

**KNOWLEDGE TRANSLATION TOOLS FOR CANCER SYMPTOM
MANAGEMENT BY HOME CARE NURSES**

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A thesis submitted to the Faculty
of Graduate and Postdoctoral Studies
in partial fulfillment of the requirements for
the degree of Master's of Science in Nursing

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Knowing is not enough; we must apply.

Willing is not enough; we must do.

Johann Wolfgang von Goethe

Thesis Abstract

Objective: To explore adult cancer symptom management by home care nurses.

Scoping review: A scoping review was conducted to describe interventions used by nurses for cancer symptom management in the home care setting. Five included studies revealed that home care nursing contributed to positive client- and system-level outcomes.

Study: A mixed-methods descriptive study explored usability of a set of 13 cancer treatment-related symptom management protocols for nurses in the home care setting. Thirty-eight nurses in home care participated. Qualitative and quantitative data indicated the protocols were highly usable. Several barriers suggested they would be better used as resources to support and train nurses rather than documentation tools.

Conclusions: Few studies have evaluated interventions for cancer symptom management by home care nurses. This set of protocols was well-received, but further research is required to determine their effectiveness and interventions for implementing with home care nurses providing cancer symptom management.

Acknowledgements

There are several individuals who have made this thesis possible. Without their support, encouragement, and sacrifice I would not have survived this journey over the past several years.

I cannot begin to express my gratitude to Dr. Dawn Stacey, who has not only been my thesis supervisor, but a brilliant mentor through my entire master's journey. She has guided me and encouraged me to achieve personal and professional growth. Her unwavering support encompassed an inspiring combination of leadership, professionalism, compassion, and understanding. Her ability to generate excitement about nursing research has started me on my own path to contribute to our professional body of knowledge. Early in my masters' studies Dawn invited me to assist with the COSTaRS project as a research assistant on account of my oncology experience. Little did I know the cascade of events that would transpire, culminating in the completion of this thesis. When she mentioned that there might be the opportunity to develop a thesis I laughed, saying I was never going to do a thesis. Never say never.

Dr. Wendy Gifford and Dr. Craig Kuziemy, my thesis committee members, were incredibly helpful and supportive throughout this project. I am grateful for their strong commitment to helping me succeed in this endeavor. From our first committee meeting, their honest and constructive feedback has shaped this research and contributed to an incredible learning opportunity.

I am grateful to Vicki Lejambe, who was instrumental through the research process, despite the fact that we have yet to meet. I have great appreciation for the nurses who participated in the study and shared their knowledge and experiences. They opened my eyes to the complexities of working as a nurse in the home care setting.

My friends, Shelley Mackenzie and Karen Graham, have been generous with words of wisdom, both personal and professional, acquired through their own journeys. Our genuine friendship is a constant reminder of what nursing has added to my life. Our conversations are engaging and thoughtful, and often include delicious wine and cheese. I love that we thrive on helping each other succeed. Shelley had the added joy of being my ‘fabulous research assistant’ for my qualitative study and her assistance was invaluable.

I was fortunate to receive financial support from the Registered Nurses Foundation of Ontario. I was also supported by the Nursing Professional Practice Department of the Ottawa Hospital, through the Kerry Marshall Nursing Bursary and the Wendy Nicklin Nursing Bursary.

My family and friends have supported and encouraged me every step of this long journey, and have been patient and understanding despite my absence in their lives. I am excited to be able to immerse myself back into the world beyond my academic pursuits.

My two boys, Brady and Cooper, have supported me with their hugs and kisses and laughter when I needed them most. They remind me that life requires balance. Brady started kindergarten this year and he thinks it is pretty funny that his mommy is still in school. I like to think of it as setting an example for them to be lifelong learners.

And finally, I am incredibly grateful for my husband Shane, who I love beyond words. His unconditional love has encouraged the pursuit of education, for both personal achievement and professional development. He has given me the gift of precious time, which has been invaluable over the past few months as this chapter of our lives comes to a happy close. I may be happy to finally be done, but I think he may be happier!

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List of Abbreviation

APN	Advanced Practice Nurse
CANO	Canadian Association of Nurses in Oncology
CCAC	Community Care Access Center
CCO	Cancer Care Ontario
CCT	Controlled Clinical Trial
CNA	Canadian Nurses Association
CNO	College of Nurses of Ontario
COSTaRS	Pan-Canadian Oncology Symptom Triage and Remote Support
ESAS	Edmonton Symptom Assessment System
OMRU	Ottawa Model of Research Use
PICO	Population, Intervention, Comparison, Outcome
PPS	Palliative Performance Scale
RCT	Randomized Controlled Trial
RN	Registered Nurse
RNAO	Registered Nurses' Association of Ontario
RPN	Registered Practical Nurse

Chapter 1

Introduction

Introduction

Relevance

Since 1970, despite rising incidence of cancer, mortality rates are decreasing, likely attributable to a combination of improved screening, prevention, treatment, and medical management practices (Kachuri, De, Ellison, Semenciw, & The Advisory Committee on Canadian Cancer Statistics, 2013). In Ontario, approximately two-thirds of individuals with cancer will receive systemic treatment (Cancer Care Ontario [CCO], 2009) and close to half will receive radiation treatments (CCO, 2007). Clients on chemotherapy and/or radiation therapy receive care in a variety of settings, including ambulatory clinics, in hospital, and within their own homes.

Distressing symptoms related to cancer and its' treatments are commonly experienced by many individuals (Barbera et al., 2010; Henry et al., 2008) and if not identified and managed early, they can escalate quickly to become life-threatening events (McCurdy & Shanholtz, 2012). When symptoms are inadequately managed, they can require urgent medical attention and result in emergency department visits. A recent systematic review of emergency department visits by individuals with cancer demonstrated admission to hospital for symptom management for more than half of the visits with mortality rates of approximately 13-20% (Vandyk, Harrison, Macartney, Ross-White, & Stacey, 2012). Inadequate symptom management has implications for all levels of care.

Most individuals receive treatment in ambulatory care settings, requiring increased need to support those experiencing symptoms at home. In addition to physical symptoms, support also needs to address all aspects of life permeated including emotional, psychological, and practical (Berry, 2011; Dodd, Cho, Cooper, & Miaskowski, 2010; Ferreira et al., 2008; Iyer,

Taylor-Stokes, & Roughley, 2013; Peters & Sellick, 2006; Stenberg, Ruland, & Miaskowski, 2010; Valeberg & Grov, 2013; van Ryn et al., 2011). Inadequate support often leads to increased symptom distress that negatively affects the quality of life of the individual (Akin, Can, Aydinler, Ozdilli, & Durna, 2010). Concurrently, symptoms in individuals with cancer also have implications on caregivers' physical and mental health, and quality of life (Gibbins et al., 2009; Stenberg et al., 2010; Valeberg & Grov, 2013).

Nurses provide cancer symptom management to individuals in ambulatory care settings through outreach from outpatient oncology programs and home care services. Many oncology programs in Canada provide remote nursing services, including symptom management, to patients at home by either proactively calling patients or by responding to telephone calls or emails (Macartney, Stacey, Carley, & Harrison, 2012; Stacey, Bakker, Green, Zanchetta, & Conlon, 2007). In this context, remote support is defined as providing nursing services from one physical location, such as an office at a cancer center, and transmitting them to the individuals' location, such as home, through the use of tele-health technologies (Stacey, Macartney, Carley, Harrison, & the Pan-Canadian Oncology Symptom Triage and Remote Support Group, 2013). However, provision of remote support by nurses requires the use of protocols to guide nursing practice (Canadian Nurses Association [CNA], 2007; College of Nurses of Ontario [CNO], 2009a). Although current guidelines recommend comprehensive assessments to guide symptom management, they do not provide the necessary tools and resources for moving the evidence into practice. In response to this lack of user-friendly guidelines to support remote nursing practice, a Pan-Canadian initiative developed and evaluated a set of 13 evidence-informed nursing protocols to manage cancer treatment-related symptoms for use remotely (Stacey et al., 2012; Stacey et al., 2013). The protocols are informed with current evidence from clinical practice guidelines and are

formatted as user-friendly tools to guide nursing assessment and triage, and support self-management of symptoms via telephone or email. The use of evidence to guide care supports best nursing practices and upholds nursing standards of care (Canadian Association of Nurses in Oncology [CANO], 2001; CNO, 2009b; Virani & Grinspun, 2007).

I was given the opportunity to become a part of the Pan-Canadian Oncology Symptom Triage and Remote Support (COSTaRS) initiative. I saw it as an opportunity to further explore the research world, improve my nursing practice, and contribute to the larger body of nursing knowledge. As an experienced nurse on a busy inpatient oncology unit, providing care that was evidence-based and client-centered was a priority for me. Time to identify and review relevant guidelines about best practices for cancer care was minimal at best, and figuring out how to incorporate those best practices was an even greater challenge. As I became more engaged in the research initiative, I understood the gap that the protocols were designed to fill. In my practice I felt my assessments were more thorough, and I felt empowered because I was confident I had the knowledge to discuss my patients' symptoms and provide education for future management. We did not have tools or resources that were easy to use in the course of a hectic day. As my practice changed, I realized that the protocols could be adapted for other clinical nursing situations. Colleagues who worked in the home care field suggested that the protocols could be a valuable tool for nurses who provide care in the community setting with limited resources. For the first time, I was excited about the idea of conducting my own research. At this point, halfway through my master's studies I committed to producing a thesis. This thesis was driven by an interest in how to provide nurses with current evidence-based knowledge to improve symptom management and in turn, hopefully improve how individuals experience cancer. This research

was designed to explore how the protocols could be applied and integrated into nursing services provided in individuals' homes.

Thesis Design and Objectives

The overall aim of this thesis is to explore adult cancer symptom management by home care nurses. Specific objectives were: a) to conduct a scoping review to describe interventions used by nurses for cancer symptom management in the home setting; and b) to explore the potential for the set of symptom management protocols to be used by nurses in face-to-face interactions in the home care setting. Chapter 2 is structured as a manuscript and addresses the first main objective of this thesis. Chapter 3 is the mixed methods proposal and provides greater context and background to the issue of cancer symptom management, as well as the methodology used to guide the study. Chapter 4 is structured as a manuscript that addresses the second main objective of this thesis. Chapter 5 provides an integrated discussion of the findings from the scoping review and the qualitative study within the broader context of cancer symptom management and highlights the implications for nursing practice. Chapter 6 outlines the contributions of various co-authors and provides acknowledgements.

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Chapter 2

Cancer symptom management in the home:

A scoping review

This chapter is based upon an unpublished manuscript formatted for submission to the journal

Canadian Oncology Nursing Journal

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Abstract

The aim of this scoping review was to examine interventions used by nurses for adult cancer symptom management in the home setting. Databases were searched (CINAHL, Medline, PubMed, EBM Reviews, Joanna Briggs Institute EBP) with key words *cancer*, *home*, *nursing*, *symptom*, and *protocol*. Out of 390 identified citations, 5 met the inclusion criteria. Studies were conducted from 1989 to 2009. Findings revealed that home care nursing services improved symptom management, promoted independence, maintained quality of life, and decreased use of health care services. Two studies used evidence-based interventions to guide cancer symptom management. Although few studies have explored nursing interventions for cancer symptom management in the home setting, limited evidence suggests they may improve client- and system-level outcomes.

Introduction

Background

Symptoms are commonly experienced by individuals with cancer and can be distressing (Barbera et al., 2010; Henry et al., 2008). If not addressed they can quickly become life-threatening events (McCurdy & Shanholtz, 2012). Effective cancer symptom management is an essential component of nursing care that leads to improved outcomes for individuals with cancer (Corner, 1997, 2003; Hoffman, 2013; Huhmann & Camporeale, 2012; Johnston et al., 2009; Rueda, Sola, Pascual, & Subirana Casacuberta, 2011; Williams, Williams, LaFaver-Roling, Johnson, & Williams, 2011). Nurses provide a vast majority of symptom management and have the potential to improve peoples' cancer experiences. Home care nurses are well-positioned to conduct assessments, triage, and provide symptom management for individuals receiving cancer treatment in the community.

Evidence-based practice is important for cancer symptom management and a fundamental element of the nursing profession (College of Nurses of Ontario, 2009; Estabrooks, 2004; Gobel, Beck, & O'Leary, 2006; Melnyk et al., 2004; Schulmeister & Gobel, 2008; Underhill, Boucher, Roper, & Berry, 2012; Walsh & Rybicki, 2006; Weber & Eskinazi, 2012). It is defined as "the integration of best research evidence with clinical expertise and patient values" (Institute of Medicine, 2001, p.47). In health care, translating best evidence into best practice can be challenging (Grol & Grimshaw, 2003), however the use of evidence-based practice can increase effectiveness and efficiency in the health care system and can facilitate positive outcomes for patients, families, communities and organizations (Benefield, 2002; Grimshaw, Eccles, Lavis, Hill & Squires, 2012; Lugtenberg, Burgers & Westert, 2009; Walshe & Rundall,

2001). The use of clinical practice guidelines and protocols in nursing is essential as it reflects the concept of best practice and optimal clinical interventions (Huffman, 2005).

Clinical practice guidelines are tools that support evidence-based cancer symptom management; unfortunately current formats often do not facilitate easy translation of the evidence into practice (Stacey et al., 2012; Brouwers, Stacey, & O'Connor, 2013). Clinical practice tools such as protocols may help bridge the gap that exists between best evidence and current practice (Graham et al., 2006). Evidence-based, standardized tools for nurses to use in the assessment and management of symptoms in patients with cancer have potential to improve patient outcomes.

Clinical resources are especially important for nurses working in the home care setting as these nurses tend to be more generalists and may lack the specialized oncology knowledge required to facilitate comprehensive symptom assessment and management (Feldman & McDonald, 2004; Ontario Home Care Association, 2011). Nurses working in the community have identified the lack of current evidence as a safety issue in their practice (Berland, Holm, Gundersen, & Bentsen, 2012) and current clinical practice guidelines available for use in the home health setting are limited (Williams et al., 2009).

Objective

The aim of this scoping review is to examine interventions used by nurses for adult cancer symptom management in the home setting.

Methods

Using a scoping review according to the typology described by Grant & Booth (2009), a search of electronic databases was conducted to identify published research studies focusing on interventions for adult cancer symptom management provided by nurses in the home. The

following databases were searched to the end of October 2013 as they relate to healthcare and nursing and are relevant to the topic of interest: Medline, PubMed, EBM Reviews, Joanna Briggs Institute EBP Database, and Cumulative Index to Nursing and Allied Health Literature (CINAHL). Key search terms included *cancer*, *home*, *nursing*, *symptom*, and *protocol*. Searching also included: key informants; reference lists of relevant literature; government agencies; and official publications from relevant population groups. Only human studies in the English language were included. Studies about managing individual symptoms were excluded. Studies focusing on symptom management by remote means only were excluded as the focus of this scoping review was on nurses working directly in the home, often with less support and resources available to them. Studies focusing on palliative care were excluded as it is often not explicit if patients are receiving cancer treatment. There were no time parameters placed on the search. Titles and abstracts were reviewed based on inclusion and exclusion criteria to ensure they would fulfill the aim of the review (Table 2.1).

Table 2.1. Selection criteria

	Inclusion	Exclusion
Population	- Adults experiencing cancer-related symptoms - Living at home/community setting	- Children - Surgery as main treatment - Non-malignant diagnoses - End-of-life/palliative
Intervention	- Any symptom management strategy/protocol provided by nurses going into the home	- Individual symptoms - Symptom management provided by remote means only (telephone, mobile device, web-based)
Outcomes	- All outcomes including patient-level and system-level	- None

Quality appraisal of included studies was conducted using methodological criteria that are applicable to a variety of study designs, as outlined by the Cochrane Effective Practice and Organization of Care Review Group (2011). Criteria were rated low risk of bias, high risk of bias, or

unclear based on study reporting for each of the following criteria: concealment of allocation for randomized controlled trials and controlled clinical trials (protection against selection bias); description of characteristics for second site as control for controlled before and after designs; follow-up of professionals (protection against exclusion bias); follow-up of patients or episode of care; blinded assessment of primary outcome(s) (protection against detection bias); baseline measurement; use of reliable primary outcome measure(s); and protection against contamination.

Framework for Analysis

The synthesis of the findings in this scoping review used the nursing process as the guiding framework given that it fits with how nurses think about what they do when providing care (Wilkinson, 2007). Key elements included assessment criteria, implementation/intervention and evaluation (Wilkinson, 2007). Assessment is the first phase of the nursing process and is the systematic gathering of relevant data that guides subsequent care. Implementation occurs when action is taken by the nurse; when the interventions are put into place to achieve the clients' goals. Evaluation is the final phase in the nursing process and is an ongoing determination of the degree of success in achieving those goals. The information gathered by evaluation is often used to inform subsequent nursing assessments. Specific questions that guided the synthesis included:

- a) Assessment – What did nurses use to guide their assessment of clients' symptoms?
- b) Intervention – What were the characteristics of the interventions that were implemented?
- c) Evaluation – What outcomes were evaluated to assess the impact of the interventions and how were the outcomes measured? What were the results from the interventions?

Results

Study Selection

A total of 878 citations were identified (Table 2.2). Of these, 488 were duplicates and eliminated from the reviewed results, for a total of 390 articles. Thirteen articles were included for full review with eight excluded. Reasons for exclusion included: not research; not focused on symptom management; non-nursing focus; palliative/end-of-life population; individual symptoms; symptom management provided only remotely; and symptom management not provided in the home setting. Five articles are included in this scoping review.

Table 2.2. Search strategy

Database	Search Terms	Number of citations
CINAHL	Cancer, nursing, home, symptom, protocol	172
All EBM Reviews (Cochrane DSR, ACP Journal Club, DARE, CCTR, CMR, HTA, and NHSEED)	Cancer, nursing, home, symptom, protocol	197
The Joanna Briggs Institute EBP Database	Cancer, nursing, home, symptom, protocol	134
Medline	Cancer, nursing, home, symptom, protocol	127
PubMed	Cancer, nursing, home, symptom, protocol	248
TOTAL		878
Manual search		0
Duplicates removed		488
Reviewed titles and abstracts		390
Abstracts Excluded		377
Articles screened		13
Excluded articles		
Not home setting		3
Not research		3
Not symptom management		2
Included for review		5

Characteristics of the Studies and Participants

Of the five articles there are two randomized controlled trials (RCT) (McCorkle et al., 1989; Molassiotis et al., 2009), two controlled clinical trials (CCT) (Benor, Delbar & Krulik, 1998; Nural, Hintistan, Gürsoy, & Duman, 2009), and one controlled before and after study (McCorkle et al., 1994) (Table 2.3). The studies were conducted in the United States (n=2), Turkey (n=1), Israel (n=1), and the United Kingdom (n=1). Four studies included participants with varying cancer diagnoses and stages, including hematological, genitourinary, breast, gynecological, astrocytoma, sarcoma, and gastrointestinal (Benor et al., 1998; McCorkle et al., 1994; Molassiotis et al., 2009; Nural et al., 2009) and one focussed exclusively on patients with lung cancer (McCorkle et al., 1989). There were from 42 to 164 participants (median=78) ranging in ages from 18 to 89 years old (median=58).

Four studies identified patients receiving cancer treatment including chemotherapy and/or radiation therapy as part of the treatment plan during the study (Benor et al., 1998; McCorkle et al., 1989, 1994; Molassiotis et al., 2009). In one study patients did not receive any cancer treatment during the study period but were receiving symptom management (Nural et al., 2009).

Quality was variable ranging from lower to higher risk of bias. Of the five included studies, a recent controlled clinical trial had the lowest risk of bias (Nural et al., 2009) and an older controlled before and after study had the highest risk of bias with unclear reporting (McCorkle et al., 1994). Four studies had unclear reporting that affected the appraisals (McCorkle et al., 1989, 1994; Molassiotis et al., 2009; Nural et al., 2009). Three studies were judged as higher risk for follow-up bias because they obtained outcome measures for less than 80% of the participants (McCorkle et al., 1989, 1994; Molassiotis et al., 2009). No studies reported blinded assessment of primary outcomes. Two studies were judged to be higher risk as

the study designs did not allow for blinding because the nurses providing the intervention were also collecting the data (Benor et al., 1998; Molassiotis et al., 2009). The other three studies did not clearly report on this criterion (McCorkle et al., 1989, 1994; Nural et al., 2009).

Table 2.3. Summary of Studies (N=5)

Author, Year, Country	Study Design, Objectives	Sample (n)	Intervention	Outcomes	Key Findings	Quality Assessment (Risk of bias)
Nural et al. 2009 Turkey	Cross-sectional controlled clinical trial To determine the effects of a home healthcare intervention on the quality of life in patients with GI cancer	Adults with GI cancer (n=42) (m=18,f=24) No active treatment during study	<i>Intervention:</i> 3 home visits (baseline, days 20 & 40); nursing care guided by evidence-based protocol <i>Control:</i> 2 home visits (baseline & day 40); standard care	Pain, disease progression, symptom distress, quality of life	Intervention group: Improved physiologic functioning, psychological concerns & total stress compared to control group; Within intervention group, decreased pain and increased performance from baseline to final interview.	1a. Low 2. Low 3. Low 4. Unclear 5. Low 6. Unclear (2/4 items) Low (2/4 items) 7. Low
Benor et al. 1998 Israel	Controlled clinical trial To measure the effect of a structured nursing intervention, nurses trained in applying the self- care model, to ambulatory cancer patients receiving treatment.	Adults with diagnosis of breast, colon, genital, prostate, lymphoma (n=94) Ages 20-70 Received active treatment (chemo/rad)	<i>Intervention:</i> Ten home visits by oncology nurses to assess, support, educate and coach about symptom management <i>Control:</i> Standard care from cancer center Baseline & 3 month interview Duration: 3 months	Symptom assessment based on intensity, independence controlling the symptom, perception of familial help and knowledge of symptom control	Decreased symptom intensity, increased independence, familial support and knowledge for intervention group Stable or reverse direction on all variables for control group	1a. High 2. Low 3. Low 4. High 5. Low 6. Low 7. Low

Author, Year, Country	Study Design, Objectives	Sample (n)	Intervention	Outcomes	Key Findings	Quality Assessment (Risk of bias)
McCorkle et al. 1989 United States	RCT Longitudinal experimental design To assess the effects of home nursing care on patients with progressive lung cancer	Adults with lung cancer (n=78) (m=47,f=31) Ages 18-89 Received active treatment (chemo/rad)	<i>Intervention A:</i> Specialized oncology nurses provided individualized care, other disciplines as needed <i>Intervention B:</i> Standard home care nurses and interdisciplinary health care team <i>Control:</i> Non-nursing office-based care provided by physician Duration: 6 months	Symptom distress, pain, current concerns, mood states, functional status, health perceptions, complications, hospitalizations, length of hospital stay	Home care groups experienced less symptom distress; remained independent for a longer period of time but had worse health perceptions over time Specialized oncology group had fewer hospital admissions	1a. Unclear 2. High 3. Low 4. Unclear 5. Low 6. Unclear 7. Low
Molassiotis et al. 2009 United Kingdom	RCT To assess the effectiveness of symptom-focused home care in patients with cancer receiving an oral chemotherapy agent	Adults with colorectal cancer (n=110); breast cancer (n=54) (m=62, f=102) Ages 26-85 Received active treatment (chemo/rad)	<i>Intervention:</i> Multimodal home care nursing program: standard care plus home visits by specialized oncology nurses, symptom management based on evidence-based protocols, 24-hour on-call specialist nursing service Baseline home visit and weekly phone contact. Additional home visits <i>Control:</i> Standard care from cancer center, 24-hour hotline at cancer center Duration: 18 weeks	Toxicity assessment, anxiety, depression, quality of life, health services utilization	Decreased symptom toxicity scores and lower utilization of health care services for intervention group.	1a. Low 2. High 3. High 4. High 5. Low 6. Unclear 7. Low

Author, Year, Country	Study Design, Objectives	Sample (n)	Intervention	Outcomes	Key Findings	Quality Assessment (Risk of bias)
McCorkle et al. 1994 United States	Controlled before and after study To evaluate the impact of home care services on symptom distress, mental health, enforced social dependency, and health perceptions of cancer patients following an acute care hospital stay	Adults with solid tumor (breast, gyne, GI, head & neck, lung, prostate, GU) (n=60) (m=23,f=37) Received current/past treatment	<i>Intervention:</i> Care by home care agencies: symptom assessment & management, education, support <i>Control:</i> No home care services Duration: 6 months	Symptom distress, enforced social dependency, health-related perceptions, mental health status	Within: Interventions group had improved symptom distress, mental health and were more independent Between: Intervention group had improved mental health and more independent	1b. High 2. High 3. High 4. Unclear 5. Low 6. Low (3/4 items) High (1/4 items) 7. Low
Quality Assessment Legend						
1a. Concealment of allocation (RCT)			Low risk – Explicit description of process to meet each quality criterion			
1b.Characteristics for studies using second site as control (CCT)			Unclear – No description of process specified			
2. Follow-up of professionals			High risk – Description of process that does not meet each quality criterion			
3. Follow-up of patients or episode of care						
4. Blinded assessment of primary outcomes						
5. Baseline measurement						
6. Reliable primary outcome measure(s)						
7. Protection against contamination						

Assessment Criteria

None of the studies described the process of symptom assessment.

Characteristics of the Interventions

Nursing care was an essential intervention component of all studies, with care delivered directly by nurses. The home care interventions were multimodal and often addressed multiple aspects of patients' and families' care needs. Two studies used standard home care nursing services provided by home care agencies (McCorkle et al., 1989, 1994). Another study applied the self-care model by using nurses to coach and support patients regarding their symptoms during structured weekly home visits (Benor et al., 1998). Only one study with participants receiving an oral chemotherapeutic agent used an intervention for symptom management for treatment-related symptoms (Molassiotis et al., 2009). The other studies examined the intervention by looking at the overall impact of the home care nursing, with a greater focus on cognitive, psychological, and psychosocial outcomes (Benor et al., 1998; McCorkle et al., 1989, 1994; Nural et al., 2009).

Time. The interventions for the studies ranged in length of time from 5 weeks to 6 months (median=12 weeks) (see Table 2.3). Contact duration between nurse and patient ranged from 10 minutes to 2 hours, and frequency of contacts ranged from twice per week to every 20 days.

The nurses' knowledge and skills. Three studies described specific oncology training and education as a component of the nursing intervention including master's degrees (McCorkle et al., 1989) and expertise in cancer care (Benor et al., 1998; Molassiotis et al., 2009). Two studies provided no information on the level of oncology knowledge of the nurses in their studies (McCorkle et al., 1994; Nural et al., 2009).

Resources to guide nurses. Two studies used evidence-based guidelines as a component of the intervention (Molassiotis et al., 2009; Nural et al., 2009) and three did not (Benor et al., 1998; McCorkle et al., 1989, 1994). One study developed written symptom management protocols based on best evidence from the literature that included pharmacologic and non-pharmacologic self-management interventions for nine common symptoms (Molassiotis et al., 2009). The other study developed a guideline based on the literature to address home care needs of patients with gastrointestinal cancers (Nural et al., 2009). Care was provided based on this guideline that identified commonly experienced symptoms and provided evidence-based, practical interventions to implement in the home setting. Neither of these studies gave details about the development or evaluation of the guidelines/protocols and they were not available for review.

Control groups. Care received by the control groups was standard care provided by ambulatory cancer centers (Benor et al., 1998; McCorkle et al., 1989; Molassiotis et al., 2009), and care guided by a pain clinic (Nural et al., 2009). The other study did not describe the care received by the control group except to note that they did not receive home care nursing services (McCorkle et al., 1994).

Evaluation

Measurement instruments. Four of the five studies included multiple instruments for data collection, using mostly self-reporting for patient domains including physical, emotional, cognitive and psychosocial (McCorkle et al., 1989, 1994; Molassiotis et al., 2009; Nural et al., 2009) with one study using a single instrument (Benor et al., 1998)(Table 2.4). Three studies used instruments that required scoring by the nurse (McCorkle et al., 1989, 1994; Nural et al., 2009) and one instrument required ratings by both the patient and the nurse (Benor et al., 1998).

