasks asked you were asked to perform may have triggered emotional reactions. As researchers, we do not provide mental health services and we will not be following up with you after the study. However, we want to provide every participants in this study with a comprehensive and accurate list of clinical resources that are available, should you decide you need assistance at any time. Please see information pertaining to local resources at the end of this form.

Confidentiality:
You may decide that you do not want your data used in this research. If you would like your data removed from the study and permanently deleted please let us know immediately, or via email, or phone. You can find the ways to reach us at the bottom of this form.

Final Report:
If you have selected that you would like to receive a copy of the final report of this study, we will contact you once it is available.

Useful Contact Information:
For information regarding the Canadian Association for Psycho-social Oncology's guidelines for the assessment and treatment of CRF, please consult this document:
http://www.capo.ca/Fatigue_Guideline.pdf

If you have any questions or concerns regarding this study, its purpose or procedures, or if you have a research-related problem, please feel free to contact the researcher, Sophie Lebel, Ph.D.

Sophie Lebel:
Email: sophie.lebel@uottawa.ca
Phone number: (613) 562-5800 ext. 4811

If you have any questions concerning your rights as a research subject, you may contact the:
Protocol Officer for Ethics in Research, University of Ottawa, Tabaret Hall, 550 Cumberland Street, Room 154, Ottawa, ON K1N 6N5
Tel.: (613) 562-5387
Email: ethics@uottawa.ca

Research Ethics Board of the Montfort Hospital, 745-A ch. Montréal Rd, suite 102, Ottawa, ON K1K 0T1

Tél. / Tel.: 613-746-4621, poste/ext. 2221
Téléc. / Fax: 613-746-4111
Email : ethique@montfort.on.ca

If you feel upset after having completed the study or find that some questions or aspects of the study triggered distress, talking with a qualified clinician may help. If you feel you would like assistance please contact:
The Mental Health Crisis Line: within Ottawa at 613-722-6914, or across Canada at 1-866-996-0991. Both are available 24 hours a day, 7 days a week.
The Ottawa Hospital: 613-798-5555, tell the operator which program you want to reach.
For a list of Ottawa psychologists, contact the Ottawa Academy of Psychologists: 613-235-2529
Maplesoft Centre for Survivorship: 613-247-3527
University of Ottawa Centre for Psychological Services and Research: 613-562-5289
In the case of an emergency, please call 911.

*****Please keep a copy of this form for your future reference. Once again, thank you for your participation in this study!*****