Nurses Supporting Cancer Survivors with the Self-Management of Symptoms

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Dedicated to my family:

Warren, Colyn, Lisa, Shira, Brian, Sasha and Whiskey

Thesis Abstract

Purpose: To examine evidence-based interventions for nurses to use when supporting cancer survivors self-manage their symptoms.

Part I: A systematic review to determine the effect of shared medical appointments (SMAs) on patients with a physical chronic illness (excluding diabetes mellitus), their healthcare providers and the healthcare system. Nine randomized controlled trials were included; one focused on breast cancer survivors. This trial was feasible and showed no difference in outcomes compared to usual care.

Part II: A descriptive study to adapt and evaluate the acceptability of an evidence-informed symptom practice guide (SPG) for use by nurses for the assessment, triage, and management of patients experiencing dyspnea due to cancer treatment-related cardiotoxicity. Guided by the CAN-IMPLEMENT© methodology, evidence from seven guidelines on heart failure was added to the original SPG. Eleven participants indicated the adapted SPG was comprehensive and easy to follow, and would be helpful for handling symptom calls from patients.

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List of Abbreviations

Abbreviation	
AGREE II Instrument	Appraisal of Guidelines for Research and Evaluation II Instrument
AMSTAR	A Measurement Tool to Assess Systematic Reviews
APN	Advanced practice nurse
CHCC	Cooperative healthcare clinic
COSTaRS	Pan-Canadian Oncology Symptom Triage and Remote Support
HF	Heart failure
OCOP	Ottawa Cardiac Oncology Program
PICO	Population, Intervention, Comparison and Outcomes
PIPOH	Population, Intervention, Professionals/Patients, Outcomes and Health Care Setting
PRISMA	Preferred Reporting Items for Systematic Reviews and Meta-Analyses
RNAO	Registered Nurses' Association of Ontario
SMA	Shared medical appointment
SPG	Symptom practice guide
TOH	The Ottawa Hospital
TOHCC	The Ottawa Hospital Cancer Centre

Chapter One

Introduction

Background

With advances in early detection and treatment, the number of cancer survivors has steadily increased since the 1970s (Hewitt, Greenfield & Stovall, 2005). Cancer represents one of the three most prevalent chronic health illnesses in Canada, alongside cardiovascular disease and diabetes (Registered Nurses' Association of Ontario [RNAO], 2010). As of May 2010, cancer survivors represented approximately three percent of Canada's population (Kazanjian, Doll & Smillie, 2010). Moreover, 63% of Canadians diagnosed with cancer are expected to survive five or more years after a cancer diagnosis (Canadian Cancer Society, 2016). The National Coalition for Cancer Survivorship states "an individual is considered a cancer survivor from the time of diagnosis, through the balance of his or her life" (Hewitt et al., 2005, p. 29). However, in their report, *From Cancer Patient to Cancer Survivor: Lost in Transition*, Hewitt and colleagues define cancer survivorship as "the phase of survivorship that follows primary treatment and lasts until cancer recurrence or end of life" (2005, p. 60). For the purposes of this thesis, it is the latter definition that will be used when referring to cancer survivors. It is this phase of the cancer trajectory that has been relatively neglected in terms of education, clinical practice, and research (Hewitt et al., 2005).

From Cancer Patient to Cancer Survivor: Lost in Transition was written in response to the increase in number of cancer survivors (Hewitt et al., 2005). The paper outlined four essential components of survivorship care: (1) prevention and detection of late and long-term effects, including recurrence; (2) surveillance for recurrence and/or new primary cancers; (3) interventions for outcomes of cancer and its treatment; and (4) coordinated care between the specialist and the primary care provider (Hewitt et al., 2005). Long-term effects may occur as a consequence of the cancer itself and/or its treatment, and can begin during therapy and persist

beyond the end of treatment (Hewitt et al., 2005). It is generally accepted that long-term effects have become more frequent as a result of delivery of more complex cancer interventions including: surgery, chemotherapy, targeted therapies, immunotherapy, endocrine therapy and radiation treatment (Hewitt et al., 2005). Such long-term effects may include cardiotoxicity, psychosocial issues, lymphedema, sterility, acute leukemia, liver failure, immune suppression, and impaired kidney function, among others (Hewitt et al., 2005). Cardiotoxicity, in particular, remains one of the most serious and life-threatening complications of cancer treatment (Hewitt et al., 2005; Yeh et al., 2007).

Following secondary malignancies, cardiotoxicity is the second leading cause of long-term morbidity and mortality among cancer survivors (Daher, Daigle, Bhatia & Durand, 2012). Cardiotoxicity is defined as the direct effects of cancer treatment on heart function and structure (Zamorano et al., 2016). Cardiovascular complications of cancer therapy are generally categorized into one of nine different categories: myocardial dysfunction and heart failure, coronary artery disease, valvular disease, arrhythmias, arterial hypertension, thromboembolic disease, peripheral vascular disease and stroke, pulmonary hypertension and pericardial complications (Zamorano et al., 2016). Although commonly seen as a late-effect of cancer therapy, the time point when cardiotoxicity manifests itself can vary substantially (Zamorano et al., 2016). Moreover, with the advance in molecular targeted cancer therapy, there has been an increase in the prevalence of cardiotoxicity among cancer survivors (Coviello, 2014). Some examples of such targeted cancer therapies include trastuzumab, lapatinib and sunitinib (Coviello, 2014).

To ensure cancer patients are able to complete their cancer therapy, while mitigating any cardiovascular complications that may arise, a clinical discipline termed cardio-oncology has

emerged (Okwuosa & Barac, 2015). Cancer survivors experiencing cardiotoxicity often present with non-specific signs and symptoms, such as dyspnea, fatigue, and tachycardia at rest (Raschi & Ponti, 2012). Cancer survivors experiencing such symptoms require guidance in symptom self-management.

Self-Management

Self-management is defined as a person's ability to manage the symptoms and effects of living with a chronic illness, including its treatment, and physical, social and lifestyle changes (Barlow, Wright, Sheasby, Turner & Hainsworth, 2002). The utilization of symptom self-management is of particular importance within the cancer survivorship trajectory, with particular attention to understanding the signs and symptoms of disease recurrence, and managing the late- and long-term effects of cancer and its treatment (McCorkle et al., 2011). Cancer survivors require support in order to obtain the required knowledge, skill and confidence to appropriately manage their chronic illness (RNAO, 2010). Supporting self-management is "the systematic provision of education and supportive interventions by healthcare staff to increase patients' skills and confidence in managing their health problems, including regular assessment of progress and problems, goal setting, and problem-solving support" (Adams, Greiner & Corrigan, 2004, pg. 57; RNAO, 2010). Nurses are appropriate healthcare professionals to offer their knowledge and skill to inform, motivate and assist cancer survivors in the successful self-management of their chronic illness (RNAO, 2010).

Nurses require tools to assist cancer survivors with the self-management of their chronic illness (RNAO, 2010). Shared medical appointments (SMAs) have been implemented and tested in the primary healthcare setting for approximately 15 years as a tool to improve patient self-management of their chronic illness (Edelman et al., 2012). Another tool to support patient self-

management are symptom practice guides (SPGs) (Stacey et al., 2016). To aid with the implementation of such self-management strategies, it has been recommended that one dedicated person, such as an advanced practice nurse (APN), be involved in the process (RNAO, 2010). The APN can provide support, clinical expertise and leadership (RNAO, 2010). The use of APNs has also been associated with reductions in readmissions, emergency room visits and costs, as well as improvements in staff nurse knowledge, nurse working performance, patient quality of life and patient satisfaction (Fulton & Baldwin, 2004; Newhouse et al., 2011).

Shared medical appointments. SMAs are medical appointments where many patients are seen concurrently by healthcare professional(s) in a supportive group setting, and in which the focus is on the delivery of medical care (Noffsinger, 2009). SMAs first emerged in the 1970s in the pediatric setting (Geller, Kulla & Shoemaker, 2015). SMAs are intended for a homogeneous group of people and are typically offered in sixty to ninety minutes per session, with six to thirteen participants, and with three to five support staff (Northern Health, 2007; Reed, Partridge & Nekhlyudov, 2015). SMAs are commonly used for individuals with a chronic illness, such as diabetes mellitus, hypertension, fibromyalgia, hematological disorders, chronic obstructive pulmonary disease and heart failure (Geller et al., 2015; Lin, Cavendish, Boren, Ofstad & Seidensticker, 2008; Prescott et al., 2016). The use of SMAs in cancer survivorship has previously been supported by the conceptual framework *Patient-Centered Communication in Cancer Care: Promoting Health and Reducing Suffering* as a tool that addresses the six core functions affecting the survivors' health outcomes: responding to emotions; exchanging information; making decisions; fostering healing relationships; enabling patient self-management; and managing uncertainty (Epstein & Street, 2007). Nonetheless, little is known

about the use of SMAs to guide cancer survivors with or without cardiotoxicity in self-managing their cancer treatment-related symptoms.

Symptom practice guides. SPGs are evidence-informed tools; systematically developed resources aimed at supporting healthcare professionals and patients to make appropriate decisions for specific, clinical circumstances within healthcare (Brouwers, Stacey & O'Connor, 2010). Fifteen evidence-based SPGs were previously developed as part of a pan-Canadian initiative to transform evidence from clinical practice guidelines into user-friendly symptom protocols for clinical use by nurses (Stacey, Macartney, Carley, Harrison & Costars, 2013). One of the SPGs produced by the pan-Canadian Oncology Symptom Triage and Remote Support (COSTaRS) team was for dyspnea (see Appendix A) (Stacey et al., 2015). The symptom protocols were developed using a systematic process guided by the CAN-IMPLEMENT© methodology (Stacey et al., 2015). The dyspnea SPG was based on a synthesis of evidence from five oncology specific clinical practice guidelines from: the Oncology Nursing Society (2014), Dy and colleagues (2008), Cancer Care Ontario (2010), Bausewein and colleagues (2008), and Bruera and colleagues (1991). The SPGs were written using simple language and reviewed by oncology nurses to enhance their ability to support cancer patients facing cancer treatment-related symptoms (Stacey et al., 2015).

There were no clinical practice guidelines or systematic reviews included that focused on symptom management for adults experiencing cancer treatment-related cardiotoxicity. Therefore, although there are evidence-based interventions available in the literature, and despite the need to identify and intervene for long-term effects of cancer and its treatment, there are no SPGs available for nurses to provide support to adults with cardiotoxicity to assist them in the self-

management of their dyspnea (Alibhai et al., 2014; Barton et al., 2013; Bower et al., 2014; Qu et al., 2015).

Summary

The number of cancer survivors in Canada is increasing due to advances in cancer treatment (Hewitt et al., 2005). However, these therapies are associated with long-term effects, such as cardiotoxicity (Hewitt et al., 2005; Yeh et al., 2007). Cancer survivors are encouraged to participate in the self-management of their cancer treatment-related symptoms, but little is known about the use of SMAs or the relevance of SPGs for cancer survivors with or without cardiotoxic symptoms.

Theoretical Framework

Chronic Care Model

The Chronic Care Model (CCM) is a conceptual framework guided by the original Model for Effective Chronic Illness Care, which was empirically developed through a process of literature synthesis and expert review (Wagner, Davis, Schaefer, Von Korff & Austin, 1999). The CCM views the healthcare system as part of the larger community (Wagner et al., 1999). For effective chronic illness management, the CCM requires a well-structured healthcare system appropriately linked with necessary resources available in the community. For patients to become both informed and motivated, and for healthcare providers to be prepared and proactive, the healthcare system itself must have the leadership, incentives and resources available to meet the needs of the chronically ill patients. Improved outcomes will be present when there are productive interactions between the informed patient and the prepared practice team. Desired outcomes include measures of clinical care, health status, satisfaction, healthcare use, and cost. A prepared healthcare provider is one who has the expertise, information, time, and appropriate

resources. Patients are informed when they have the information and confidence to be actively involved in their care.

Successful self-management supports patients and their families in coping with the challenges of living with and treating their chronic illness. Effective self-management programs offer a collaborative process between the patients and their healthcare providers to define issues, set priorities, establish goals, create treatment plans and solve problems. Such programs are possible when there are appropriate educational resources, skills training and opportunities for psychosocial support.

Productive interactions are further improved when attention is given to the delivery system design, including having clear and complementary roles for the healthcare providers involved in the healthcare team (Wagner et al., 1999). Delivery system designs function well when there is a focus on support for self-management and behavior change, and close follow-up to assess response to treatment and self-management competence (Wagner, 2001). This may require delegation from the physicians to other healthcare providers, such as nurse case managers. Healthcare providers must have access to the expertise necessary to care for their patients, termed *decision support* in the CCM. Clinical information systems that offer data about individual patients and populations of patients with a similar chronic illness further allows for effective programming.

The model next points to the appropriate resources and policies necessary in the community that allows for improvement of the healthcare system (Wagner et al., 1999). Such characteristics include a consistent approach to system improvement, leadership for improving clinical outcomes, and enticements to healthcare providers and patients to improve care and adhere to guidelines.

The use of SMAs and SPGs as evidence-based interventions for nurses to use when supporting cancer survivors with the self-management of their symptoms fits well within the CCM. The use of SMAs is one delivery system design that has been suggested to offer healthcare providers the time needed to: assess patients; allow for proper patient management; and offer regular and planned follow-ups (Wagner et al., 1999). Through a system redesign within the healthcare organization, SMAs have been suggested to support productive interactions between informed and activated patients, and a prepared and proactive team, as well as assist with the connection between the community and the healthcare system (Kirsh et al., 2007). SMAs developed based on the CCM have also reported improved patient outcomes when run by a nurse case manager (Kirsh et al., 2007).

SPGs are an additional educational resource available for nurses to support patients in the self-management of their care and, therefore, help the patients to become informed and activated (Barr et al., 2003; Wagner et al., 1999). SPGs make use of evidence-based guidelines designed for nurses to use in clinical practice to support their patients with clinical decision-making (Barr et al., 2003).

Research Purpose and Objectives

The overall aim of this thesis was to examine evidence-based interventions for nurses to use when supporting cancer survivors self-manage their symptoms. The objectives of this thesis were: (I) to determine the effect SMAs have on patients with a physical chronic illness (excluding diabetes mellitus), their healthcare providers and the healthcare system; and (II) to adapt and evaluate the acceptability of an evidence-informed SPG for use by nurses over the telephone for the assessment, triage, and management of patients experiencing dyspnea due to cancer treatment-related cardiotoxicity.

Thesis Organization

This thesis encompasses five chapters. The second chapter represents the methodological proposals established a priori for the two studies conducted as part of this thesis. Chapter Three, a systematic review of SMAs, is the first study that was conducted as part of this thesis. Chapter Four, a descriptive study to adapt and evaluate the acceptability of an evidence-informed SPG, is the second study that was conducted as part of this thesis. Chapter Five provides a general discussion of the overarching findings from this thesis, provides implications for nursing practice with a specific focus on the role of the advanced practice nurse, and identifies areas for future research.

References

Adams K., Greiner A. & Corrigan J. (Eds.). (2004). Report of a summit. *The 1st annual crossing the quality chasm summit – A focus on communities.* Washington, CD: National Academic Press.