Instruments used mainly Likert-type rating systems or checklist formats. They ranged from a single item to 72 items per instrument. Of the 18 instruments, the Symptom Control Assessment was reported as reliable and valid (Benor et al., 1998), 6 instruments were reported as reliable, and 2 were reported as valid.

Table 2.4. Characteristics of instruments used in studies

Study Author	Instrument	# of Items	Reporter/Design	Reliability	Validity
Nural et al. (2009)	Eastern Cooperative Oncology Group (ECOG) Performance Status	1	Interviewer scored; Likert scale	NR	NR
	Rolls-Royce Quality of Life Scale	42	Self-report; Likert scale	NR	Internal validity $r=0.996$ ($p<.001$)
	Rotterdam Symptom Checklist	27	Self-report; Likert scale	Cronbach's alpha= 0.81 and 0.79	NR
	Visual Analog Scale	1	Self-report; Likert scale	NR	NR
Benor et al. (1998)	Symptom Control Assessment	64	Self-report and Interviewer scored; Likert scale	Cronbach's alpha=0.85	✓ Content validity
McCorkle et al. (1989)*	Enforced Social Dependency Scale	10	Interviewer scored; Likert scale	NR	NR
	Health Perceptions Questionnaire (General Health Index)	22	Self-report; Likert scale	NR	NR
	Inventory of Current Concerns	72	Self-report; checklist	NR	NR
	McGill-Melzack Pain Questionnaire	4	Self-report; Likert scale, checklist	NR	NR
	Profile of Mood States	65	Self-report; Likert scale	NR	NR
	Symptom Distress Scale	13	Self-report; Likert scale	NR	NR
Molassiotis et al. (2009)*	European Organization for Research and Treatment of Cancer Quality of Life Questionnaire C30	30	Self-report; Likert scale	NR	NR
	Hospital Anxiety and Depression Scale	14	Self-report; Likert scale	NR	NR
	National Cancer Institute – Common Toxicity Criteria	9	Interviewer scored; Likert scale	NR	NR
McCorkle et al. (1994)	Enforced Social Dependency Scale	10	Interviewer scored; Likert scale	Cronbach's alpha= 0.81 and 0.90	NR
	Health Perceptions Questionnaire (General Health Index)	22	Self-report; Likert scale	Cronbach's alpha= 0.83 and 0.85	NR
	Mental Health Status Inventory 5	5	Self-report; Likert scale	Cronbach's alpha= 0.85 and 0.80	NR
	Symptom Distress Scale	13	Self-report; Likert scale	Cronbach's alpha= 0.70 and 0.85	NR

NR=Not reported; * Reported that instruments had adequate psychometric properties

Impact on patient outcomes. All five studies reported that overall, the home care nursing interventions helped patients to remain less symptomatic and maintain more independence, both of which contribute to improved quality of life. Other positive effects noted in the experimental groups for specific studies include improved mental health ($p=0.04$) (McCorkle et al., 1994), increased knowledge related to symptom management ($p<0.05$) (Benor et al., 1998), decreased physiological, psychological, and total stress ($p<0.05$), and maintained quality of life compared to a decrease in the control group (Nural et al., 2009).

Impact on health care system outcomes. Two studies reported the positive implications for the larger health care system. Compared to usual care or office care, an oncology home care program demonstrated lower use of health care services with fewer inpatient days (57 intervention vs. 167 control; 258 intervention vs. 317 office care) (McCorkle et al., 1989; Molassiotis et al., 2009), fewer emergency hotline calls (32 intervention vs. 91 control), and lower additional visits to health services (33 intervention vs. 74 control) (Molassiotis et al., 2009).

Discussion

This scoping review included five studies of variable quality that focused on cancer symptom management interventions by nurses in the home care setting. Symptom assessment processes were not described in the studies. The interventions evaluated in the studies were often multimodal and were delivered by generalist home care nurses and expert oncology nurses, with two studies using evidence-based resources to guide nursing care for symptom management. All studies evaluated patient outcomes including symptom distress and quality of life. Additionally, two studies included system outcomes such as utilization of health care services. Overall, the studies revealed that home care nursing interventions improved individuals' physical and

emotional well-being, and reduced the use of health care resources. Cancer treatments can be the cause of many symptoms; therefore, it was encouraging to note that four of the five studies included patients who were receiving chemotherapy, radiation therapy or both (Benor et al., 1998; McCorkle et al., 1989, 1994; Molassiotis et al., 2009). The improvement in symptom management observed in these studies was similar to nursing in other clinical conditions. Improved outcomes have also been identified in a variety of home health nursing practices including the management of enterostomal therapy and wound care (Baich, Wilson, & Cummings, 2010), diabetes (Hartman, Litchman, Reed, & Burr, 2009), heart failure (Riggs, Madigan, & Fortinsky, 2011), mental health (Thobaben, 2013), and urinary incontinence (Egnatios, Dupree, & Williaims, 2010), supporting the contribution these nurses make to improved client care. Improved symptom management and greater independence suggested that home care nurses have the opportunity and the potential to improve the cancer experience. Although positive outcomes were noted, two studies that used standard home care services were conducted more than 30 years ago and it is difficult to know the state of the home care nursing agencies at that time (McCorkle et al., 1989, 1994). There was no description of the characteristics of the nurses or the agencies providing the care so it is not possible to further examine elements of their programs that may have contributed to the improved outcomes or how they compare to current services.

More recent studies included evidence-based interventions to guide the nursing care for symptom management (Molassiotis et al., 2009; Nural et al., 2009), which reflect the shift in recent years towards nursing practice guided by evidence (Estabrooks, 2004). These studies showed improvements in patient and system outcomes. Although nurses' perceptions are an important element that must be considered when developing and implementing evidence-based

tools for nurses to use, these two studies did not discuss the nurses' perceptions. Other research has demonstrated that nurses want evidence in formats that are accessible, easy to use, and applicable to their clinical practice (Jeffs et al., 2013) and nursing engagement throughout the process of developing clinical practice tools can increase the likelihood of sustained changes to practice (Harrison, Légaré, Graham, & Fervers, 2010).

Interestingly, four studies evaluated interventions that were conducted through home care programs with care provided by expert nurses who had extensive oncology nursing knowledge, training, and experience (Benor et al., 1998; McCorkle et al. 1989; Molassiotis et al., 2009; Nural et al. 2009). Nurses for these studies were recruited specifically for the research study and had intervention-specific training. These studies highlight the value of expert oncology nurses and these findings are consistent with other studies of specialized oncology nurses that they improve individuals' experience of cancer through their expert knowledge and ability to provide specialized care (Howell, Fitch, & Caldwell, 2002; Koutsopoulou, Papathanassoglou, Katapodi, & Patiraki, 2010; McCorkle et al., 2011). In contrast, home care nurses are more generalists and given their role in providing cancer symptom management, it would be useful to understand their perspectives on this issue (Feldman & McDonald, 2004).

Most of the programs and protocols implemented in the five studies were complex and resource intensive based on the frequency and length of contact the study nurses had with patients. Although benefits were highlighted, the feasibility of replicating and implementing such complex programs seems unlikely at this time for various reasons, including fiscal restraints in Canadian health care (Dhalla, Guyatt, Stabile, & Bayoumi, 2011). The implementation of simpler, more affordable interventions needs to be evaluated to determine if positive outcomes

can still be achieved while using health care resources more efficiently (Wensing, Bosch, & Grol, 2010).

Symptom assessment methods were not described nor discussed in any of the articles. Two valid and reliable assessment instruments were used in two of the studies but they were used to measure outcomes, not for the purpose of symptom assessment. One study clearly stated this, indicating that the toxicity scores were used as the primary outcome (Molassiotis et al., 2009). This is somewhat concerning because assessment is the first phase of the nursing process and the information obtained during the assessment is what drives the remaining phases (Wilkinson, 2007). If evidence is not being used to inform the entire process, it raises questions about the consistency and comprehensiveness of symptom assessments. The Edmonton Symptom Assessment System (Bruera, Kuehn, Miller, Selmsler, & Macmillan, 1991) is now consistently being used to screen for cancer related symptoms across Ontario oncology programs (Barbera et al., 2010).

Limitations

There are three main limitations to this scoping review. First, on an individual study level, there was a paucity of articles identified that qualified for this review and those identified had variable risk of bias. Therefore, caution was used with interpreting the findings.

Second, at the review level, although a thorough search of the literature was conducted using clear inclusion and exclusion criteria, it is possible that relevant articles were missed particularly given only one person was involved in study selection. It is also possible that the search strategy did not identify all available literature and that screening by one person only was less rigorous (Shea et al., 2007). Considering only articles published in English may also have

limited the review (Shea et al., 2007). The evaluation of the studies' quality was conducted by only one person.

Finally, given the focus on symptom management in general, no searches were conducted for individual symptoms as that was beyond the scope of this review. A more in-depth search for each symptom may reveal further evidence.

Conclusion

Few studies have evaluated interventions by nurses for cancer symptom management for individuals in the home setting. These five identified studies demonstrate that home care nursing services may offer patients a better cancer experience by improving symptom management, promoting independence, maintaining quality of life, and decreasing use of health care services. The use of evidence-informed tools, such as symptom management protocols, to inform nursing practice in the home care setting, was only evaluated in two of these studies, highlighting the very limited evidence available in this area. Further research is required to determine the effectiveness of the protocols and to explore sustainable approaches to integrate evidence into everyday clinical practice to improve home care nurses' abilities to manage symptoms related to cancer.

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Chapter 3

Knowledge Tools for Cancer Symptom Management by Home Care Nurses: A Mixed Methods Study Proposal

Introduction

Background

Cancer prevalence.

In Canada, 40% of women and 45% of men will be diagnosed with cancer in their lifetime (Canadian Cancer Society's Steering Committee on Cancer Statistics, 2011). An estimated 187,600 individuals, or 21 per hour, were given a cancer diagnosis in 2013 (Canadian Cancer Society's Advisory Committee on Cancer Statistics, 2013). Cancer is now viewed as a chronic disease because people with cancer are living longer as a result of scientific advancements in the areas of screening, prevention, treatment, and medical management practices (Kachuri, De, Ellison, Semenciw, & The Advisory Committee on Canadian Cancer Statistics, 2013). At the beginning of 2009, 838 724 Canadians with a cancer diagnosed in the previous 10 years were still alive (Canadian Cancer Society's Advisory Committee on Cancer Statistics, 2013). Hence, cancer affects the lives of countless individuals directly or indirectly, every day.

Impact of cancer treatment and symptoms.

Common cancer treatments include surgery, chemotherapy, radiotherapy, and hormones, provided in a variety of combinations. In Ontario, approximately two-thirds of individuals with cancer will receive systemic treatment (Cancer Care Ontario, 2009) and close to half will receive radiation treatments (Cancer Care Ontario, 2007). Cancer Care Ontario estimates that more than 40,000 people received chemotherapy treatment in the year 2012-13 (Cancer Care Ontario, 2009). Radiation and chemotherapy may be given with the intention of curing the cancer, or with palliative intent, focusing on managing symptoms and improving quality of life (Cancer Care Ontario, 2007; 2009). Often there is no clear line that separates curative treatment from

palliative treatment on the cancer care continuum; rather it is a gradual shift that occurs over time in the context of disease progression (Canadian Hospice Palliative Care Association, 2013).

Individuals, on chemotherapy and/or radiation therapy for cancer, receive care in a variety of settings, including ambulatory clinics, in hospital, and within their own homes. While these treatments are intended to benefit individuals, they are not without side effects.

Symptoms experienced by individuals with cancer can be caused by cancer treatments or by the disease itself; but regardless of the source symptoms can be distressing and affect many aspects of daily living. Symptom prevalence and intensity have been well-studied across disease sites suggesting that adequate symptom management has not been achieved in the cancer population (Barbera et al., 2010; Henry et al., 2008; Iyer, Taylor-Stokes, & Roughley, 2013; Teunissen et al., 2007). A large cohort study of 45,118 patients in ambulatory cancer clinics in Ontario, described self-reported symptom scores based on the Edmonton Symptom Assessment System (ESAS) (Barbera et al., 2010). Fatigue was identified as the most prevalent symptom, followed by poor sense of well-being, loss of appetite, anxiety, and pain. Pain or shortness of breath were identified by about half of the patients, with about half of those indicating moderate to severe intensity. Although ESAS includes the nine most common symptoms across the cancer population, other symptoms such as constipation, sleep disturbances, or site-specific symptoms are not included (Howell et al., 2012). A systematic review including 46 studies about symptom prevalence had similar findings, revealing that fatigue, pain, lack of energy, weakness, and appetite loss occurred in more than 50% of patients with incurable cancer (Teunissen et al., 2007). A total of 37 symptoms were identified, with all but one occurring in $\geq 10\%$ of the patients included in this systematic review. For adults receiving chemotherapy and radiation, a cross-sectional survey in the United States identified fatigue, pain, nausea/vomiting, anxiety, and

insomnia as the most prevalent symptoms (Henry et al., 2008). Most of the patients reported at least one symptom during treatment (88%), but it is concerning that almost one-third of patients experienced 5 -7 symptoms and another third experienced 8-13 symptoms. In Canada, oncology nurses identified common symptoms requiring management including fatigue, anxiety, pain, nausea, and constipation (Macartney, Stacey, Carley, & Harrison, 2012) and a systematic review of emergency department visits by oncology patients showed the most common of 28 symptoms were febrile neutropenia, infection, pain, fever, and dyspnea with more than half of the visits requiring hospital admission for symptom management (Vandyk, Harrison, Macartney, Ross-White, & Stacey, 2012). In summary, individuals with cancer experience a range of symptoms, sometimes requiring emergency department visits and hospitalization.

Cancer symptoms impact individuals' physical, emotional, and psychological well-being, especially in the presence of multiple symptoms (Berry, 2011; Dodd, Cho, Cooper, & Miaskowski, 2010; Ferreira et al., 2008; Iyer et al., 2013; Peters & Sellick, 2006). Physical, emotional, and psychological well-being are elements of health-related quality of life (HRQOL), which reflects individuals' perceptions of their current situation (Nural, Hintistan, Gürsoy, & Duman, 2009). Common symptoms associated with reductions in HRQOL domains include pain, depression, fatigue, insomnia, constipation, lack of appetite, dyspnea, nausea, vomiting, and diarrhea (Ferreira et al., 2008; Iyer et al., 2013). The relationship between fatigue and quality of life was explored in patients undergoing cancer treatments (Gupta, Lis, & Grutsch, 2007). Findings revealed that increasing fatigue was strongly associated with declines in the domains of social and economic function, psychological and spiritual function, family function, and global function. The largest decline was found in the health and functioning domain. Furthermore, higher levels of symptom distress have been associated with diminished quality of life (Akin,

Can, Aydiner, Ozdilli, & Durna, 2010). Individuals experiencing multiple symptoms with greater severity are at greater risk for poorer outcomes, including decreased quality of life and poorer functional status (Dodd et al., 2010). Conversely, well-managed symptoms can contribute to improved well-being (Benor, Delbar, & Krulik, 1998; Nural et al., 2009).

Family caregivers of individuals with cancer are also impacted by the effects of symptoms. Through the cancer trajectory they frequently assume responsibility as the primary care provider for physical, emotional, and practical domains of care (Glajchen, 2012; Northouse, Katapodi, Schafenacker, & Weiss, 2012). In addition to providing assistance with usual activities of daily living, informal caregivers often provide direct care, including managing symptoms and treatment-related side effects, administering medication, and changing dressings with almost half indicating they received inadequate training in these areas (van Ryn et al., 2011).

Caregiver burden has been shown to impact caregivers' physical and mental health, as well as quality of life. The relationship between gender, the caregivers' appraisal of providing care (positive or negative experience), and quality of life was examined (Kim, Baker, & Spillers, 2007). Findings suggested that the caregivers' esteem (positive or negative caregiving experience) and caregiver stress were strong predictors of the caregivers' quality of life. Furthermore, studies on the effects of sleep disturbances on individuals with cancer and their caregivers revealed that: a) patients who reported poor quality sleep were more anxious and had increased pain compared to their counterparts who reported good quality sleep; b) caregivers were found to be more anxious; and c) sleep disturbance symptoms were correlated with increased levels of depression of caregivers (Gibbins et al., 2009; Valeberg & Grov, 2013). An extensive list of more than 200 problems, burdens, and responsibilities experienced by caregivers of individuals with cancer included: physical, social, and emotional problems; social problems

and need for information; responsibilities and impact on daily life; and physical health problems and quality of life (Stenberg, Ruland, & Miaskowski, 2010). This systematic review highlights the tremendous breadth and depth of caregiver experiences, contributing to the understanding of the complexities they deal with on a daily basis as caregivers for individuals with cancer. Family caregivers are essential to support individuals with cancer in the home. The negative impact of providing care identified in the literature suggests a need to better support caregivers and patients in symptom management in their homes.

Nursing services in the home.

Home care nursing is defined by the Ontario Home Care Association (OHCA) (2011) as providing care in community settings such as homes, schools, or workplaces. It requires nurses to possess advanced assessment and evaluation skills, critical thinking, as well as a comprehensive knowledge base to provide care to individuals with a wide range of diagnoses in the community setting (OHCA, 2011).

Home care nurses work as generalists, providing care in a decentralized environment that is often lacking in peer and administrative support, and both human and material resources, (Feldman & McDonald, 2004). This is in contrast to nurses practicing on inpatient units or in ambulatory oncology settings, where there tends to be greater specialization and access to continuing education. As home care nurses are expected to provide care to patients with a wide range of illnesses and diseases, the depth of oncology knowledge and experience caring for patients with cancer may vary greatly. Furthermore, the overall lack of evidence-based nursing practice in the home care setting has been highlighted as an area of concern, including outdated and non-existent nursing policies and procedures (Berlund, Holm, Gundersen, & Bentsen, 2012). Although there has been an increase in the number of guidelines, the proportion for use in home

care is still relatively small (Chapter 2; Williams et al., 2009). Despite these challenges, home care nurses are well-positioned to conduct assessments, to triage, and to provide symptom management for patients receiving cancer treatment in the community. As members of the interprofessional health care team, nurses have the potential to complement and enhance care and improve patients' cancer experiences (Howell, Fitch, & Caldwell, 2002; McCorkle et al., 1989; Molassiotis et al., 2009; Nural et al., 2009).

Evidence-based nursing practice in symptom management.

Evidence-based practice is important for cancer symptom management and a fundamental element of the nursing profession (College of Nurses of Ontario, 2009; Estabrooks, 2004; Gobel, Beck, & O'Leary, 2006; Melnyk et al., 2004; Schulmeister & Gobel, 2008; Underhill, Boucher, Roper, & Berry, 2012; Walsh & Rybicki, 2006; Weber & Eskinazi, 2012). Cancer Care Ontario and the Oncology Nursing Society (ONS) have both embraced this philosophy and have developed guidelines for cancer symptom management (Cancer Care Ontario, 2014; Gobel et al., 2006; Schulmeister & Gobel, 2008).

Cancer Care Ontario (2014) has recently developed seven evidence-based guidelines to support health care professionals providing symptom management to individuals with cancer and their families. Symptoms include pain, dyspnea, nausea and vomiting, delirium, loss of appetite, bowel care (constipation and diarrhea), and oral care (mucositis, xerostomia, infections, and dysgeusia). Each symptom includes an algorithm, a pocket guide, and a full guide-to-practice document that are available on their website. Three additional guidelines are provided that were developed through other Canadian partnerships that address the symptoms of fatigue, depression, and anxiety (Howell et al., 2010; Howell et al., 2011). The guidelines include evidence-based information about assessment, diagnosis, pharmacological and non-pharmacological treatment

options for cancer symptom management. The guidelines include details on the rigorous development process used to create the tools (Cancer Care Ontario, 2010). Clinical practice guidelines are tools that support evidence-based cancer symptom management; however, incorporating the evidence into practice can be more challenging (Stacey et al., 2012; Brouwers, Stacey, & O'Connor, 2013). While the development of these guidelines is relevant and timely, at this time there is no research available evaluating their implementation or use.

The ONS has also been developing nursing-sensitive patient outcome resources titled Putting Evidence into Practice (PEP)© (Gobel et al., 2006). These resources aim to enhance the use of evidence in nursing practice. Presently there are 20 different topics available on the ONS website for a variety of physical and psychosocial symptoms and problems experienced by individuals with cancer and their families (ONS, 2014). Again, information is available about the development process to ensure transparency. A brief document accompanies the complete guideline that summarized the interventions that are: recommended for practice, likely to be effective, effectiveness not established, and not recommended for practice. It is unclear the extent to which these guidelines have successfully been implemented and evaluated in clinical settings (Underhill et al., 2012).

Research has also explored the barriers to oncology nurses using research in telephone practice. A survey of oncology nurses in Ontario revealed a variety of barriers including lack of awareness of protocols, lack of time, the challenge of managing multiple symptoms, and variations in physician preferences regarding approaches to symptom management (Stacey, Bakker, Green, Zanchetta, & Conlon, 2007). Canadian oncology nurses highlighted similar issues citing barriers of lack of time, lack of training, lack of knowledge, and multiple and complex symptoms (Macartney et al., 2012).

Clinical practice guidelines synthesize evidence from research findings and make recommendations for practice, however uptake and use in practice are variable due to complexity of recommendations, inadequate knowledge, and lack of resources to implement recommendations (Harrison, Légaré, Graham, & Fervers, 2010). This leads to a gap between what evidence shows should be done in practice and what is actually being done in practice. In some clinical settings, patients are receiving health care that is not based on current evidence and/or receiving treatments that are ineffective and even harmful (Grimshaw, Eccles, Lavis, Hill, & Squires, 2012). Knowledge translation tools narrow this know-do gap by presenting best available evidence using formats sensitive to how nurses think and what nurses do (Brouwers et al., 2013). Evidence-based protocols to guide clinical practice are examples of knowledge translation tools that take guideline recommendations and present them in formats that are tangible and user-friendly for nurses, while still maintaining the integrity of the guideline (Harrison et al., 2010). There is a paucity of evidence-based, standardized tools that translate cancer symptom management guidelines into practical applications for nurses (Chapter 2).

The Pan-Canadian Oncology Symptom Triage and Remote Support (COSTaRS) project has acknowledged this gap in oncology nursing services and are taking steps to address it. COSTaRS is a national collaborative initiative focussing on improving cancer symptoms experienced by patients living in the community (Bakker & Steele, 2009). With funding from the Canadian Partnership Against Cancer and the CAN-IMPLEMENT© methodology guiding the development process (Harrison, Graham, van den Hoek, Dogherty, Carley, & Angus, 2013), the COSTaRS project produced 13 evidence-informed symptom protocols specifically for remote use including telephone and internet by nurses (Appendix A). CAN-IMPLEMENT© is a

framework developed to facilitate the process of guideline adaptation and implementation, providing methodology and resources to support the process (Harrison et al., 2013).

The process began by convening a Steering Committee with representation from eight provinces and includes researchers, an information systems researcher, a library scientist, and knowledge users such as advanced practice nurses, nurse practitioners and additional experts in oncology nursing. A systematic review was conducted for each symptom to identify existing clinical practice guidelines published since 2002. A total of 43 guidelines were identified, including those from ONS and CCO, but they lacked tools to support integration into the clinical practice of nurses. The guidelines were used to inform the development of the symptom protocols (median 3 guidelines per protocol; range 1 to 7) (Stacey et al., 2011). The quality of the guidelines was appraised using the AGREE instrument (AGREE Collaboration, 2003). Rigour scores are included on the reference lists of each protocol to show the strength of each guideline. Throughout the protocols, plain language is used to facilitate communication between nurses using the protocols and patients/families. Each protocol has five recommendations for the nurse: a) assess symptom severity; b) triage patient for symptom management based on highest severity; c) review medications being used for the symptom; d) review self-management strategies; and e) summarize and document the plan agreed upon with the patient. Although the protocols have been developed and validated with oncology nurses and researchers for use in remote settings (Stacey, Macartney, Carley, Harrison, & the Pan-Canadian Oncology Symptom Triage and Remote Support Group, 2013), their usability in the home care setting has not yet been evaluated.

In summary, nurses providing home care services to oncology patients on chemotherapy and radiation therapy are often generalist with less access to oncology specific resources and

continuing education. Oncology patients on treatment experience on average 5 to 13 symptoms and require guidance in symptom management to minimize emergency department visits and hospital admissions. Practice guidelines for cancer symptom management are available that synthesize the evidence but they are not formatted to be used in practice. Knowledge translation tools such as symptom protocols that are based on practice guidelines present best available evidence in user-friendly, implementable formats (Brouwers et al., 2010). Implementation of these protocols is underway for remote symptom support by ambulatory oncology nurses but little is known about their usefulness for guiding home care nurses.

Theoretical Support

The Knowledge-to-Action Framework and the Ottawa Model of Research Use are common implementation frameworks. The Knowledge-to-Action Framework is a conceptual model that facilitates knowledge translation (Graham et al., 2006; Straus & Holroyd-Leduc, 2008). According to the Canadian Institutes of Health Research, knowledge translation is defined as: “a dynamic and iterative process that includes synthesis, dissemination, exchange and ethically-sound application of knowledge to improve the health of Canadians, provide more effective health services and products and strengthen the health care system” (2011). The action cycle applies knowledge in phases based on planned-action theoretical concepts from 31 theories (Graham et al., 2006; Straus, Tetroe, & Graham, 2009). The first element of the process is knowledge creation, which includes three phases to tailor the knowledge: a) knowledge inquiry involves conducting individual studies; b) knowledge synthesis is the process of gathering what is known from individual studies and making sense of it through summaries such as systematic reviews; and c) knowledge tools, such as practice guidelines or protocols are developed based on synthesized evidence (Staus et al., 2009). Knowledge tools are 3rd generation knowledge that

close the evidence-practice gap (Brouwers et al., 2013). To enhance the likelihood of successful uptake of knowledge tools, steps in the action cycle of the framework include: adapting the knowledge to the local context; evaluating barriers and facilitators, selecting and tailoring interventions to support implementation (Brouwers et al., 2013; Harrison et al., 2010; Harrison et al., 2013; Straus et al., 2009). When uptake of the knowledge occurs, the next phase begins, including: monitoring knowledge use; evaluating the implementation process; evaluating outcomes; and supporting sustained knowledge use (Harrison et al., 2013).

The Knowledge-to-Action Framework will guide the design of the study, with specific emphasis on the Adaptation and Barriers Assessment phases of the action cycle (Graham et al., 2006; Harrison et al., 2013). The evidence-informed protocols being implemented in the proposed study are an example of a knowledge tool (Brouwers et al., 2013). Adapting this knowledge tool for use by home care nurses will require an iterative process that will seek to elicit perceptions about the value, usefulness, and appropriateness of the protocols in the community practice setting (Graham et al., 2006; Harrison et al., 2010). Adaptation phase is defined as the process that potential knowledge users go through when considering applying specific knowledge to their specific situation, including steps taken to tailor the knowledge to fit with their unique circumstances. A barriers assessment provides the opportunity to assess potential challenges to introducing and using the knowledge tool in practice. Potential support systems that should be taken advantage of should also be identified in this process.

The Ottawa Model of Research Use (OMRU) will guide the clustering of themes in the qualitative analysis (Logan & Graham, 1998; Graham & Logan, 2004). The OMRU was developed to facilitate evidence-based practice through transferring and incorporating health-related research findings into practice. There are three phases of research use: assess barriers and

facilitators; monitor interventions and degree of use; and evaluate outcomes (Graham & Logan, 2004). These three phases incorporate six key framework elements: practice environment, potential adopters, evidence-based innovation, research transfer strategies, evidence adoption, and health-related or other outcomes (Logan & Graham, 1998). In this proposed research study, the elements of the assessment phase (practice environment, potential adopters, and evidence-based innovation) will be used to categorize the barriers and facilitators identified in the focus groups and interviews. The practice environment is multi-dimensional and includes several factors of the setting for consideration: patients, social, structural, economic, and uncontrolled events. The potential adopters are the target audience of the innovation that require assessments of their awareness, attitudes, knowledge and skill levels, concerns, and current practices. The evidence-based innovation or the research evidence refers to the attributes of the particular innovation, as well as the development process.

Objectives

The overall aim of this proposed study is to explore the potential for a set of 13 symptom management protocols to be used by nurses in the home care setting when caring for individuals with cancer. Specific research questions include: How usable are the protocols for assessing, triaging, guiding clients in self-management, and documenting cancer treatment-related symptoms in face-to-face interactions? What are the perceived barriers and facilitators to using the protocols for documentation in clinical practice?

Method

Study Design

A mixed methods descriptive study design will be used to answer the research questions. Data collection methods will include focus groups and a usability survey. Quantitative data collected with the usability evaluation tool (Appendix B) will elicit general perceptions about the set of protocols. Focus groups will enhance the depth and quality of information obtained from participants in an efficient manner by using group dynamics to enrich the discussion (Morse & Field, 1996). Qualitative and quantitative data will be collected concurrently during the focus groups and interviews. Qualitative and quantitative findings will be integrated to support convergence, synthesis, and validation of findings (Zhang & Creswell, 2013). Numbers from quantitative research and words from qualitative research are two elements of communication that can complement and support each other (Polit & Beck, 2012). Validation occurs when the findings of the study are supported and enriched by the multiple complementary approaches of qualitative and quantitative research elements (Zhang & Creswell, 2013). Furthermore, using a mixed methods approach can attempt to address biases that are inherent in each methodological approach (Lee & Smith, 2012).

Setting

Participants will be recruited from a not-for-profit home healthcare organization that provides community and home health care services across Canada. However at this time, nursing services from this organization for oncology clients are only available in Ontario. Home and community health care services are delivered through 14 regional offices throughout urban and rural Ontario. Overall, the organization employs more than 5,000 nurses, personal support workers, and rehabilitation therapists delivering nearly five million hours of health care services

(W. Gifford, personal communication, May 30, 2012). The organization has a well-documented history of being involved in research initiatives supporting knowledge creation, knowledge utilization, knowledge dissemination/exchange, and guideline implementation ([organization], 2012). They also maintain their status as a Registered Nurses' Association of Ontario (RNAO) Spotlight Organization which means they are committed to implementing, supporting, and evaluating evidence-based practice (RNAO, 2014). An established academic affiliation already exists between the University of Ottawa and the organization, thus facilitating the research process.

The organization has agreed to sites in Toronto and Ottawa for data collection. Toronto represents an urban center where Ottawa serves a mixed urban and rural population in the Ottawa and Eastern County district including Renfrew, Lanark, and Cornwall. Within both of these locations, nurses provide nursing care in clients' homes and in retirement residences. The Toronto Central district regional office employs approximately 250 staff, with more than 180 registered nurses and registered practical nurses. The Champlain district regional offices serve the greater Ottawa area and employ over 180 staff including approximately 80 registered nurses and registered practical nurses.

Participants

Participants eligible for the study will be: (a) a registered nurse (RN) or registered practical nurse (RPN); (b) able to read and understand English; (c) employed either full-time or part-time with the home care agency; and (d) provide direct patient care or provide mentorship/guidance to nurses who provide direct patient care to oncology patients receiving cancer treatment. A specified minimum oncology patient caseload will not be included in eligibility criteria so as to be inclusive of nurses with varying levels of exposure to patients

undergoing cancer treatment. Registered nurses and registered practical nurses are both regulated by the College of Nurses of Ontario. Similarities between the two groups include: legislative scope of practice statement, including the number of controlled acts they can perform; applicability of the College's practice standards and guidelines; and accountability (College of Nurses of Ontario, 2006). Key differences are related to education and practice expectations. RNs currently have a four year bachelor's degree in nursing whereas RPNs have a two year diploma. This is reflected in a greater breadth and depth of knowledge possessed by RNs. Registered nurses are also more autonomous in their practice. They are able to make decisions and independently carry out patient care where RPNs may be required to consult and collaborate in order to meet complex care needs of patients.

Sampling Strategy

Purposeful sampling will aim to reach RNs, RPNs, and individuals with varying levels of leadership within the organization. This approach will aim to include participants with the particular knowledge and experience to provide information that is rich in both depth and detail (Higginbottom, 2004; Tuckett, 2004). Four planned focus groups will aim to reach: a) a group of 5 to 8 RNs in Ottawa; b) a group of 5 to 8 RPNs in Ottawa; c) a group of 5 to 8 RNs in Toronto; and d) a group of 5 to 8 RPNs in Toronto. Given that focus groups are best conducted when there is homogeneity amongst the participants (Krueger & Casey, 2009), focus groups for RNs and RPNs will be conducted separately.

For interviews, purposeful sampling will include individuals with varying levels of influence within the organization, including clinical educators, managers, and advanced practice nurses. There are 17 clinical educators and 6 advanced practice nurses throughout Ontario. Individual interviews will be used to facilitate data collection from 4 to 6 key informants within

the organization as well as allow nurses who were unable to attend the focus groups the opportunity to participate in the research. Given the very specific nature of this research, it is reasonable to expect that the sample size and number of focus groups and interviews will generate knowledge with sufficient depth to answer the research questions and make a meaningful contribution to what is known about cancer symptom management in the home care setting. Sample size was determined based on the guiding formula described by Francis et al. (2009) that identifies the initial sample size of approximately 10, with saturation usually being reached with 3 additional interviews.

Participants will be recruited by sending the Invitation to Participate (Appendix C) to individuals' organization email account. The email will be distributed by a liaison person within the organization on behalf of the researcher, who has rightful access to the participants email addresses. Invitations will also be posted in approved locations at the offices at both sites. Interested individuals will contact the liaison person at the organizational office, or the researcher directly, as contact information for both is provided on the Invitation to Participate.

Intervention

Evidence-based protocols.

The symptom management protocols are knowledge tools that have been developed based on clinical practice guidelines to provide guidance to nurses providing remote support via telephone or internet to patients with cancer experiencing treatment related symptoms (Stacey et al., 2013). There are 13 evidence-based protocols to address the following symptoms: anxiety; bleeding; constipation; depression; diarrhea; dyspnea; fatigue; febrile neutropenia; loss of appetite; nausea/vomiting; peripheral neuropathy; skin reaction; and stomatitis. There is an accompanying general assessment form for general information including a narrative description

of the situation, and to help determine if there are multiple symptoms requiring assessment, triage, and management. Each protocol starts with definition of the symptom as supported by the literature. A subjective assessment of the symptom is conducted by the inclusion of a question from the Edmonton Symptom Assessment System (ESAS), a reliable and validated screening tool for symptoms in patients with cancer (Barbera et al., 2010; Bruera et al., 1991; Nekolaichuk, Watanabe & Beaumont, 2008). Objective questions provide guidance in the assessment, which also direct the nurse to triage based on the highest severity identified in the assessment. Relevant medications used for the symptom are reviewed to identify if the patient has symptom-relevant prescriptions, and how they have been taken. Appropriate self-management strategies are provided, with guidance to identify what has been tried in the past, and determine what the patient is willing to try. Finally, the plan developed and agreed upon between the patient and the nurse is summarized and documented. One key feature of these protocols is that all documentation is done directly on the tool as a permanent record and can easily be made part of the patient's health record. An additional element of the protocols is that the supporting clinical guideline references are available on each protocol to facilitate accessibility if users wish to review the original literature.

Data Collection Tools

An interview guide (Appendix D) will be used for the focus groups and the individual interviews. The interview guide was developed using elements of the Knowledge-to-Action Framework (Graham et al., 2006). Questions included will probe the current situation of symptom management, assess how the "knowledge" (e.g. symptom protocols) might be adapted to the home care setting, and identify barriers and facilitators to using the protocols in clinical practice. The questions pertaining to adapting the protocols for use in-person within the home

care setting are particularly important as the original protocols were developed for remote use via telephone or internet.

Usability of the protocols will be evaluated with a usability evaluation tool developed by members of the COSTaRS steering committee (Appendix B). Originally developed in the field of human-computer interactions, usability is defined as “the capacity of a system to allow users to carry out their tasks safely, effectively, efficiently, and enjoyably” (Kushniruk & Patel, 2004, p.56). It is increasingly being used for the evaluation of health information technology (Yen & Bakken, 2012). The usability evaluation tool to be used in this study was used to evaluate the initial version of the protocols in 2010 with nurses and nurse researchers. Questions related to information content, understandability of concepts and terms, readability and ease of use, workflow, and open-ended questions ask about what is liked about the protocol and suggestions for improving the protocol which were adapted from usability categories developed by Kushniruk & Patel (2004). Face validity of the usability tool was assessed by members of the COSTaRS steering committee and feedback was provided regarding terminology and layout, which were incorporated into the revised tool. Previous research has shown that approximately 80% of usability issues are identified by 4 or 5 individuals (Virzi, 1992) therefore this approach was chosen because a role playing exercise is planned.

Demographic data and practice characteristics will be collected from the participants to be able to describe the characteristics of the participants (Appendix E).

Data Collection Procedures

Focus group procedures.

A 1-hour time frame for focus groups has been chosen after speaking with the home care agency and determining that this would be the maximum amount of time nurses can be available

during a work day without impacting patient care. Each focus group will include a moderator and a research assistant for taking field notes.

Preparation for the focus groups will include: a) reserving a room for 2 hours (1 hour focus group, ½ hour set up, ½ hour clean up); b) arranging for food and beverages for participants; c) setting up audio recording equipment; and d) arranging furniture in room to improve visibility and create an environment that will facilitate open discussion amongst the participants.

Following introductions of the moderator and the research assistant, the study will be explained in detail and participants will have the opportunity to read the information sheet (Appendix F). Written consent will be obtained using the consent approved by The Ottawa Hospital Research Ethics Board (Appendix F). Participants will complete the demographic survey, followed by participant introductions. Focus groups will use an interview guide developed with elements of the Knowledge-to-Action Framework (Graham et al., 2006). The opening discussion will explore current nursing practices for providing cancer-related symptom management in the home, in order to have a context in which to situate the participants' comments and feedback. Next, a brief introduction of the 13 protocols will be given, providing some background context about their development. Participants will be paired up to complete a 5 minute role play exercise using the protocol of their choice with one participant being the simulated patient and the other being the nurse, using the protocol to guide managing the symptom. They will be instructed to act as a patient experiencing the symptom their partner had chosen. The simulated situation will evolve as the protocol is worked through, with the participant drawing on knowledge and past experiences to develop a simulated patient requiring immediate symptom management. And although it is not an actual situation, the process that they

will work through with the protocol is somewhat reflective of how the tool would be used in clinical practice. This approach was used in the initial development of the protocols and was found to be an effective means of identifying areas that required modification and clarification (Stacey et al., 2013). Through using the tool with a simulated “patient”, usability will be evaluated and participants will have the opportunity to provide feedback. They will then switch roles, allowing both participants the opportunity to use the protocols. Following this activity, the participants will complete the usability evaluation tool.

Key questions will guide the subsequent focus group discussion. The questions will aim to determine: a) factors that may promote the use of the evidence-based protocols in clinical practice; b) obstacles to using the protocols in clinical practice; c) constructive feedback on how to adapt the protocols for use face to face in the home care setting; d) suggested interventions to overcome identified barriers; and e) the potential to use the protocols as a training tool to enhance nurses’ knowledge of cancer symptom management.

Individual interview procedures.

Individual interviews lasting 30-45 minutes will be conducted using the same interview guide. Preparation for the interviews will include: a) arranging a meeting for 45 minutes; and b) setting up audio recording equipment. Interviews will be conducted via telephone or face-to-face. Packages containing the necessary documents will be mailed and sent electronically to participants in advance.

Similar to the focus groups, the study will be explained in detail and the participant will have the opportunity to read the information sheet. Verbal consent will be obtained at the beginning of the interview. Written consent will be obtained using the consent approved by The Ottawa Hospital Research Ethics Board and if the interview is done by telephone, will be

returned in the mail, along with the demographic questionnaire, and usability evaluation tool in the stamped envelope that will be provided. For interviews, the role playing exercise will be completed with the moderator acting as the patient and the participant playing the role of the nurse.

Member Checking

Member checking is a strategy for enhancing credibility of findings (Lincoln & Guba, 1985). Participants in the focus groups and interviews will be invited to review a summary of the findings to verify the accuracy of the findings from the analysis and to provide feedback about any factual errors or interpretive deficiencies. They will also be given the opportunity to provide any additional feedback not included in the initial focus group or interview.

Data Analysis

Demographic and usability survey data will be coded numerically and entered into Microsoft Excel for analysis. Double data entry will be used to identify and correct data entry errors. Analysis will include frequency distribution and descriptive statistics. Audiotapes from focus groups and interviews will be transcribed verbatim. Directed thematic analysis of the transcripts will be used to identify key themes and patterns (Hsieh & Shannon, 2005). Guided by the Ottawa Model of Research Use (OMRU), barriers and facilitators will be clustered at the level of the innovation, potential adopters, and practice environment (Logan & Graham, 1998; Graham & Logan, 2004). The primary researcher (KN) and the research assistant (SM) will independently analyze the data by: a) reading each transcript in its entirety to identify any overarching themes; b) coding the data by section to identify specific categories in relation to each research question; and c) comparing findings. Discrepancies will be reconciled through discussion and reaching consensus. Data will then be reviewed and categories will be grouped

inductively into broader themes to answer the research questions. A codebook of decisions and definitions used for the analysis will be maintained. The analysis process and results will be audited by the thesis supervisor.

Strengths

Several techniques will be used to enhance the credibility, dependability, confirmability, and transferability of the study findings (Lincoln and Guba, 1985). Credibility will be enhanced through different types of triangulation (Denzin, 1989). Method triangulation will incorporate the qualitative and quantitative data from the participants to reach conclusions. Investigator triangulation will include the research assistant conducting data analysis independent of the primary researcher, with the thesis supervisor auditing data coding and analysis decisions. Data source triangulation will be addressed by multiple focus groups including registered nurses and registered practical nurses, as well as interviews with individuals in leadership positions in the organization to include a variety of perspectives. Member checking is another technique that will enhance the credibility of findings.

Dependability refers to the potential to replicate the study findings with similar participants in a similar context (Polit & Beck, 2012). This will be achieved by transcription of the audiotaped focus groups and interviews that will allow for data analysis to be conducted by two people independently. Development of an audit trail will allow for transparency of the research process. Focus groups and interviews will be conducted by the same person to ensure consistency.

Confirmability will be supported through member checking, which also enhances credibility (Lincoln & Guba, 1985). Furthermore, an audit trail will include a collection of

documents acquired throughout the research process that would allow an independent reviewer to reach conclusions with the same data.

Transferability is the extent to which the study findings can be applied to other contexts (Lincoln & Guba, 1985). Therefore a thick description of the setting and participants will be developed to provide consumers of the research adequate information to evaluate transferability of the findings. Together, the four elements of credibility, dependability, confirmability, and transferability will enhance the trustworthiness of the research findings.

Ethical Considerations

In accordance with the University of Ottawa research ethics guidelines, ethical approval will be obtained from the Ottawa Hospital Research Ethics Board, with reciprocal approval received from the University of Ottawa and the organization (University of Ottawa, 2012).

A written consent form will be signed by each participant and stored separately from the collected research data. The consent form includes relevant information about the study such as the purpose of the research, voluntary participation, and ethical considerations such as risk and benefits, privacy and confidentiality, and contact information of the researchers as well as the Ottawa Hospital Research Ethics Board (Canadian Institutes of Health Research, Natural Sciences and Engineering Research Council of Canada, & Social Sciences and Humanities Research Council of Canada, 2010).

Participation in this study will be voluntary. The information provided will be kept strictly confidential. The information collected will be used solely for the purposes of this research. Anonymity will be protected by assignment of a participant code. No individual identifying information will be included in any publications resulting from this thesis. Individuals who will have access to the collected data will include the researcher, Kathryn

Nichol; a research assistant, Shelley Mackenzie; and the thesis committee members, Dawn Stacey, Wendy Gifford, and Craig Kuziemy, all of whom will have had to complete the Tri-Council Policy Statement II tutorial (Canadian Institutes of Health Research et al., 2010). The audiotapes will be transcribed verbatim and destroyed once the transcripts are verified, as part of the analysis. Electronic data will be stored on an external hard drive that is password-protected and allows for encryption of data. The data will be stored by the thesis supervisor in a locked filing cabinet in the Ottawa Hospital Research Institute General Campus for a period of 10 years, at which time it will be destroyed by shredding paper copies and deleting electronic files.

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Chapter 4

Knowledge Tools for Cancer Symptom Management by Home Care Nurses: A Mixed Methods Study

This chapter is based upon an unpublished manuscript formatted for submission to the journal

Home Healthcare Management & Practice

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Abstract

A mixed methods descriptive study explored the usability of evidence-based cancer symptom management protocols by nurses in the home care setting. Twenty-one registered nurses and 17 registered practice nurses in home care participated in an interview or focus group and completed a survey. Usability testing revealed high readability, the right amount of information, appropriate terms, fit with clinical workflow and being self-evident for how to complete the symptom protocols. Several barriers and facilitators to using the protocols were identified at the level of the client, nurse, and organization. The protocols were considered a good resource for training nurses about cancer symptom management. Given the current organizational structure they would be most useful as a nursing resource, with suggestions to create a client resource.

Introduction

Background

Effective cancer symptom management is a crucial element of nursing care that improves client outcomes including physical distress, emotional distress, and quality of life (Corner, 1997, 2003; Hoffman, 2013; Huhmann & Camporeale, 2012; Johnston et al., 2009; Rueda, Sola, Pascual, & Subirana Casacuberta, 2011; Williams, Williams, LaFaver-Roling, Johnson, & Williams, 2011). Many individuals receiving chemotherapy and/or radiation therapy for cancer are living at home and can experience a wide range of symptoms that can require additional management through ambulatory clinic visits or emergency departments (Barbera et al., 2010; Henry et al., 2008; Vandyk, Harrison, Macartney, Ross-White, & Stacey, 2012). Alternatively, individuals may have access to home care nurses for symptom management. However, given that home care nurses provide care to clients with a wide range of illnesses and have a broad range of knowledge, they are considered generalists and their expertise related to cancer symptom management may be variable (Feldman & McDonald, 2004; Ontario Home Care Association, 2011).

Despite a lack of research in cancer symptom management by home care nurses, studies have shown home care nursing interventions help oncology clients remain less symptomatic, maintain more independence in functional activities, and contribute to improved quality of life (Benor, Delbar, & Krulik, 1998; McCorkle et al. 1989, 1994; Molassiotis et al., 2009; Nural, Hintistan, Gürsoy, & Duman, 2009). However, the use of evidence-informed tools, such as symptom management protocols, to inform nursing practice in the home care setting, was only evaluated in two studies. In one study, written protocols were informed by current literature and included pharmacologic and non-pharmacologic self-management interventions that the nurses

could suggest to individuals with either breast or gastrointestinal cancer when symptoms developed while receiving an oral chemotherapy agent (Molassiotis et al., 2009). The other study involved a guideline to address the common symptoms experienced by patients with gastrointestinal cancer receiving symptom management, but no active cancer treatment during the study period, that included evidence-based nursing interventions for use in the home setting (Nural et al., 2009). Both studies reported significantly lower toxicity scores for several symptoms in the experimental groups. However, the protocols used in these studies are not available for review and involved care provided by expert nurses who had extensive oncology nursing knowledge and experience. Therefore little is known about the use of protocols or guidelines for symptom management by home care nurses who are more generalists and provide the majority of oncology care within the community.

Clinical practice guidelines are a resource to guide nurses in symptom management, however in their current forms they do not present information adequately for moving the evidence into practice (Stacey et al., 2012; Brouwers, Stacey, & O'Connor, 2013). The Pan-Canadian Oncology Symptom Triage and Remote Support (COSTaRS) project was initiated to improve cancer symptom management of individuals living in the community (Bakker & Steele, 2009). The COSTaRS project is a national group with representation from eight provinces who have produced 13 evidence-informed symptom protocols for nurses providing support remotely via telephone or internet to individuals experiencing cancer treatment-related symptoms (Appendix A) (Stacey et al., 2012; Stacey, Macartney, Carley, Harrison, & the Pan-Canadian Oncology Symptom Triage and Remote Support Group, 2013). The symptom management protocols are knowledge tools that have been developed based on a synthesis of evidence from clinical practice guidelines. Each protocol has five recommendations for the nurse: a) assess

symptom severity; b) triage client for symptom management based on highest severity; c) review medications being used for the symptom; d) review self-management strategies; and e) summarize and document the plan agreed upon with the client (www.cano-acio.ca). Throughout the protocols, plain language is used to facilitate communication between nurses using the protocols and clients/families. Although the protocols have been developed and validated with oncology nurses within ambulatory oncology programs for use remotely (Stacey et al., 2013), little is known about their usability by home care nurses.

Objectives

The overall aim of this study was to explore the potential for a set of 13 symptom management protocols to be used by nurses in the home care setting when caring for patients with cancer. Specific research questions included: How usable are the protocols for assessing, triaging, guiding clients in self-management, and documenting cancer treatment-related symptoms in face-to-face interactions? What are the perceived barriers and facilitators to using the protocols for documentation in clinical practice?

Methods

Study Design

A mixed methods descriptive study was conducted, guided by the Knowledge-to-Action Framework. The Knowledge-to-Action Framework is a conceptual model that facilitates knowledge translation (Graham et al., 2006; Straus & Holroyd-Leduc, 2008). The knowledge funnel is a transformation process that refines knowledge, resulting in potentially useful tools or products for end-users (Straus, Tetroe, & Graham, 2009). The action cycle applies knowledge in phases based on planned-action theoretical concepts (Graham et al., 2006; Straus et al., 2009). In order to enhance the likelihood of successful uptake of evidence, the framework includes an

evaluation of barriers and facilitators, the identification and selection of appropriate interventions to overcome known barriers, and monitoring impact on outcomes. The evidence-informed protocols in the current study are examples of knowledge tools (Brouwers et al., 2013). This study focused primarily on the adaptation and barriers/facilitators assessment phase of the action cycle (Graham et al., 2006; Harrison et al., 2010).

Ethics approval was obtained from the Ottawa Hospital Research Ethics Board, with reciprocal approval received from the University of Ottawa and the organization (Appendix G).

Setting

Participants were recruited from a provider of home care services coordinated by the Community Care Access Centers (CCAC) in Ontario, Canada. The organization is a not-for-profit provider of home health care services across Canada committed to implementing, supporting, and evaluating evidence-based practice. Two regional offices were purposefully chosen for data collection to represent both urban and rural settings. Together, these two offices employ approximately 180 registered nurses and 80 registered practical nurses. Nurses provide care in clients' homes and remotely support clients, caregivers, and other nurses via telephone or email, when required. Clients with cancer can receive home care nursing services for a variety of reasons including pain and symptom management, management of central venous catheters, and chemotherapy delivery.

Documentation of nursing services involves organizational documentation tools and the chart-in-the-home that was created and is managed by CCAC. Chart-in-the-home is used by the various home care agencies and health care providers when a client has a Palliative Performance Scale score of 60% or less, regardless of whether they are receiving chemotherapy or radiation therapy. The Palliative Performance Scale version 2 (PPSv2) is used to describe and

communicate a patient's current functional level (Victoria Hospice Society, 2006). In addition, screening for nine symptoms is currently done using the Edmonton Symptom Assessment System (ESAS) on a scale of 0 to 10 (Bruera, Kuehn, Miller, Selmser, & Macmillan, 1991). Clients that rate symptoms ≥ 4 out of 10 are flagged for further assessment and management.

Participants and Sampling

Participants who were eligible for the study: (a) were a registered nurse (RN) or registered practical nurse (RPN) working with this agency; (b) were able to read and understand English; (c) were employed either full-time or part-time; and (d) provided direct care to oncology clients receiving cancer treatment or supported nurses who provide direct client care to these clients (Appendix C). Focus groups aimed to have five to eight participants for each group. Given that focus groups are best conducted when there is homogeneity amongst the participants, focus groups for RNs and RPNs were conducted separately (Krueger & Casey, 2009). Individual interviews with key informants used purposeful sampling that aimed to include individuals at various leadership levels within the organization.

Procedures

After obtaining written consent (Appendix F), participants completed the demographic survey (Appendix E). Focus groups and interviews used an interview guide developed with elements of the Knowledge-to-Action Framework (Graham et al., 2006) and involved four parts (Appendix D). First, participants were asked to describe their current practices for providing cancer-related symptom management to have a context in which to situate their comments and feedback.

Second, following a brief introduction to the protocols, participants were asked to work through one of the protocols. A role playing exercise was used in one focus group and all individual interviews. Due to time restrictions it was not used in three focus groups.

Third, participants completed the usability evaluation tool (Appendix B). The usability tool included questions related to information content, understandability, readability, ease of use, and fit with workflow that were adapted for the paper-based symptom management protocols (Kushniruk & Patel, 2004; Stacey et al., 2013). Previous research has shown that approximately 80% of usability issues are identified by four or five individuals (Virzi, 1992).

Fourth, the interview/focus group continued with key questions to explore facilitators and barriers to using the set of protocols as a documentation tool in clinical practice and other uses for the protocols. Focus groups were conducted face-to-face and interviews were conducted face-to-face or over the telephone by the primary researcher (KN) and audio-recorded. Field notes were taken during focus groups by an observer (SM). All participants were invited to review a summary of the findings to verify the accuracy and provide feedback about any factual errors or interpretive deficiencies (Appendix H). They were given the opportunity to provide any additional feedback. Six nurses responded indicating their agreement with the summary and no further comments were given.

Data Analysis

Demographic and usability survey data was coded numerically and entered into Microsoft Excel for analysis. Using double data entry, one error was identified and corrected out of 836 data points (<1%). Analysis included frequency distribution and descriptive statistics. Audio-tapes from focus groups and interviews were transcribed verbatim. Directed thematic analysis of the transcripts was used to identify key themes and patterns (Hsieh & Shannon,

2005). Guided by the Ottawa Model of Research Use (OMRU), barriers and facilitators were coded at the level of the innovation, potential adopters, and practice environment (Logan & Graham, 1998; Graham & Logan, 2004). The primary researcher (KN) and the research assistant (SM) independently analyzed the data by: a) reading each transcript in its entirety to identify any overarching themes; b) coding the data by section to identify specific categories in relation to each research question; and c) comparing findings. Discrepancies were reconciled through discussion and reaching consensus. Data was then reviewed and categories were grouped inductively into broader themes to answer the research questions. A codebook of decisions and definitions used for the analysis was maintained.

Results

A total of 38 individuals participated in four focus groups (n=31) or individual interviews (n=7) (Table 3.1). The four focus groups involved 8 RNs and 6 RPNs at one site, and 6 RNs and 11 RPNs at the other site. Individual interviews were conducted with nurses in the roles of clinical educator, clinical resource nurse, health service manager, and advanced practice consultant. Nurses ranged in age (<25 to >55 years old), educational background (college diploma, university degree, and graduate degree), nursing experience (<5 to >25 years) and length of employment with the organization (<1 to >20 years). Fourteen nurses (37%) had a specialty nursing certification, with six of these holding certifications relevant to symptom management in oncology clients (e.g. oncology, palliative care).

Table 3.1 Participant and Practice Characteristics

Demographic	Interview	Focus Group	Focus Group
	RN n=7	RN n=14	RPN N=17
Title			
Staff Nurse	0	13	17
Nurse Manager	2	0	0
Nurse Educator	2	0	0
Other (eg. Clinical Resource Nurse, Advanced Practice Consultant)	3	1	0
Length of Employment			
Less than 3 years	1	3	5
3-10 years	5	5	11
More than 10 years	1	6	1
Employment status			
Full-time	7	7	11
Part-time, ≥ 20 hr/wk	0	7	6
Age			
Under 35	1	4	8
35-44	2	4	3
45-54	3	0	4
55 and older	1	6	2
Sex			
Female	6	12	16
Male	1	2	1
Education*			
College diploma in nursing	4	9	17
University degree(s)	3	7	2
Specialty certification identified	5	2	7
Nursing Experience			
Less than 5 years	0	4	9
6-15 years	1	2	6
16-25 years	3	3	2
More than 25 years	3	5	0

RN=Registered Nurse RPN=Registered Practical Nurse

*** Allows for multiple answers**

Usability of the Protocols for Documentation in Clinical Practice

Information content. Of 38 nurses, 36 (95%) rated protocols as just the right amount of information and two (5%) said too much information (Table 3.2). The themes about content were ‘comprehensive and concise’, ‘evidence-informed’ and ‘adds to ESAS’. Nurses liked that they were ‘comprehensive and concise’, with enough information to assess and manage the symptoms thoroughly, as one nurse said:

I think the questions to cue me around what questions to ask to explore further are really great, they're practical, very hands on, tangible pieces of information that I as a nurse can ask a client to be able to complete the assessment piece (RN, Int5)

Nurses expressed an appreciation that the protocols are ‘evidence-informed’, using current literature to guide care. Another theme was ‘adds to ESAS’. Nurses felt that the protocols would elaborate upon the number provided on the ESAS. *“This gives you a really like more in-depth look at what that 5 out of 10 means to the client, because a 5 out of 10 to her could be different, you know, to another client”*(RN, FG3). Four nurses indicated a need to add a protocol on pain.