Alibhai S., O'Neil S., Fisher-Schlombs K., Breunis H., Timilshina N., Brandwein J., Minden M., Tomlinson G. & Culos-Reed S. (2014). A pilot phase II RCT of a home-based exercise intervention for survivors of AML. *Support Care Cancer, 22*(4): 881 – 889. doi: 10.1007/s00520-013-2044-8

American Thoracic Society. (1999). Dyspnea. Mechanisms, assessment, and management: A consensus statement. *American Journal of Respiratory and Critical Care Medicine, 159*(1): 321 – 340. doi: 10.1164/ajrccm.159.1.ats898

Barlow J., Wright C., Sheasby J., Turner A. & Hainsworth, J. (2002). Self-management approaches for people with chronic conditions: A review. *Patient Education and Counseling, 48*(2): 177 – 187.

Barr V., Robinson S., Marin-Link B., Underhill L., Dotts A., Ravensdale D. & Salivaras S. (2003). The expanded chronic care model: An integration of concepts and strategies from population health promotion and the chronic care model. *Healthcare Quarterly, 7*(1): 73 – 82. doi: 10.12927/hcq.2003.16763

Barton D., Liu H., Dakhil S., Linquist B., Sloan J., Nichols C., McGinn T., Stella P., Seeger G., Sood A. & Loprinzi C. (2013). Wisconsin Ginseng (Panax quinquefolius) to improve cancer-related fatigue: A randomized, double-blind trial, N07C2. *Journal of the National Cancer Institute, 105*(16): 1230 – 1238. doi: 10.1093/jnci/djt181

Bausewein C., Booth S., Gysels M. & Higginson I. (2008). Non-pharmacological interventions for breathlessness in advanced stages of malignant and non-malignant diseases. *The Cochrane Database of Systematic Reviews, 2*: CD005623. doi: 10.1002/14651858.CD005623.pub2

Biegel D., Sales E. & Schulz R. (1991). *Family caregiving in chronic illness: Alzheimer's disease, cancer, heart disease, mental illness and stroke.* Family caregiver applications series, Vol. 1. Thousand Oaks, CA, US: Sage Publications.

Bower J., Bak K., Berger A., Breitbart W., Escalante C., Ganz P., Schnipper H., Lacchetti C., Ligibel J., Lyman G., Ogaily M., Pirl W. & Jacobsen, P. (2014). Screening, assessment, and management of fatigue in adult survivors of cancer: An American society of clinical oncology clinical practice guideline adaptation. *Journal of Clinical Oncology, 32*(17): 1840 – 1850. doi: 10.1200/JCO.2013.53.4495

Brouwers M., Stacey D. & O'Connor A. (2010). Knowledge creation: synthesis, tools and products. *Canadian Medical Association Journal, 182*(2): E68 – E72. doi: 10.1503/cmaj.081230

Bruera E., Kuehn N., Miller M., Selmser P. & Macmillan K. (1991). The Edmonton symptom assessment system (ESAS): A simple method for the assessment of palliative care patients. *Journal of Palliative Care, 7*(2): 6 – 9.

Canadian Cancer Society. (2016). *Cancer statistics at a glance.* Retrieved from http://www.cancer.ca/en/cancer-information/cancer-101/cancer-statistics-at-a-glance/?region=on

Cancer Care Ontario. (2010). Symptom management guide-to-practice: Dyspnea. Toronto, Ontario, Canada.

Cancer Care Ontario. (2015). *How to manage your fatigue.* Retrieved from https://www.cancercare.on.ca/common/pages/UserFile.aspx?fileId=348063

Chatterjee K., Zhang J., Honbo N. & Karliner J. (2010). Doxorubicin cardiomyopathy. *Cardiology, 115*(2): 155 – 162. doi: 10.1159/000265166

Coviello J. (2014). Cardiac side effects of targeted therapies. *Seminars in Oncology Nursing, 30*(3): 175 – 182. doi: 10.1016/j.soncn.2014.05.005

Daher I., Daigle T., Bhatia N. & Durand J. (2012). The prevention of cardiovascular disease in cancer survivors. *Texas Heart Institute Journal, 39*(2): 190 – 198.

Donald F., Kilpatrick K., Reid K., Carter N., Martin-Misener R., Bryant-Lukosius D., Harbman P., Kaasalainen S., Marshall D., Charbonneau-Smith R., Donald E., Lloyd M., Wickson-Griffiths A., Yost J., Baxter P., Sangster-Gormley E., Hubley P., Laflamme C., Campbell-Yeo M., Price S., Boyko J. & DiCenso A. (2014). A systematic review of the cost-effectiveness of nurse practitioners and clinical nurse specialists: What is the quality of the evidence? *Nursing Research and Practice, 2014*(Epub 2014): 1 – 28. doi: 10.1155/2014/896587

Dy S., Lorenz K., Naeim A., Sanati H., Walling A. & Asch S. (2008). Evidence-based recommendations for cancer fatigue, anorexia, depression, and dyspnea. *Journal of Clinical Oncology, 26*(23): 3886 – 3895. doi: 10.1200/JCO.2007.15.9525

Edelman D., McDuffie J., Oddone E., Gierisch J., Nagi A. & Williams W. (2012). *Shared medical appointments for chronic medical conditions: A systematic review.* Washington, DC: Department of Veterans Affairs.

Epstein R. & Street R. (2007). Patient-centered communication in cancer care: Promoting health and reducing suffering. National Cancer Institute, NIH Publication No. 07-6225. Retrieved from http://appliedresearch.cancer.gov/areas/pcc/communication/pcc_monograph.pdf

Feinstein M., Krebs P., Coups E., Park B., Steingart R., Burkhalter J., Logue A. & Ostroff J. (2010). Current dyspnea among long-term survivors of early-stage non-small cell lung cancer. *Journal of Thoracic Oncology, 5*(8): 1221 – 1226. doi: 10.1097/JTO.0b013e3181df61c8

Fulton J. & Baldwin K. (2004). An annotated bibliography reflecting CNS practice and outcomes. *Clinical Nurse Specialist, 18*(1): 21 – 39.

Geller J., Kulla J. & Shoemaker A. (2015). Group medical visits using an empowerment-based model as treatment for women with chronic pain in an underserved community. *Global Advances in Health, 4*(6): 27 – 31. doi: 10.7453/gahmj.2015.057

Hammer M., Ercolano E., Wright F., Dickson V., Chyun D. & Melkus G. (2015). Self-management for adult patients with cancer: An integrative review. *Cancer Nursing, 38*(2): E10 – E26. doi: 10.1097/NCC.0000000000000122

Hewitt M., Greenfield S. & Stovall E. (Eds.). (2005). *From cancer patient to cancer survivor: Lost in Transition.* Washington, DC: National Academies Press.

Kazanjian A., Doll R. & Smillie K. (Eds.). (2010). *Fostering cancer survivorship research in Canada: Building capacity through a research consortium.* Retrieved from http://www.bccancer.bc.ca/survivorship-site/Documents/Consortium_Proceedings_FINAL.pdf

Kirsh S., Watts S., Pascuzzi K., O'Day M., Davidson D., Strauss G., Kern E. & Aron D. (2007). Shared medical appointments based on the chronic care model: A quality improvement project to address the challenges of patients with diabetes with high cardiovascular risk. *Quality and Safety in Health Care, 16*(5): 349 – 353.

Lin A., Cavendish J., Boren D., Ofstad T. & Seidensticker D. (2008). A pilot study: Reports of benefits from a 6-month, multidisciplinary, shared medical appointment approach for heart failure patients. *Military Medicine, 173*(12): 1210 – 1213.

Lorig K., Sobel D., Ritter P., Laurent D. & Hobbs M. (2001). Effect of a self-management program on patients with chronic disease. *Effective Clinical Practice, 4*(6): 256 – 262.

McCorkle R., Ercolano E., Lazenby M., Schulman-Green D., Schilling L., Lorig K. & Wagner E. (2011). Self-management: Enabling and empowering patients living with cancer as a chronic illness. *CA Cancer J Clin, 61*(1): 50 – 62. doi: 10.3322/caac.20093

Noffsinger E. *Running group visits in your practice.* New York, NY: Springer, 2009.

Northern Health. (2007). *Group medical appointments – DIGMAs – Physicals SMAs – CHCCs.* Retrieved from http://www.hqontario.ca/Portals/0/documents/qi/learningcommunity/roadmap%20resources/advanced%20access%20and%20efficiency/step%205/pc-nha-group-medical-appointments-manual-en.pdf

Okwuosa T. & Barac A. (2015). Burgeoning cardio-oncology programs. Challenges and opportunities for early career cardiologists/faculty directors. *Journal of the American College of Cardiology, 66*(10): 1193 – 1197. doi: 10.1016/j.jacc.2015.07.033

Oncology Nursing Society. (2014). *Putting evidence into practice: Dyspnea.* Retrieved from : https://www.ons.org/practice-resources/pep/dyspnea

pan-Canadian Oncology Symptom Triage and Remote Support (COSTaRS). (n.d.). *Factors influencing nurses using symptom practice guides for remote support of patients undergoing cancer treatments. Baseline survey.* Retrieved from http://www.ktcanada.ohri.ca/costars/docs/Baseline_Barriers_Survey.pdf

Prescott L., Dickens A., Guerra S., Tanha J., Phillips D., Patel K., Umberson K., Lozano M., Lowe K., Brown A., Taylor J., Soliman P., Garcia E., Levenback C. & Bodurka D. (2016). Fighting cancer together: Development and implementation of shared medical appointments to standardize and improve chemotherapy education. *Gynecologic Oncology, 140*(1): 114 – 119. doi: 10.1016/j.ygyno.2015.11.006

Qu D., Zhang Z., Yu X., Zhao J., Qiu F. & Huang J. (2015). Psychotropic drugs for the management of cancer-related fatigue: A systematic review and meta-analysis. *European Journal of Cancer Care.* doi: 10.1111/ecc.12397

Raschi E. & Ponti F. (2012). Cardiovascular toxicity of anticancer-targeted therapy: Emerging issues in the era of cardio-oncology. *Internal and Emergency Medicine, 7*(2): 113 – 131. doi: 10.1007/s11739-011-0744-y

Reed S., Partridge A. & Nekhlyudov L. (2015). Shared medical appointment in cancer survivorship care: A review of the literature. *Journal of Oncology Practice, 11*(1): 6 – 11. doi: 10.1200/JOP.2014.001411

Registered Nurses' Association of Ontario. (2010). *Strategies to support self-management in chronic conditions: Collaboration with clients.* Retrieved from http://rnao.ca/sites/rnao-ca/files/Strategies_to_Support_Self-Management_in_Chronic_Conditions_-_Collaboration_with_Clients.pdf

Sarna L., Evangelista L., Tashkin D., Padilla G., Holmes C., Brecht M. & Grannis F. (2004). Impact of respiratory symptoms and pulmonary function on quality of life of long-term survivors of non-small cell lung cancer. *Chest, 125*(2): 439 – 445.

Stacey D., Green E., Ballantyne B., Skrutkowski M., Whynot A., Tardif L., Tarasuk J., Carley M. & The Pan-Canadian Oncology Symptom Triage and Remote Support (COSTaRS) Team.

(2016). Patient and family experiences with accessing telephone cancer treatment symptom support: A descriptive study. *Support Cancer Care, 24*(2): 893 – 901. doi: 10.1007/s00520-015-2859-6

Stacey D., Macartney G., Carley M., Harrison M. & The Pan-Canadian Oncology Symptom Triage and Remote Support Group. (2013). Development and evaluation of evidence-informed clinical nursing protocols for remote assessment, triage and support of cancer treatment-induced symptoms. *Nursing Research and Practice, 2013*(171872). doi: 10.1155/2013/171872

Stacey D., Skrutkowski M., Carley M., Kolari E., Shaw T. & Ballantyne B. (2015). Training oncology nurses to use remote symptom support protocols: A retrospective pre-/post study. *Oncology Nursing Forum, 42*(2): 174 – 182. doi: 10.1188/15.ONF.174-182

Swain S., Whaley F. & Ewer M. (2003). Congestive heart failure in patients with doxorubicin. A retrospective analysis of three trials. *Cancer, 97*: 2869 – 2879.

Takemura G. & Fujiwara H. (2007). Doxorubicin-induced cardiomyopathy from the cardiotoxic mechanisms to management. *Prog Cardiovasc Dis, 49:* 339 – 352.

Vandyk A., Harrison M., Macartney G., Ross-White A. & Stacey, D. (2012). Emergency department visits for symptoms experienced by oncology patients: A systematic review. *Supportive Care in Cancer, 20*(8): 1589 – 1599. doi: 10.1007/s00520-012-1459-y

Wagner E., Austin B., Davis C., Hindmarsh M., Schaefer J., Bonomi A. (2001). Improving chronic illness care: Translating evidence into action. *Health Affairs (Millwood), 20*(6): 64 – 78.

Wagner E., Davis C., Schaefer J., Von Korff M. & Austin, B. (1999). A survey of leading chronic disease management programs: Are they consistent with the literature? *Managed Care Quarterly, 7*(3): 56 – 66.

Yeh E., Tong A., Lenihan D., Yusuf W., Swafford J., Champion C., Durand J., Gibbs H., Zafarmand A. & Ewer M. (2007). Cardiovascular complications of cancer therapy: Diagnosis, pathogenesis and management. *Journal of the American College of Cardiology, 53*(24) : 2231 – 2247. doi: 10.1016/j.jacc.2009.02.050

Zamorano J., Lancellotti P., Rodriguez Munõz D., Aboyans V., Asteggiano R., Galderisi M., Habib G., Lenihan D., Lip G., Lyon A., Lopez Fernandez T., Mohty D., Piepoli M., Tamargo J., Torbicki A., Suter T. & Authors/Task Force Members & ESC Committee for Practice Guidelines. (2016). 2016 ESC position paper on cancer treatments and cardiovascular toxicity developed under the auspices of the ESC committee for practice guidelines: The task force for cancer treatments and cardiovascular toxicity of the European society of cardiology (ESC). *European Heart Journal,* pli: ehw211. doi: 10.1093/eurheartj/ehw211

Chapter Two

Methodology

Introduction

In this chapter, I report the methodological approach for this thesis established a priori. The methodology is separated into Part I for the systematic review, and Part II for the descriptive study. Each part outlines the objective, the research questions, the study methods/design, and the strengths and limitations of the study. The overarching timeline that guided this thesis is outlined, as well as the steps taken to ensure the thesis was ethically appropriate.

Methodology – Part I

Objective

To determine the effects shared medical appointments (SMAs) have on patients with a physical chronic illness (excluding diabetes mellitus), their healthcare providers and the healthcare system.

Research Questions.

1. What effect do SMAs have on patients, their healthcare providers and the healthcare system?
2. What are the characteristics of SMAs?

Method/Design. A systematic review designed to meet the Preferred Reporting Items for Systematic Reviews and Meta-Analyses (PRISMA) criteria, the A Measurement Tool to Assess Systematic Reviews (AMSTAR) checklist, and guided by the Cochrane Handbook for Systematic Reviews of Interventions was conducted (Higgins & Green, 2011; Moher, Liberati, Tetzlaff, Altman & The Prisma Group, 2009). Systematic reviews are valuable for thorough identification, appraisal, and synthesis of the available research-based evidence (Mulrow, 1994).

The PRISMA statement is a useful, evidence-informed tool designed to assist authors with improving the reporting of their systematic reviews and meta-analyses (Moher et al., 2009).