Understandability of concepts and terms. Nurses agreed that the terms made sense (n=37; 97%) and it is self-evident how to complete each section (n=34; 92%) (Table 3.2). Three nurses identified sections on the protocols requiring further clarification on how to complete: assessment, triage, and documentation.

Themes focused on understandability were ‘plain language’ and ‘normalizing the symptom’. Nurses felt the ‘plain language’ would be easy to work into conversation and the definitions would help clients understand their symptoms better. They also suggested the protocols could help ‘normalize symptoms’ (especially anxiety and depression), making it easier for clients to say when they are feeling this way. *“The depression section, for them to read it out,*

it just makes them think a little bit differently about it instead of just hearing that one word”
(RPN, FG2).

Readability and ease of use. Thirty-three nurses (94%) found the fonts and icons were readable and 30 nurses (83%) found there was adequate space for data entry (Table 3.2). Over 95% of nurses indicated excellent or good for how the information was presented in: general symptom assessment (n=37); assessment of symptom severity (n=36); triage for symptom management (n=37); review of medications (n=37); review of self-management strategies (n=36); and documentation of outcomes (n=36) (Table 3.3). Themes related to readability and ease of use were ‘easy to use’, ‘good flow’ and ‘useful prompts’. Nurses found the protocols ‘easy to use’, liked the formatting, especially the tick boxes, and felt they had ‘good flow’ from one section to the next.

Nurses felt the green (mild), yellow (moderate), and red (severe) colours were ‘useful prompts’ that could help them visually gauge symptom severity. They also liked that the rating scale prompts of mild, moderate, and severe help clients more easily situate how they are feeling, and that the rating scale aligns with the ESAS scoring system.

Workflow. Sixteen nurses (42%) indicated that the protocols would fit with their clinical workflow, or fit after some alterations (n=21, 55%). Compared with RNs (n=8/21; 38%), RPNs (n=13/17; 76%) suggested a greater need to alter the protocols. One nurse (3%) indicated they would not fit with current workflow, citing time restraints as the reason. Themes related to workflow were ‘simplify documentation’, ‘proactive in symptom management’, ‘fit with nursing process’, and ‘support clinical decisions’. Nurses suggested that because the protocols were so comprehensive, they could ‘simplify documentation’ and eliminate duplication.

Nurses also felt the protocols would help them to be more ‘proactive in symptom management’ as stated by one nurse, *“being able to intervene a little bit more can kind of help to alleviate longer term problems that they may run into”* (RPN, FG2).

Nurses liked that the protocols ‘fit with the current nursing process’. *“I like it because it goes from, it goes through sort of the nursing process, you know, assess, do something about it, and then what you’re going to do afterwards, or what the plan is”* (RN, FG3).

Nurses stated that they appreciated that the protocols ‘support clinical decisions’ and could facilitate appropriate resource utilization as one nurse said, *“this helps us articulate that this in fact is serious and it’s appropriate to call the clinic and they can’t be mad at you because you’ve identified appropriately”* (RN, Int1).

Table 3.2 Usability feedback on cancer treatment-related symptom protocols

		Interview	Focus Group	Focus Group
	n	RN n=7	RN n=14	RPN n=17
Information Content				
Amount of Information				
Just right	38	7	12	17
Too much		0	2	0
Too little		0	0	0
Would like information added/removed				
Yes	20	0	2	2
No		4	5	7
Understandability of Concepts and Terms				
Terms make sense				
Yes	37	7	13	17
No		0	0	0
Self-evident how to complete each section				
Yes	37	7	13	14
No		0	1	2
Readability and Ease of Use				
Fonts and icons readable				
Yes	35	6	13	14
No		1	0	1
Enough space for data entry				
Yes	36	6	12	12
No		0	1	5
Workflow				
Fit with clinical workflow				
Yes, as it is	38	3	9	4
Yes, with some alterations		3	5	13
No		1	0	0

RN=Registered Nurse RPN=Registered Practical Nurse

Table 3.3 Feedback on information presented within sections of the protocols

		Interview	Focus Group	Focus Group
	n	RN n=7	RN n=14	RPN n=17
General Symptom Assessment				
Excellent	37	6	7	11
Good		1	6	6
Fair		0	0	0
Poor		0	0	0
Assessment of Severity of Symptom				
Excellent	37	6	9	11
Good		1	4	5
Fair		0	0	1
Poor		0	0	0
Triage for Symptom Management				
Excellent	37	5	8	12
Good		2	5	5
Fair		0	0	0
Poor		0	0	0
Review of Medications				
Excellent	37	6	5	11
Good		1	8	6
Fair		0	0	0
Poor		0	0	0
Review of Self-management Strategies				
Excellent	36	5	9	13
Good		1	4	4
Fair		0	0	0
Poor		0	0	0
Documentation of Outcomes				
Excellent	36	5	6	9
Good		1	7	8
Fair		0	0	0
Poor		0	0	0

RN=Registered Nurse RPN=Registered Practical Nurse

Barriers and Facilitators

Barriers and facilitators to integrating and using the protocols in clinical practice for documentation were identified (Appendix H). Key themes identified as barriers were at the level of the protocol (n=3), organization (n=3), nurse (n=2), and client (n=2). Key themes identified as facilitators were at the level of the protocol (n=4), organization (n=4), and nurse (n=2).

Barriers.

Protocol level barriers (n=3). Themes identified as barriers at the level of the set of protocols included ‘too long’, ‘large paper volume’, and ‘inadequate for multiple concurrent symptoms’. Nurses described the set of protocols as being ‘too long’ in the context of the number of protocols, as one nurse stated *“just the sheer number of them”* [would be challenging] (RN, Int7). ‘Large paper volume’ was also felt to be an issue given that the protocols are one-time use and nurses would have to travel with replacement copies to put in the charts. As one nurse said, *“I think the fact that there’s so many of them makes it very difficult to carry them all with you”* (RN, Int2). Nurses indicated that they may be ‘inadequate for managing clients with multiple concurrent symptoms’. They expressed concern about having to complete several individual symptom protocols when a client has multiple issues. *“If they have six symptoms how do I feasibly complete six tools?”*(RN, Int5).

Organization level barriers (n=3). Themes identified as barriers at the organizational level were found to be ‘lack of time’, ‘perceived extra costs’, and ‘paper-based documentation system’. ‘Lack of time’ was identified as a barrier by many of the nurses. They described inadequate time in each visit to assess, triage, manage, and document the multiple needs of complex clients, having to focus on the most distressing issues within the time available.

Forty-five minutes to get in there and do wound care, talk about advance care planning, put an advance care plan in place, talk about expected death in the home and deal with symptoms, and then to have to use all the right documentation tools... (RN, Int5)

Nurses ‘perceived extra costs’ as a source for concern related to implementing the protocols as there may be an associated increase in visit length and overall cost. The fee-for-service business model and how that may affect the decision to implement a new tool is summarized by this RN,

I would just caution, like that absolutely 100% they'd be interested but we always have to be careful too, that financially it's not giving us a hit. Because we can be the most wonderful place in the world but we've got to run a business (RN, Int1).

Nurses raised concerns about the logistics of a ‘paper-based documentation system’. There are a multitude of paper documentation tools already being used and they expressed concerns about adding more. As well, concerns were raised about printing and distributing the protocols as highlighted by this nurses’ comment,

As paper tools the only thing I'd say, they're great, it's just the operationalization of them in a community setting just wouldn't work...how do they get printed, how do they stay current, how do they get out to a community nurse who may be two hours away from the office, and most of her interactions is with her team and not in the office (RN, Int5).

Nurse level barriers (n=2). Themes identified as barriers at the level of the nurse were ‘learning curve’ and ‘reliance on previous experience’. ‘Learning curve’ is the time required for training and practicing for nurses to become comfortable using the protocols. This was felt to be a barrier by some as initially it could interrupt the flow of the interaction which “*diminishes how the client feels*” (RN, Int4). Learning anything new requires time, as stated by this nurse, “*Initially it would probably slow you down because it's going to take a while to get used to and do, but I think that in the long run it would help like put your focus onto what the client needs*” (RPN, FG4). ‘Relying on previous experience’ that isn’t necessarily evidence-based to inform

practice was also found to be a barrier to using the protocols. As one nurse said, *“sometimes we just use intuition”* (RPN, FG2).

Client level barriers (n=2). Themes identified as barriers at the level of the client were ‘too unwell’ and ‘annoyed with repetitive questions’. When clients are ‘too unwell’ one nurse described that, *“they might not be well enough to open up [to answer questions]....They just want you to fix them”* (RN, Int4). Nurses felt that clients get ‘annoyed with repetitive questions’, as this nurse stated, *“they won’t do it, a lot of them won’t do it. So you go in and you do it with them and then they go, why are you asking me the same questions over and over and over?”* (RPN, FG4). Another nurse commented on how this lack of engagement has further implications in symptom management saying, *“the barrier is not so much using the tool...is having engaged clients be able to uptake some of those health management strategies”* (RN, Int5).

Facilitators.

Protocol level facilitators (n=4). Themes identified as facilitators at the level of the protocols include ‘high usability’, ‘fill a void’, ‘promote continuity of care’, and ‘educate and empower clients’. As presented earlier, the protocols were found to be ‘highly usable’ with very positive feedback. Nurses suggested that the set of protocols could ‘fill a void’ because they lack a comprehensive documentation tool for symptom management. Despite having access to algorithms and care plans, they do not find them to be user-friendly in the community setting. For example, one nurse said, *“some of these tools are ones that we don’t have a lot of information, so like skin reaction one and the neuropathy one...and the mouth care one”* (RN, Int3). Nurses stated the protocols would ‘promote continuity of care’ for the clients by improved communication between nurses because they summarize the clients’ symptoms and interventions and allow nurses to see client trends over time.

I think it's also the way you divided what strategies are already being used, the suggestion, and agreed to try. Because if that's in the chart and the next nurse comes in, doesn't know what happened previous, this is so easy to see (RPN, FG4).

Nurses felt that using the protocols could create more opportunities to 'educate and empower clients' about self-managing their symptoms.

I think this would really help with patient education and just to give them some empowerment, and to understand things better, things that they might not have even thought about or no-one else had discussed with them. It can be the littlest tiniest thing but it can make a big, big difference to them (RPN, FG2).

Organization level facilitators (n=4). Themes identified as facilitators at the level of the organization were 'mandate to be evidence-based', 'current remote symptom support role', 'audit and feedback process' and 'education and training'. Within the organization practice is 'mandated to be evidence-based'. Presently nurses develop "*a client-specific care plan, but use the evidence-informed tools to create that client care plan*" (RN, Int5). Nurses currently provide 'remote symptom management support' to clients, caregivers, and other nurses, via telephone or online support. Nurses suggested that there could be opportunity to enhance this current role with the protocols. Current telephone advice documentation is not tailored for symptom management as the form is generic and not helpful, as one nurse said,

We've never been instructed to use it.... A lot of nurses will choose to write a nursing note if it's really important or something major has happened, but generally on the phone we give our advice and then they hang up the phone and that's the end of it (RN, FG3).

Telephone advice is provided by on-call nurses to nurses requiring additional support who are in a clients' home after regular business hours. The organization also offers a support line that community clients and caregivers are able to call and online chat is available on their website. Although not common, remote symptom management is done by this service. An 'audit and feedback process' currently uses ESAS scores to monitor client symptoms and management, and tracks client outcomes. This information is then provided to the nurses as updates on trends

about symptom management, as stated by this nurse, *“The nurses every week, they get feedback about how they're doing with their palliative clients”* (RN, Int1). Pain and symptom management is provided as part of ‘education and training’. The organization values symptom management and provides it as a component of orientation and training, as highlighted by one nurse, *“They get a lot of training. There's the online training. There's the classroom training...Starts out very general however, in our orientation, pain and symptom management are very important to us”* (RN, Int1). Nurses felt the protocols could teach all nurses the key questions that would help develop and refine observational and assessment skills, and ensure comprehensive symptom assessments. They also felt they would be more knowledgeable about non-pharmacological management options. It was suggested that the information in the protocols could be incorporated into the theoretical aspect of the orientation and continuing education sessions. The organization has an online program available to the nurses that houses self-directed learning modules which could also be taken advantage of to maximize the educational potential.

I can see them in orientation for sure, being used. ... I can see these absolutely becoming part of that protocol for review so that people know the symptoms, the questions to be asking and the symptoms that they are looking for and some of those self-management techniques that they might not have thought of, are all here. ... I can see it being part of a sort of a re-certification program. So an annual re-cert program where, you know what? These are at least reviewed. (RN, Int7)

Nurse level facilitators (n=2). Themes identified as facilitators at the level of the nurse were ‘current role’ and ‘interested in evidence-based tools’. Nurses do symptom screening, assessment, triage, and management as part of their ‘current role’ and the protocols may be able to enhance that aspect of care. Some nurses indicated that they are familiar with using algorithms to help guide their practice. The protocols may appeal to newer nurses because they are often ‘interested in using evidence-based tools’. *“[There are] a lot of younger nurses and their*

education has all been real evidence-based. And so I think that they're looking more and more for tools that they can use that are evidence-based” (RN, Int7).

Table 3.4. Summary of barriers and facilitators to protocol use

	Barriers to Protocol Use	Facilitators to Protocol Use
Protocol Level Factors	- Too long - Large paper volume - Inadequate for multiple concurrent symptoms	- Highly usable - Fill a void - Promote continuity of care - Educate and empower clients
Nurse Level Factors	- Reliance on previous experience - Learning curve	- Current nursing role - Interested in using evidence-based tools
Client Level Factors	- Too unwell - Annoyed by repetitive questions	
Organization Level Factors	- Lack of time - Perceived extra costs - Paper-based documentation system	- Current remote symptom support role - Audit and feedback process - Education and training - Mandate to be evidence-based

Other Uses for the Protocols

Nurses expressed ideas for alternative uses for the protocols. Themes identified were ‘nursing resource’ and ‘client resource’. Several nurses suggested creating a ‘nursing resource’ by formatting the protocols into a small booklet they could easily carry and access when needed as stated by one nurse, *“This would be great if they were little pocket cards, little plasticized cards”*(RPN, FG4). Nurses also felt that they would be valuable as a ‘client resource’ that could be given to clients to read and review independently as suggested by one nurse, *“This would be really useful to have like a package in the home...where we could give it to the patient themselves to go through it”*(RPN, FG2).

Discussion

To our knowledge, this is the first reported study exploring usability, barriers, and facilitators related to evidence-based protocols for cancer symptom management by nurses in the

home care setting. Overall, nurses liked the protocols but they identified several barriers to implementing and using them in practice. Nurses rated the set of protocols as highly usable, with mostly positive comments relating to the information content, format, layout, and general flow. Despite having had no training on their use, most nurses rated them as easy to use and felt they would fit with their current clinical workflow either as is, or with some modifications. Feedback indicated the protocols could be a valuable resource for teaching and training nurses with varying levels of experience in cancer symptom management. Although several facilitators were identified that would support the use of the protocols in practice, significant barriers to using them as a documentation tool were identified that may prove to be very challenging. If the protocols are to be implemented within this organization, tailored interventions addressing the barriers will be necessary to improve the likelihood of successful uptake of this knowledge tool (Wensing, Bosch, & Grol, 2010).

Nurses indicated that although they currently have access to symptom management information, it is not formatted as a tool that is comprehensive and easy to use. Research about evidence-based, standardized tools for cancer symptom management by home care nurses is limited. Only two known studies evaluated nursing protocols for cancer symptom management in the home care setting (Molassiotis et al., 2009; Nural et al., 2009). Both had specialized oncology nurses with specific training deliver the home care program with symptom toxicity and patient's quality of life as primary outcome measures. The implications for nursing were not explored by Molassiotis et al. or Nural et al. other than to acknowledge that the interventions were resource intensive. The current study differs because it presented an evidence-based tool and sought to understand the perspectives of generalist nurses who provide the bulk of cancer symptom management within the community. It generated nursing knowledge about the potential

role for the set of protocols, and highlighted issues relevant to cancer symptom management in the home care setting.

Although protocols were intended to be documentation tools, the current organization structure lends them to be better used as a reference tool. Nurses felt strongly that even if the protocols were not adopted by the organization as a documentation tool, they would have great value as a resource to guide assessment, triage, management, and documentation of cancer treatment-related symptoms. Several suggestions were made to transform the protocols into pocket cards or a pocket guide format. Nurses want something small, portable, and easy to use in a client's home. The use of pocket cards and pocket guides by health care professionals have been evaluated for multiple clinical situations including dermatology, substance abuse during pregnancy, end-of-life care, analgesic prescribing, and gerontology (Bianchi, Page, & Robertson, 2012; Midmer, Kahan, Kim, Ordean, & Graves, 2011; Mikhael, Baker, & Downar, 2008; Rosenbluth, Wilson, Maselli, & Auerbach, 2011; Siebens, Tucker, & Leander, 2004). They have been shown to increase knowledge levels (Midmer et al., 2011; Mikhael, et al., 2008; Rosenbluth et al., 2011) and result in positive changes to practice (Mikhael et al., 2008; Rosenbluth et al., 2011). They have been found to be useful and practical for use in clinical practice, with high levels of user satisfaction (Bianchi et al., 2012; Midmer et al., 2011; Siebens et al., 2004). This suggests that a pocket-sized resource of cancer symptom management protocols could have positive implications for nursing practice. The development of a pocket resource would be a feasible way to introduce the evidence-informed tools and overcome the obstacles inherent in a paper-based documentation system.

Within this organization there are two distinct roles for nurses in symptom management – through home visits and the remote symptom triage service. Telephone triage was discussed as a

component of the nurses' roles, often requiring direct management of clients that are unfamiliar to them or acting as a resource for nurses in the home that require additional support in managing clients. Nurses felt the protocols would be an extremely valuable resource to guide the assessment, triage and appropriate symptom management of clients, but they also suggested that it would be an excellent tool to document telephone advice given to clients about symptom management. Nurses indicated that they regularly provide telephone advice but not all nurses document the conversation because there is a lack of awareness of current telephone advice guidelines. The protocols in this study were created for use remotely and meet the requirements for a tele-practice documentation tool as outlined by the nursing organizations in Canada and the literature (Canadian Nurses Association, 2007; College of Nurses of Ontario, 2009).

Nurses identified the need to develop client versions of the protocols. They suggested that much of the content could be taken and used to create a client resource that could encourage and empower clients to be more proactive in self-managing their symptoms. Evidence-based client resources promote self-management and can improve health outcomes when the approach combines education with clinician support (Coulter & Ellins, 2007). For example, it may facilitate earlier identification of symptoms and implementation of appropriate interventions, alleviating more severe symptoms in the future. A resource for clients would also support client centered care, which has been emphasized to be a fundamental element requiring greater attention in our evolving health care system (Institute of Medicine, 2001, 2011; Registered Nurses Association of Ontario [RNAO], 2002). Furthermore, client-centered care would include the key elements of encouraging autonomy, individualizing care, and the caring attitude of the nurse and promote opportunities for self-determination and participation in decision-making (Lusk & Fater, 2013; RNAO, 2002).

Strengths and Limitations

This study should be considered in the context of potential limitations as well as strengths. Usability feedback is usually based on individuals using the tool and it should be noted that while all nurses reviewed the set of protocols, due to time restrictions not everyone had the opportunity to use the tool in a role playing scenario. In addition, while seven interviews were completed with nurses in advanced level positions, they did not include nurses in senior management positions who may have added additional perspectives. However those who did participate are in more direct contact with frontline staff and are involved with implementing changes to nursing practice.

Credibility of findings was enhanced by: transcribing verbatim the audio recordings; triangulating qualitative and quantitative data; investigator triangulation (research assistant in data analysis, thesis supervisor audit of data coding and analysis decisions); developing an audit trail; and member checking (Lincoln & Guba, 1985). All focus groups and interviews were conducted by the same person to ensure consistency. The setting and participants are described to facilitate transferability of the research findings.

Conclusion

While the set of cancer symptom management protocols were well-received by home care nurses, if they are to be integrated and used in clinical practice, tailored interventions are required to overcome the multiple barriers identified. Many elements are already in place that could facilitate successful implementation of the protocols. This research adds to the sparse body of knowledge related to interventions for cancer symptom management by nurses in the home care setting. Further research should focus on the process of implementation of the protocols, monitoring use and evaluating both nursing and client outcomes. Increasing evidence-based

nursing knowledge related to symptom management will continue to improve the experience of people with cancer.

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Chapter 5

Integrated Discussion

Thesis Summary

Introduction

The overall aim of this thesis was to explore interventions for adult cancer symptom management by home care nurses. A scoping review was concurrently conducted (Chapter 2) as part of a review of the literature (Chapter 3), followed by a mixed methods descriptive study (Chapter 4). This chapter will summarize the findings of these three chapters, provide an integrated discussion of issues generated by the thesis findings, highlight implications of these thesis findings for nursing, and identify opportunities for further research.

Summary of Thesis Findings

Scoping review. A scoping review was conducted to describe the interventions used by nurses for adult cancer symptom management in the home setting (Chapter 2). Only five studies were identified. No studies discussed symptom assessment methods. Most interventions included expert oncology nurses delivering time- and resource-intensive programs, including frequent contact between participants and nurses with specialized training. Furthermore, all the identified studies focused on patient and system outcomes with no studies reporting the perspectives of the nurses providing the interventions. Two studies used evidence-based resources to guide the nursing care but details about the evidence were not provided (Molassiotis et al., 2009; Nural, Hintistan, Gürsoy, & Duman, 2009). Positive client outcomes were demonstrated by home care nursing interventions that improved symptom management, promoted independence, and maintained quality of life. Decreased use of health care resources demonstrated economic benefits. Overall, this review highlighted the paucity of published research related to cancer symptom management by generalist nurses in the home.

Mixed methods descriptive study. A mixed methods descriptive study was conducted to explore nurses' perception of the acceptability and perceived usability of a set of cancer

symptom management protocols in face-to-face interactions in the home care setting (Chapter 4). Thirty-eight home care nurses participated in a focus group or interview and completed a usability survey. Survey responses showed that most of the nurses found the protocols to be highly usable based on content, understandability, ease of use, and fit with their workflow. Qualitative findings highlighted several facilitators that would support the use of the protocols as well as multiple barriers at the level of the client, the nurse, and the organization. Examples of identified barriers to using the protocols included: challenges of a paper-based documentation system, lack of time, inadequate for multiple concurrent symptoms, and the learning curve for nurses to be skilled and comfortable using the protocols. Facilitators identified to support using the protocols included: high usability, useful for education and training, and symptom management as part of the current nursing role. If the protocols were to be implemented, tailored interventions to overcome identified barriers would be beneficial to facilitate successful uptake (Grimshaw, Eccles, Lavis, Hill, & Squires, 2012; Wensing, Bosch, & Grol, 2010). Suggestions to facilitate use of the protocols included having them as a pocket resource, incorporating them into the remote support role within the home care organization, and having a related resource for their clients. Overall the protocols could potentially be used as documentation tools by the nurses who provide remote telephone support within the home care agency, but for nurses in the field, being formatted as a pocket resource would likely be a better fit. Working with these nurses as potential users of the symptom protocols is an integrated knowledge translation approach that has been shown to enhance research outcomes including increased uptake of research findings (Jagosh et al., 2012; Parry, Salsberg, & Macaulay, 2013). In summary, this research has demonstrated that nurses' perceptions are valuable when developing, implementing, and evaluating tools for clinical nursing practice.

Integrated Discussion

Through the process of conducting this scoping review, literature review, and mixed methods descriptive study about home care nurses providing cancer symptom management, three key considerations have become apparent: a) lack of published research about interventions for cancer symptom management by home care nurses; b) lack of evidence-based tools being used by nurses; and c) need for best practices supporting generalist home care nurses in providing care to oncology clients.

Lack of Published Research about Interventions for Cancer Symptom Management by Home Care Nurses

Despite the fact that most people with cancer are living at home and that home care nursing services are commonly provided (Caffrey, Sengupta, Moss, Harris-Kojetin, & Valverde, 2011; Martin, Scheet, & Stegman, 1993), this thesis has demonstrated that published research about interventions for cancer symptom management by home care nurses is lacking. Cancer prevalence is well documented (Canadian Cancer Society's Advisory Committee on Cancer Statistics, 2013) and cancer research is available through numerous scholarly journals and websites, however the scoping review identified only five studies focusing on the general topic of cancer symptom management in the past 30 years and none were conducted in Canada (Chapter 2). Although past research may be lacking, there is increasing capacity to support research in home care. In response to the recent shift towards evidence-based practice (College of Nurses of Ontario [CNO], 2009a; Estabrooks, 2004), provincial and national research partnerships have been established to develop strategies that address knowledge gaps in the home care and community settings (Canadian Research Network for Care in the Community,

2013; Ontario Home Care Research Network, 2013). These initiatives will facilitate research in home care including implementation of research findings into clinical practice.

The limited number of identified studies may also be attributed to terminology used in the search strategy. For example, the search focused on home nursing services for clients continuing to receive cancer treatment rather than palliative or end of life care. Comments made by nurses during the descriptive study (Chapter 4) suggested that home care services often only become involved when a client is transitioning towards a palliative approach and moving away from active treatment. The implications of this may be that studies with home care nurses providing symptom management may be more focused on palliative individuals which were excluded from the scoping review. Palliative care is defined by the World Health Organization (2013) as

an approach that improves the quality of life of patients and their families facing the problems associated with life-threatening illness, through the prevention and relief of suffering by means of early identification and impeccable assessment and treatment of pain and other problems, physical, psychosocial and spiritual.

Based on this definition, active treatment and palliative care are not mutually exclusive terms, in fact they often overlap but it is the focus of the care that shifts from active to increasingly palliative throughout the disease trajectory (Canadian Hospice Palliative Care Association, 2013). Therefore, individuals may be deemed palliative, however still continue to receive cancer therapies including targeted oral agents and radiotherapy (Dumitresco, van den Heuvel-Olaroiu, & van den Heuvel, 2007; Peters & Sellick, 2006; Sun, 2012). Therefore, to understand the full scope of symptom management by nurses within the home setting for individuals with cancer, subsequent reviews could be expanded to include palliative care.

In the future, to identify the state of the knowledge regarding cancer symptom management in the home setting, more rigorous methodological approaches could be used to support the process. It may be valuable to design the search strategy with the assistance of a

health science librarian who has the expertise to strengthen the comprehensiveness of the search (Medical Library Association, 2005). Using PICO (population, intervention, comparator, outcome(s)) with an expanded inclusion criteria may also identify more literature for review (Stone, 2002). This insight may better inform future interventions designed to support home care nurses cancer symptom management by reviewing the literature with a wider lens.

Lack of Evidence-based Tools Used by Nurses

This thesis also identified that there is lack of evidence-based clinical practice tools used by nurses to guide in symptom assessment, triage, and management. Only two studies identified in the scoping review used evidence-based resources to guide nursing symptom management (Chapter 2). Although one study provided examples of evidence-based resources that were used to guide nursing care (Molassiotis et al., 2009), the resources were not available for review (Molassiotis et al.; Nural et al., 2009). Findings from the focus groups and interviews indicated that nurses felt they did not have adequate tools or resources to support and guide symptom management (Chapter 4). Findings from my thesis are similar to previous studies of nurses working within oncology programs that showed that although required, according to nursing guidelines, symptom management protocols for remote support are not necessarily being used in nursing practice (Macartney, Stacey, Carley, & Harrison, 2012; Stacey, Bakker, Green, Zanchetta, & Conlon, 2007). The protocols presented to home care nurses in this thesis (Chapter 4) were developed to fill this gap using a rigorous process guided by the CAN-IMPLEMENT© methodology (Harrison, Graham, van den Hoek, Dogherty, Carley, & Angus, 2013; Harrison & van den Hoek, 2012). This thesis is original in that we have taken the remote support symptom protocols and explored alternative uses for the protocols by specifically addressing the ‘adaptation’ and ‘barriers assessment’ phases of the Knowledge to Action Framework (Straus,

Tetroe, & Graham, 2009). These elements may help to precipitate change at the level of individual nursing practice and the health care system (Harrison, Légaré, Graham, & Fervers, 2010).