The AMSTAR checklist is a reliable instrument, intended to assess the methodological quality of systematic reviews, focusing on the quality of reporting and conducting (Shea et al., 2009). The psychometric properties of AMSTAR show good agreement, reliability, construct validity and feasibility (Shea et al., 2009).

Search Strategy. The search strategy was developed in collaboration with an academic librarian (RS) and an expert in systematic review methodology (DS). Inclusion/exclusion criteria were established using the elements of a research question, and included population, intervention, comparator, and outcome (PICO) (see Table 3.1) (Higgins & Green, 2011). Eligible studies were randomized controlled trials evaluating SMAs used for adults with a homogenous physical chronic illness versus any other comparator. Outcomes involved measures of patients (e.g. quality of life, knowledge, self-management, satisfaction, symptom outcomes), healthcare providers (e.g. satisfaction) and the healthcare system (e.g. hospital admissions, emergency department visits, costs). Excluded were trials evaluating SMAs for patients diagnosed with diabetes mellitus and a mental illness. In keeping with the Specialty cooperative healthcare clinic model definition of SMAs, included were trials in which: healthcare provider(s) saw the same group of patients; had homogeneous patient groupings by disease; and included both a mandatory group segment and an as-needed individual consultation (Noffsinger, 2009).

The search was conducted in five databases: Medline, CINAHL, PsychINFO, CENTRAL and EMBASE. To supplement the database search, bibliography searches of the reference lists of included articles were also assessed (Higgins & Green, 2011).

To identify all studies related to SMAs published between January 1970 and September 2016, a combination of the following search terms was used: group, shared, processes, appointment, schedule and visit (see Table 3.2). Searches did not have any filters or limitations

other than year due to the perceived restricted number of studies on SMAs. The year 1970 was selected given SMAs were first introduced in the 1970s (Geller, Kulla & Shoemaker, 2015).

Screening of Studies. Following the identification of citations, duplicates were removed. Two reviewers conducted three levels of screening (FC, CL, RM, DS). Level one screening included a title screen to determine study relevance to the focus of the systematic review. Level two screening used the PICO criteria to review abstracts. For both level one and level two screening, citations indicated as *excluded* by both reviewers were removed, and citations rated as *included*, *unsure* or *excluded* by one reviewer were included for the next level of screening. Level three screening used full text of citations. For discrepancies at full-text screening, the reviewers met to discuss and reach consensus. If necessary, a third member was consulted for unresolved discrepancies (DS) (Furlan, Singh, Hsieh & Fehlings, 2011).

Data Collection. For included citations, data was extracted using a standardized format. Data included authors, publication year, country, study design, setting (e.g. disease focus), SMA characteristics (e.g. number of SMA visits, attendance rates, length of the group session, number of attendees, invitation for family members to attend, lead healthcare providers, other healthcare providers involved), and outcomes on the patients, the healthcare providers, and the healthcare system.

Study Quality. Two reviewers (FK, JH) appraised the methodological quality of the included randomized controlled trials using the Cochrane Collaboration Risk of Bias Tool (Higgins & Green, 2011). The Cochrane Collaboration Risk of Bias Tool has been previously tested and results show slight inter-rater agreement for individual domains, and fair to moderate inter-rater agreement in the final grade assigned to the same studies (Armijo-Olivo, Stiles, Hagen, Biondo & Cummings, 2012). Any discrepancies were resolved through consensus and a third

reviewer (DS) was consulted as necessary. Studies were not excluded based on their methodological quality.

Analysis. Studies were synthesized descriptively by comparing and contrasting study findings relevant to the research questions (FK, JH). Two or fewer of the included studies had comparable biophysical outcomes; therefore, although a meta-analysis was planned a priori, it was not conducted. Elements of the included articles were analyzed via descriptive analysis and were presented in a narrative format, as recommended by the PRISMA statement (Liberati et al., 2009).

Strengths and Limitations. The use of a systematic review allowed the researcher to determine if there were any inconsistencies in the literature regarding SMAs, and further reflected the reality of their use (Mulrow, 1994). To reduce the risk of bias, the protocol for the systematic review was developed a priori (Mulrow & Cook, 1998). A comprehensive literature search was performed in five electronic databases, as well as in the grey literature (Shea et al., 2007). Two reviewers screened the identified literature, removed duplicate articles, participated in data extraction, and appraised the quality of the included studies (Higgins & Green, 2011). A list of included and excluded studies was provided, and the data extracted was reported in a table format (Shea et al., 2007). The systematic review was also registered in PROSPERO, an international database of systematic reviews with health-related outcomes (Moher et al., 2015). Registration took place prior to initiation to avoid any unplanned duplication of systematic reviews (Moher et al., 2015).

Methodology – Part II

Objective

The objective was to adapt and evaluate the acceptability of an evidence-informed SPG for use by nurses over the telephone for the assessment, triage, and management of patients experiencing dyspnea due to cancer treatment-related cardiotoxicity.

Research Questions.

1. What adaptations are required when cardiology clinical practice guidelines are added to the original COSTaRS Breathlessness/Dyspnea Practice Guide?

2. Is the adapted Breathlessness/Dyspnea Practice Guide acceptable for oncology nurses to use when providing symptom support?

Method/Design. The CAN-IMPLEMENT© methodology guided the study. It was developed to support Canadian practitioners in adapting guidelines for local use (Harrison & van den Hoek J, 2012). CAN-IMPLEMENT© recommends six steps for guideline adaptation: (1) a call to action; (2) plan; (3) search and screen; (4) assess and select; (5) draft, revise and endorse recommendations; and (6) obtain user-centered feedback to plan implementation (Harrison, van den Hoek & Graham, 2014). It has previously been reported that iteratively incorporating feedback from potential users (healthcare professionals with an expertise in either oncology and/or cardiology) is more likely to result in a knowledge translation tool relevant to their needs (Abras, Maloney-Krichmar & Preece, 2004).

A Call to Action. Step one involves clarifying the incentive for developing a SPG (Harrison et al., 2014). The incentive for this study was the increasing prevalence of patients with cancer treatment-related cardiotoxicity and the lack of tools available for nurses to use to assist this patient population with symptom self-management.

Plan. Step two includes: establishing the scope of the guideline; articulating the clinical question; determining the feasibility of the adaptation; forming an organizing committee; and

writing the work plan (Harrison et al., 2014). The problem was identified and the research question was stated as follows: What adaptations are required when cardiology clinical practice guidelines are added to the original COSTaRS Breathlessness/Dyspnea Practice Guide? A research team was formed and made up of experts in cardio-oncology, cancer survivorship and SPG development. Key stakeholders further included healthcare professionals with an expertise in oncology and/or cardiology.

Systematic Search and Screen. Step three involves identifying and searching for guidelines related to the specified topic (Harrison et al., 2014). A systematic search of the available literature to identify clinical practice guidelines and systematic reviews for assessing, triaging and offering self-management strategies for adults experiencing cardiotoxic- and/or heart failure (HF)-related dyspnea was conducted. The literature search was reported to meet the PRISMA criteria (Moher et al., 2009). The search strategy was designed in collaboration with a health science librarian (RS) and based on the strategy used for COSTaRS (Stacey et al., 2013). Inclusion/exclusion criteria were established using the PIPOH framework (Population, Intervention, Professionals/Patients, Outcomes and Health Care Setting) (see Table 4.1) (Stacey et al., 2013; The ADAPTE Collaboration, 2009). Eligible citations were systematic reviews and clinical practice guidelines evaluating cardiac-related symptom interventions to assess, rate severity or manage dyspnea in adults.

The search focused on all key databases relevant to the subject matter: Medline, Cochrane Database of Systematic Reviews, CINAHL and Web of Science. Articles were searched from January 2010 until December 2016 to identify current evidence. To supplement the database search, grey literature searches were also conducted on websites known or

suspected to have cardiology practice guidelines related to symptom self-care and known guideline clearinghouse websites (Peters et al., 2015; Stacey et al., 2013).

Assess and Select. Step four includes assessing the quality, content, consistency, acceptability and applicability of the guideline recommendations, and subsequently making an informed and transparent decision about which recommendations can be effectively adapted (Harrison et al., 2014). Following the identification of citations, duplicates were removed. Two reviewers independently conducted three levels of screening (FK, DS). Level one screening included a title screen to determine citation relevance to the focus of the SPG. Level two screening used the PIPOH criteria to review abstracts. For both level one and level two screening, citations indicated as *excluded* by both reviewers were removed and citations rated as *included, unsure* or *excluded* by one reviewer were included for the next level of screening. Level three used full text screening. For discrepancies at full-text screening, the reviewers met to discuss and reach consensus (Furlan et al., 2011).

Two reviewers (FK, JH) independently used the Appraisal of Guidelines for Research and Evaluation (AGREE) II Instrument to appraise the guidelines (Brouwers et al., 2010a). The AGREE II Instrument has been proven reliable and valid for assessing the quality of clinical practice guidelines by evaluating the methodological rigor and transparency in which the original guideline was generated and used (Brouwers et al., 2010a; Brouwers et al., 2010b). The AGREE II Instrument has six quality domains: (1) scope and purpose; (2) stakeholder involvement; (3) rigor of development; (4) clarity of presentation; (5) applicability; and (6) editorial independence (Brouwers et al., 2010a). It is recommended that each guideline be evaluated by a minimum of two appraisers to increase the reliability of the assessment (Brouwers et al., 2010c). For this study, only the quality domain of rigour of development was used. Although the methodological

quality of systematic reviews was planned a priori to be assessed using AMSTAR, no systematic reviews were eligible (Shea et al., 2007).

After selection and appraisal of the identified guidelines and systematic reviews, one author independently extracted data (FK), which was then audited independently by a second reviewer (MC). Characteristics that were extracted included the author and the publication year, symptom definition, criteria to assess and triage dyspnea, medications, and self-care items for symptom management. A recommendation matrix was populated with the extracted characteristics to allow for comparison.

Draft, Revise and Endorse Recommendations. Step five of the CAN-IMPLEMENT© methodology involves preparing an SPG for external review (Harrison et al., 2014). The original COSTaRS Breathlessness/Dyspnea Practice Guide was adapted to incorporate the eligible cardiology guidelines based on the ADAPTE methodology. ADAPTE, a guideline adaptation methodology, is founded on the basis that using best evidence is necessary for delivering high quality care, and that available guidelines are a crucial tool to inform evidence-based practice (Harrison et al., 2010).

The ADAPTE methodology has the goal of establishing a standard of transparency, rigor and replicability through the following core principles: (1) respect of evidence-based principles in guideline development; (2) use of reliable and consistent methods to ensure the quality of the adapted guideline; (3) participation of key stakeholders to foster acceptance and ownership of the adapted guideline and promotion of its use; (4) consideration of context during adaption to ensure relevance for local practice and policy; (5) transparent reporting to promote confidence in the recommendations of the adapted guideline; (6) use of a flexible format to accommodate

specific needs and circumstances; and (7) respect for, and acknowledgement of guideline materials used as sources (Harrison et al., 2010).

The recommendations from the HF guidelines were added to the original COSTaRS Dyspnea SPG. Two reviewers (DS, SC) then further reviewed the adapted SPG.

Obtain User-Centered Feedback to Plan Implementation. For step six, feedback on the adapted SPG was gathered during interviews with eligible healthcare professionals, including nurses/advanced practice nurses (APNs) with an expertise in oncology and/or cardiology, and other healthcare professionals with an expertise in cardio-oncology at a large academic teaching hospital in Canada.

Setting and Participants. The adapted SPG was validated with oncology nurses, who provide remote symptom support at The Ottawa Hospital Cancer Centre (TOHCC), healthcare experts in cardio-oncology at The Ottawa Hospital Ottawa Cardiac Oncology Program (OCOP), and members of the original COSTaRS team, including APNs.

The OCOP, which opened in 2008, gives referred patients' access to well-timed cardiac assessment and treatment, thereby resulting in better quality of patient care (Sulpher et al., 2015). Using a multidisciplinary team, consisting of an oncologist, cardiologists and a pharmacist, the program incorporates three mandates, including clinical service, research and education (Sulpher et al., 2015) The OCOP offers a prompt assessment of cancer patients who are at risk of, or who have experienced, cardiotoxicity as a result of their cancer treatment (Sulpher et al., 2015). Once stable from a cardiology perspective, the patient is discharged from the clinic back to their oncologist, primary care provider, or a cardio-oncology survivorship clinic.

A minimum of ten participants were included, and sampling continued until data saturation was reached (Polit & Beck, 2008). Initial sampling involved purposeful sampling of

oncology and/or cardiology nurses/APNs and healthcare experts in cardio-oncology, and snowball sampling was also used (Polit & Beck, 2008). Maximum variation sampling was used to ensure those with differing backgrounds were represented (Polit & Beck, 2008). Those who were purposively sampled included: physicians with an expertise in cardio-oncology; nurse practitioners with a focus on cardio-oncology; oncology nurses/APNs who were familiar with COSTaRS; and cardiology nurses/APNs.

Data Collection. The researcher conducted interviews with healthcare professionals, as well as distributed an acceptability survey (see Appendices B and C). The nurse manager at TOHCC and the OCOP receptionist asked the potential participants via a formal invitation (see Appendix D). Members of the original COSTaRS team received a formal invitation from the COSTaRS research team coordinator. Eligibility criteria included English speaking, as the SPG was initially only developed in English. After agreeing to participate in the study, the participant was asked to sign the consent form (see Appendix E). To ensure involvement in the proposed research project was not considered an added burden to the healthcare professionals, the acceptability survey and the interviews were conducted at a convenient time and place. The interviews and the acceptability survey were conducted to collect feedback from these key stakeholders to evaluate the SPGs' acceptability for providing symptom support (Stacey et al., 2015). There was no anticipated benefit to the study population, but rather a potential future benefit for nurses providing remote symptom support for adults experiencing dyspnea due to cancer treatment-related cardiotoxicity.

After reviewing and signing the consent form with the researcher, the participant completed an interview lasting 30 to 45 minutes using a semi-structured interview format. The researcher guided the healthcare professional through the SPG and asked him/her to provide

feedback throughout. During the interview, healthcare professionals were asked for their first impressions of the revised SPG, their thoughts regarding its helpfulness for handling symptom calls from patients on cancer treatments, any other changes that should be made to ensure the SPG was more useful, and whether any cardiology guidelines were missed.

The acceptability survey consisted of fifteen questions, including nine general participant information, three likert scale questions, and three open ended questions (Stacey et al., 2013). The acceptability survey was completed during the interview. The survey items, taken from previous surveys, were used for implementing COSTaRS in clinical practice and have demonstrated face validity (COStaRS, n.d.; Stacey et al., 2015). The survey asked the healthcare professional to rate the amount of information on the revised SPG, their comfort using the SPG and referring the SPG to others, and the comprehensiveness of the SPG. Non-identifying demographic information was also collected, including: the participant's current position, their length of time working within that position, their hours worked per week, their birth year, their sex, their highest level of education, and the length of time working in their professional position.

The researcher digitally recorded the interviews and took verbatim transcription of the recordings, thereby leaving her with a transcript-based analysis, a highly rigorous analysis type with a low risk of error (Onwuegbuzie, Dickinson, Leech & Zoran, 2009). Field notes from the researcher were also included as part of the collected data. Iterative changes to the SPGs were made based on the feedback received from the interviews and the acceptability survey.