Fraser Health Authority (2012) in British Columbia and Cancer Care Ontario (CCO) (2010) have released evidence-based symptom management guides for use by health care professionals to assist with appropriate symptom assessment and management. Although not developed for nurses specifically, each guide is evidence-based, including assessment criteria, and pharmacologic and non-pharmacologic management. Both organizations used the AGREE instrument (AGREE Collaboration, 2003) to evaluate the guidelines used to inform their practice guides. Fraser Health Authority does not provide any clinical tools to accompany their guide, whereas Cancer Care Ontario provides a pocket reference and a two-page algorithm for each symptom. However, uptake of evidence into practice is challenging and few health professionals are likely to use it with passive dissemination as done through the websites of these organizations (Grimshaw et al., 2012). At this time, there does not appear to be any further projects or research related to the key elements of the knowledge-to-action cycle to promote knowledge uptake and sustained knowledge use (Straus et al., 2009).

Supporting Generalist Home Care Nurses in Providing Care to Oncology Clients

The challenges in home care of working in isolation with limited resources and support while managing a wide range of client needs were highlighted in our study (Chapter 4), suggesting that further clarity is required about how best to provide evidence to support home care nurses caring for patients with cancer. Working in the decentralized home care environment presents a unique set of circumstances for nurses as “a dispersed, generalist workforce serving a diverse patient population and lacking strong peer contact or on-site support and supervision”

(Feldman & McDonald, 2004, p. 57). Evidence-based clinical tools to support generalist nurses working in isolation are valuable elements in the home care setting.

Home care nurses have identified the lack of current evidence in their practice as a patient safety issue (Berland, Holm, Gundersen, & Bentsen, 2012), yet guidelines for use in home care are limited (Williams et al., 2009). Therefore, the challenge is to translate current evidence into tangible, practical tools that can be used by nurses in the home care setting. However, previous research has also identified lack of time (Koehn & Lehman, 2008; Macartney et al., 2012) and multiple documentation tools (Feldman & McDonald, 2004) as common barriers to using evidence in practice, both of which were identified within our study (Chapter 4). Nurses suggested having the symptom management protocols as a pocket resource they could refer to when necessary, which bypasses several barriers to implementation including those related to a paper-based documentation system. Although positive outcomes have been noted in the use of pocket resources in other clinical health care settings (Bianchi, Page, & Robertson, 2012; Midmer, Kahan, Kim, Ordean, & Graves, 2011; Mikhael, Baker, & Downar, 2008; Rosenbluth, Wilson, Maselli, & Auerbach, 2011; Siebens, Tucker, & Leander, 2004), further evaluation would be required to assess the uptake and impact of pocket cards to support home care nursing providing cancer symptom management. For example, evidence-based email reminders were effective in a randomized controlled trial to support home care nurses providing care to clients with heart failure or pain related to cancer (Feldman & McDonald, 2004; Feldman, Murtaugh, Pezzin, McDonald, & Peng, 2005; McDonald, Pezzin, Feldman, Murtaugh, & Peng, 2005; Murtaugh, Pezzin, McDonald, Feldman, & Peng, 2005).

Implications for Nursing

The results of the scoping review and descriptive study in this thesis have several implications for nursing at various levels within the home care setting (Table 4.1). Standards of care for nursing practice have been outlined that should be reflected when providing care to individuals with cancer (Canadian Association of Nurses in Oncology [CANO], 2001). All nurses have the responsibility to uphold the standards of our profession in the domains of clinical practice, education, leadership, and research (CNO, 2009a). Professional standards for nursing can be related to using evidence in practice, particularly the standards of accountability, knowledge, knowledge application, continuing competence, and leadership (CNO, 2009a). Implications from the findings of this thesis can be framed in relation to these contexts and guide nursing care for evidence-based cancer symptom management.

Clinical practice. Nurses in direct clinical practice are well-positioned to improve the cancer experience for clients by ensuring consistent, comprehensive, and evidence-based assessment, triage, and management of cancer-related symptoms (Molassiotis et al., 2009; Nural et al., 2009; Schulmeister & Gobel, 2008). Clinical practice tools, such as the cancer symptom management protocols in this thesis, support these desirable practices, therefore it is beneficial for nurses to participate in processes required to integrate the evidence in practical and user-friendly ways. Identification of barriers to using evidence in practice and formulating interventions to address those barriers is one example of this (Straus et al., 2009). Clinical nurses have a responsibility to participate in research to promote discovery related to nursing knowledge. They are expected to understand and have an appreciation for nursing research and its' relevance to informing evidence-based practice (CNO, 2009a). Nurses can also use the therapeutic relationship to promote and support clients in self-managing their symptoms through on ongoing process of engagement and empowerment (CNO, 2009b).

Education. Nurses as educators can teach and support nurses in clinical practice about how evidence can support best practices for cancer symptom management (Canadian Nurses Association, 2008; CNO, 2009a). They have the opportunity to educate nurses about the importance of using evidence to guide practice and the implications for improving client, nursing, and system outcomes. Through the establishment of supportive learning environments educators can assist nurses in identifying and evaluating relevant evidence and evidence-based tools, and facilitate their integration into nursing practice.

Leadership. Nurses at all levels can assume leadership roles that include elements of role modelling, advocacy, and support (CNO, 2009a). Nurse leaders can help to ensure the establishment of organizational mandates that support the implementation of evidence-based practices (Newhouse, 2007; Sandström, Borglin, Nilsson, & Willman, 2011). This includes the commitment of resources to support ongoing development, implementation, and evaluation of interventions for cancer symptom management. Innovative and dynamic individuals are then needed to lead nurses in developing an organizational culture that strives for excellence related to evidence-based management in clinical practice (Gifford, Davies, Edwards, Griffin, & Lybanon, 2007). Nurse leaders have the opportunity to create positive environments that foster professional growth and development (Mannix, Wilkes, & Daly, 2013).

Table 4.1. Implications of scoping review and study findings for nursing

Nursing context	Actions proposed
1. Nurses as clinicians	• Conduct cancer symptom assessment, triage, and management using evidence to guide practice. • Use evidence-based resources/tools for symptom management at point-of-care. • Participate in development of tailored interventions to overcome identified barriers to using evidence-based tools in practice. • Participate in research to improve evidence-based cancer symptom management. • Engage clients in cancer symptom management practices to support self-management.
2. Nurses as educators	• Provide educational opportunities for nurses about evidence-based cancer symptom management. • Discuss how using evidence can improve client, nursing, and system outcomes. • Support nurses in identifying and incorporating evidence into practice.
3. Nurses as researchers	• Evaluate cancer symptom management using evidence-based tools based on nursing outcomes and client outcomes. • Adapt and evaluate knowledge tools to support clients in cancer symptom management. • Engage nurses in research process to facilitate uptake of research. • Develop and evaluate feasible and sustainable interventions for cancer symptom management. • Disseminate knowledge related to evidence-base cancer symptom management.
4. Nurses as leaders	• Establish organizational mandate that supports evidence-based cancer symptom management. • Provide resources to support development, implementation, and evaluation of evidence-based cancer symptom management strategies and clinical practice tools. • Advocate for support to improve nursing knowledge related to cancer symptom management.

Research. As researchers, nurses have opportunities to conduct research and generate knowledge related to cancer symptom management (CNO, 2009a). This thesis has demonstrated that there is a lack of research about interventions for cancer symptom management by home care nurses and identified a gap in nursing knowledge (Chapter 2). This suggests a need for

research that further evaluates the phases of the Knowledge-to-Action Cycle in the context of cancer symptom management for both nursing and client outcomes (Straus et al., 2009).

Currently, feasible and sustainable interventions for cancer symptom management by home care nurses are lacking and this area requires further attention (Chapter 2). Nurse researchers have a responsibility to engage nurses in the research process to promote uptake of the evidence (Harrison et al., 2010; Jagosh et al., 2012).

Further research. The findings of this thesis have identified knowledge gaps and highlighted important areas that require further investigations related to evidence-based cancer symptom management. First, as suggested by the scoping review (Chapter 2), there is limited published research on the general topic of interventions for cancer symptom management, by home care nurses. A more rigorous review using systematic review methodology would be useful to validate these findings and further clarify knowledge gaps (Grant & Booth, 2009). Broader search criteria to include palliative care with an oncology focus should be considered, given the extensive overlap of terms (Chapter 2).

Based on the findings of the study in this thesis (Chapter 4), a subsequent study should evaluate the use of the symptom management protocols as a pocket resource. Next phases of the knowledge-to-action cycle include tailoring the intervention to address barriers, implementation, and evaluation (Straus et al., 2009). Home care nurses work independently and have limited interactions with their colleagues, minimizing the risk of contamination, therefore they could be randomized to use pocket guides or CCO symptom management guide mobile application and evaluate the impact on nursing and client outcomes. Based on findings from this study (Chapter 4), nurses clearly identified the need for training to ensure a clear understanding of how to use

the protocols to guide assessment, triage, and management of cancer treatment-related symptoms.

Finally, the development of a parallel client resource needs to be explored. Client resources are one method to engage individuals in their own care that can improve self-management, especially when supported by clinicians, and client safety (Coulter & Ellins, 2007). An environmental scan would be beneficial to identify similar tools, with a subsequent evaluation of their quality. This could be used to inform the process for developing a client tool (Straus et al., 2009). Involvement of clients in the development process would be a key element (Jagosh et al., 2012). With regards to evaluation of a client resource, the previously suggested RCT could be expanded to compare nurses using the pocket resource versus nurses using the pocket resource with clients using a parallel tool. Decision making processes and behaviour can be improved when interventions target both the health care providers and clients (Légaré et al., 2010).

Conclusion

This thesis has explored interventions for adult cancer symptom management by nurses in the home care setting. The evidence in this area has shown positive effects with home care nursing interventions but highlighted that there are limited evidence-based tools for symptom management available to nurses (Chapter 2). The descriptive study (Chapter 4) explored the usability of a set of 13 remote support symptom management protocols to be adapted for use in the home care setting. Despite identified barriers, positive feedback indicated that the nurses would like the protocols to be formatted as a pocket resource and also suggested the development of a parallel client resource. Further research is required to implement and evaluate the protocols in the home care setting for both nurses and clients.

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Chapter 6
Co-Authorship Contributions
& Acknowledgments

Contributions of Collaborators

Co-Authorship

Several authors contributed to this thesis. Kathryn Nichol RN, BScN, CON(C) (KN) conceived, participated in, and directed all aspects of this research project in partial fulfillment of the requirements for a Master's Degree in Nursing at the University of Ottawa. KN is a registered nurse at the Ottawa Hospital with a particular interest in oncology and palliative care. She is also a member of the steering committee for the pan-Canadian Oncology Symptom Triage and Remote Support (COSTaRS) initiative.

Three thesis committee members, Dr. Dawn Stacey RN, PhD, CON(C) (DS) (supervisor), Dr. Wendy Gifford RN, PhD (WG), and Dr. Craig Kuziemsky, PhD (CK) also participated in several phases of the thesis including guiding me in developing the thesis proposal, providing feedback throughout the research process, editing and revising the thesis for important intellectual content, and approving the final thesis (Table 5.1).

DS is a registered nurse and an Associate Professor at the University of Ottawa in the School of Nursing. She is a member of the Nursing Best Practice Research Centre and holds the position of University Research Chair in Knowledge Translation to Patients. She is also a Scientist at the Ottawa Hospital Research Institute and is the Director of the Patient Decision Aids Research Group. She has extensive experience in knowledge translation, patient decision support, patient decision aids, decision coaching, interprofessional shared decision making, oncology nursing and telephone consultation. She holds several awards including the 2012 Canadian Association of Nurses in Oncology/Pfizer award of excellence in nursing research. She established and is currently leading the COSTaRS initiative.

WG is a registered nurse and holds a joint position as an Assistant Professor at the University of Ottawa in the School of Nursing and Senior Research Associate at Saint Elizabeth

Healthcare. Her research focuses on leadership and knowledge translation to improve patient outcomes and nursing care. She is involved in multiple interprofessional initiatives and recently received funding from the Canadian Institute of Health Research (CIHR) to lead international research on leadership and clinical practice guideline use in community and hospital settings.

CK is an Associate Professor at the University of Ottawa in the Telfer School of Management. He is the current Director of the Masters in Health Systems Program. His research is focused on health informatics and how best to support and improve collaborative health care delivery. His areas of interest are diverse including palliative care, and interprofessional collaboration. He is also a steering committee member of the COSTaRS initiative.

Collaborator Acknowledgements

A research assistant and an advanced practice consultant were also involved in particular aspects of the research process. Shelley Mackenzie (SM) is a master's prepared registered nurse who helped with data collection by assisting with the co-ordination and execution of the focus groups for the study and participated in data analysis of the transcripts. Vicki Lejambe (VL) is an advanced practice nurse (APN) practicing as an Advanced Practice Consultant. She contributed to the development of the study design with her in-depth knowledge of the health care setting.

Funding Acknowledgements

Funding to support this academic endeavour was generously provided by the a) Registered Nurses Foundation of Ontario through the Dr. Sheela Basrur and GE Oncology Nursing Education Scholarship; and b) The Ottawa Hospital through the Kerry Marshall Nursing Bursary and the Wendy Nicklin Nursing Bursary.

Table 5.1. Summary of collaborator contributions

	Chapter 1 General Introduction	Chapter 2 Scoping Review	Chapter 3 Study Proposal	Chapter 4 Mixed Methods Descriptive Study	Chapter 5 Integrated Discussion
Conception and Study Design	KN	KN DS WG CK	KN DS WG CK	KN DS WG CK VL	KN
Collect Data	KN	KN	KN	KN SM	KN
Analyze and Interpret Data	KN	KN	KN	KN DS SM	KN
Draft Manuscript	KN	KN	KN	KN	KN
Edit and Revise for Important Intellectual Content	KN DS WG CK	KN DS WG CK	KN DS WG CK	KN DS WG CK	KN DS WG CK
Approve Final Version to be Published	KN DS WG CK	KN DS WG CK	KN DS	KN DS WG CK	KN DS WG CK
Responsible for Overall Content	KN	KN	KN	KN	KN

Appendices

Appendix A

General Assessment Protocols for the Remote Assessment, Triage, and Management of Symptoms in Adults Undergoing Cancer Treatment

Name _____
Date of Birth _____
Sex _____
Hospital card number _____

Date and time of encounter _____ Caller _____
Type of Cancer _____ Primary Oncologist _____
Other practitioners (most responsible) _____

1. **Tell me about your symptom(s)** (Supporting Evidence: Expert Consensus)
(PQRST- Provoking factors, Quality, Radiating, Relieving factors, Severity, Other symptoms, Timing, Triggers, Location)

2. **Conduct general symptom assessment** (Supporting Evidence: Expert Consensus)

Receiving cancer treatment:

☐ Radiation: Site of radiation _____
☐ Chemotherapy: Name of Chemotherapy _____
Date of last treatment(s) _____

Length of time since symptom started? _____

New symptom? ☐ Yes ☐ No ☐ Unsure

Told symptom could occur? ☐ Yes ☐ No ☐ Unsure

Other symptoms? ☐ Yes ☐ No If Yes, specify:

☐ Anorexia	☐ Depression	☐ Fatigue	☐ Peripheral Neuropathy
☐ Anxiety	☐ Diarrhea	☐ Febrile Neutropenia	☐ Skin Reactions
☐ Bleeding	☐ Dyspnea	☐ Nausea/Vomiting	☐ Stomatitis
☐ Constipation	☐ Other _____		

Recent exposure to known virus/flu? ☐ Yes ☐ No ☐ Unsure If Yes, specify _____

3. **Assess current use of medications, herbs, natural health products (name, dose, current use)**

Medication	Dose Prescribed	Taking as prescribed/Last dose if PRN
		☐ Yes ☐ No /
		☐ Yes ☐ No /
		☐ Yes ☐ No /
		☐ Yes ☐ No /

Are any medications new or are there recent changes? ☐ Yes ☐ No If Yes, specify: _____

4. **See appropriate symptom protocol(s) for further assessment, triage and management.**

Anxiety Protocol

Remote Assessment, Triage, and Management of Anxiety in Adults Undergoing Cancer Treatment

Anxiety: an emotional or physiologic response to known or unknown causes that ranges from a normal reaction to extreme dysfunction. It may impact on decision making, adherence to treatment, functioning, or quality of life¹; nervousness; concern; worry; apprehension.

Name
Date of Birth
Sex
Hospital card number

Date and Time

1. Assess severity of the anxiety (Supporting evidence: 2/2 guidelines)

Tell me what number from 0 to 10 best describes how anxious you are feeling

Not anxious 0 1 2 3 4 5 6 7 8 9 10 Worst possible anxiety^{ESAS}

Do have any concerns that are making you feel more anxious (e.g. life events, new information about cancer/treatment, making a decision)? ☐ Yes ☐ No If Yes, describe: _____

Ask patient to indicate which of the following are present or absent

Patient rating (see ESAS above) ^{1,2,3}	0 – 3	☐	4 – 6	☐	7 – 10	☐
Have you felt this anxious for 2 weeks or longer? ²	No	☐	Yes, off/on	☐	Yes, continuous	☐
Are you re-living or facing events in ways that make you feel more anxious (e.g. dreams, flashbacks)? ^{2,3} Describe.	None/Mild	☐	Moderate	☐	Severe	☐
Are you having panic attacks; periods/spells of sudden fear, discomfort, intense worry, uneasiness? ^{2,3} Describe.	None/Mild	☐	Moderate	☐	Severe	☐
How much does your anxiety affect your daily activities at home and/or at work? ² Describe.	None	☐	Some	☐	Yes, significant	☐
How much does your anxiety affect your sleep? ²	None	☐	Some	☐	Yes, significant	☐
Are any of the following relevant to you? (circle risk factors): waiting for test results, financial problems, history of anxiety or depression, recurrent/advanced disease, withdrawal from alcohol/ substance use, living alone, younger age (< 30), not exercising? ^{2,3}	None	☐	Some	☐	Several	☐
Are you feeling (symptom-related risk factors for anxiety): Fatigue ☐ Yes ☐ No Short of breath ☐ Yes ☐ No Pain ☐ Yes ☐ No Other ☐ Yes ☐ No If yes, see appropriate symptom protocol.	None	☐	Some	☐	Several, with 1 or more symptoms assessed as severe	☐

2. Triage patient for symptom management based on highest severity (Supporting evidence: 1/2 guidelines)

1 Mild	2 Moderate	3 Severe
☐ Review self-care. Verify medication use, if appropriate.	☐ Review self-care. Verify medication use, if appropriate. Advised to call back if symptom worsens, new symptoms occur, or no improvement in 1-2 days.	☐ If 1 or more symptoms present with any anxiety, seek medical attention immediately.

If patient is experiencing other symptoms, did you also refer to the appropriate protocols? If yes, please specify:

Additional Comments:

Patient Name _____

3. Review medications patient is using for anxiety, including prescribed, over the counter, and/or herbal supplements (Supporting evidence: 2/2 guidelines)

Current use	Medications for anxiety	Notes (eg. dose, suggest to use as prescribed)	Type of Evidence
☐	Benzodiazepines - lorazepam (Ativan [®]), diazepam (Valium [®]), alprazolam (Xanax [®]) ^{2,3}		Single RCT & Consensus
☐	Antipsychotics - haloperidol (Haldol [®]) ^{2,3}		Single RCT & Consensus
☐	Antihistamines - hydroxyzine (Atarax [®]) ^{2,3}		Single RCT & Consensus
☐	SSRIs - fluoxetine (Prozac [®]), sertraline (Zoloft [®]), paroxetine (Paxil [®]), citalopram (Celexa [®]), fluvoxamine (Luvox [®]), escitalopram (Lexapro [®]) ^{2,3}		Systematic review

*Use of antidepressant depends on side effect profiles of medications and the potential for interaction with other current medications.

4. Review self-management strategies (Supporting evidence: 2/2 guidelines)

What strategies are already being used?	Strategy suggested/ education provided	Patient agreed to try	Self-care strategies
1. ☐	☐	☐	What helps when you feel anxious? Reinforce as appropriate. Specify:
2. ☐	☐	☐	Would more information about your cancer or your treatment help to ease your worries? If yes, provide appropriate information or suggest resources.
3. ☐	☐	☐	Would more information about your symptoms help to ease your worries? If yes, provide appropriate information or suggest resources.
4. ☐	☐	☐	Do you feel you have enough help at home and with getting to appointments/treatments (transportation, financial assistance, medications)? ²
5. ☐	☐	☐	Do you participate in any support groups ^{2,3} and/or have family/friends you can rely on for support?
6. ☐	☐	☐	Have you tried relaxation therapy, breathing techniques, guided imagery? ^{2,3} (systematic review with meta-analysis)
7. ☐	☐	☐	Have you tried massage therapy? ²
8. ☐	☐	☐	Have you tried a program such as cognitive-behavioural therapy or received personal counseling that provides more in-depth guidance on managing anxiety? ^{2,3}

5. Summarize and document plan agreed upon with caller including ongoing monitoring (check all that apply)

☐	No change, continue with self-care strategies and if appropriate, medication use
☐	Patient agrees to try self-care items #:
☐	How confident are you that you can try what you agreed to do (0=not confident, 10=very confident)?
☐	Patient agrees to use medication to be consistent with prescribed regimen
☐	Specify:
☐	Referral (service & date):
☐	Patient agrees to seek medical attention; specify time frame:
☐	Advised to call back in 1-2 days if no improvement, symptom worsens, or new symptoms occur

Name	Signature	Date
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Bleeding Protocol
Remote Assessment, Triage, and Management of
Bleeding in Adults Undergoing Cancer Treatment
(not for patients undergoing bone marrow transplant)

Bleeding: Loss of blood, bruising or petechiae that may be the result of a reduction in the quantity or functional quality of platelets, an alteration of clotting factors, a paraneoplastic syndrome, or a combination of these ¹; hemorrhage.

Name _____
 Date of Birth _____
 Sex _____
 Hospital card number _____

Date and Time _____

1. Assess severity of the bleeding (Supporting evidence: 1/1 guideline)

Where are you bleeding from? _____ How much blood loss? _____

How worried are you about your bleeding?

Not worried 0 1 2 3 4 5 6 7 8 9 10 Extremely worried

Ask patient to indicate which of the following are present or absent

How much are you bleeding? ¹	Minor	☐	Evident	☐	Gross	☐
Patient rating of worry about bleeding (see above)	0-5	☐	6-10	☐		
Do you have any bruises? ¹	No	☐	Few	☐	Generalized	☐
Have you had any problems with your blood clotting? ☐ Unsure	No	☐		☐	Yes	☐
Do you have a fever > 38° C? ☐ Unsure	No	☐		☐	Yes	☐
Do you have any blood in your stool or is it black? ¹ ☐ Unsure	No	☐		☐	Yes	☐
Do you have any blood in your vomit or does it look like coffee grounds? ¹ ☐ No vomiting	No	☐		☐	Yes	☐
Do you know what your last platelet count was? Date: ☐ Unsure	≥ 100	☐	20-99	☐	< 20	☐

	1 Mild	2 Moderate	3 Severe
2. Triage patient for symptom management based on highest severity (Supporting evidence: 1/1 guideline)	☐ Review self-care. Verify medication use, if appropriate.	☐ Review self-care. Verify medication use, if appropriate. Advised to call back if symptom worsens, new symptoms occur, or no improvement in 12-24 hours.	☐ If 1 or more symptoms present with any bleeding, seek medical attention immediately.

If patient is experiencing other symptoms, did you also refer to the appropriate protocols? If yes, please specify:

Additional comments:

Patient Name _____

3. Review medications patient is using that may affect bleeding, including prescribed, over the counter, and/or herbal supplements (Supporting evidence: Expert Consensus)

Current use	Medications	Notes (e.g. dose)	Type of Evidence
☐	acetylsalicylic acid (Aspirin [®])		Expert Consensus
☐	warfarin (Coumadin [®])		Expert Consensus
☐	Injectable blood thinner - heparin, dalteparin (Fragmin [®]), tinzaparin (Innohep [®]), enoxaparin (Lovenox [®])		Expert Consensus

4. Review self-management strategies (Supporting evidence: 1/1 guideline)

What strategies are already being used?	Strategy suggested/ education provided	Patient agreed to try	Self-care strategies
1. ☐	☐	☐	Are you trying to apply direct pressure for 10-15 minutes when the bleeding occurs? ¹
2. ☐	☐	☐	Are you trying to use ice packs? ¹
3. ☐	☐	☐	If you have a dressing, is there bleeding when it is changed? If yes, do you try to minimize how often the dressing is done, and use saline to help remove the dressing so it does not stick to the tissue? ¹
4. ☐	☐	☐	Are you using any special dressings to control bleeding of a wound? ¹
5. ☐	☐	☐	Would more information about your symptoms help you to manage them better? If yes, provide appropriate information or suggest resources.
6. ☐	☐	☐	Have you spoken with a pharmacist or doctor about medications you are taking that may affect bleeding?

5. Summarize and document plan agreed upon with caller (check all that apply)

☐	No change, continue with self-care strategies and if appropriate, medication use
☐	Patient agrees to try self-care items #: How confident are you that you can try what you agreed to do (0=not confident, 10=very confident)?
☐	Patient agrees to use medication to be consistent with prescribed regimen Specify:
☐	Referral (service & date):
☐	Patient agrees to seek medical attention; specify time frame:
☐	Advised to call back in 12-24 hours if no improvement, symptom worsens, or new symptoms occur

Name	Signature	Date
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Breathlessness/Dyspnea Protocol
Remote Assessment, Triage, and Management of
Breathlessness/Dyspnea in Adults Undergoing Cancer Treatment

Breathlessness/Dyspnea: A subjective experience described as breathing discomfort of varying intensities.¹ Includes descriptors such as hard to breathe, feeling smothered, tightness in chest, unable to catch breath, panting, gasping.

Name
 Date of Birth
 Sex
 Hospital card number

Date and Time

1. Assess severity of the breathlessness (Supporting evidence: 1/3 guidelines)

Tell me what number from 0 to 10 best describes your shortness of breath?

No shortness of breath 0 1 2 3 4 5 6 7 8 9 10 Worst possible shortness of breath ^{ESAS}

How worried are you about your shortness of breath?

Not worried 0 1 2 3 4 5 6 7 8 9 10 Extremely worried

Ask patient to indicate which of the following are present or absent

Patient rating (see ESAS above) ^{3,4}	0-3	☐	4-6	☐	7-10	☐
Patient rating of worry about shortness of breath (see above)	0-5	☐	6-10	☐		
With what level of activity do you experience this shortness of breath?	Moderate activity	☐	Mild activity	☐	At rest	☐
Do you have pain in your chest when you breathe? ³	No	☐			Yes	☐
Is your breathing noisy, rattly or congested? ³	No	☐			Yes	☐
Do you have a new cough with phlegm/sputum?	No	☐			Yes	☐
Do you have a fever > 38° C? ³ ☐ Unsure	No	☐			Yes	☐
Does your shortness of breath interfere with your daily activities at home and/or at work? Describe.	No	☐	Yes, some	☐	Yes, significantly	☐
	 1 Mild		 2 Moderate		 3 Severe	
2. Triage patient for symptom management based on highest severity (Supporting evidence: 1/3 guidelines)	☐ Review self-care. Verify medication use, if appropriate.		☐ Review self-care. Verify medication use, if appropriate. Advised to call back if symptom worsens, new symptoms occur, or no improvement in 12-24 hours.		☐ If 1 or more symptoms present with any shortness of breath, seek medical attention immediately.	