Data Analysis Plan. Quantitative findings from the acceptability survey were entered into a Microsoft Excel© spreadsheet and analyzed descriptively. The acceptability survey had been previously tested for face validity (Stacey et al., 2015). Participant qualitative feedback from the interviews and the open-ended survey questions were also analyzed descriptively, using

data-driven codes rather than a pre-existing set of rules (Lambert & Lambert, 2012). One author (FK) independently performed the data analysis (Lambert & Lambert, 2012). The qualitative analysis findings were entered into a table to compare the similarities and differences across the interviews (Colorafi & Evans, 2016). To improve the rigor of the qualitative analysis findings, a second author (DS) audited the table (Cohen & Crabtree, 2008).

Strengths and Limitations. To improve quality and reduce the risk of bias: (a) the protocol for the systematic search was developed a priori; (b) a comprehensive search of four electronic databases and grey literature was conducted; and (c) two reviewers screened the identified literature and appraised the quality of the included studies (Higgins, 2011; Moher, 2015; Shea, 2007). Semi-structured interviews were used to introduce participants to the adapted SPG and offered participants the freedom to respond to questions in their own words with as much detail as they desired (Onwuegbuzie et al., 2009; Polit & Beck, 2008).

Timeline

The proposed research project was designed to take 13 months (see Appendix F). Prior to starting objective II of the research project, ethics approval was sought.

Ethics

Ethics approval was sought from the Ottawa Health Science Network Research Ethics Board (20160752-01H), with an application for reciprocal approval by the University of Ottawa (A12-16-02). The Tri-Council Policy Statement is based on three core principles: respect for persons, concern for welfare, and justice (Government of Canada, 2015). The core principles were acknowledged by the researcher and guided each stage of the research project.

The researcher reached out and gained the interest of the OCOP and TOHCC. The researcher provided the participants with an information sheet, and a verbal explanation of the

study prior to the interview. The discussion with healthcare professionals included sufficient provision of information concerning the study, alongside any potential risks and benefits. Appropriate response to the key stakeholders' questions ensured that they understood the information provided. Collection of voluntary agreement to participate in the research project was obtained using the consent form, and ongoing provision of sufficient information as the participant or the situation required was offered (Canadian Institutes of Health Research, Natural Sciences and Engineering Research Council of Canada, and Social Sciences and Humanities Research Council of Canada, 2014). It was further conveyed to the healthcare professional that he/she had the right to not answer any single question, as well as to withdraw completely from the interview at any time throughout the process. Moreover, the researcher made clear that any of the interview and/or acceptability survey material not be used at the participants' request. As per the consent form, the contents from the interviews and acceptability survey were only used for the adaptation and evaluation of acceptability of the SPG.

Any information kept on the computer was password protected and client identifications were anonymous. Information was only kept on a workplace computer.

References

Abras C., Maloney-Krichmar D. & Preece J. (2004). User-centered design. In W. Bainbridge (Eds.), *Encyclopedia of human-computer interaction* (p. 1 – 14). Thousand Oaks, California: Sage Publications.

The ADAPTE Collaboration. (2009). *The ADAPTE process: Resource toolkit for guideline adaptation. Version 2.0.* Retrieved from http://www.g-i-n.net.

Armijo-Olivo S., Stiles C., Hagen N., Biondo P. & Cummings G. (2012). Assessment of study quality for systematic reviews: A comparison of the Cochrane collaboration risk of bias tool and the effective public health practice project quality assessment tool: Methodological research. *Journal of Evaluation in Clinical Practice, 18*(1): 12 – 18. doi: 10.1111/j.1365-2753.2010.01516.x

Brouwers M., Kho M., Browman G., Burgers J., Cluzeau F., Feder G., Fevers B., Graham I., Grimshaw J., Hanna S., Littlejohns P., Makarski J., Zitzelsberger L. & AGREE Next Steps Consortium. (2010a). *Canadian Medical Association Journal, 182*(18): E839 – E42. doi: 10.1503/cmaj.090449

Brouwers M., Kho M., Browman G., Burgers J., Cluzeau F., Feder G., Fervers B., Graham I., Hanna S., Makarski J. & AGREE Next Steps Consortium. (2010b). Development of the AGREE II, part 2: Assessment of validity of items and tools to support application. *Canadian Medical Association Journal, 182*(10): E472 – E478. doi: 10.1503/cmaj.091716

Brouwers M., Kho M., Browman G., Cluzeau F., Feder G., Fervers B., Hanna S. & Makarski J. on behalf of the AGREE Next Steps Consortium. (2010c). AGREE II: Advancing guideline development, reporting and evaluation in healthcare. *Canadian Medical Association Journal, 182*: E839 – E842. doi: 10.1503/cmaj.090449

Canadian Institutes of Health Research. (2015). *CBPHC objectives and priority areas.* Retrieved from http://www.cihr-irsc.gc.ca/e/44765.html

Canadian Institutes of Health Research, Natural Sciences and Engineering Research Council of Canada, and Social Sciences and Humanities Research Council of Canada. (2014). *Tri-council policy statement: Ethical conduct for research involving humans.* Retrieved from http://www.pre.ethics.gc.ca/pdf/eng/tcps2-2014/TCPS_2_FINAL_Web.pdf

Cohen D. & Crabtree B. (2008). Evaluative criteria for qualitative research in health care: Controversies and recommendations. *Annals of Family Medicine, 6*(4): 331 – 339. doi: 10.1370/afm.818

Colorafi K. & Evans B. (2016). Qualitative descriptive methods in health science research. *Health Environments Research & Design Journal, 9*(4): 16 – 25. doi: 10.1177/1937586715614171.

Furlan J., Singh J., Hsieh J. & Fehlings M. (2011). Methodology of systematic reviews and recommendations. *Journal of Neurotrauma, 28*(8): 1335 – 1339. doi: 10.1089/neu.2009.1146

Geller J., Kulla J. & Shoemaker A. (2015). Group medical visits using an empowerment-based model as treatment for women with chronic pain in an underserved community. *Global Advances in Health and Medicine, 4*(6): 27 – 31. doi: 10.7453/gahmj.2015.057

Government of Canada. (2015). *TCPS 2 – Chapter 1. Ethics framework.* Retrieved from http://www.pre.ethics.gc.ca/eng/policy-politique/initiatives/tcps2-eptc2/chapter1-chapitre1/#toc01-1b

Harrison M., van den Hoek J. & Graham I. (2014). *Can-Implement©: Planning for best-practice implementation.* Philadelphia, PA: Lippincott Williams & Wilkins.

Harrison M., Légaré F., Graham I. & Fervers B. (2010). Adapting clinical practice guidelines to local context and assessing barriers to their use. *Canadian Medical Association Journal, 182*(2): E78 – E84. doi: 10.1503/cmaj.081232

Harrison M.B. & van den Hoek J., for the Canadian Guideline Adaptation Study Group. (2012). *CANIMPLEMENT©: A Guideline Adaptation and Implementation Planning Resource.* Kingston, Ontario: Queen's University School of Nursing and Canadian Partnership Against Cancer.

Higgins J. & Green S. (Eds). (2011). *Cochrane handbook for systematic reviews of interventions, version 5.1.0.* The Cochrane Collaboration. Retrieved from www.handbook.cochrane.org

Lambert V. & Lambert C. (2012). Editorial: Qualitative descriptive research: An acceptable design. *Pacific Rim International Journal of Nursing Research, 16*(4): 255 – 256.

Liberati A., Altman D., Tetzlaff J., Mulrow C., Gøtzsche P., Ioannidis J., Clarke M., Devereaux P., Kleijnen J. & Moher D. (2009). The PRISMA statement for reporting systematic reviews and meta-analyses of studies that evaluate health care interventions: Explanation and elaboration. *Journal of Clinical Epidemiology, 62*(10): e1 – e34. doi: 10.1016/j.jclinepi.2009.06.006

Moher D., Liberati A., Tetzlaff J., Altman D. & The Prisma Group. (2009). Preferred reporting items for systematic reviews and meta-analysis: The PRISMA statement. *Public Library of Science Medicine, 3*(2): 123 – 130. doi: 10.1371/journal.pmed.1000097

Moher D., Shamseer L., Clarke M., Ghersi D., Liberati A., Petticrew M., Shekelle P., Stewart L. & PRISMA-P Group. (2015). Preferred reporting items for systematic review and meta-analysis protocols (PRISMA-P) 2015 statement. *Systematic Reviews, 4*(1). doi: 10.1186/2046-4053-4-1

Mulrow C. (1994). Rationale for systematic reviews. *British Medical Journal, 309*(6954): 597 – 599.

Mulrow C. & Cook D. (1998). *Systematic reviews: Synthesis of best evidence for health care decisions.* Philadelphia, Pennsylvania: American College of Physicians.

Noffsinger E. *Running group visits in your practice.* New York, NY: Springer, 2009.

Onwuegbuzie A., Dickinson W., Leech N. & Zoran A. (2009). A qualitative framework for collecting and analyzing data in focus group research. *International Journal of Qualitative Methods, 8*(3): 1 – 21. doi: 10.1177/160940690900800301

Peters M., Godfrey C., Khalil H., McInerney P., Parker D. & Soares C. (2015). Guidance for conducting systematic scoping reviews. *International Journal of Evidence-Based Healthcare, 13*(3): 141 – 146. doi: 10.1097/XEB.0000000000000050

Polit D. & Beck C. (2008). *Nursing research: Generating and assessing evidence for nursing practice.* (8th ed.). Philadelphia: Lippincott Williams & Wilkins.

Shea B., Grimshaw J., Wells G., Boers M., Andersson N., Hamel C., Porter A., Tugwell P., Moher D. & Bouter L. (2007). Development of AMSTAR: A measurement tool to assess the methodological quality of systematic reviews. *BMC Medical Research Methodology, 15*(7): 10. doi: 10.1186/1471-2288-7-10

Shea B., Hamel C., Wells G., Bouter L., Kristjansson E., Grimshaw J., Henry D. & Boers M. (2009). AMSTAR is a reliable and valid measurement tool to assess the methodological quality of systematic reviews. *Journal of Clinical Epidemiology, 62*(10): 1013 – 1020. doi: 10.1016/j.jclinepi.2008.10.009

Stacey D., Macartney G., Carley M., Harrison M. & The Pan-Canadian Oncology Symptom Triage and Remote Support Group. (2013). Development and evaluation of evidence-

informed clinical nursing protocols for remote assessment, triage and support of cancer treatment-induced symptoms. *Nursing Research and Practice, 2013*(171872). doi: 10.1155/2013/171872

Stacey D., Skrutkowski M., Carley M., Kolari E., Shaw T. & Ballantyne B. (2015). Training oncology nurses to use remote symptom support protocols: A retrospective pre-/post study. *Oncology Nursing Forum, 42*(2): 174 – 182. doi: 10.1188/15.ONF.174-182

Sulpher J., Graham N., Johnson C., Turek M., Mathur S., Law A., Stadnick E., Wentzell J. & Dent S. (2015). Cardiac oncology: Improving cardiac safety, advancing cancer care.

Chapter Three

Shared medical appointments for patients with a non-diabetic physical chronic illness: A systematic review

Accepted By: Chronic Illness

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Abstract

Objectives: Shared medical appointments (SMAs) are group appointments, with an optional individual consultation, for patients diagnosed with chronic illnesses. SMAs improve diabetes management but little is known about their use for other illnesses. The objective was to determine the effect SMAs have on patients with a physical chronic illness, healthcare providers, and the healthcare system.

Methods: A systematic review was conducted searching databases from January 1970 to September 2016. Eligible trials evaluated SMAs for patients with a homogeneous chronic illness, excluding diabetes and mental illness. Screening, data extraction and risk of bias were conducted independently by two authors. Analysis was descriptive.

Results: Of 2364 citations, nine randomized trials were included. SMAs were evaluated for cardiovascular illnesses (four studies), breast cancer, chronic kidney disease, Parkinson disease, stress urinary incontinence and carpal tunnel syndrome. Compared to usual care, no negative effects on patient quality of life, knowledge and satisfaction were reported. One study reported no difference in healthcare provider satisfaction. Another study showed fewer hospital admissions for patients who attended SMAs.

Discussion: Few rigorous studies evaluated the use of SMAs for chronic illnesses. Overall there appears to be no patient harms. Further studies should include more objective outcomes and larger sample sizes.

Key Words (5): Shared medical appointment, physical chronic illness, self-management, systematic review

Introduction

Since the 1970s, shared medical appointments (SMAs) have been used to improve patient self-management of their chronic illness (Edelman et al., 2012; Geller, Kulla & Shoemaker, 2015). The SMA is comprised of three major models: (1) the cooperative healthcare clinic (CHCC); (2) the drop-in group medical appointment; and (3) the physicals shared medical appointment (Noffsinger, 2009). Each model consists of unique features that differentiate it from the others. The CHCC consists of follow-up visits and targets the same 15 – 20 high-utilizing, multi-morbid geriatric patients for monthly follow-ups (Noffsinger, 2009). Unique benefits of the CHCC include reduced nursing home, emergency room and hospitalization costs, and offers opportunities for patient bonding (Noffsinger, 2009). Weaknesses of the CHCC include ensuring the session does not become a lecture, and that patients are dedicated to regular attendance (Noffsinger, 2009). The drop-in group medical appointment focuses on follow-up visits, targets most patients in a provider's practice and consists of different patients at each visit (Noffsinger, 2009). Benefits of the drop-in group medical appointment include increased productivity, increased access, and increased disease management (Noffsinger, 2009). Weaknesses of the drop-in group medical appointment include ensuring the sessions maintain an ideal group size, and overcoming multiple operational challenges (Noffsinger, 2009). The physicals shared medical appointment focuses on physical examinations, targets most patients in a healthcare provider's practice or chronic illness program who require a private, physical examination, and consists of different patients at each visit (Noffsinger, 2009). Unique benefits of this model include increased productivity and increased access. Weaknesses of the physicals shared medical appointment are the same as the drop-in group medical appointment (see Appendix G) (Noffsinger, 2009).

The CHCC model, initially developed as a way to meet the complex and time-consuming needs of geriatric patients with multi-morbid illnesses, has since evolved into the Specialty CHCC (Noffsinger, 2009). The Specialty CHCC consists of a homogeneous group of people experiencing the same diagnosis or health illness, such as diabetes mellitus, hypertension, chronic obstructive pulmonary disease and heart failure (Geller et al., 2015; Lin et al., 2008; Noffsinger, 2009; Prescott et al., 2016). Although participants of the Specialty CHCC may have multiple other medical illnesses, the primary objective of the Specialty CHCC is to provide disease-specific care and information to its participants as effectively as possible (Noffsinger, 2009).

It should further be noted that patients with a physical chronic illness may have mental health issues as well (Seesing et al., 2013). Such mental health issues, such as depression, may be part of the SMA programming, notably when it affects the course or management of the physical chronic illness (Seesing et al., 2013). Nonetheless, SMAs with a focus on treating patients for a mental illness were excluded in this systematic review given the current Canadian health care system frequently separates the services available for the management of physical and mental illnesses (Austin & Boyd, 2010).

The Specialty CHCC is typically offered in 2.5-hour sessions, which incorporates a 1.5-hour group segment, followed by one hour of individual care to approximately one third of the participants (Noffsinger, 2009). The Specialty CHCC generally accommodates 15 to 20 participants and has a minimum of two support staff, such as a nurse and a physician (Noffsinger, 2009). The individual consultation, intended only for patients who need it, is scheduled following the group segment, while others may leave after the group segment has finished (Noffsinger, 2009). Those who use the individual consultation typically include patients the

physician wants to see, patients who request to be seen, and patients due for their routine health maintenance visit (Noffsinger, 2009). It is imperative with all SMAs that concerns regarding confidentiality and privacy are addressed, and that time is available at every session for patients to have a brief discussion or examination, as required (Noffsinger, 2009). Given the flexibility of the Specialty CHCC model, there is variability in how it is used for SMAs (Noffsinger, 2009).

Five systematic reviews have previously reported on the use of SMAs for patients with diabetes mellitus (Burke et al., 2011; Edelman et al., 2012; Edelman et al., 2015; Housden, Wong & Dawes, 2013; Riley & Marshall, 2010). The most recent and methodologically sound systematic review, as rated by AMSTAR, was undertaken by Edelman and colleagues (Edelman et al., 2015). The systematic review included 17 studies from January 1996 to April 2012 comparing diabetes SMAs with usual care or enhanced care (Edelman et al., 2015). Findings from the systematic review reported that those who attended SMAs had improved hemoglobin A1c (Δ=-0.55 percentage points [95% CI, -0.11 to -0.99]) and improved systolic blood pressure (Δ=-5.2mmHg [95% CI, -3.0 to -7.4]), but did not have improved LDL cholesterol (Δ=-6.6 mg/dl [95% CI, 2.8 to -16.1]) (Edelman et al., 2015). Nonbiophysical outcomes, such as patient experience outcomes, utilization and economic outcomes, were reported too infrequently to perform a meta-analysis or draw conclusions (Edelman et al., 2015).

Despite that, little is known about the use of SMAs for patients with a homogeneous physical chronic illness other than diabetes mellitus. One systematic review (2010) has previously been performed to assess the effectiveness of group visits for patients with chronic illnesses (Quiñones et al., 2014). However, the studies that included an individual consultation were purposely excluded from the review, as this is how the authors differentiated a *group visit* from a *shared medical appointment*, as defined by the Specialty CHCC model (Quiñones et al.,

2014). Of 80 included citations, it was reported that group visit interventions improved patient self-efficacy in the short-term, but participation rates were often low (Quiñones et al., 2014).

The purpose of this systematic review was to determine the effectiveness of SMAs on patients with a physical chronic illness (excluding diabetes mellitus). Research questions were: (1) what effect do SMAs have on patients, their healthcare providers and the healthcare system?; and (2) what are the characteristics of SMAs?

Methods

A systematic review was conducted based on the Cochrane Handbook for Systematic Reviews of Interventions and reported to meet the Preferred Reporting Items for Systematic Reviews and Meta-Analyses (PRISMA) criteria (Higgins & Green, 2011; Moher et al., 2009).

Search Strategy

The search strategy was developed in collaboration with an academic librarian (RS) and an expert in systematic review methodology (DS). Inclusion/exclusion criteria were established using the elements of a research question, and included population, intervention, comparator and outcome (PICO) (see Table 3.1) (Higgins & Green, 2011). Eligible studies were randomized controlled trials evaluating SMAs used for adults with a homogenous physical chronic illness versus any other comparator. Outcomes involved measures of patients (e.g. quality of life, knowledge, self-management, satisfaction, symptom outcomes), healthcare providers (e.g. satisfaction) and the healthcare system (e.g. hospital admissions, emergency department visits, costs). Excluded were trials evaluating SMAs for patients diagnosed with diabetes mellitus. In keeping with the Specialty CHCC model definition of SMAs, included were trials in which: healthcare provider(s) saw the same group of patients; had homogeneous patient groupings by

disease; and included both a mandatory group segment and an as-needed individual consultation (Noffsinger, 2009).

The search was conducted in multiple databases: Medline, CINAHL, PsychINFO, CENTRAL and EMBASE. To supplement the database search, bibliography searches of the reference lists of included articles were also assessed (Higgins & Green, 2011).

Search

To identify all studies related to SMAs published between January 1970 and September 2016, a combination of the following search terms was used: group, shared, processes, appointment, schedule and visit (see Table 3.2). Searches did not have any filters or limitations other than year due to the perceived restricted number of studies on SMAs. The year 1970 was selected given SMAs were first introduced in the 1970s (Geller et al., 2015).

Screening of Studies

Following the identification of citations, duplicates were removed. Two reviewers conducted three levels of screening (FC, CL, RM, DS). Level one screening included a title screen to determine study relevance to the focus of the systematic review. Level two screening used the PICO criteria to review abstracts. For both level one and level two screening, citations indicated as *excluded* by both reviewers were removed, and citations rated as *included*, *unsure* or *excluded* by one reviewer were included for the next level of screening. Level three screening used full text of citations. For discrepancies at full-text screening, the reviewers met to discuss and reach consensus. If necessary, a third member was consulted for unresolved discrepancies (DS) (Furlan et al., 2011).

Data Collection and Items

For included citations, data was extracted using a standardized format. Data included authors, publication year, country, study design, setting (e.g. disease focus), SMA characteristics (e.g. number of SMA visits, attendance rates, length of the group session, number of attendees, invitation for family members to attend, lead healthcare providers, other healthcare providers involved), and outcomes on the patients, the healthcare providers, and the healthcare system.

Study Quality

Two reviewers (FK, JH) appraised the methodological quality of the included randomized controlled trials using the Cochrane Collaboration Risk of Bias Tool (Higgins & Green, 2011). Any discrepancies were resolved through consensus and a third reviewer (DS) was consulted as necessary. Studies were not excluded based on their methodological quality.

Analysis

Studies were synthesized descriptively by comparing and contrasting study findings relevant to the research questions (FK, JH). Two or fewer of the included studies had comparable biophysical outcomes; therefore, although a meta-analysis was planned a priori, it was not conducted.

Results

The search identified 2364 citations (see Figure 3.1). Of the 102 full-text articles screened, nine randomized controlled trials were included (reported in 10 articles). The 92 excluded articles were not randomized controlled trials (*n*=66), participants of the SMA did not have a chronic illness (*n*=8), the full paper was not available (*n*=5), abstract only (*n*=4), the SMA did not have an optional individual consultation (*n*=3), the SMA did not group by one homogeneous chronic illness (*n*=2), not peer-reviewed (*n*=2), the SMA did not have a group segment (n=1) and a protocol (*n*=1) (see Appendix H).

Of the nine included studies, four focused on chronic cardiovascular illnesses, two on heart failure and two on hypertension. An additional five each focused on breast cancer survivors, carpal tunnel syndrome, chronic kidney disease, Parkinson disease and stress urinary incontinence. Four of the studies were conducted in the United States, and one each in Canada, China, Germany, Greece and the Netherlands (see Table 3.4). There was an increase in the use of SMAs for patients with cardiovascular illnesses since 2009 and a more recent surge in the use of SMAs for other chronic illnesses (e.g. breast cancer survivors, carpal tunnel syndrome, chronic kidney disease and Parkinson disease).

Study Quality

Risk of bias was rated as high in four of seven domains (1 study), three domains (1 study), two domains (3 studies) and one domain (3 studies) (see Table 3.3). The two most common methodological problems included (a) an inadequate approach to blinding the participants and personnel in which the outcome was likely to be influenced (7 studies), and (b) self-reported outcomes, which are subjective and likely to be influenced by lack of blinding (3 studies).

Characteristics of Included Study Participants

The mean age of patients who attended SMAs ranged from 47.8 to 72.1 years of age. Eight studies reported sex with mostly females in five studies (range 51.3% to 100%) and a minority of females in three studies (range 33% to 44%). Three studies reported race and Caucasian was the majority in all three (range 53% to 100%) (Dorsey et al., 2011; Montoya, Sole & Norris, 2016; Smith et al., 2014). Four studies reported the education levels of their participants, with a majority of attendees having greater than high school education as their highest level of education (range 50.1% to 100%) (3 studies) and one trial reported the majority of attendees having high school education or less as their highest level of education (100%)

(Dorsey et al., 2011; Junling et al., 2015; Montoya et al., 2016; Wong et al., 2016). Two studies reported their participants work demographics, with both reporting a minority of patients being employed (6.3% and 17%) (Montoya et al., 2016; Smith et al., 2014).

Characteristics of Shared Medical Appointments

The number of SMA visits was 12 visits (1 study), four to nine visits (5 studies), and one visit (3 studies) (Table 3.5). The length of SMAs varied from 35 to 120 minutes (9 studies). Number of participants per SMA was four to twelve (8 studies), and the remaining study had 18 to 20 participants. Three studies allowed family members to attend the SMA. The SMAs were led by teams of one to two clinicians, including physicians, physiotherapists, and nurses. Attendance rates ranged from 72.3% to 100% (9 studies).

Patient Outcomes

Two studies evaluated the effect of SMAs on biophysical outcomes. One trial of adults with hypertension reported improved diastolic blood pressure for SMA compared to usual care (decrease in SMA = 1.5mmHg, decrease in usual care = 0.4mmHg, p=0.047), but showed no difference in systolic blood pressure changes or body mass index (Junling et al., 2015). Another trial showed no difference in systolic or diastolic blood pressure in adults with chronic kidney disease (Montoya et al., 2016). There were no significant differences between patients with chronic kidney disease who attended usual care and SMAs for other biophysical outcomes, including body mass, weight, creatinine, glomerular filtration rate, phosphorus, potassium, and hemoglobin (Montoya et al., 2016).

Four studies reported on patients' health-related quality of life with one showing significant improvement and three showing no difference (Table 3.6). The improved quality of life index score was 4.9 out of 6 (SD±0.7) for patients with stress urinary incontinence who

attended SMAs compared to 3.6 (SD±1.5) for usual care (p=0.02).[21] Four studies reported on patient knowledge, with improvement in two studies and no difference in two studies. Compared to usual care, the SMA for patients with heart failure had greater knowledge scores six months post-SMA (p=0.05) and twelve months post-SMA (p=0.01) (Smith et al., 2015). Using the Heart Failure Knowledge Test, the mean scores improved significantly more from baseline (9.33 out of 15) to eight weeks (10.67 out of 15) for those who attended SMAs compared to usual care (10.33 out of 15 at baseline to 9.56 out of 15 at eight weeks) (p=0.038) (Yehle et al., 2009).

Of four studies measuring patient self-management, two studies noted no difference for those who attended SMAs (heart failure and chronic kidney disease) and two studies noted patients were better able to self-manage their chronic illness (hypertension and heart failure). One study reported that, compared to usual care, those with hypertension who attended SMAs had higher self-efficacy in managing symptoms (p<0.001), managing disease in general (p<0.001) and self-efficacy of physical activity (p<0.001) (Junling et al., 2015). In the other study on heart failure, the SMA group had greater self-management of reducing sodium intake, adhering to heart failure medications and exercising versus those who attended usual care (p=0.03) (Smith et al., 2015).

Of four studies that measured symptom outcomes, two studies reported no difference (Parkinson disease and breast cancer survivors) and two studies reported significant improvement for SMAs versus usual care (hypertension and stress urinary incontinence). For example, there was significant improvement for self-reported health (p=0.009) and energy (p=0.001) for patients with hypertension who attended SMAs compared to usual care (Junling et al., 2015). Using the Patient Global Impression of Improvement to assess patients' self-reported improvement, patients with stress urinary incontinence attending SMAs were significantly better

than usual care (100% vs. 20%, p=0.000) (Konstantinidou et al., 2007). Of the four studies that measured patient satisfaction, there was no significant difference between SMA and usual care (Dorsey et al., 2011; Montoya et al., 2016; Visser et al., 2015; Wong et al., 2016).

Healthcare Provider Outcomes

One trial reported on healthcare provider satisfaction with the SMA for breast cancer survivors, measured using a 5-point scale (Visser et al., 2015). Healthcare provider satisfaction was no different between SMA and usual care (Visser et al., 2015).

Healthcare System Outcomes

One study reported on healthcare service use for heart failure, finding fewer hospital admissions for the patients who attended SMAs compared to usual care (p=0.04) (Smith et al., 2015). One study further reported on cost between SMAs and usual care, reporting higher intervention costs for SMAs for breast cancer survivors compared to usual care (p=0.00), and no difference in healthcare costs, productivity costs and total costs (Visser et al., 2015).

Discussion

Our systematic review identified nine unique randomized controlled trials comparing SMAs to usual care. Our findings were consistent with systematic reviews for SMAs for patients with diabetes mellitus (Burke et al., 2011; Edelman et al., 2012; Edelman et al., 2015; Housden et al., 2013; Riley et al., 2010). Overall, there was no harm when SMAs were used across seven different homogeneous physical chronic illnesses. These nine studies showed improvement or no difference compared to usual care. Specifically, results were improved or no different for biophysical outcomes, health-related quality of life, patient knowledge, self-management, and symptom outcomes. Improvement in the context of healthcare service use was reported in fewer hospital admissions for heart failure and no difference in total healthcare costs for breast cancer

survivors. No difference was noted for patient and healthcare provider self-reported satisfaction with the SMA. These findings lead to four important issues for discussion.

First, one of the goals of SMAs is to improve patient self-management (Edelman et al., 2012). Only four studies measured self-management using different scales. Two showed improvement (hypertension and heart failure) and two showed no difference (heart failure and chronic kidney disease) compared to usual care. The two studies that showed improvement had much larger sample sizes (N=1204 and N=198, respectively) than those that showed no difference (N=23 and N=30, respectively). SMAs uniquely offer increased time with a multitude of healthcare providers, and the peer-support of other patients with the same chronic illness (Noffsinger, 2009). As self-management is a combination of knowledge and self-efficacy, it is an important outcome that should be further assessed (Yehle et al., 2009).

Second, although it has been suggested that SMAs are beneficial for all chronic illnesses, there remains a gap in the literature for studies analyzing illnesses other than diabetes mellitus (Jaber, Braksmajer & Trilling, 2006; Jones, Kaewluang & Lekhak, 2014; Noffsinger, 2009). The evaluation of the use of SMAs for other chronic illnesses is increasingly crucial with the aging population. Of all direct healthcare costs, 67% is used for the treatment of chronic illnesses, costing the Canadian economy $190 billion annually (Elmslie, 2012). Of that expenditure, $68 billion is attributed to direct treatment and the remainder is lost productivity (Elmslie, 2012). Chronic heart failure, in particular, is the leading cause of hospitalizations for those 65 years of age and over, with each hospital admission costing between $6000 and $15,000 (Azad & Lemay, 2014). One study for patients with heart failure reported that those who attended SMAs had fewer hospital admissions than those who attended usual care (Smith et al., 2014). As SMAs

offer an alternative way to support patients to be appropriately treated in the primary healthcare system, they are proposed to be a sound substitute in comparison to the individualized visit.

Third, few studies reported on healthcare system use or healthcare provider outcomes. As the facilitators and contributors to the SMAs, it is critical to have healthcare providers committed to providing effective SMAs (Ratanawongsa et al., 2012). A poorly run SMA could lead to low attendance and, therefore, lack of knowledge acquisition and self-management skills. Other descriptive studies have reported not only on healthcare provider interest for conducting SMAs, but also on their increased level of satisfaction in comparison to usual care (Egger et al., 2015; Prescott et al., 2016; Stevens et al., 2014). Provider satisfaction with SMAs arise from the ability to deliver improved care, a relaxed environment, and improved patient compliance with self-management advice when agreed on by other patients present at the SMA (Egger et al., 2015; Noffsinger, 2009). Further research requires not only evaluation of healthcare provider satisfaction, one of the primary goals of SMAs, but also objective healthcare provider outcomes, such as number of specialist referrals and number of patient phone calls to their physician (Noffsinger, 2009).