If patient is experiencing other symptoms, did you also refer to the appropriate protocols? If yes, please specify:

Additional comments:

Patient Name _____

3. Review medications patient is using for shortness of breath, including prescribed, over the counter, and/or herbal supplements (Supporting evidence: 3/3 guidelines)

Current use	Medications for shortness of breath	Notes (eg. dose, suggest to use as prescribed)	Type of Evidence
☐	Oxygen ^{1,2}		Expert Opinion
☐	Bronchodilators- salbutamol (Ventolin®) ¹		Expert Opinion
☐	Immediate-release oral or parenteral opioids - morphine (Statex®), hydromorphone (Dilaudid®), fentanyl ^{1,2,3}		Systematic Review

4. Review self-management strategies (Supporting evidence: 2/3 guidelines)

What strategies are already being used?	Strategy suggested/ education provided	Patient agreed to try	Self-care strategies
1. ☐	☐	☐	What helps when you are short of breath? Reinforce as appropriate. Specify:
2. ☐	☐	☐	Have you tried to use a fan or open window to increase air circulation directed at your face? ¹
3. ☐	☐	☐	Are you trying to rest in upright positions that can help you breathe? ^{1,3}
4. ☐	☐	☐	Are you trying different breathing exercises (eg. diaphragmatic breathing, pursed lip breathing)? ^{1,3}
5. ☐	☐	☐	Are you trying to avoid cold air, humidity, & tobacco smoke? ³
6. ☐	☐	☐	Are you trying to save energy for things that are important to you? ³
7. ☐	☐	☐	Have you tried to turn down the temperature in your house? ^{1,3}
8. ☐	☐	☐	If you have a wheelchair, portable oxygen or other assistive device, are you trying to use them to help with activities that cause your shortness of breath? ¹
9. ☐	☐	☐	Would more information about your symptoms help you to manage them better? If yes, provide appropriate information or suggest resources.
10. ☐	☐	☐	Have you tried a program such as cognitive behavioural therapy (relaxation therapy, guided imagery) to help manage your shortness of breath? ^{1,3} (Can decrease anticipatory worry associated with exertional dyspnea)

5. Summarize and document plan agreed upon with caller (check all that apply)

☐	No change, continue with self-care strategies and if appropriate, medication use
☐	Patient agrees to try self-care items #:
☐	How confident are you that you can try what you agreed to do (0=not confident, 10=very confident)?
☐	Patient agrees to use medication to be consistent with prescribed regimen
☐	Specify:
☐	Referral (service & date):
☐	Patient agrees to seek medical attention; specify time frame:
☐	Advised to call back in 12-24 hours if no improvement, symptom worsens, or new symptoms occur

Name	Signature	Date
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Constipation Protocol

Remote Assessment, Triage, and Management of Constipation in Adults Undergoing Cancer Treatment

Constipation: A decrease in the passage of formed stool characterized by stools that are hard and difficult to pass.¹

Name
Date of Birth
Sex
Hospital card number

Date and Time

1. Assess severity of the constipation (Supporting evidence: 1/2 guidelines)

Tell me what number from 0 to 10 best describes your constipation

No constipation 0 1 2 3 4 5 6 7 8 9 10 Worst possible constipation ^{ESAS}

How worried are you about your constipation?

Not worried 0 1 2 3 4 5 6 7 8 9 10 Extremely worried

Ask patient to indicate which of the following are present or absent

Patient rating (see ESAS above) ³	0-3	☐	4-6	☐	7-10	☐
Patient rating of worry about constipation (see above)	0-5	☐	6-10	☐		
How many days has it been since you had a bowel movement? ²	≤ 2 days	☐	3 days or more	☐	3 days or more on meds	☐
Are you currently taking medication to help relieve your constipation?	No	☐	Yes, intermittently	☐	Yes, regularly	☐
Do you have any abdominal pain? ² Describe.	No/Mild 0-3	☐	Moderate 4-6	☐	Severe 7-10	☐
Is your abdomen bigger than normal? ⁴ Does it feel harder than normal? ☐ Unsure	None	☐	Increasing	☐	Severe, rigid	☐
Have you had any nausea/lack of appetite or have you vomited? ^{1,2}	No	☐	Nausea/lack of appetite	☐	Vomiting	☐
If you vomited, did it smell like stool? ⁴ ☐ Unsure	No	☐			Yes	☐
Have you recently had abdominal surgery? ⁴	No	☐			Yes	☐
Have you noticed any change in your sense of touch (numbness, tingling, burning)?	No	☐	Yes	☐		
Do you have new weakness in your arms or legs? ⁴	No	☐			Yes	☐
Have you noticed a change in your urination pattern (voiding you can't control or feeling like you can't empty your bladder)?	No	☐			Yes	☐
Does your constipation interfere with your daily activities at home and/or at work? Describe.	No	☐	Yes, some	☐	Yes, significantly	☐
	1 Mild		2 Moderate		3 Severe	
2. Triage patient for symptom management based on highest severity (Supporting evidence: 1/2 guidelines)	☐ Review self-care. Verify medication use, if appropriate.		☐ Review self-care. Verify medication use, if appropriate. Advised to call back if symptom worsens, new symptoms occur, or no improvement in 12-24 hours.		☐ If 1 or more symptoms present with any constipation, seek medical attention immediately.	

If patient is experiencing other symptoms, did you also refer to the appropriate protocols? If yes, please specify:

Additional comments:

Patient Name _____

3. Review medications patient is using for constipation, including prescribed, over the counter, and/or herbal supplements (Supporting evidence: 1/2 guidelines)

Current use	Medications for constipation*	Notes (eg. dose, suggest to use as prescribed)	Type of Evidence
☐	senna (Senokot®) ¹		Expert Opinion
☐	docusate sodium (Colace®) ¹		Expert Opinion
☐	Suppositories** (Dulcolax®/bisacodyl, glycerin) ¹		Expert Opinion
☐	Golytely® ¹		Expert opinion + Low level evidence
☐	Lactulose ¹		Expert Opinion
☐	magnesium hydroxide (Milk of magnesia®) ¹		Expert Opinion

*Opioid-induced constipation must be considered. Inadequate/limited evidence for cancer-treatment related constipation.

** Verify blood count before using suppositories.

4. Review self-management strategies (Supporting evidence: 1/2 guidelines)

What strategies are already being used?	Strategy suggested/education provided	Patient agreed to try	Self-care strategies
1. ☐	☐	☐	What helps when you are constipated? Reinforce as appropriate. Specify:
2. ☐	☐	☐	What is your normal bowel routine? Reinforce as appropriate. Specify:
3. ☐	☐	☐	Are you trying to drink fluids, 8 glasses per day, especially warm or hot fluids? ¹
4. ☐	☐	☐	Have you increased the fiber in your diet?(Only appropriate if adequate fluid intake and physical activity) ¹
5. ☐	☐	☐	Do you have a comfortable, quiet, private environment for going to the bathroom? ¹
6. ☐	☐	☐	Do you have easy access to a toilet or bedside commode, and any necessary assistive devices (raised toilet seat)? If possible, try to avoid the use of a bedpan. ¹
7. ☐	☐	☐	Are you avoiding non-sterilized corn syrup and castor oil? ¹ (Corn syrup can be a source of infection; castor oil can cause severe cramping)
8. ☐	☐	☐	If you have a low neutrophil count are you trying to avoid rectal exams, suppositories, enemas? ¹
9. ☐	☐	☐	Would more information about your symptoms help you to manage them better? If yes, provide appropriate information or suggest resources.
10. ☐	☐	☐	Have you spoken with a doctor or pharmacist about medications you may be taking that can be constipating? ¹
11. ☐	☐	☐	Have you spoken with a dietitian? ¹

5. Summarize and document plan agreed upon with caller (check all that apply)

☐	No change, continue with self-care strategies and if appropriate, medication use
☐	Patient agrees to try self-care items #:
☐	How confident are you that you can try what you agreed to do (0=not confident, 10=very confident)?
☐	Patient agrees to use medication to be consistent with prescribed regimen
☐	Specify:
☐	Referral (service & date):
☐	Patient agrees to seek medical attention; specify time frame:
☐	Advised to call back in 12-24 hours if no improvement, symptom worsens, or new symptoms occur

Name	Signature	Date
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References

1. Woolery, M., Bisanz, A., Lyons, H. F., Gaido, L., Yankovich, M., et al. (2008). Putting evidence into practice: Evidence-based interventions for the prevention and management of constipation in patients with cancer. *Clinical Journal of Oncology Nursing*, 12(2), 317-337. (AGREE Rigour score 80%)
2. Cancer Care Ontario. (2004). Telephone nursing practice and symptom management guidelines. Retrieved from: <http://www.onfca.on.ca/library/repository/mon/9000/245778.pdf>. (AGREE Rigour score 11%)
3. Bruera E, Kuehn N, Miller MJ, Selmsler P, Macmillan K. The Edmonton symptom assessment system (ESAS): a simple method for the assessment of palliative care patients. *J Palliat Care* 1991; 7(2):6-9.
4. National Institutes of Health: National Cancer Institute. (2010). Common terminology criteria for adverse events (CTCAE) v4.03. Retrieved from: <http://www.ncti.nih.gov/ftp1/CTCAE/About.html>.

Depression Protocol

Remote Assessment, Triage, and Management of Depression in Adults Undergoing Cancer Treatment

Depression: a range of feelings and emotions from normal sadness to chronic, depressed emotional affect including clinical depression using criteria for a psychiatric disorder³; feelings of despair, hopelessness

Name _____
Date of Birth _____
Sex _____
Hospital card number _____

Date and Time _____

1. Assess severity of the depression (Supporting evidence: 2/2 guidelines)

Tell me what number from 0 to 10 best describes how depressed you are feeling

Not depressed 0 1 2 3 4 5 6 7 8 9 10 Worst possible depression ESAS

How worried are you about feeling depressed?

Not worried 0 1 2 3 4 5 6 7 8 9 10 Extremely worried

Are there any concerns contributing to your feelings of depression (e.g. life events, sleep deprivation, financial problems)

☐ Yes ☐ No Specify: _____

Ask patient to indicate which of the following are present or absent

Patient rating (see ESAS above) ^{1,2,3}	0-3	☐	4-6	☐	7-10	☐
Patient rating of worry about depression (see above)	0-5	☐	6-10	☐		
Have you felt depressed or had a loss of pleasure for at least 2 weeks almost all day, every day? ^{2,3}	No	☐			Yes	☐
Have you experienced any of the following for 2 weeks or longer (circle): feeling worthless, feeling guilty, sleeping too little or too much, weight gain or weight loss? ^{2,3}	None	☐	2 present	☐	4 present	☐
Does feeling depressed interfere with your daily activities at home and/or at work? ² Describe.	No	☐	Yes, some	☐	Yes, significant	☐
Have you felt tired or fatigued? ^{2,3} Describe.	No/Mild	☐	Moderate	☐	Severe	☐
Have you felt agitated (which may include twitching or pacing) or slowing down of your thoughts? ^{2,3}	No	☐	Yes, some	☐	Yes, severe	☐
Do you have any other risk factors such as (circle): bothersome symptoms, a lack of social support, a history of depression or substance abuse, living alone, recurrent/advanced disease, younger age (< 30)? ²	None	☐	Yes, some	☐	Yes, several	☐

2. Triage patient for symptom management based on highest severity (Supporting evidence: 1/2 guidelines)

 1 Mild	 2 Moderate	 3 Severe
☐ Review self-care. Verify medication use, if appropriate.	☐ Review self-care. Verify medication use, if appropriate. Advised to call back if symptom worsens, new symptoms occur, or no improvement in 1-2 days.	☐ Have you had recurring thoughts of dying, trying to kill yourself or harming yourself? ^{2,3} If yes, immediate referral for further evaluation. ☐ If no, and 1 or more symptoms present with any depression, seek non-urgent medical attention. Review self-care. Verify medication use, if appropriate.

If patient is experiencing other symptoms, did you also refer to the appropriate protocols? If yes, please specify:

Additional Comments:

Patient Name _____

3. Review medications patient is using for depression, including prescribed, over the counter, and/or herbal supplements (Supporting evidence: 2/2 guidelines)

Current use	Medications for depression*	Notes (eg. dose, suggest to use as prescribed)	Type of Evidence
☐	SSRIs - fluoxetine (Prozac [®]), sertraline (Zoloft [®]), paroxetine (Paxil [®]), citalopram (Celexa [®]), fluvoxamine (Luvox [®]), escitalopram (Lexapro [®]) ¹		Systematic review
☐	Tricyclic antidepressants - amitriptyline (Elavil [®]), imipramine (Tofranil [®]), desipramine (Norpramin [®]), nortriptyline (Pamelor [®]), doxepin (Sinequan [®]) ³		Systematic review

*Use of antidepressant depends on side effect profiles of medications and the potential for interaction with other current medications.

4. Review self-management strategies (Supporting evidence: 2/2 guidelines)

What strategies are already being used?	Strategy suggested/ education provided	Patient agreed to try	Self-care strategies
1. ☐	☐	☐	What helps when you feel depressed? Reinforce as appropriate. Specify:
2. ☐	☐	☐	Would more information about your symptoms help you to manage them better? If yes, provide appropriate information or suggest resources. ²
3. ☐	☐	☐	Do you feel you have enough help at home and with getting to appointments/treatments (transportation, financial assistance, medications)? ²
4. ☐	☐	☐	Do you participate in any support groups ^{2,3} and/or have family/friends you can rely on for support?
5. ☐	☐	☐	Have you tried relaxation therapy or guided imagery? ^{2,3} (systematic review with meta-analysis)
6. ☐	☐	☐	Have you tried a program such as cognitive-behavioural therapy or received personal counseling that provides more in-depth guidance on managing depression? ^{2,3}

5. Summarize and document plan agreed upon with caller (check all that apply)

☐	No change, continue with self-care strategies and if appropriate, medication use
☐	Patient agrees to try self-care items #:
	How confident are you that you can try what you agreed to do (0=not confident, 10=very confident)?
☐	Patient agrees to use medication to be consistent with prescribed regimen
	Specify:
☐	Referral (service & date):
☐	Referral (service & date):
☐	Patient agrees to seek medical attention; specify time frame:
☐	Advised to call back in 1-2 days if no improvement, symptom worsens, or new symptoms occur

Name	Signature	Date
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References

- Bruscia E, Kuehn N, Miller MJ, Selmsler P, Macmillan K. The Edmonton symptom assessment system (ESAS): a simple method for the assessment of palliative care patients. *J Palliat Care* 1991; 7(2):6-9.
- Howell D, Currie S, Mayo S, Jones G, Boyle M, et al. (2009) A Pan-Canadian Clinical Practice Guideline: Assessment of Psychosocial Health Care Needs of the adult cancer patient. Toronto: Canadian Partnership Against Cancer (Cancer Journey Action Group) and the Canadian Association of Psychosocial Oncology. Retrieved from: <http://www.capo.ca/about-capo/professional-student-info/>. (AGREE rigour score 83.4%)
- Fulcher CD, Badger T, Gunter AK, Marrs JA, Reese JM. (2008, Feb). Putting Evidence Into Practice: Interventions for Depression. *Clinical Journal of Oncology Nursing*. 12(1), 131-140. (AGREE rigour score 43.8%)

Diarrhea Protocol				Name Date of Birth Sex Hospital card number		
Remote Assessment, Triage, and Management of Diarrhea in Adults Undergoing Cancer Treatment (not for patients undergoing bone marrow transplant)				Date and Time		
Diarrhea: An abnormal increase in stool liquidity and frequency over baseline (> 4-6 stools/day) which may be accompanied by abdominal cramping. ^{3,5}						
1. Assess severity of the diarrhea (Supporting evidence: 6/6 guidelines) Tell me what number from 0 to 10 best describes your diarrhea No diarrhea 0 1 2 3 4 5 6 7 8 9 10 Worst possible diarrhea ^{ESAS} How worried are you about your diarrhea? Not worried 0 1 2 3 4 5 6 7 8 9 10 Extremely worried Have you been tested for c-difficile? If yes, do you know the results? ☐ Yes ☐ No ☐ Unsure Results: _____						
Ask patient to indicate which of the following are present or absent						
Patient rating (see ESAS above) ^a	0-3	☐	4-6	☐	7-10	☐
Patient rating of worry about diarrhea (see above)	0-5	☐	6-10	☐		
Think about your normal bowel pattern. How many extra bowel movements are you having per day (including at night), above what is normal for you? ^{2,3,5,6}	< 4 stools	☐	4-6 stools	☐	≥ 7 stools	☐
Ostomy: How much extra output are you having, above what is normal for you? ^{2,3,5,6}	Mild	☐	Moderate	☐	Severe	☐
Do you have a fever > 38° C? ^{2,3,5,6} ☐ Unsure	No	☐			Yes	☐
Do you have pain in your abdomen or rectum with or without cramping or bloating? ^{2,5,6}	No	☐			Yes	☐
Do you have any blood in your stool or is it black? ^{2,5,6} ☐ Unsure	No	☐			Yes	☐
Does your diarrhea interfere with your daily activities at home and/or at work? ^{2,5} Describe.	No	☐	Yes, some	☐	Yes, significantly	☐
Have you vomited and/or had moderate nausea? ^{2,3,5,6}	No	☐			Yes	☐
Are you feeling dehydrated, which can include feeling dizzy, a dry mouth, increased thirst, fainting, rapid heart rate, decreased amount of urine? ^{2,3,5,6}	No	☐			Yes	☐
Have you been able to drink fluids? ^{5,6}	Yes	☐			No	☐
	 1 Mild		 2 Moderate		 3 Severe	
2. Triage patient for symptom management based on highest severity (Supporting evidence: ½ guidelines)	☐ Review self-care. Verify medication use, if appropriate.		☐ Review self-care. Verify medication use, if appropriate. Advised to call back if symptom worsens, new symptoms occur, or no improvement in 12-24 hours.		☐ If 1 or more symptoms present with any diarrhea, seek medical attention immediately.	

If patient is experiencing other symptoms, did you also refer to the appropriate protocols? If yes, please specify:

Additional Comments:

Patient Name _____

3. Review medications patient is using for diarrhea, including prescribed, over the counter, and/or herbal supplements (Supporting evidence: 5/6 guidelines)

Current use	Medications for diarrhea	Notes (eg. dose, suggest to use as prescribed)	Type of Evidence
☐	Loperamide (Imodium [®]) ^{2,3,4,5}		Systematic Review
☐	Atropine-diphenoxylate (Lomotil [®]) ^{3,4,5}		Systematic Review
☐	Octreotide (Sandostatin [®]) ^{1,2,3,4,5}		Systematic Review
☐	Psyllium fiber (Metamucil [®]) ³		Randomized control trial

4. Review self-management strategies (Supporting evidence: 5/6 guidelines)

What strategies are already being used?	Strategy suggested/ education provided	Patient agreed to try	Self-care strategies
1. ☐	☐	☐	What helps when you have diarrhea? Reinforce as appropriate. Specify:
2. ☐	☐	☐	Are you trying to drink 8-10 glasses clear fluids per day (e.g. water, sports drinks, broth)? ^{2,3,4,5,6}
3. ☐	☐	☐	Do you know what kinds of foods you should be trying to eat? Suggest: applesauce, oatmeal, bananas, cooked carrots, rice, white toast, plain pasta, well cooked eggs, skinned turkey or chicken, mashed potatoes, cooked or canned fruit without skin ^{2,3,4,5,6} (Foods high in soluble fiber and low in insoluble fiber)
4. ☐	☐	☐	Are you trying to replace electrolytes (eg. potassium and sodium or salt) that your body may be losing with the diarrhea by eating foods such as bananas and potatoes and drinking sports drinks or peach/apricot nectar? ³
5. ☐	☐	☐	Are you trying to eat 5-6 small meals? ^{2,3,5,6}
6. ☐	☐	☐	Are you trying to avoid lactose-containing products (milk, yoghurt, cheese) ^{2,3,5,6}
7. ☐	☐	☐	Are you trying to avoid alcohol and minimize caffeine (<2-3 servings) (coffee, chocolate) ^{2,3,4,5,6}
8. ☐	☐	☐	Are you trying to avoid greasy/fried and spicy foods? ^{2,3,6}
9. ☐	☐	☐	Are you trying to avoid large amounts fruit juices or sweetened fruit drinks? ^{2,3}
10. ☐	☐	☐	Are you trying to avoid raw vegetables, whole grain bread, nuts, popcorn, skins, seeds, legumes? ^{2,3,6} (Insoluble fiber)
11. ☐	☐	☐	Are you trying to keep skin around your rectum or ostomy clean to avoid skin breakdown? ³
12. ☐	☐	☐	Have you been keeping track of the number of stools you are having and are you aware of other problems you should be watching for with your diarrhea? (e.g. fever, dizziness) ^{2,3} (review criteria listed above in assessment)
13. ☐	☐	☐	Would more information about your symptoms help you to manage them better? If yes, provide appropriate information or suggest resources.
14. ☐	☐	☐	Have you spoken with a doctor or pharmacist about medications you may be taking that can cause or worsen your diarrhea? ³

5. Summarize and document plan agreed upon with caller (check all that apply)

☐	No change, continue with self-care strategies and if appropriate, medication use
☐	Patient agrees to try self-care items #: How confident are you that you can try what you agreed to do (0=not confident, 10=very confident)?
☐	Patient agrees to use medication to be consistent with prescribed regimen. Specify:
☐	Referral (service & date):
☐	Patient agrees to seek medical attention; specify time frame:
☐	Advised to call back in 12-24 hours if no improvement, symptom worsens, or new symptoms occur

Name	Signature	Date
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References

- Major, P., Figueroa, A., Tardes, V., Ilmorog, V., Chantre, M., Oliver, T., et al. (2004). The role of octreotide in the management of patients with cancer. Practice guideline report #12-7. Cancer Care Ontario. Retrieved from: <http://www.cancercare.on.ca/foodnet/qualityguidelines/cclio-program/systemic-drug/>. (AGREE: Rigor score 85%)
- Benson, A.B., III, Ajani, J.A., Catalano, R.B., Engelson, C., Kornblith, S.M., Martenson, J.A., Jr., et al. (2004). Recommended guidelines for the treatment of cancer treatment-induced diarrhea. *Journal of Clinical Oncology*, 22(14), 2918-2926. (AGREE: Rigor score 73%)
- Oncology Nursing Society. (2008). Diarrhea: What interventions are effective in preventing and treating diarrhea in adults with cancer receiving chemotherapy or radiation therapy? ONS PEP. Retrieved from: <http://www.ons.org/Research/PEP/Diarrhea>. (AGREE: Rigor score 48%)
- British Columbia Cancer Agency. (2004). BCCA Guidelines for management of chemotherapy-induced diarrhea. Retrieved from: <http://www.bccancer.bc.ca/109/CancerManagementGuidelines/SupportiveCare/Chemotherapy-Induced-Diarrhea.htm>. (AGREE: Rigor score 17%)
- British Columbia Cancer Agency. (2008). Professional practice nursing standards - Symptom management guidelines: Cancer-related diarrhea. Retrieved from: <http://www.bccancer.bc.ca/NR/rdonlyres/5D986439-3614-4017-9E56-79E0C73C45D1/50139/Diarrhea.pdf>. (AGREE: Rigor score 17%)
- Cancer Care Ontario. (2004). Telephone nursing practice and symptom management guidelines. Retrieved from: <http://www.ontario.ca/library/inpository/mco/9000/245778.pdf>. (AGREE: Rigor score 11%)
- National Institutes of Health: National Cancer Institute. (2010). Common terminology criteria for adverse events (CTCAE) v4.03. Retrieved from: <http://eva.nci.nih.gov/ftp1/CTCAE/About.html>.
- Breen, E., Kuehn, N., Miller, M.J., Selinger, P., Macmillan, K. The Edmonton symptom assessment system (ESAS): a simple method for the assessment of palliative care patients. *J. Palliat Care* 1991; 7(2):6-9.

Fatigue/Tiredness Protocol

Remote Assessment, Triage, and Management of Fatigue/Tiredness in Adults Undergoing Cancer Treatment

Fatigue: a subjective feeling of tiredness or exhaustion prompted by cancer or cancer treatment that is disproportionate to the level of recent exertion, is not relieved by rest and interferes with usual daily activities.¹

Name
Date of Birth
Sex
Hospital card number

Date and Time

1. Assess severity of the fatigue/tiredness (Supporting evidence: 3/3 guidelines)

Tell me what number from 0 to 10 best describes how tired you are feeling

Not tired 0 1 2 3 4 5 6 7 8 9 10 Worst possible tiredness^{ESAS}

How worried are you about your fatigue/tiredness?

Not worried 0 1 2 3 4 5 6 7 8 9 10 Extremely worried

Ask patient to indicate which of the following are present or absent

Patient rating (see ESAS above) ^{1,2}	0-3	☐	4-6	☐	7-10	☐
Patient rating of worry about fatigue (see above)	0-5	☐	6-10	☐		
Do you have the following: shortness of breath at rest, sudden onset of severe fatigue, excessive need to sit or rest, rapid heart rate, rapid blood loss, or pain in your chest?	No	☐			Yes	☐
How would you describe the pattern of fatigue?	Intermittent	☐		☐	Constant/ Daily for two weeks	☐
Does your fatigue interfere with your daily activities at home and/or at work? Describe.	No	☐	Yes, some	☐	Yes, significantly	☐
Are there times when you feel exhausted? Describe.	No	☐	Yes, intermittently	☐	Yes, constantly for two weeks	☐
	 1 Mild		 2 Moderate		 3 Severe	
2. Triage patient for symptom management based on highest severity (Supporting evidence: 1/2 guidelines)	☐ Review self-care.		☐ Review self-care. Advised to call back if symptom worsens, new symptoms occur, or no improvement in 1-2 days.		☐ If 1 or more symptoms present with any fatigue/tiredness, seek medical attention immediately. *If severe fatigue is stabilized, review self-management strategies.	

If patient is experiencing other symptoms, did you also refer to the appropriate protocols? If yes, please specify:

Additional Comments:

Patient Name _____

3. Review medications patient is using for fatigue, including prescribed, over the counter, and/or herbal supplements (Supporting evidence: 3/3 guidelines)

Current use	Medications for fatigue	Notes	Type of Evidence
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☐ *Use of pharmacological agents for cancer-related fatigue is experimental and NOT recommended (e.g. psycho-stimulants, sleep medications, low dose corticosteroids) unless for select patients at end of life with severe fatigue

4. Review self-management strategies (Supporting evidence: 3/3 guidelines)

What strategies are already being used?	Strategy suggested/ education provided	Patient agreed to try	Self-care strategies
1. ☐	☐	☐	What helps when you feel fatigued/tired? Reinforce as appropriate. Specify:
2. ☐	☐	☐	Do you understand what cancer-related fatigue is? Provide education about how it differs from normal fatigue, that it is expected with cancer treatment
3. ☐	☐	☐	Would more information about your symptoms help you to manage them better? If yes, provide appropriate information or suggest resources.
4. ☐	☐	☐	Are you monitoring your fatigue levels?
5. ☐	☐	☐	Are you trying to save energy for things that are important to you?
6. ☐	☐	☐	What are you doing for physical activity? Moderate level of physical activity during and after cancer treatment is encouraged (e.g. 30 min of moderate intensity activity most days of the week: fast walk, cycle, swim, resistance exercise) *Use with caution in patients with some conditions (ie. bone metastases)
7. ☐	☐	☐	Do you think you are eating/drinking enough to meet your body's energy needs?
8. ☐	☐	☐	Have you tried activities such as reading, games, music, gardening, experiences in nature?
9. ☐	☐	☐	Do you participate in any support groups and/or have family/friends you can rely on for support?
10. ☐	☐	☐	Have you tried activities to make you more relaxed? Such as relaxation therapy, deep breathing, yoga, guided imagery, or massage therapy? (3 RCT's sessions lowered fatigue scores)
11. ☐	☐	☐	Have you done any of the following to improve the quality of your sleep? Avoid long or late afternoon naps; limit time in bed to actual sleep; go to bed when sleepy; use bed for sleep and sexual activity only; have consistent schedule for bedtime and getting up; avoid caffeine and stimulating activity in the evening; relax for 1 hour before going to bed; establish a bedtime routine
12. ☐	☐	☐	Have you spoken with or would you like to speak with a health care professional to help guide you in managing your fatigue? (physiotherapist, occupational therapist, dietitian)
13. ☐	☐	☐	Have you tried a program such as cognitive behavioural therapy to manage your fatigue?