Fourth, a definite term and description of what a SMA entails must be established to make it easier to determine what has already been evaluated in the literature. Although the term most often used in the included studies was *group visit*, group visit is the more all-inclusive term that encompasses the three major models of SMAs (Noffsinger, 2009). It is therefore suggested the term *shared medical appointment* be used, and that this implies the inclusion of a mandatory educational session and/or group discussion, as well as an optional individual assessment as needed (Noffsinger, 2009). Although the educational session and group discussion are inherent in the term *shared*, it is the individual assessment that remains inconsistent in the literature. The

Specialty CHCC model is conventionally conducted with an individual segment, and patients who use this option are typically those who are experiencing an overriding illness, a flare in the chronic illness, or for routine health maintenance (Noffsinger, 2009). Additionally, although the Specialty CHCC is meant to target disease-specific management and guidance, it is not uncommon that patients attending such sessions will also be experiencing other chronic health issues. Those with multiple chronic illnesses should therefore either be offered additional support included in the SMA programming, or it should be made explicit where one can find supplementary counseling.

Strengths and Limitations

To improve quality and reduce the risk of bias: (a) the protocol for the systematic review was developed a priori and registered in PROSPERO; (b) a comprehensive search of five electronic databases and grey literature was conducted; and (c) two reviewers screened the identified literature, extracted the data, and appraised the quality of the included studies.[13, 32, 33] Although the Specialty CHCC is meant to be flexible, it was important that the search strategy of the systematic review included a multitude of terms to ensure a relevant citation was not missed. The included studies in this review used a multitude of terms other than SMA, including group patient visits, group visits, group medical visits, group medical consultation, shared medical visit and group clinic appointments.

A further limitation was the intervention criteria. As the intervention criteria was based on Noffsinger's definition of a Specialty CHCC, our systematic review was limited to RCTs consisting solely of that style of SMA, thereby failing to consider other SMA approaches, such as the drop-in group medical appointment or the physicals shared medical appointment. Our systematic review also did not include studies that grouped patients together with a focus on

more than one chronic illness, nor did it include those that did not offer an optional individual consultation.

Limitations of the trials included in this review were: (a) small sample sizes; (b) inadequate blinding of participants and personnel; (c) self-reported outcomes, which are subjective and likely to be influenced by lack of blinding; and (d) lack of consistent measures to be able to conduct a meta-synthesis of the findings. As a result of the small sample sizes, seven of the nine trials had low statistical power, thereby negatively impacting the probability of finding true effects (Dorsey et al., 2011; Konstantinidou et al., 2007; Montoya et al., 2016; Polit & Beck, 2008; Wong et al., 2016; Visser et al., 2015; Yehle et al., 2009). Although it has been previously noted that this type of intervention is not possible to run as a double-blind trial, measures, such as patient satisfaction, are likely to have measurement bias (Farrokhyar et al., 2010; Trento et al., 2002).

Conclusion

SMAs are emerging as an approach to guide patients in managing their chronic illness. Although there are multiple systematic reviews of SMAs for patients with diabetes mellitus, few trials have measured SMAs for other chronic illnesses. This systematic review is the first to assess SMAs versus usual care for patients with a homogeneous physical chronic illness, other than diabetes mellitus, and included nine trials reporting no negative effects on patient outcomes. Further research should focus on use of similar outcomes to facilitate meta-analysis and outcomes with minimal risk of bias. Future studies should also aim for larger sample sizes to ensure adequate statistical power. Moreover, as few studies measured healthcare provider or healthcare system outcomes, additional research is required to fill this knowledge gap.

References

Austin W. & Boyd M.A. (2010). *Psychiatric and mental health nursing for Canadian practice, second edition.* China: Lippincott Williams & Wilkins.

Azad N. & Lemay G. (2014). Management of chronic heart failure in the older population. *Journal of Geriatric Cardiology, 11*(4): 329 – 337.

Burke R., Ferrara S., Fuller A., Kelderhouse J. & Ferrara L. (2011). The effectiveness of group medical visits on diabetes mellitus type 2 (dm2) specific outcomes in adults: A systematic review. *The Joana Briggs Institute Database of Systematic Reviews and Implementation Reports, 9*(23): 833 – 885.

Dorsey E., Deuel L., Beck C., Gardiner I., Scoglio N., Scott J., Marshall F. & Biglan K. (2011). Group patient visits for Parkinson disease: A randomized feasibility trial. *Neurology, 76*(18): 1542 – 1547. doi: 10.1212/WNL.0b013e3182194bad

Edelman D., Gierisch J., McDuffie J., Oddone E. & Williams J. (2015). Shared medical appointments for patients with diabetes mellitus: A systematic review. *Journal of General Internal Medicine, 30*(1): 99 – 106. doi: 10.1007/s11606-014-2978-7

Edelman D., McDuffie J., Oddone E., Gierisch J., Nagi A. & Williams W. (2012). *Shared medical appointments for chronic medical conditions: A systematic review.* Washington, DC: Department of Veterans Affairs.

Egger G., Dixon J., Meldrum H., Binns A., Cole M., Ewald D. & Stevens J. (2015). Patients' and providers' satisfaction with shared medical appointments. *Australian Family Physician, 44*(6): 674 – 679.

Elmslie K. (2012). *Against the growing burden of disease*. Retrieved from: http://www.ccgh-csih.ca/assets/Elmslie.pdf

Farrokhyar R., Karanicolas P., Thoma A., Simunovic M., Bhandari M., Devereaux P., Anvari M., Adili A. & Guyatt G. (2010). Randomized controlled trials of surgical interventions. *Annals of Surgery, 251*(3): 409 – 416. doi: 10.1097/SLA.0b013e3181cf863d

Furlan J., Singh J., Hsieh J. & Fehlings M. (2011). Methodology of systematic reviews and recommendations. *Journal of Neurotrauma, 28*(8): 1335 – 1339. doi: 10.1089/neu.2009.1146

Geller J., Kulla J. & Shoemaker A. (2015). Group medical visits using an empowerment-based model as treatment for women with chronic pain in an underserved community. *Global Advances in Health, 4*(6): 27 – 31. doi: 10.7453/gahmj.2015.057

Higgins J. & Green S. (Eds). (2011). *Cochrane handbook for systematic reviews of interventions, version 5.1.0.* The Cochrane Collaboration. Retrieved from www.handbook.cochrane.org

Housden L., Wong S. & Dawes M. (2013). Effectiveness of group medical visits for improving diabetes care: A systematic review and meta-analysis. *Canadian Medical Association Journal, 185*(13): E635 – E644. doi: 10.1503/cmaj.130053

Jaber R., Braksmajer A. & Trilling J. (2006). Group visits for chronic illness care: Models, benefits and challenges. *Family Practice Management, 13*(1): 37 – 40.

Jones K., Kaewluang N. & Lekhak N. (2014). Group visits for chronic illness management: Implementation challenges and recommendations.

Junling G., Yang L., Junming D., Pinpin Z. & Hua F. (2015). Evaluation of group visits for Chinese hypertensives based on primary health care center. *Asia Pacific Journal of Public Health, 27*(2): NP350 – NP360. doi: 10.1177/1010539512442566.

Konstantinidou E., Apostolidis A., Kondelidis N., Tsimtsiou Z., Hatzichristou D. & Ioannides E. (2007). Short-term efficacy of group pelvic floor training under intensive supervision versus

unsupervised home training for female stress urinary incontinence: A randomized pilot study. *Neurology and Urodynamics, 26*(4): 486 – 491. doi: 10.1002/nau.20380

Lin A., Cavendish J., Boren D., Ofstad T. & Seidensticker D. (2008). A pilot study: Reports of benefits from a 6-month, multidisciplinary, shared medical appointment approach for heart failure patients. *Military Medicine, 173*(12): 1210 – 1213.

Moher D., Liberati A., Tetzlaff J., Altman D. & The Prisma Group. (2009). Preferred reporting items for systematic reviews and meta-analysis: The PRISMA statement. *Public Library of Science Medicine, 3*(2): 123 – 130. doi: 10.1371/journal.pmed.1000097

Moher D., Shamseer L., Clarke M., Ghersi D., Liberati A., Petticrew M., Shekelle P., Stewart L. & PRISMA-P Group. (2015). Preferred reporting items for systematic review and meta-analysis protocols (PRISMA-P) 2015 statement. *Systematic Reviews, 4*(1). doi: 10.1186/2046-4053-4-1

Montoya V., Sole M. & Norris A. (2016). Improving the care of patients with chronic kidney disease using group visits: A pilot study to reflect an emphasis on the patients rather than the disease. *Nephrology Nursing Journal, 43*(3): 207 – 222.

Noffsinger E. (2009). *Running group visits in your practice.* New York, NY: Springer.

Polit D. & Beck C. (2008). *Nursing research: Generating and assessing evidence for nursing practice. 8th ed.* Philadelphia: Lippincott Williams & Wilkins.

Prescott L., Dickens A., Guerra S., Tanha J., Phillips D., Patel K., Umberson K., Lozano M., Lowe K., Brown A., Taylor J., Soliman P., Garcia E., Levenback C. & Bodurka D. (2016). Fighting cancer together: Development and implementation of shared medical appointments to standardize and improve chemotherapy education. *Gynecologic Oncology, 140*(1): 114 – 119. doi: 10.1016/j.ygyno.2015.11.006

Quiñones A., Richardson J., Freeman M., Fu R., O'Neil M., Motu'apuaka M. & Kansagara D. (2014). Educational group visits for the management of chronic health conditions: A systematic review. *Patient Education and Counseling, 95*(1): 3 – 29. doi: 10.1016/j.pec.2013.12.021

Ratanawongsa N., Bhandari V., Handley M., Rundall T., Hammer H. & Schillinger D. (2012). Primary care provider perceptions of the effectiveness of two self-management support programs for vulnerable patients with diabetes. *Journal of Diabetes Science and Technology, 6*(1): 116 – 124. doi: 10.1177/193229681200600114

Riley S. & Marshall E. (2010). Group visits in diabetes care: A systematic review. *The Diabetes Educator, 36*(6): 936 – 944. doi: 10.1177/0145721710385013

Seesing F., Zijlstra W., Pasmans S., L'Hoir M, Drost G., van Engelen B. & van der Wilt G. (2013). Group medical appointments for people with physical illness (Protocol). *Cochrane Database of Systematic Reviews, 10*(CD010721). doi: 10.1002/14651858.CD010721

Shea B., Grimshaw J., Wells G., Boers M., Andersson N., Hamel C., Porter A., Tugwell P., Moher D. & Bouter L. (2007). Development of AMSTAR: A measurement tool to assess the methodological quality of systematic reviews. *BMC Medical Research Methodology, 15*(7): 10. doi: 10.1186/1471-2288-7-10

Simon B. & Sawicki P. (2015). Quality improvement in chronic care delivery for patients with arterial hypertension through Group Medical Visits: Patient acceptance and attendance in the German pilot project. *Quality in Primary Care, 23*(2): 106 – 112.

Smith C., Piamjariyakul U., Wick J., Spertus J., Russell C., Dalton K., Elyachar A., Vacek J., Reeder K., Nazir N. & Ellerbeck E. (2014). Multidisciplinary group clinic appointments: The

self-management and care of heart failure (SMAC-HF) trial. *Circulation: Heart Failure, 7*(6): 888 – 894. doi: 10.1161/CIRCHEARTFAILURE.113.001246

Smith C., Piamjariyakul U., Dalton K., Russell C., Wick J. & Ellerbeck E. (2015). Nurse-led multidisciplinary heart failure group clinic appointments: Methods, materials, and outcomes used in the clinical trial. *Journal of Cardiovascular Nursing, 30*(4 Suppl 1): S25 – S34. doi: 10.1097/JCN.0000000000000255

Stevens J., Cole M., Binns A., Dixon J. & Egger G. (2014). A user assessment of the potential for shared medical appointments in Australia. *Australian Family Physician, 43*(11): 804 – 807.

Trento M., Passera P., Bajardi M., Tomalino M., Grassi G., Borgo E., Donnola C., Cavallo F., Bondonio P., Porta M. (2002). Lifestyle intervention by group care prevents deterioration of type II diabetes: A 4-year randomized controlled clinical trial. *Diabetologia, 45*(9): 1231 – 1239.

Visser A., van Laarhoven H., Govaert P., Schlooz M., Jansen L., van Dalen T. & Prins J. (2015). Group medical consultations in the follow-up of breast cancer: A randomized feasibility study. *Journal of Cancer Survivorship, 2015*(9): 450 – 461. doi: 10.1007/s11764-014-0421-z

Wong A., Martin J., Wong M., Bezuhly M. & Tang D. (2016). Shared medical appointments as a new model for carpal tunnel surgery consultation: A randomized clinical trial. *Plastic Surgery, 24*(2): 107 – 111.

Yehle K., Sands L., Rhynders P. & Newton G. (2009). The effect of shared medical visits on knowledge and self-care in patients with heart failure: A pilot study. *Heart & Lung, 38*(1): 25 – 33. doi: 10.1016/j.hrtlng.2008.04.004

Table 3.1. The PICO criteria used for the systematic review.

	Inclusion	**Exclusion**
Population	Adults, 18 years of age or older, with a physical chronic illness.	Children aged 17 years of age or younger
Intervention	Shared medical appointments based on the Specialty Cooperative Health Care Clinic, defined as: - Healthcare provider(s) who see the same group of patients - Homogeneous patient groupings by disease - Group segment mandatory and individual care offered as needed	- Groupings of patients with different chronic illnesses - Individual consultation not offered - Patients with diabetes mellitus and/or mental health
Comparator	Any comparison, including usual care	--
Outcomes	SMA characteristics (e.g. length of the SMA, disease focus, number of SMA visits, attendance rates, number of attendees, inclusion of family members, primary SMA healthcare leader and other healthcare providers involved), patients outcomes (e.g. biophysical outcomes, quality of life, knowledge, self-management, satisfaction and symptom outcomes), healthcare provider outcomes (e.g. satisfaction with SMA), and healthcare system outcomes (e.g. hospital admissions, emergency department visits and cost)	--
Intervention Studies	Randomized control trials	Systematic review Cohort study Pre-/post-test study Case-control study Cross-sectional study Case reports and series Editorials, Opinions Interrupted time series

Table 3.2. The search strategy used for Medline.

1	Group Processes/
2	“Appointments and Schedules”/
3	1 and 2
4	((group or shared) adj3 appointment*).tw.
5	((group or shared) adj visit*).tw.
6	3 or 4 or 5
7	(group or shared).tw adj medical visit*.tw
8	6 or 7

Figure 3.1. The PRISMA flow diagram.

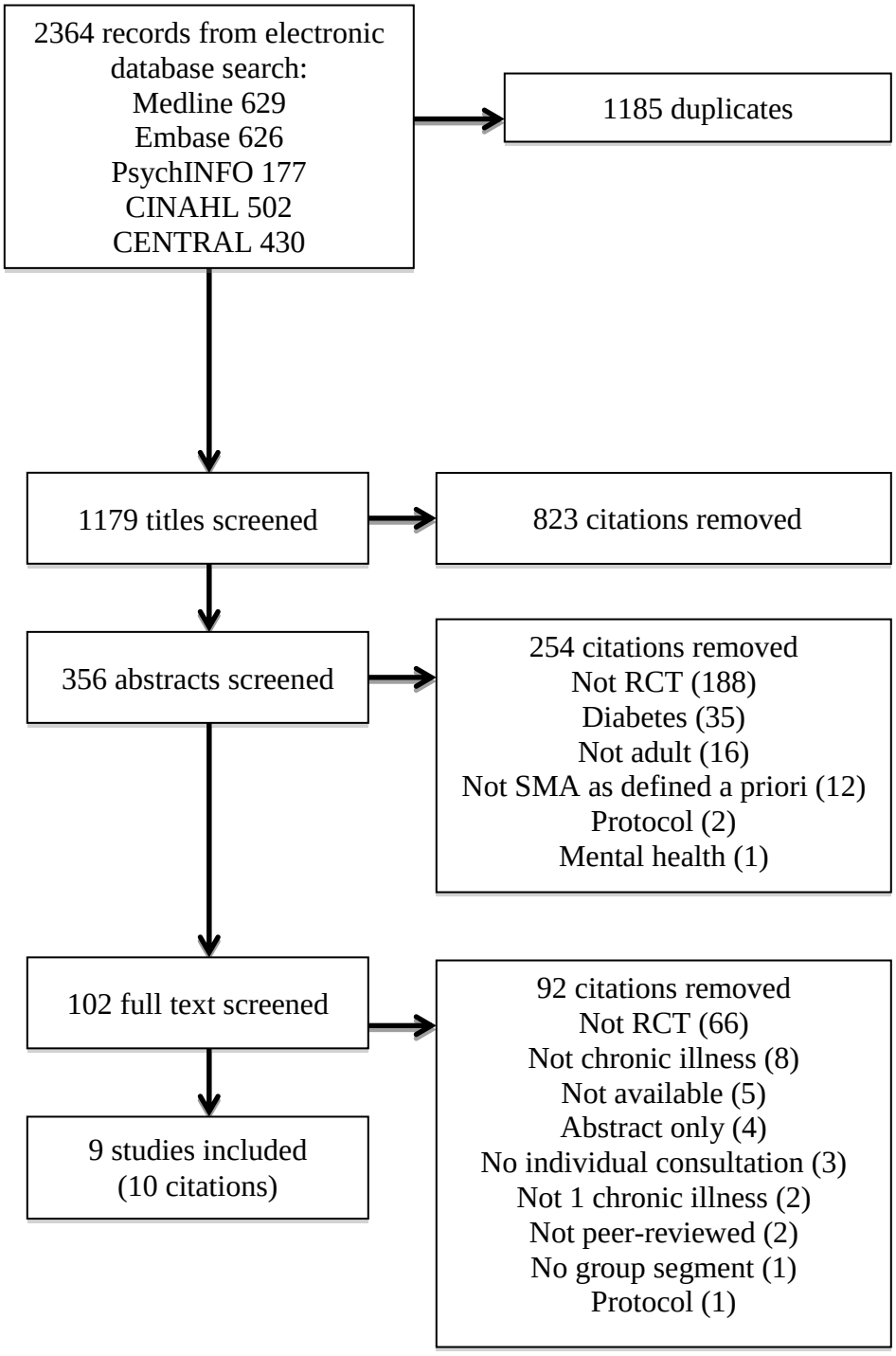

Table 3.3. Risk of bias of the included randomized controlled trials using the Cochrane Collaboration Risk of Bias Tool.

Study	Random Sequence Generation	Allocation Concealment	Blinding of Participants and Personnel	Blinding of Outcome Assessment	Incomplete Outcome Data	Selective Reporting	Other Bias
Cardiovascular (Heart Failure & Hypertension)							
Junling 2015	Unclear	Unclear	High	Low	Low	Low	High
Simon 2015	Unclear	Unclear	Low	Low	Low	Low	Low
Smith 2014, 2015	Unclear	Low	High	Low	Unclear	Low	Low
Yehle 2009	Low	Low	Low	Unclear	Low	High	Low
Other (Breast cancer survivor, Carpal tunnel syndrome, Chronic kidney disease, Parkinson disease & Stress urinary incontinence)							
Dorsey 2011	Low	Unclear	High	Unclear	Low	Low	High
Konstantinidou 2007	High	High	High	High	Low	Low	Low
Montoya 2016	Low	Low	High	High	Low	Low	Low
Visser 2015	Unclear	Unclear	High	High	Unclear	Low	High
Wong 2016	Low	Low	High	Low	Low	Low	Low

Table 3.4. Characteristics of the nine included randomized controlled trials.

Study	Setting	Sample Size	Patient Population	Age (mean ± SD) (range)	Female (%)
Cardiovascular (Heart failure, Hypertension)					
Junling 2015	China	SMA: 600 Control: 604	Hypertension	SMA: 66.0 ± 9.3 Control: 67.1 ± 10.3	SMA: 60.2 Control: 57.0
Simon 2015	Germany	SMA: 24 Control: 24	Hypertension	--	--
Smith 2014, 2015	USA	SMA: 92 Control: 106	Heart failure	SMA: 62.6 ± 14.1 Control: 62.1 ± 12.5	SMA: 44 Control: 34
Yehle 2009	USA	SMA: 13 Control: 10	Heart failure	Total: 67.3 ± 14.5	Total: 41
Other (Breast cancer survivor, Carpal tunnel syndrome, Chronic kidney disease, Parkinson disease & Stress urinary incontinence)					
Dorsey 2011	USA	SMA: 15 Control: 15	Parkinson disease	SMA: 72.1 ± 8.6 Control: 66.7 ± 11.8	SMA: 33 Control: 40
Konstantinidou 2007	Greece	SMA: 10 Control: 12	Stress urinary incontinence	Total: 47.8 ± 7.5 (34 – 60)	SMA: 100 Control: 100
Montoya 2016	USA	SMA: 16 Control: 14	Chronic kidney disease	Total: 68.1 ± 10.1	SMA: 56.3 Control: 50
Visser 2015	Netherlands	SMA: 38 Control: 31	Breast cancer survivors	SMA: 55.03 ± 10.52 Control: 57.16 ± 10.50	SMA: 100 Control: 100
Wong 2016	Canada	SMA: 36 Control: 39	Carpal tunnel syndrome	SMA: 54.9 (32-75) Control: 56.0 (32-75)	SMA: 72.2 Control: 51.3

-- = Not reported; Control = usual care

Table 3.5. Characteristics of the SMAs (nine randomized controlled trials).

Study	Number of SMA Visits	Attendance Rates (%)	SMA Length (minutes)	Number of Attendees	Family Members	Primary SMA Leader(s)	Other HCPs Involved
Cardiovascular (Heart failure, Hypertension)							
Junling 2015	9	72.3	120	18 – 20	--	MD	Nurse, community health worker
Simon 2015	6	81.6	60 – 90	9.8 (Mean)	--	MD	--
Smith 2014, 2015	5	92	120	4 – 8	--	NP	Dietitian, social worker, mental health nurse specialist
Yehle 2009	1	100	70	7	Yes	NP and primary investigator	--
Other (Breast cancer survivor, Carpal tunnel syndrome, Chronic kidney disease, Parkinson disease & Stress urinary incontinence)							
Dorsey 2011	4	90	90	6 – 13	Yes	MD	--
Konstantinidou 2007	12	80	--	5	--	Physiotherapist	--
Montoya 2016	6	92	90 – 120	8	Yes	NP	MD, dietician, pharmacist, social worker
Visser 2015	1	100	97±16	4-8	--	CNS or social worker	MD (oncologist and surgeon)
Wong 2016	1	100	35-95	8-12	--	MD	--

-- = Not reported; NP = Nurse practitioner; MD = Physician; RN = Registered nurse; CNS = Clinical nurse specialist; HCP = Healthcare provider

Table 3.6. Other outcomes determined a priori (nine randomized controlled trials).

Study, Illness & Sample Size	QOL	Pt. Knowledge	Self-Management	Pt. &HCP Satisfaction	Symptom Outcome	Service Use & Cost
Junling 2015 Hypertension N=1204	--	--	Difference (95%CI) SEMS SMA: 2.75 (2.39,3.11) Control: 1.76 (1.39,2.13) (p<0.001) SEMDG SMA: 0.98 (0.74,1.23) Control: 0.38 (0.11,0.65) (p<0.001)	--	Difference (95%CI) Self-reported health SMA: -0.38 (-0.54,-0.37) Control: -0.30 (-0.38,-0.23) (p<0.001) Energy SMA: 0.27 (0.18,0.35) Control: 0.06 (-0.03,0.14) (p<0.001)	--
Smith 2014, 2015 Heart failure N=198	No diff*	HF Patient Self-Management Knowledge t=2.76 (p=0.01)*	HF Self-Management Skills 6-mos: X^2=4.92 (p=0.03) 12-mos: X^2=4.99 (p=0.03)*	--	--	HF Related Rehospitalizations $X^2_{(1)} = 3.9$ (p=0.04)*
Yehle 2009 Heart failure N=23	--	HFKT Mean Score Change SMA: 9.33-10.67 Control: 10.33-9.56 (p=0.038*)	No diff*	--	--	--
Dorsey 2011 Parkinson disease N=30	No diff*	--	--	No diff	No diff	--
Konstantinidou	QOL	--	--	--	PGI-I	--

Study, Illness & Sample Size	QOL	Pt. Knowledge	Self-Management	Pt. &HCP Satisfaction	Symptom Outcome	Service Use & Cost
2007 Stress urinary incontinence N=22	Index Score 4.9±0.7 vs. 3.6±1.5 (*p*=0.02)				SMA: 100% Control: 20% (*p*=0.000)*	
Montoya 2016 Chronic kidney disease N=30	--	No diff*	No diff*	No diff*	--	--
Visser 2015 Breast cancer survivors N=69	No diff	--	--	No diff	No diff*	SMA: €53±9 Control: €35±11 (*p*=0.00[a]) No diff[b,c,d]
Wong 2016 Carpal tunnel syndrome N=75	--	No diff*	--	No diff*	--	--

--=Not measured; No diff. = No difference; *=Primary outcome; Pt. = Patient; QOL = Quality of life; mos = Months; HCP = Healthcare provider; SEMS=self-efficacy in managing symptoms; SEMDG=self-efficacy in managing disease in general; HFKT=Heart Failure Knowledge Test; PGI-I=Patient Global Impression of Improvement; [a]=Intervention costs; [b]=Healthcare costs; [c]=Productivity costs; [d]=Total cost

Chapter Four

Symptom Practice Guide for Telephone Assessment of Patients with Cancer Treatment-Related Cardiotoxic Dyspnea: Adaptation and Evaluation of Acceptability

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Abstract

Background: Patients with cancer treatment-related cardiotoxicity, which may manifest as heart failure (HF), can present with dyspnea. Nurses frequently assess, triage and offer self-care strategies to patients experiencing dyspnea in both the cardiology and oncology settings. However, there are no known tools available for nurses to manage patients in the setting of cancer treatment-related cardiotoxicity. The objective of this study was to adapt and evaluate the acceptability of an evidence-informed symptom practice guide (SPG) for use by nurses over the telephone for the assessment, triage, and management of patients experiencing dyspnea due to cancer treatment-related cardiotoxicity.

Methods: The CAN-IMPLEMENT© methodology guided this descriptive study. A systematic search was conducted in four databases to identify cardio-oncology and HF guidelines and systematic reviews. Screening was conducted by two reviewers, with data extracted into a recommendation matrix from eligible guidelines and systematic reviews on: assessment criteria, medications, and/or self-care strategies to manage dyspnea. Healthcare professionals with an expertise in oncology and/or cardiology were recruited using purposeful and snowball sampling. Evaluation of acceptability of the adapted SPG was gathered through semi-structured interviews and a survey with open- and closed-ended questions. Quantitative findings and participant feedback from the interviews and the open-ended survey questions were analyzed descriptively.

Results: Of 490 citations, seven HF guidelines were identified. Evidence from these guidelines was added to the original SPG. Eleven healthcare professionals completed the interview and acceptability survey. The adapted SPG was iteratively revised three times during the interviews. The original SPG was adaptable, and participants indicated the adapted SPG was comprehensive, easy to follow, and would be useful in clinical practice.

Conclusions: This study highlights the lack of knowledge tools and available clinical practice guidelines to guide healthcare professionals to assess, triage and/or offer self-care strategies to patients with cancer treatment-related cardiotoxic dyspnea. Moreover, most nurses require assistance to differentiate among the various causes of dyspnea from oncology treatment in order to triage severity appropriately. Further research should focus on evaluating the adapted SPG in clinical practice and consider creating a patient version.

Keywords: symptom practice guide; cancer treatment-related cardiotoxicity; self-management/care

Background

With the delivery of more complex cancer interventions, including chemotherapy, targeted therapies and radiation treatment, cancer treatment-related cardiotoxicity has emerged as a potential consequence (Hewitt, Greenfield & Stovall, 2005; Lewis, Dirksen, Heitkemper, Bucher & Camera, 2014; Witte & Clark, 2007). Cardiotoxicity is defined as the direct effects of cancer treatment on heart function and structure, and is the second leading cause of long-term morbidity and mortality among those treated with cancer therapies (Daher, Daigle, Bhatia & Durand, 2012; Zamorano et al., 2016). Dyspnea is one symptom patients with cancer treatment-related cardiotoxicity may experience (Lewis et al., 2014).

Dyspnea is defined as a subjective feeling of breathing discomfort or difficulty that may vary in intensity, and is a symptom patients treated with cancer therapies may experience (American Thoracic Society, 1999; Vandyk, Harrison, Macartney, Ross-White & Stacey, 2012). Dyspnea is associated with lower levels of physical performance and decreased social functioning, thereby negatively affecting the overall quality of life of adults treated with cancer therapies (Henry et al., 2008; Barbera et al., 2010; Sarna et al., 2004). Dyspnea may also indicate a more severe complication of cancer and its treatment, such as heart failure (HF), pulmonary embolism, and anemia.

Nurse-led support is offered in both the cardiology setting, with regards to patient self-management of HF, and the oncology setting. Nurses can assess and triage patient's experiencing dyspnea before it becomes potentially life threatening, and they may assist in the development of strategies to help alleviate the distress patients experience with dyspnea (Behl, Hendrickson & Moynihan, 2010; Cox & Wilson, 2003). Assessment, triage and guidance in self-management of

dyspnea in such patients can occur over the telephone from ambulatory clinics (Stacey, Bakker, Green, Zanchetta & Conlon, 2007).

Clinical outcomes for HF depend largely on patient self-management (Bashi, Karunanithi, Fatehi, Ding & Walters, 2017). Inadequate symptom monitoring and treatment during exacerbations may result in patients being hospitalized (Bashi et al., 2017). To avoid this, in some settings, remote patient monitoring systems and cost-effective disease management strategies have been established (Bashi et al., 2017). A previous randomized controlled trial evaluated the use of nurse-led telephone monitoring (intervention) versus usual care (GESICA Investigators, 2005). Nurses used predetermined standardized questions to assess a variety of signs and symptoms, such as dyspnea, daily weight monitoring, drug adherence, and physical activity (GESICA Investigators, 2005). Based on their assessment, nurses were then able to either adjust medical therapy, such as dose of diuretic in patients with HF, or recommend a nonscheduled medical visit (GESICA Investigators, 2005). Those in the intervention group had fewer re-hospitalizations both in the short term, and one to three years following the intervention (Ferrante et al., 2010; GESICA Investigators, 2005).