5. Summarize and document plan agreed upon with caller (check all that apply)

☐	No change, continue with self-care strategies
☐	Patient agrees to try self-care items #:
☐	How confident are you that you can try what you agreed to do (0=not confident, 10=very confident)?
☐	Referral (service & date):
☐	Patient agrees to seek medical attention; specify time frame:
☐	Advised to call back in 1-2 days if no improvement, symptom worsens, or new symptoms occur

Name	Signature	Date
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References

- Howell D, Keller-Olaman S, Oliver TK, et al. (2012, in press) A Pan-Canadian Practice Guideline: Screening, Assessment and Care of Cancer-Related Fatigue in Adults with Cancer. Canadian Partnership Against Cancer: The National Advisory Working Group on behalf of the Cancer Journey Portfolio. Other guidelines referenced within this guideline are:
 - Oncology Nursing Society (ONS). Putting Evidence into Practice (PEP) Topics – Fatigue. Accessed December 2009. Retrieved from: <http://www.ons.org/Research/PEP/Fatigue>. (AGREE rigour score 35.2%)
 - Clinical Practice Guidelines in Oncology – Cancer-Related Fatigue, V.2.2009 (June 2009). National Comprehensive Cancer Network (NCCN). Retrieved from: http://www.nccn.org/professionals/physician_gls/f_guidelines.asp. (AGREE rigour score 28.5%)
- Bruera E, Kishin N, Miller MJ, Selms P, Macmillan K. The Edmonton symptom assessment system (ESAS): a simple method for the assessment of palliative care patients. *J. Palliat Care* 1991; 7(2):6-9.

Febrile Neutropenia Protocol
Remote Assessment, Triage, and Management of
Febrile Neutropenia in Adults Undergoing Cancer Treatment
(not for patients undergoing bone marrow transplant)

Fever: A single oral temperature of $\geq 38.3^{\circ}\text{C}$ (101°F) or a temperature of $\geq 38.0^{\circ}\text{C}$ (100.4°F) for ≥ 1 hour.

Neutropenia: A neutrophil count of < 500 cells/ mm^3 or a count of < 1000 cells/ mm^3 with a predicted decrease to < 500 cells/ mm^3 .

Febrile neutropenia: A neutrophil count of < 1000 cells/ mm^3 and a single oral temperature of $\geq 38.3^{\circ}\text{C}$ (101°F) or a temperature of $\geq 38.0^{\circ}\text{C}$ (100.4°F) for ≥ 1 hour.

Name _____
 Date of Birth _____
 Sex _____
 Hospital card number _____

Date and Time _____

1. Assess severity of the fever and neutropenia (Supporting evidence: 4/4 guidelines)

How worried are you about your fever?

Not worried 0 1 2 3 4 5 6 7 8 9 10 Extremely worried

What is your temperature in the last 24 hours? Current: _____ Previous temperatures: _____

Have you taken any acetaminophen (Tylenol®) or ibuprofen (Advil®), if yes, how much and when? _____

Ask patient to indicate which of the following are present or absent

Temperature of $\geq 38.0^{\circ}\text{C}$ (100.4°F)? ^{1,2,3,4,5}	No	☐	Yes	☐
Last known neutrophil count ^{1,2,3,5} _____	>1000 cells/ mm^3	☐	<500 cells/ mm^3 or 1000 cells/ mm^3 with expected drop	☐
Date: _____ ☐ Unsure				
Have you received either chemotherapy or radiation treatment within the past 1-4 weeks? ⁴	No	☐	Yes	☐

1

Mild

3

Severe

2. Triage patient for symptom management based on highest severity (Supporting evidence: 1/4 guidelines)

☐ Review self-care.

☐ If fever with known or suspected neutropenia, in addition to any other symptoms, seek medical attention immediately.

Note: Although guidelines indicate the need to take action when a temperature is $\geq 38.3^{\circ}\text{C}$ (101°F) at any time or a temperature is $\geq 38.0^{\circ}\text{C}$ (100.4°F) for ≥ 1 hour, for consistency across symptom protocols a temperature of 38.0°C is used.

Additional Comments:

Patient Name _____

3. Review medications patient is using for fever, including prescribed, over the counter, and/or herbal supplements

Current use	Medications	Notes	Type of Evidence
☐			

*Use of medications to lower fever in cancer patients is controversial and should not be used to mask a fever of unknown origin.

4. Review self-management strategies to minimize risk of infection (Supporting evidence: 1/4 guidelines)

What strategies are already being used?	Strategy suggested/ education provided	Patient agreed to try	Self-care strategies
1. ☐	☐	☐	Are you washing your hands frequently? ⁴
2. ☐	☐	☐	Are you trying to increase your fluid intake to 8-12 glasses per day? ⁴
3. ☐	☐	☐	Are you brushing your teeth with a soft toothbrush? ⁴
4. ☐	☐	☐	Are you trying to avoid enemas, suppositories, tampons and invasive procedures? ⁴
5. ☐	☐	☐	Are you trying to keep any wounds clean and dry? ⁴
6. ☐	☐	☐	Are you trying to avoid crowds and people who might be sick? ⁴
7. ☐	☐	☐	Would more information about your symptoms help you to manage them better? If yes, provide appropriate information or suggest resources.

5. Summarize and document plan agreed upon with caller (check all that apply)

☐	No change, continue with self-care strategies
☐	Patient agrees to try self-care items #:
☐	How confident are you that you can try what you agreed to do (0=not confident, 10=very confident)?
☐	Patient agrees to seek medical attention; specify time frame:
☐	Advised to call back in 12-24 hours if no improvement, symptom worsens, or new symptoms occur

Name	Signature	Date
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References

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2. National Comprehensive Cancer Network. (2008). NCCN Clinical practice guidelines in oncology: Prevention and treatment of cancer-related infections. Version 1. Retrieved from: http://www.nccn.org/professionals/physician_gls/f_guidelines.asp. (AGREE Rigour score 48%)
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Loss of Appetite Protocol

Remote Assessment, Triage, and Management of Loss of Appetite in Adults Undergoing Cancer Treatment

Anorexia: An involuntary loss of appetite¹; being without appetite.

Name
Date of Birth
Sex
Hospital card number

Date and Time

1. Assess severity of the anorexia (Supporting evidence: 1/3 guideline)

Tell me what number from 0 to 10 best describes your appetite

Best appetite 0 1 2 3 4 5 6 7 8 9 10 Worst possible appetite ^{ESAS}

How worried are you about your poor appetite?

Not worried 0 1 2 3 4 5 6 7 8 9 10 Extremely worried

Ask patient to indicate which of the following are present or absent

Patient rating (see ESAS above) ⁴	0-3	☐	4-6	☐	7-10	☐
Patient rating of worry about poor appetite (see above)	0-5	☐	6-10	☐		
How much have you had to eat and drink in past 24 hours (eg. at each meal)? ³	Some	☐	Minimal	☐	None	☐
Does your poor appetite interfere with your daily activities at home and/or at work? ³ Describe.	No	☐	Yes, some	☐	Yes, significantly	☐
Are you feeling dehydrated, which can include feeling dizzy, a dry mouth, increased thirst, fainting, rapid heart rate, decreased amount of urine? ³	No	☐			Yes	☐
Have you lost weight in the last 1-2 weeks? Amount: ☐ Unsure	No	☐	Yes	☐		

1 Mild

2 Moderate

3 Severe

2. Triage patient for symptom management based on highest severity (Supporting evidence: 1/3 guidelines)

☐ Review self-care. Verify medication use, if appropriate.

☐ Review self-care. Verify medication use, if appropriate. Advised to call back if symptom worsens, new symptoms occur, or no improvement in 1-2 days.

☐ If 1 or more symptoms present with any anorexia, seek medical attention immediately.
*If severe loss of appetite is stabilized, review self-management strategies.

If patient is experiencing other symptoms, did you also refer to the appropriate protocols? If yes, please specify:

Additional comments:

Patient Name _____

3. Review medications patient is using for anorexia, including prescribed, over the counter, and/or herbal supplements (Supporting evidence: 1/3 guideline)

Current use	Medications for appetite	Notes (eg. dose, suggest taking as prescribed)	Type of Evidence
☐	Corticosteroids - dexamethasone (Decadron [®]), prednisone ¹		Systematic review
☐	megestrol (Megace [®]) ¹		Systematic review

4. Review self-management strategies (Supporting evidence: 3/3 guidelines)

What strategies are already being used?	Strategy suggested/ education provided	Patient agreed to try	Self-care strategies
1. ☐	☐	☐	What helps when you feel like you are not hungry? Reinforce as appropriate. Specify:
2. ☐	☐	☐	Are you trying to eat 5-6 small meals? ³
3. ☐	☐	☐	Are you trying to eat more when you feel most hungry? ³
4. ☐	☐	☐	Are you trying to eat foods that are higher in protein and calories such as cheese, yogurt, eggs, or milk shakes? ³
5. ☐	☐	☐	Are you using any food supplements (Ensure, Glucerna, Boost [®])? ¹
6. ☐	☐	☐	Are you trying to limit drinking ½ hour before a meal to avoid feeling too full? ³
7. ☐	☐	☐	Did you know that cold foods are sometimes better tolerated? ³
8. ☐	☐	☐	Are you trying to sit up after each meal for 30-60 minutes to help digest your food? ³
9. ☐	☐	☐	Have you spoken with a dietitian? ^{1,2}
10. ☐	☐	☐	Would more information about your symptoms help you to manage them better? If yes, provide appropriate information or suggest resources.

5. Summarize and document plan agreed upon with caller (check all that apply)

☐	No change, continue with self-care strategies and if appropriate, medication use
☐	Patient agrees to try self-care items #:
☐	How confident are you that you can try what you agreed to do (0=not confident, 10=very confident)?
☐	Patient agrees to use medication to be consistent with prescribed regimen
☐	Specify:
☐	Referral (service & date):
☐	Patient agrees to seek medical attention; specify time frame:
☐	Advised to call back in 1-2 days if no improvement, symptom worsens, or new symptoms occur

Name	Signature	Date
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References

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3. Cancer Care Ontario. (2004). Telephone nursing practice and symptom management guidelines. Retrieved from: <http://www.oncfa.on.ca/library/repository/mcn/9000/245778.pdf>. (AGREE Rigour score 11%)
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Mouth Sores/Stomatitis Protocol
Remote Assessment, Triage, and Management of
Mouth Sores/Stomatitis in Adults Undergoing Cancer Treatment
(not for patients undergoing bone marrow transplant)

Mouth sores/Stomatitis/Oral Mucositis: An inflammatory and potentially ulcerative process of the mucous membranes, resulting in severe discomfort that can impair patients' ability to eat, swallow, and talk, and is accompanied by a risk for life-threatening bacteremia and sepsis.³

Name
Date of Birth
Sex
Hospital card number

Date and Time

1. Assess severity of the mouth sores (Supporting evidence: 4/4 guidelines)

Tell me what number from 0 to 10 best describes your mouth sores?

No mouth sores 0 1 2 3 4 5 6 7 8 9 10 Worst possible mouth sores ^{ESAS}

How worried are you about your mouth sores?

Not worried 0 1 2 3 4 5 6 7 8 9 10 Extremely worried

Ask patient to indicate which of the following are present or absent

Patient rating (see ESAS above) ⁵	0-3	☐	4-6	☐	7-10	☐
Patient rating of worry about mouth sores (see above)	0-5	☐	6-10	☐		
How many sores/ulcers/blisters do you have? ^{2,3,4}	0-4	☐	>4	☐	Coalescing/ Merging/Joining	☐
Do the sores in your mouth bleed? ^{2,3,4}	No	☐	Yes, with eating or oral hygiene	☐	Yes, spontaneously	☐
Are the sores painful? ^{1,2,3,4}	No/Mild 0-3	☐	Moderate 4-6	☐	Severe 7-10	☐
Are you able to eat and drink? ^{2,3,4}	Yes	☐			No	☐
Are you having trouble breathing? ⁴	No	☐			Yes	☐

2. Triage patient for symptom management based on highest severity
(Supporting evidence: 1/4 guidelines)

1 Mild	2 Moderate	3 Severe
☐ Review self-care. Verify medication use, if appropriate.	☐ Review self-care. Verify medication use, if appropriate. Advised to call back if symptom worsens, new symptoms occur, or no improvement in 12-24 hours.	☐ If 1 or more symptoms present with any mouth sores, seek medical attention immediately.

If patient is experiencing other symptoms, did you also refer to the appropriate protocols? If yes, please specify:

Additional Comments:

Patient Name _____

3. Review medications patient is using for mouth sores, including prescribed, over the counter, and/or herbal supplements (Supporting evidence: 1/4 guidelines)

Current use	Medications for mouth sores	Notes (eg. dose, suggest to use as prescribed)	Type of Evidence
☐	benzylamine hydrogen chloride (Tantum mouth rinse) ²		1 Randomized trial

*Many other medications have been tested however their effectiveness has not been established.

4. Review self-management strategies (Supporting evidence: 4/4 guidelines)

What strategies are already being used?	Strategy suggested/ education provided	Patient agreed to try	Self-care strategies
1. ☐	☐	☐	What helps when you have mouth sores? Reinforce as appropriate. Specify:
2. ☐	☐	☐	Are you trying to rinse your mouth 4 times a day with a bland rinse? For 1 cup warm water, add 2.5 ml (1/2 tsp.) table salt, baking soda or both. Swish 15 ml (1 tablespoon) in your mouth for at least 30 seconds and spit out. ^{2,4} Store extra solution in the fridge or at room temperature.
3. ☐	☐	☐	Are you trying to brush your teeth at least twice a day using a soft toothbrush and flossing once daily or as tolerated? ^{1,2,4}
4. ☐	☐	☐	If you wear dentures and your mouth is sensitive, do you try to use your dentures only at mealtimes? ⁴
5. ☐	☐	☐	Are you using water-based moisturizers to protect your lips? ^{2,4}
6. ☐	☐	☐	Do you allow your toothbrush to air dry before storing? ^{2,4}
7. ☐	☐	☐	Are you trying to avoid tobacco and alcohol, including alcohol-based mouthwashes? ^{2,4}
8. ☐	☐	☐	Are you trying to drink 8-10 glasses of fluids per day? ^{2,4}
9. ☐	☐	☐	Are you trying to eat a soft diet? Suggest: oatmeal, bananas, applesauce, cooked carrots, rice, pasta, eggs, mashed potatoes, cooked or canned fruit without skin, soft cheese, creamed soups, puddings/milkshakes. ^{2,4}
10. ☐	☐	☐	Are you trying to avoid foods and drinks that are acidic, salty, spicy, or very hot (temperature)? ^{2,4}
11. ☐	☐	☐	Would more information about your symptoms help you to manage them better? If yes, provide appropriate information or suggest resources.

5. Summarize and document plan agreed upon with caller (check all that apply)

☐	No change, continue with self-care strategies and if appropriate, medication use
☐	Patient agrees to try self-care items #:
☐	How confident are you that you can try what you agreed to do (0=not confident, 10=very confident)?
☐	Patient agrees to use medication to be consistent with prescribed regimen
☐	Specify:
☐	Referral (service & date):
☐	Patient agrees to seek medical attention; specify time frame:
☐	Advised to call back in 12-24 hours if no improvement, symptom worsens, or new symptoms occur

Name	Signature	Date
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4. Cancer Care Ontario. (2004). Telephone nursing practice and symptom management guidelines. Retrieved from: <http://www.onfa.on.ca/library/repository/mcn/9000/245778.pdf>. (AGREE Rigour score 11%)
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Nausea & Vomiting Protocol
Remote Assessment, Triage, and Management of
Nausea & Vomiting in Adults Undergoing Cancer Treatment
(not for patients undergoing bone marrow transplant)

Nausea: A subjective perception that emesis may occur. Feeling of queasiness.
 Vomiting: A forceful expulsion of stomach contents through the mouth and may include retching (gastric and esophageal movement without vomiting – dry heaves.)⁷

Name
 Date of Birth
 Sex
 Hospital card number

Date and Time

1. Assess severity of nausea/vomiting (Supporting evidence: 3/7 guidelines)

Tell me what number from 0 to 10 best describes your nausea

No nausea 0 1 2 3 4 5 6 7 8 9 10 Worst possible nausea ^{ESAS}

Tell me what number from 0 to 10 best describes your vomiting?

No vomiting 0 1 2 3 4 5 6 7 8 9 10 Worst possible vomiting ^{ESAS}

How worried are you about your nausea/vomiting?

Not worried 0 1 2 3 4 5 6 7 8 9 10 Extremely worried

Ask patient to indicate which of the following are present or absent

Patient rating for nausea (see ESAS above) ⁹	0-3	☐	4-6	☐	7-10	☐
Patient rating for vomiting (see ESAS above) ⁹	0-3	☐	4-6	☐	7-10	☐
Patient rating of worry about nausea/vomiting (see above)	0-5	☐	6-10	☐		
How many times per day are you vomiting or retching? ⁸ ☐ No vomiting	≤1	☐	2-5	☐	>5	☐
Have you been able to eat within last 24 hours? ^{7,8}	Yes	☐	Yes, reduced	☐	No	☐
Have you been able to tolerate drinking fluids? ⁸	Yes	☐			No	☐
Are you feeling dehydrated, which can include feeling dizzy, a dry mouth, increased thirst, fainting, rapid heart rate, decreased amount of urine? ^{3,7}	No	☐			Yes	☐
Do you have any blood in your vomit or does it look like coffee grounds? ⁷ ☐ No vomiting	No	☐			Yes	☐
Do you have any abdominal pain? ⁷	No/Mild 0-3	☐	Moderate 4-6	☐	Severe 7-10	☐
Does your nausea/vomiting interfere with your daily activities at home and/or at work? Describe.	No	☐	Yes, some	☐	Yes, significantly	☐

1

Mild

2

Moderate

3

Severe

2. Triage patient for symptom management based on highest severity (Supporting evidence: 3/7 guidelines)

☐ Review self-care. Verify medication use, if appropriate.

☐ Review self-care. Verify medication use, if appropriate. Advised to call back if symptom worsens, new symptoms occur, or no improvement in 12-24 hours.

☐ If 1 or more symptoms present with any vomiting or severe nausea, seek medical attention immediately.

If patient is experiencing other symptoms, did you also refer to the appropriate protocols? If yes, please specify:

Additional Comments:

Patient Name _____

3. Review medications patient is using for nausea/vomiting, including prescribed, over the counter, and/or herbal supplements (Supporting evidence: 6/7 guidelines)

Current use	Medications for nausea/vomiting	Notes (eg. dose, suggest to use as prescribed)	Type of Evidence
☐	ondansetron (Zofran [®]), granisetron (Kytrel [®]), dolasetron (Anszemet [®]) ^{1,2,3,4,5,6}		Systematic review
☐	metoclopramide (Maxeran [®]) ^{1,2,3,5,6}		Systematic review
☐	prochlorperazine (Stemetil [®]) ^{1,2,3,4,6}		Systematic review
☐	aprepitant (Emed [®]) ^{4,5,6}		Systematic review

4. Review self-management strategies (Supporting evidence: 4/7 guidelines)

What strategies are already being used?	Strategy suggested/ education provided	Patient agreed to try	Self-care strategies
1. ☐	☐	☐	What helps when you have nausea/vomiting? Reinforce as appropriate. Specify:
2. ☐	☐	☐	Are you trying to drink 8-10 glasses clear fluids per day (e.g. water, sports drinks, broth)? ⁷
3. ☐	☐	☐	Have you tried relaxation techniques that may include guided imagery, music therapy, progressive muscle relaxation? ^{3,6}
4. ☐	☐	☐	Are you taking anti-emetic medications prior to your meals so that they are effective during and after meals? ^{6,7}
5. ☐	☐	☐	Are you trying to: - eat 5-6 small meals? ⁷ - eat foods that minimize your nausea and are your "comfort foods"? ⁶ - avoid greasy/fried, highly salty, and spicy foods? ^{6,7} - eat foods that are cold, avoiding extreme temperatures? ^{6,7} - reduce food aromas and avoid other strong odors? ^{6,7}
6. ☐	☐	☐	Have you tried acupuncture or acupressure to help with your nausea/vomiting? ^{3,5,6} (supporting evidence: systematic review)
7. ☐	☐	☐	Would more information about your symptoms help you to manage them better? If yes, provide appropriate information or suggest resources.

5. Summarize and document plan agreed upon with caller (check all that apply)

☐	No change, continue with self-care strategies and if appropriate, medication use
☐	Patient agrees to try self-care items #: How confident are you that you can try what you agreed to do (0=not confident, 10=very confident)?
☐	Patient agrees to use medication to be consistent with prescribed regimen. Specify:
☐	Referral (service & date):
☐	Patient agrees to seek medical attention; specify time frame:
☐	Advised to call back in 12-24 hours if no improvement, symptom worsens, or new symptoms occur

Name	Signature	Date
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Peripheral Neuropathy Protocol
Remote Assessment, Triage, and Management of
Peripheral Neuropathy in Adults Undergoing Cancer Treatment

Neuropathy: Described as numbness, tingling, pins and needles, tremor, balance disturbances, pain. The end result of peripheral, motor, sensory, and autonomic neuron damage caused by neurotoxic chemotherapy agents that inactivate the components required to maintain the metabolic needs of the axon.¹

Name
 Date of Birth
 Sex
 Hospital card number

Date and Time

1. Assess severity of the neuropathy (Supporting evidence: 3/3 guidelines)

Tell me what number from 0 to 10 best describes your neuropathy/numbness/tingling?

No neuropathy 0 1 2 3 4 5 6 7 8 9 10 Worst possible neuropathy^{ESAS}

How worried are you about your neuropathy/numbness/tingling?

Not worried 0 1 2 3 4 5 6 7 8 9 10 Extremely worried

Ask patient to indicate which of the following are present or absent

Patient rating (see ESAS above)*	0-3	☐	4-6	☐	7-10	☐
Patient rating of worry about neuropathy (see above)	0-5	☐	6-10	☐		
Do you have pain in your _____ (neuropathy location)? ^{1,2,3} Describe.	No/Mild 0-3	☐	Moderate 4-6	☐	Severe 7-10	☐
Do you have new weakness in your arms or legs? ^{1,2}	No	☐			Yes	☐
Have you noticed problems with your balance or how you walk, if yes, how much? ^{1,2}	No/Mild	☐	Moderate	☐	Severe	☐
Are you constipated? ^{1,2}	No/Mild	☐	Moderate	☐	Severe	☐
Does your neuropathy/numbness/tingling interfere with your daily activities at home and/or at work (e.g. buttoning clothing, writing, holding coffee cup)? ^{1,2} Describe.	No	☐	Yes, some	☐	Yes, significantly	☐

	1 Mild	2 Moderate	3 Severe
2. Triage patient for symptom management based on highest severity (Supporting evidence: 1/3 guidelines)	☐ Review self-care. Verify medication use, if appropriate.	☐ Review self-care. Verify medication use, if appropriate. Advised to call back if symptom worsens, new symptoms occur, or no improvement in 12-24 hours.	☐ If 1 or more symptoms present with any neuropathy, seek medical attention.

If patient is experiencing other symptoms, did you also refer to the appropriate protocols? If yes, please specify:

Additional Comments:

Patient Name _____

3. Review medications patient is using for neuropathy, including prescribed, over the counter, and/or herbal supplements (Supporting evidence: 2/3 guidelines)

Current use	Medications for neuropathy	Notes (eg. dose, suggest to use as prescribed)	Type of Evidence
☐	Anti-convulsants – gabapentin, pregabalin (Lyrica®) ²		Expert Opinion
☐	Tricyclic anti-depressants – amitriptyline, nortriptyline, duloxetine (Cymbalta®), venlafaxine (Effexor®), bupropion (Wellbutrin®, Zyban®) ^{2,3}		Expert Opinion
☐	Opioids – fentanyl, morphine (Statex®), hydromorphone (Dilaudid®), codeine, oxycodone ^{2,3}		Expert Opinion
☐	Topical agent – lidocaine patch ^{2,3}		Expert Opinion

4. Review self-management strategies (Supporting evidence: 3/3 guidelines)

What strategies are already being used?	Strategy suggested/ education provided	Patient agreed to try	Self-care strategies
1. ☐	☐	☐	What helps with managing your neuropathy? Reinforce as appropriate. Specify:
2. ☐	☐	☐	Do you look at your hands and feet every day for sores/blisters that you may not feel? ^{1,2}
3. ☐	☐	☐	If neuropathy in feet: Do you have footwear that fits you properly? ^{1,2}
4. ☐	☐	☐	In your home: - are the walkways clear of clutter? ^{1,2} - do you have a skid-free shower or are you using bath mats in your tub? ^{1,2} - have you removed throw rugs that may be a tripping hazard? ^{1,2}
5. ☐	☐	☐	When you are walking on uneven ground, do you try to look at the ground to help make up for the loss of sensation in your legs or feet? ^{1,2}
6. ☐	☐	☐	If any neuropathy: To avoid burns due to decreased sensation: - Have you lowered the water temperature in your hot water heater? ¹ - Do you use a bath thermometer to ensure water in shower or tub is < 120°F/49°C? ¹
7. ☐	☐	☐	Do you try to dangle your legs before you stand up to avoid feeling dizzy? ^{1,2}
8. ☐	☐	☐	Do you try eat a high-fiber diet and drink adequate fluids to avoid becoming constipated? ^{1,2}
9. ☐	☐	☐	Have you tried acupuncture? ²
10. ☐	☐	☐	Have you spoken with a physiotherapist about: - a walker, cane, or a splint to help with your balance and improve walking? ^{1,2} - a physical training plan or TENS (transcutaneous electrical nerve stimulation)? ^{2,3}
11. ☐	☐	☐	Have you spoken with an occupational therapist for suggestions such as: - switching to loafer-style shoes or using Velcro shoe laces - adaptive equipment such as enlarged handles on eating utensils, button hooks, Velcro on computer keys to stimulate sensation?
12. ☐	☐	☐	Would more information about your symptoms help you to manage them better? If yes, provide appropriate information or suggest resources.

5. Summarize and document plan agreed upon with caller monitoring (check all that apply)

☐	No change, continue with self-care strategies and if appropriate, medication use
☐	Patient agrees to try self-care items #:
☐	How confident are you that you can try what you agreed to do (0=not confident, 10=very confident)?
☐	Patient agrees to use medication to be consistent with prescribed regimen
☐	Specify:
☐	Referral (service & date):
☐	Referral (service & date):
☐	Patient agrees to seek medical attention; specify time frame:
☐	Advised to call back in 12-24 hours if no improvement, symptom worsens, or new symptoms occur

Name	Signature	Date
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References

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- National Comprehensive Cancer Network. (2009). NCCN Clinical practice guidelines in oncology: Adult cancer pain. Version 1. Retrieved from: http://www.nccn.org/professionals/physician_gls/pdf_guidelines.asp. (AGREE Rigor score 78%)
- Brems, E., Kuehn, N., Miller, M.J., Selinger, P., Macmillan, K. The Edmonton symptom assessment system (ESAS): a simple method for the assessment of palliative care patients. *J. Palliat Care* 1991; 7(2):6-9.

Skin Reaction Protocol
Remote Assessment, Triage, and Management of
Skin Reactions in Adults Undergoing Cancer Treatment
(not for patients undergoing bone marrow transplant)

Skin reaction/alteration: A change in the colour, texture or integrity of the skin.²

Name
 Date of Birth
 Sex
 Hospital card number

Date and Time

1. Assess severity of the skin reaction (Supporting evidence: 3/3 guidelines)

Tell me what number from 0 to 10 best describes your skin reaction

No skin reaction 0 1 2 3 4 5 6 7 8 9 10 Worst possible skin reaction^{ESAS}

How worried are you about your skin reaction?

Not worried 0 1 2 3 4 5 6 7 8 9 10 Extremely worried

Site of skin reaction(s) _____

Ask patient to indicate which of the following are present or absent

Patient rating (see ESAS above) ³	0-3	☐	4-6	☐	7-10	☐
Patient rating of worry about skin reaction (see above)	0-5	☐	6-10	☐		
Is your skin red? ^{1,2,4}	None	☐	Faint/dull	☐	Tender/bright	☐
Is your skin peeling? ^{1,2,4}	No/Dry	☐	Patchy, moist	☐	Generalized, moist	☐
Do you have any swelling around the skin reaction area? ^{1,2}	No/Mild	☐	Moderate	☐	Pitting	☐
Do you have pain at the skin reaction area? ^{2,4}	No/Mild 0-3	☐	Moderate 4-6	☐	Severe 7-10	☐
Do you have any ulcers? ^{1,4}	No	☐			Yes	☐
Do you have any bleeding? ^{1,4}	No	☐			Yes	☐
Do you have any areas of black skin or dead tissue? ^{1,4}	No	☐			Yes	☐
Do you have any open, draining wounds? ^{2,4}	No	☐			Yes	☐
Do you have a new rash?	No	☐			Yes	☐
Do you have a fever > 38° C? ² ☐ Unsure	No	☐			Yes	☐
Have you started a new medication? ⁴	No	☐			Yes	☐
Does your skin reaction interfere with your daily activities at home and/or at work? ^{2,4} Describe.	No	☐	Yes, some	☐	Yes, significantly	☐
If you have a Port-o-cath, a PICC or another kind of access device that goes directly into your blood stream, are there any signs of infection that you notice, such as redness, tenderness, discharge, or swelling at the site? ²	No	☐			Yes	☐

	 1 Mild	 2 Moderate	 3 Severe
2. Triage patient for symptom management based on highest severity (Supporting evidence: 1/3 guidelines)	☐ Review self-care. Verify medication use, if appropriate.	☐ Review self-care. Verify medication use, if appropriate. Advised to call back if symptom worsens, new symptoms occur, or no improvement in 12-24 hours.	☐ If 1 or more symptoms present with any skin reaction, seek medical attention immediately.

If patient is experiencing other symptoms, did you also refer to the appropriate protocols? If yes, please specify:

Additional Comments:

Patient Name _____

3. Review medications patient is using for skin reaction, including prescribed, over the counter, and/or herbal supplements (Supporting evidence: 2/3 guidelines)

Current use	Medications for skin reaction to radiation therapy ^a	Notes (eg. dose, suggest to use as prescribed)	Type of Evidence
☐	Calendula ointment ^{1,4}		1 randomized trial
☐	Hyaluronic acid cream ⁴		1 randomized trial
☐	Low-dose corticosteroid cream ^{1,4*}		Expert opinion

* There is insufficient evidence to support or refute other specific topical agents (i.e., corticosteroids, sacralfate cream, Biafine[®], ascorbic acid, aloe vera, chamomile cream, almond ointment, polymer adhesive skin sealant) for the prevention of acute skin reaction.

4. Review self-management strategies (Supporting evidence: 3/3 guidelines)

What strategies are already being used?	Strategy suggested/education provided	Patient agreed to try	Self-care strategies
1. ☐	☐	☐	What helps when you have a skin reaction? Reinforce as appropriate. Specify:
2. ☐	☐	☐	Are you trying to take warm showers or immersion in warm baths (not soaking in the tub) using mild soap, and patting dry (no rubbing)? ^{1,2,4} (Randomized control trial evidence)
3. ☐	☐	☐	Are you trying to use plain, non-scented, lanolin-free, water-based creams on intact skin only? ^{1,2,4}
4. ☐	☐	☐	Are you using deodorant if skin is intact? ⁴ (Randomized control trial evidence)
5. ☐	☐	☐	Are you trying to drink 8-12 glasses of fluids per day to maintain hydration? ²
6. ☐	☐	☐	Are you trying to use an electric razor OR avoid shaving the area that is irritated? ^{2,4}
7. ☐	☐	☐	Are you avoiding skin creams or gels in the treatment area before each treatment? ⁴
8. ☐	☐	☐	Are you trying to avoid chlorinated pools and Jacuzzis? ^{2,4}
9. ☐	☐	☐	Are you trying to avoid temperature extremes in the treatment area (eg. ice pack or heating pad) to the reaction area? ^{2,4}
10. ☐	☐	☐	Are you trying to protect the treatment area from the sun and the cold? ⁴
11. ☐	☐	☐	Are you trying to avoid tape or Band-aids in the treatment area? ^{2,4}
12. ☐	☐	☐	Would more information about your symptoms help you to manage them better? If yes, provide appropriate information or suggest resources.

5. Summarize and document plan agreed upon with caller (check all that apply)

☐	No change, continue with self-care strategies and if appropriate, medication use
☐	Patient agrees to try self-care items #: How confident are you that you can try what you agreed to do (0=not confident, 10=very confident)?
☐	Patient agrees to use medication to be consistent with prescribed regimen Specify:
☐	Patient agrees to seek medical attention; specify time frame:
☐	Advised to call back in 12-24 hours if no improvement, symptom worsens, or new symptoms occur

Name	Signature	Date
------	-----------	------

References

- Bolderston, A., Lloyd, N. S., Wong, R. K. S., Holden, L., Robb-Blanderman, L., et al. (2005). The prevention and management of acute skin reactions related to radiation therapy: A clinical practice guideline. Retrieved from: <http://www.cancercare.on.ca/pdf/pbcl3-7s.pdf>. (AGREE Rigour score 85.4%)
- Cancer Care Ontario. (2004). Telephone nursing practice and symptom management guidelines. Retrieved from: <http://www.onfa.on.ca/library/repository/mon/9000/245778.pdf>. (AGREE Rigour score 11%)
- Bruscia E, Knaehn N, Miller MJ, Selmsar P, Macmillan K. The Edmonton symptom assessment system (ESAS): a simple method for the assessment of palliative care patients. J Palliat Care 1991; 7(2):6-9.
- Feight D, Baney T, Bruce S, McQuestion M. (2011). Putting evidence into practice: Evidence-based interventions for radiation dermatitis. Clinical Journal of Oncology Nursing, 15(5), 481-492.

Appendix B

Usability Evaluation Tool

Participant Code: _____

Date: _____

Information Content

- The amount of information included in the protocol was (check one)
 - ☐ Too much
 - ☐ Too little
 - ☐ Just right
- Is there information missing that you would like to see added or removed? ☐ Yes ☐ No
If so, please describe.

Understandability of Concepts and Terms

- Do the various terms in the protocol make sense? ☐ Yes ☐ No
- Is it self-evident how to complete each section of the protocol? ☐ Yes ☐ No
If no, please indicate which section requires further clarification.
 - ☐ General symptom assessment
 - ☐ Assessment of severity of symptom
 - ☐ Triage patient for symptom management
 - ☐ Review of medications
 - ☐ Review of self-management strategies
 - ☐ Document triage outcomes/ongoing monitoring

Readability and Ease of Use

- Are the font and icons (check boxes etc.) readable (i.e. font type and size)? ☐ Yes ☐ No
- Is there enough space for data entry? ☐ Yes ☐ No
- Please rate each section of the protocol by circling 'poor', 'fair', 'good', or 'excellent' to show what you think about the way the information was presented on:

General symptom assessment	poor	fair	good	excellent
Assessment of severity of symptom	poor	fair	good	excellent
Triage patient for symptom management	poor	fair	good	excellent
Review of medications	poor	fair	good	excellent
Review of self-management strategies	poor	fair	good	excellent
Document triage outcomes/ongoing monitoring	poor	fair	good	excellent

Workflow

- Would the protocol fit with your clinical workflow if it was used in everyday practice?
 - ☐ Yes, as it is
 - ☐ Yes, but with some alterations
 - ☐ No

Please tell us which protocol you chose and if there was a specific reason you chose it.

Comments:

Thank you for taking the time to provide us with your feedback.

Remote Assessment, Triage, and Management of Symptoms in Adults Undergoing Cancer Treatment
COSTaRS Protocol Development V3.0 March 20, 2012



Appendix C

You are being asked to participate in...

A research study about new protocols to guide symptom management for patients receiving cancer treatment

WHO: Registered nurses and registered practical nurses (full-time or part-time) working in the home care setting who support nurses who provide care to patients receiving chemotherapy or radiation therapy (Please note that this study is being conducted in English only)

WHAT: Participate in a 30–45 minute interview where you will be asked to provide feedback on new protocols* for cancer symptom management.

WHERE: Interviews will be held at the [REDACTED] office or via phone

WHEN: At your convenience [REDACTED]

Potential benefits of participating:

- Learn more about new guidelines for symptom management in adults undergoing cancer treatment
- Meet the CNO requirements for continued learning
- Help us understand how to best support home care nurses providing symptom management to individuals undergoing cancer treatment

Potential inconveniences of participating:

- There are no anticipated risks or harms of participating

***More Details:** This research has evolved out of a larger national collaborative called the Pan-Canadian Oncology Symptom Triage and Remote Support (COSTaRS) project. A primary objective of this project is to improve the symptom experience of patients with cancer living in the community. To date, the COSTaRS project has developed 13 evidence-informed protocols for use by nurses remotely. These protocols are based on current clinical practice guidelines and have been created to help guide nurses when assessing, triaging and managing symptoms. Now we want to explore how nurses can best use the protocols in various practice settings.

To find out more about this project, please contact:

Kathryn Nichol at [REDACTED]

This research study was approved by the Ottawa Hospital Research Ethics Board and [REDACTED]



You are being asked to participate in...

A research study about new protocols to guide symptom management for patients receiving cancer treatment

WHO: Registered nurses and registered practical nurses (full-time or part-time) working in the home care setting who provide care to patients receiving chemotherapy or radiation therapy (Please note that this study is being conducted in English only)

WHAT: Participate in a 60 minute focus group where you will be asked to provide feedback on new protocols* for cancer symptom management.

WHERE: Focus groups will be held at the [REDACTED]

WHEN: [REDACTED]

RN focus group – 12:30-1:30

RPN focus group – 2:00-3:00

Potential benefits of participating:

- Learn more about new guidelines for symptom management in adults undergoing cancer treatment
- Meet the CNO requirements for continued learning
- Help us understand how to best support home care nurses providing symptom management to individuals undergoing cancer treatment

Potential inconveniences of participating:

- There are no anticipated risks or harms of participating

***More Details:** This research has evolved out of a larger national collaborative called the Pan-Canadian Oncology Symptom Triage and Remote Support (COSTaRS) project. A primary objective of this project is to improve the symptom experience of patients with cancer living in the community. To date, the COSTaRS project has developed 13 evidence-informed protocols for use by nurses remotely. These protocols are based on current clinical practice guidelines and have been created to help guide nurses when assessing, triaging and managing symptoms. Now we want to explore how nurses can best use the protocols in various practice settings.

To find out more about this project, please contact:

Kathryn Nichol at [REDACTED]

This research study was approved by the Ottawa Hospital Research Ethics Board and [REDACTED]



Appendix D

Interview Guide for Focus Groups/Interviews

Elements of Knowledge-to-Action Framework	Questions	Notes
Current situation	What is currently used to guide assessment, triage, and management of cancer symptoms? (eg. algorithms, tools) How are symptom assessment, triage, and management documented?	
Adapt Knowledge	What do you like about the protocols? What would you change to make the protocols more user-friendly in your practice?	
Barriers/facilitators Nurses— awareness, attitudes, knowledge/skill Environment – organization, economic	Can you identify factors that would help nurses use the protocols in their practice? What factors might interfere with using the protocols in practice? Can you identify some strategies to overcome the barriers that you have identified?	
Adapt Knowledge	Can you see the protocols being useful as a training tool as part of an orientation program or ongoing education to enhance nurses' knowledge of cancer symptom management? Other uses?	
	Additional comments?	

Appendix E

Participant Demographics and Practice Characteristics

Please tell us a little about yourself...

Participant Code: _____

Date: _____

1. What is your position within [REDACTED]?

- ☐ Staff nurse
- ☐ Nurse Manager
- ☐ Nurse Educator
- ☐ Advanced Practice Consultant
- ☐ Other: _____

2. How long have you worked for [REDACTED]?

- ☐ Less than 1 year
- ☐ 1-2 years
- ☐ 3-5 years
- ☐ 6-10 years
- ☐ 10-20 years
- ☐ More than 20 years

3. What are you currently working?

- ☐ Full-time
- ☐ Part-time
- ☐ Casual

If part-time or casual, approximately how many hours per week do you work at [REDACTED]?

- ☐ Less than 5
- ☐ 5-10
- ☐ 10-20
- ☐ 20-30
- ☐ More than 30

Participant Code: _____

Date: _____

4. Your age range:

- ☐ Under 25
- ☐ 25-34
- ☐ 35-44
- ☐ 45-54
- ☐ 55 and older

5. Your gender:

- ☐ Female
- ☐ Male

6. Your highest level of education completed:

- ☐ College diploma in nursing
- ☐ Undergraduate university degree in nursing
- ☐ Undergraduate university degree other than nursing, please specify _____
- ☐ Graduate university degree in nursing
- ☐ Graduate university degree other than nursing, please specify: _____

7. How long have you been working within the field of nursing?

- ☐ Less than 2 years
- ☐ 2-5 years
- ☐ 6-10 years
- ☐ 11-15 years
- ☐ 16-20 years
- ☐ 21-25 years
- ☐ 26-30 years
- ☐ More than 30 years

8. Are you a:

- ☐ Registered Nurse
- ☐ Registered Practical Nurse

9. Do you have a specialty certification (eg. oncology, palliative care)?

- ☐ No
- ☐ Yes, please specify: _____

Appendix F



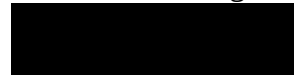
Information Sheet for Interview

Title of the Study: Knowledge tools for cancer symptom management by home care nurses

Researcher:

Kathryn Nichol, RN, BScN, MScN(c), BA, CON(C)

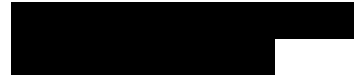
School of Nursing, Faculty of Health Sciences, University of Ottawa



Thesis Supervisor:

Dawn Stacey RN, PhD, CON(C)

Director, Patient Decision Aids Research Group



Thesis Committee Members:

Wendy Gifford RN, PhD



Craig Kuziemsky, PhD

Associate Professor



Introduction: You are being asked to participate in the above mentioned research study conducted by Kathryn Nichol, supervised by Dr. Dawn Stacey. Since the tools being used in this study are only available in English, you must be comfortable reading and speaking in English in order to participate.

Purpose of the Study: The aim of the proposed study is to explore home care nurses' perceptions of usability of a set of evidence-based protocols to guide symptom management in adults undergoing cancer treatment. Researchers will explore how usable the protocols are in face-to-face interactions, how usable the protocols are for training nurses in symptom management, and barriers and facilitators to integrating the protocols into clinical practice. This research is being conducted as a component of a master's thesis.

Participation: Your participation will consist of participating in one interview approximately 30-45 minutes in length during which a discussion guided by an interview guide will aim to explore and answer the research questions. A role play exercise approximately 5 minutes in length will take place during the interview. Demographic data and information regarding the usability of the protocols will be collected through questionnaires. The interview session will be audiotaped. You will be given the opportunity to review and verify the accuracy of the findings from the analysis.

Risks: There are no anticipated risks or harms of participating in this research.

Benefits: Through your participation in this study, you will:

- learn more about current guidelines for symptom management in adults undergoing cancer treatment
- meet the College of Nurses requirements for continued learning
- contribute to the understanding of how to best support home care nurses providing symptom management to individuals undergoing cancer treatment

Confidentiality and anonymity: The information you will share will remain strictly confidential and will be used solely for the purpose of this research. It is also requested that you respect the other participants and maintain confidentiality. Anonymity will be protected by the assignment of a participant code which will be stored separately from collected data. If the results of this study are published, no individual identifying information will be included in the publication. All information you provide will be kept in a secure manner. This includes audio recordings of the interview, transcripts, and questionnaires. The audio recordings will be deleted immediately upon transcription. Electronic data will be stored on a password-protected hard drive, and hard copies will be stored in a locked filing cabinet. Individuals who will have access to the collected data include the researcher, Kathryn Nichol; a research assistant, Shelley Mackenzie; and the thesis committee members, Dr. Dawn Stacey, Dr. Wendy Gifford and Dr. Craig Kuziemy. The Ottawa Hospital Research Ethics Board and The Ottawa Hospital Research Institute may review all study documentation for audit purposes, under the supervision of the researcher, Kathryn Nichol. Once the research findings have been published, the data will be stored in a locked filing cabinet in the Ottawa Hospital Research Institute General Campus for a period of 10 years, at which time it will be destroyed by shredding paper copies and deleting electronic files.

Voluntary Participation: Your participation in this study is voluntary. You are under no obligation to participate and if you choose to participate, you can withdraw at any time and/or choose not to answer any questions, without suffering any negative consequences.

Questions about the Study: If you have any questions about the study, you may contact the researcher or her supervisor at the phone numbers or email addresses provided on the first page of this document.

The Ottawa Hospital Research Ethics Board (OHREB) has reviewed this protocol. The OHREB considers the ethical aspects of all research studies involving human participants at The Ottawa Hospital. If you have any questions about your rights as a research participant, you may contact the Chairperson of the Ottawa Hospital Research Ethics Board at [REDACTED]
[REDACTED]



Consent Form for Interview

Title of the Study: Knowledge tools for cancer symptom management by home care nurses

Consent to Participate in Research

I understand that I am being asked to participate in a research study exploring the use of new protocols to guide symptom management for patients receiving cancer treatment. This study has been explained to me by Kathryn Nichol.

I have read this 3-page Information Sheet and Consent Form. All my questions have been answered to my satisfaction. If I decide at a later stage in the study that I would like to withdraw my consent, I may do so at any time.

I voluntarily agree to participate in this study.

A copy of the signed Information Sheet and Consent Form will be provided to me.

Signatures

Participant's Name (Please Print)

Participant's Signature

Date

Investigator Statement

I have carefully explained to the research participant the nature of the above research study. To the best of my knowledge, the research participant signing this consent form understands the nature, demands, risks and benefits involved in participating in this study. I acknowledge my responsibility for the care and well-being of the above research participant, to respect the rights and wishes of the research participant, and to conduct the study according to applicable Good Clinical Practice guidelines and regulations.

Name of Investigator/Delegate (Please Print)

Signature of Investigator/Delegate

Date

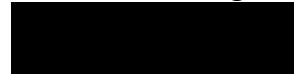


Information Sheet for Focus Group

Title of the Study: Knowledge tools for cancer symptom management by home care nurses

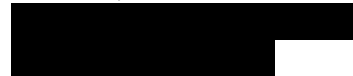
Researcher:

Kathryn Nichol, RN, BScN, MScN(c), BA, CON(C)
School of Nursing, Faculty of Health Sciences, University of Ottawa



Thesis Supervisor:

Dawn Stacey RN, PhD, CON(C)
Director, Patient Decision Aids Research Group



Thesis Committee Members:

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Participation: Your participation will consist of participating in one focus group approximately one hour in length during which a discussion will aim to explore and answer the research questions. A role play exercise approximately 5 minutes in length will take place during the focus group. Demographic data and information regarding the usability of the protocols will be collected through questionnaires. The focus group session will be audio- and videotaped. You will be given the opportunity to review and verify the accuracy of the findings from the analysis.

Risks: There are no anticipated risks or harms of participating in this research.

Benefits: Through your participation in this study, you will:

- learn more about current guidelines for symptom management in adults undergoing cancer treatment
- meet the College of Nurses requirements for continued learning
- contribute to the understanding of how to best support home care nurses providing symptom management to individuals undergoing cancer treatment

Costs: This research will occur during the business hours of [REDACTED] and as such, you will be paid as part of your regular workday.

Confidentiality and anonymity: The information you will share will remain strictly confidential and will be used solely for the purpose of this research. It is also requested that you respect the other participants and maintain confidentiality. Anonymity will be protected by the assignment of a participant code which will be stored separately from collected data. If the results of this study are published, no individual identifying information will be included in the publication. All information you provide will be kept in a secure manner. This includes audio recordings of the focus group, transcripts, and questionnaires. The audio recordings will be deleted immediately upon transcription. Electronic data will be stored on a password-protected hard drive, and hard copies will be stored in a locked filing cabinet. Individuals who will have access to the collected data include the researcher, Kathryn Nichol; a research assistant, Shelley Mackenzie; and the thesis committee members, Dr. Dawn Stacey, Dr. Wendy Gifford and Dr. Craig Kuziemy. The Ottawa Hospital Research Ethics Board and The Ottawa Hospital Research Institute may review all study documentation for audit purposes, under the supervision of the researcher, Kathryn Nichol. Once the research findings have been published, the data will be stored in a locked filing cabinet in the Ottawa Hospital Research Institute General Campus for

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The Ottawa Hospital Research Ethics Board (OHREB) has reviewed this protocol. The OHREB considers the ethical aspects of all research studies involving human participants at The Ottawa Hospital. If you have any questions about your rights as a research participant, you may contact the Chairperson of the Ottawa Hospital Research Ethics Board at [REDACTED]



Consent Form for Focus Group

Title of the Study: Knowledge tools for cancer symptom management by home care nurses

Consent to Participate in Research

I understand that I am being asked to participate in a research study exploring the use of new protocols to guide symptom management for patients receiving cancer treatment. This study has been explained to me by Kathryn Nichol.

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I voluntarily agree to participate in this study.

A copy of the signed Information Sheet and Consent Form will be provided to me.

Signatures

Participant's Name (Please Print)

Participant's Signature

Date

Investigator Statement

I have carefully explained to the research participant the nature of the above research study. To the best of my knowledge, the research participant signing this consent form understands the nature, demands, risks and benefits involved in participating in this study. I acknowledge my responsibility for the care and well-being of the above research participant, to respect the rights and wishes of the research participant, and to conduct the study according to applicable Good Clinical Practice guidelines and regulations.

Name of Investigator/Delegate (Please Print)

Signature of Investigator/Delegate

Date

Appendix G


Ottawa Hospital Research Ethics Boards / Conseils d'éthique en recherches

November 29, 2012

Dr. Kathryn Nichol

Dear Dr. Nichol:

Re: Protocol # [REDACTED] Knowledge tools for cancer symptom management by home care nurses: A mixed methods study proposal

Protocol approval valid until - November 28, 2013

I am pleased to inform you that this protocol underwent delegated review by the Ottawa Hospital Research Ethics Board (OHREB) and is approved for the recruitment of English speaking participants only. No changes, amendments or addenda may be made to the protocol or the consent forms without the OHREB's review and approval.

Approval is for the following:

- Research Proposal, version dated September 2012
- English Focus Group Participation Invitation, version 1, dated November 22, 2012
- English Interview Participation Invitation, version 1, dated November 22, 2012
- English Focus Group Information Sheet and Consent Form, version 1, dated November 22, 2012
- English Interview Information Sheet and Consent Form, version 1, dated November 22, 2012
- English Symptoms Protocol, version 3.1, dated Mar/12 & Feb/12
- English Usability Evaluation Tool, version 3.0, dated March 20, 2012
- English Guide for Focus Group/Interview, version 1.0, dated July 2012
- English Participant Demographics & Practice Characteristics, version 1.0, dated July 2012

The validation date should be indicated on the bottom of all consent forms and information sheets (see copy attached). If the study is to continue beyond the expiry date noted above, a Renewal Form should be submitted to the OHREB approximately six weeks prior to the current expiry date. If the study has been completed by this date, a Termination Report should be submitted.

The Ottawa Hospital Research Ethics Board is constituted in accordance with, and operates in compliance with the requirements of the Tri-Council Policy Statement: Ethical Conduct for Research Involving Humans; Health Canada Good Clinical Practice: Consolidated Guideline; Part C Division 5 of the Food and Drug Regulations of Health Canada; and the provisions of the Ontario Health Information Protection Act 2004 and its applicable Regulations.

Yours sincerely,

[REDACTED]
Francine F-A. Sarazin, Ph.D., C.Psych
Vice Chairman
Ottawa Hospital Research Ethics Board

/hm

encl.

**Université d'Ottawa University of Ottawa**

Bureau d'éthique et d'intégrité de la recherche Office of Research Ethics and Integrity

December 18, 2012

Dawn Stacey
School of Nursing
University of Ottawa

Kathryn Nichol
School of Nursing
University of Ottawa

Re: U of O Ethics file no. A 12-12-02 – “ Knowledge Tools for Cancer
Symptom Management by Home Care Nurses: A Mixed Methods Study
Proposal”

Dear Professor Stacey and Ms. Nichol,

Thank you for the protocol documents and Certificate of Approval from the OHREB (OH
REB # 20120786-01H) for your project named above.

This is to confirm that, in accordance with the agreement between the University of
Ottawa and OHREB, the University of Ottawa has authorized this board to act as Board
of Record for the review and oversight of research involving humans conducted at or
through the hospital.

We remind you of your obligation to:

- Follow all procedures of the OHREB including reporting and renewal procedures;
- Submit to the authority of the OHREB and that you are subject to OHREB
requirements, including, without limitation, the requirement to modify or stop the
research on demand of the OHREB.

If you have any questions, please contact my office at [REDACTED]

Sincerely yours,



Director, Office of Research Ethics and Integrity

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Appendix H

COSTaRS protocols for cancer symptom management by home care nurses

Below is a summary of findings from 4 focus groups and 7 individual interviews with a total of 38 nurses working at [organization]. The findings are reported as barriers or facilitators to using the set of 13 cancer symptom management protocols. Please review the summary to ensure the findings include your comments shared in the focus group or interview.

	Barriers to Protocol Use	Facilitators to Protocol Use
Protocol Level Factors	- Too long – set of 13 protocols is too long, too many of them - Large paper volume for nurses to carry and put in chart, single-use form - Inadequate for multiple concurrent symptoms - do not easily address multiple symptoms client may experience at the same time	- Highly usable <i>Information content</i> - comprehensive, concise, evidence-based, informed with current literature - add context to the symptoms, better describes how the client is feeling <i>Concepts and terms</i> - language is good to use with clients - help normalize the symptoms (especially anxiety and depression), make the client feel like it is okay to say they are feeling this way <i>Readability and ease of use</i> - easy to use, protocols flow well, good format, useful prompts such as green (mild), yellow (moderate) and red (severe) colours <i>Workflow</i> - organization and layout of protocols are consistent with how nurses approach symptom management and nursing process in general (assess, triage, intervene/provide direction, evaluate outcomes, document) - document directly on tool (captures what needs to be documented about a symptom, save time, increase efficiency, eliminate duplication) - support clinical decisions (increase confidence, support appropriate triage/action) - help nurses to be proactive and implement earlier interventions and avoid problems later - Fill a void in current resources for some symptoms - protocols for symptoms that are less common (ie. febrile neutropenia, neuropathy, skin reactions) - no current tool that is part of the chart for managing symptoms, especially in regular [organization] chart - Promote continuity of care over time – help to see trends in client scores/symptoms and facilitate communication between nurses - Using protocols may create opportunities to educate and empower clients about self-managing symptoms by teaching what signs to watch for, reviewing medications and reviewing self-care strategies

	Barriers	Facilitators
Nurse Level Factors	- Reliance on previous experience as a guiding tool to assess and manage symptoms instead of using evidence-based tools to guide care and management - Learning curve -time required to learn and become comfortable with protocols, time required for training, need to become more familiar with protocols to overcome initial discomfort of using the tool and the interference in the interaction with the client	- Symptom management is part of current nursing role - nurses use ESAS for symptom screening which is incorporated into the protocols - aware of algorithms for symptom management - Interested in using evidence-based tools - nurses are keen on evidence-based tools to use in practice
	Barriers	Facilitators
Client Level Factors	- Too unwell, too sick to open up and answer questions about symptoms, just want to be fixed - Annoyed by repetitive questions, tired of describing symptoms at appointments then again at home, not interested in discussions about symptoms	
	Barriers	Facilitators
Organization Level Factors	- Lack of time - not enough time in a visit, visits are too short to do everything, trying to manage competing complex care needs in limited time (physical, psychosocial, financial, practical) - Perceived extra costs – implications of a business model, fee-for-service payment system, using the protocols may increase visit length causing increase costs - Paper-based documentation system, challenge to incorporate into entire organization on a practical level (e.g. printing, keeping protocols current, distributing, carrying) - multiple documentation tools already, various flow sheets	- Current remote symptom support role guides clients and nurses in determining best course of action through telephone or online advice - Audit and feedback process for symptom severity, currently track client outcomes through ESAS scores and provide feedback to nurses about trends of symptom scores - Education and training currently includes pain and symptom management, [organization] values symptom management, provided as part of orientation, ongoing education is an expectation of the organization - Mandate to be evidence-based, [organization] supports the use of evidence-based tools