To support oncology nurses with the assessment, triage, documentation and guidance of patients to self-manage their cancer treatment-related symptoms, the pan-Canadian Oncology Symptom Triage and Remote Support (COSTaRS) team developed and evaluated 15 evidence-based symptom practice guides (SPGs) (Stacey et al., 2014). The COSTaRS SPGs have been implemented in multiple ambulatory oncology programs across Canada, and their uptake has been previously evaluated in three different healthcare systems (Stacey et al., 2016). One of the SPGs produced by the COSTaRS team was for dyspnea (Stacey et al., 2014). The original COSTaRS Dyspnea SPG consisted of five recommendations for the nurse to (a) assess symptom

severity, (b) triage a patient for symptom management based on the highest assessment item of 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 (Stacey et al., 2013). The original COSTaRS Dyspnea SPG, however, did not include clinical practice guidelines or systematic reviews with a focus on symptom management for dyspnea due to cancer treatment-related cardiotoxicity.

The original COSTaRS Dyspnea SPG was chosen to be reviewed and adapted for patients experiencing cancer treatment-related cardiotoxicity given that new and spontaneous reporting of dyspnea is one symptom that may present in this patient population (Keefe, 2002). Dyspnea in those experiencing cancer treatment-related cardiotoxicity may be non-specific and should therefore be triaged appropriately (Keefe, 2002).

The objective of this study was to adapt and evaluate the acceptability of an evidence-informed SPG for use by nurses over the telephone for the assessment, triage, and management of patients experiencing dyspnea due to cancer treatment-related cardiotoxicity. The research questions were: (1) what adaptations were required when cardiology clinical practice guidelines were added to the original COSTaRS Dyspnea SPG?; and (2) was the adapted dyspnea SPG acceptable for oncology nurses to use when providing symptom support?

Methods

The CAN-IMPLEMENT© methodology guided this descriptive study. CAN-IMPLEMENT© recommends six steps for knowledge tool adaptation: (1) a call to action; (2) plan; (3) search and screen; (4) assess and select; (5) draft, revise and endorse recommendations; and (6) obtain user-centered feedback to plan implementation (Harrison, van den Hoek & Graham, 2014). Ethics approval for this study was received from the Ottawa Health Science

Network Research Ethics Board (20160752-01H) and the University of Ottawa Research Ethics Board (A12-16-02). All participants provided written informed consent.

Step One: A Call to Action

Step one involves clarifying the incentive for the adaptation (Harrison et al., 2014). The incentive for this study was the increasing prevalence of patients with cancer treatment-related cardiotoxicity and the lack of tools available for nurses to use to assist this patient population with symptom self-management.

Step Two: Plan

Step two includes establishing the scope of the knowledge tool, determining the feasibility of the adaptation, forming an organizing committee, and writing the work plan (Harrison et al., 2014). For this study, the research question was: what adaptations were required when cardiology clinical practice guidelines were added to the original COSTaRS Dyspnea SPG? A research team was formed consisting of experts in cardio-oncology (SD), cancer survivorship (RM), and SPG development (DS). A research proposal was then established.

Step Three: Systematic Search and Screen

Step three is searching and identifying eligible guidelines related to the specified topic (Harrison et al., 2014). We conducted a systematic search of the available literature for clinical practice guidelines and systematic reviews about assessing, triaging and offering self-management strategies for adults experiencing dyspnea due to cardiotoxicity or HF. The search strategy was designed in collaboration with a health science librarian (RS) and was based on the strategy used for the COSTaRS SPGs (Stacey et al., 2013). The systematic search was reported to meet the Preferred Reporting Items for Systematic Reviews and Meta-Analyses (PRISMA) criteria (Moher et al., 2009). The search focused on all key databases relevant to the subject

matter: Medline, Cochrane Database of Systematic Reviews, CINAHL and Web of Science. Articles were searched from January 2010 until December 2016 to identify current evidence. To supplement the database search, grey literature searches were also conducted on websites known or suspected to have cardiology practice guidelines related to symptom self-care and known guideline clearinghouse websites (see Table 4.1) (Peters et al., 2015; Stacey et al., 2013).

Inclusion/exclusion criteria were established using the PIPOH framework (Population, Intervention, Professionals/Patients, Outcomes and Health Care Setting) (see Table 4.2) (Stacey et al., 2013; The ADAPTE Collaboration, 2009). Eligible citations were systematic reviews and clinical practice guidelines evaluating cardiac-related symptom interventions to assess, rate severity and/or manage dyspnea in adults with cardiotoxicity and/or HF.

Step Four: Assess and Select

Step four includes assessing the quality, content, consistency, acceptability and applicability of the guideline recommendations (Harrison et al., 2014). After duplicates were removed, two reviewers independently conducted three levels of screening (FK, DS). Level one screening included a title screen to determine citation relevance to the focus of the SPG. Level two screening used the PIPOH criteria to review abstracts. For both level one and level two screening, citations indicated as *excluded* by both reviewers were removed and citations rated as *included, unsure* or *excluded* by one reviewer were included for the next level of screening. Level three used full text screening. For discrepancies at full-text screening, the reviewers met to discuss and reach consensus.

Two reviewers independently appraised the guidelines using the domain of rigour in the Appraisal of Guidelines for Research and Evaluation (AGREE) II Instrument (FK, JH) (Brouwers et al., 2010a). The AGREE II Instrument has been proven reliable and valid for

assessing the quality of clinical practice guidelines (Brouwers et al., 2010a; Brouwers et al., 2010b). The quality rating for the included guidelines was calculated using the AGREE II formula. Although the methodological quality of systematic reviews was planned a priori to be assessed using AMSTAR, no systematic reviews were eligible (Shea et al., 2007).

After selection and appraisal of the identified guidelines, one author independently extracted data (FK), which was then independently audited by a second reviewer (MC). Characteristics that were extracted included the author and the publication year, criteria to assess and triage dyspnea, medications, and self-care items for symptom management. A recommendation matrix was populated with the extracted characteristics to allow for comparison (Appendix I).

Step Five: Draft, Revise and Endorse Recommendations

Step five of the CAN-IMPLEMENT© methodology involves preparing an adapted knowledge tool for external review (Harrison et al., 2014). The original COSTaRS Dyspnea SPG was adapted to incorporate evidence from the eligible cardiology guidelines. Data was extracted from the cardiac guidelines using a recommendation matrix. Two co-authors then further reviewed the adapted SPG (DS, SC).

Step Six: Obtain User-Centered Feedback to Plan Implementation

Feedback on the adapted SPG was gathered during interviews with eligible healthcare professionals at The Ottawa Hospital. The hospital is a large academic teaching hospital in Canada, serving a population of 1.3 million people (Ontario Local Health Integration Network, 2014). Purposeful sampling was used, followed by snowball sampling (Polit & Beck, 2008). Those who were purposively sampled included oncology nurses/advanced practice nurses (APNs) (RN-onc) who were familiar with COSTaRS at The Ottawa Hospital Cancer Centre,

cardiology nurses/APNs (RN-cardiac), nurse practitioners (NPs) with a focus on cardio-oncology, and physicians (MDs) with an expertise in cardio-oncology from the Ottawa Cardiac Oncology Program.

Participants were interviewed using a semi-structured interview guide, as well as completing an acceptability survey. The interviewer guided the healthcare professional through the adapted SPG and invited the participant to provide feedback. During the interview, healthcare professionals were asked for their first impressions of the adapted SPG, their thoughts regarding its helpfulness for handling symptom calls from cardio-oncology patients, changes that should be made to ensure the SPG was more useful, and whether any cardiology guidelines were missed.

The acceptability survey was completed during the interview. The survey items, taken from previous surveys, were used for implementing COSTaRS in clinical practice and have demonstrated face validity (COStaRS, 2015; Stacey et al., 2015). Participants were asked to rate the amount of information on the adapted SPG, their comfort using the adapted SPG, referring the adapted SPG to others, and the comprehensiveness of the adapted SPG. Demographic information was also collected.

A researcher (FK) digitally recorded the interviews and took verbatim transcription of the recordings. This approach offers a highly rigorous data set with a low risk of error (Onwuegbuzie, Dickinson, Leech & Zoran, 2009). Iterative changes to the adapted SPG were made based on the feedback from the interviews and the acceptability survey.

Analysis

Quantitative findings from the acceptability survey were entered into a Microsoft Excel© spreadsheet and analyzed descriptively. Participant qualitative feedback from the interviews and

the open-ended survey questions were also analyzed descriptively, using data-driven codes rather than a pre-existing set of rules (Lambert & Lambert, 2012). One author (FK) independently performed the data analysis (Lambert & Lambert, 2012). The qualitative analysis findings were entered into a table to compare the similarities and differences across the interviews (Colorafi & Evans, 2016). To improve the rigor of the qualitative analysis findings, a second author (DS) audited the table (Cohen & Crabtree, 2008).

Results

Systematic Search to Identify Cardiology Evidence

A total of 490 citations were identified for cardiology-related dyspnea (see Figure 4.1). Grey literature searches, including the guideline clearinghouse and websites from cardiac or cardiac-related organizations, identified an additional 13 guidelines. Of the 35 full-text articles screened, seven guidelines for HF were included (see Table 4.3). The 28 excluded articles were not systematic reviews or guidelines (*n*=12), had no dyspnea-related assessment, triage or self-care items (*n*=11), not for adults (*n*=3), a protocol (*n*=1), and for pulmonary hypertension (*n*=1) (see Appendix J). The eligible HF guidelines were found in peer-reviewed publications (*n*=4), and on websites of national cardiology organizations (*n*=3). The AGREE II domain of rigour of development had a median score of 71% (range 23% to 92%).

Adapting the Dyspnea Symptom Practice Guide

Evidence from seven clinical guidelines was added to the original COSTaRS Dyspnea SPG. Four reviewers (FK, DS, SC, MC) further modified the adapted SPG prior to participant evaluation. These initial changes included: removing assessment items recommended for symptoms of HF not specific to dyspnea (e.g. vomiting/diarrhea, feelings of dizziness or lightheaded, feelings of confusion, and feelings of syncope); removing medications

recommended for symptoms of HF not seen as specific for managing dyspnea (e.g. angiotensin-converting enzyme inhibitor, beta-blockers, digoxin, etc.); and removing the self-care recommendation to have an annual influenza vaccine (see Table 4.4). To enhance ease of readability by healthcare professionals, colour-coding sections specific to *oncology*, *cardiology* and *both* was added, as well as groupings of the items together based on their originating guidelines (oncology, cardiology or both). The assessment items regarding chest pain remained separate as the item recommended by oncology guidelines focused on assessing for a pulmonary embolism, whereas the item recommended by HF guidelines focused on assessing for an acute coronary syndrome event.

Characteristics of Participants

Eleven healthcare professionals were interviewed including oncology nurses/APNs (n=4), cardiology nurses/APNs (n=4), and cardiologists with an expertise in cardio-oncology (n=3) (see Table 4.5)**.** The mean age of the participants was 47 years of age and 10 were female.

SPG Revisions

Three iterative revisions were made to the adapted SPG during the interviews based on participant feedback (see Table 4.6). The first revision included four changes. For example, the language used to assess patients for tachycardia was unclear. This was supported by the quote "*And then, I'm not sure how I would answer as a patient 'Do you have a fast heart beat that won't slow down?'"* (RN-onc.). The adapted SPG was therefore revised to replicate the language used in the BC Guidelines (2015), "Do you have a fast heartbeat that does not slow down when you rest?"

The second revision involved nine changes. For example, adding tick-boxes to indicate whether chest pain went away with either rest or medication, and adding space to write which

medication relieved the pain, if applicable. This was supported by the quote "*So should the clinician be able to, document whether the pain does subside with medication or with rest?"* (RN-cardiac.) The adapted SPG was therefore revised to "If you have chest pain, does it go away with: ☐ Rest or ☐ Medication?_____".

The third revision had four changes. For example, adding the assessment question regarding paroxysmal nocturnal dyspnea. This was supported by the quote "*I notice you don't ask about PND though in here, right?"* (MD.) The adapted SPG was therefore revised to "Are you waking up at night with shortness of breath?" (see Figure 4.2).

Adapted SPG Acceptability

Participants evaluated the acceptability of the adapted SPG during the interviews (see Tables 4.7 and 4.8). Most participants (n=10) found the SPG understandable and all participants stated they would be comfortable or very comfortable telling someone about the adapted SPG as a resource to assist adults with cardiotoxicity with the self-management of their dyspnea. Further suggestions included: (1) use the adapted SPG with cancer survivors in the primary healthcare setting; (2) develop a pocket version of the adapted SPG; and (3) make the adapted SPG into a mobile application.

First impressions of the healthcare professionals from the interviews were that the adapted SPG was comprehensive and easy to follow:

> *Very positive. I thought it was excellent. This cardio-oncology is all new to me. As I said I've never worked in it so I was really impressed there was a guide like this in place. I thought this was far more comprehensive, as I said, than the other one* [original COSTaRS Dyspnea SPG] *and easier to walk through with far more detail.* (RN-cardiac.)

Participants also liked having the evidence colour-coded and grouped together based on origin of the evidence:

> *…colour-coding, that was a smart thing to do. So then if it's anything like this you're going towards interventions for shortness of breath. And then if it's anything in there then you're going for interventions around cardiac toxicity?* (RN-onc.)

Participants further believed the adapted SPG would be helpful for handling symptom calls from patients with cardiotoxicity:

> *I think so. I absolutely do because I think whoever's on the other end, which will be an oncology nurse, but we have to realize that the, many of these patients are on potentially cardiotoxic treatments.* (MD.)

Discussion

The CAN-IMPLEMENT© methodology used for developing the original COSTaRS Dyspnea SPG was replicated when adapting the SPG to include cardiology guidelines. A systematic and rigorous approach was used to search and screen for available guidelines, to extract data using a recommendation matrix, and to be transparent in how the evidence was used to inform the adapted SPG. Participant feedback led to three iterative revisions of the adapted SPG. Participants found the adapted SPG understandable, comprehensive, easy to follow, and believed it would be helpful for handling symptom calls from patients with dyspnea due to cancer treatment-related cardiotoxicity. These findings lead to three areas of discussion.

First is the apparent lack of clinical guidelines or systematic reviews with available tools for nurses to assess, triage and/or offer self-care strategies to their patients with cardiotoxic-related symptoms. Cardio-oncology is a relatively new field of study. In the last year a small number of guidelines have been published, however, these guidelines tended to focus on the diagnosis and medical management of cardiotoxicity, rather than offer self-care management recommendations for nurses to support their patients with symptom management (Armenian et al., 2016; Chen et al., 2016; Virani et al., 2016; Zamorano et al., 2016). As a result, the scope for the systematic search for cardiology evidence was expanded to include HF guidelines. Nurses are

appropriate healthcare professionals who possess the requisite knowledge and skill to inform, motivate and assist patients in the successful self-management of their chronic illness, such as dyspnea related to long-term cardiotoxicity (Registered Nurses' of Ontario [RNAO], 2010). However, nurses require user-friendly evidence-informed tools to help them guide patients in self-management (RNAO, 2010).

Our study highlights the need for healthcare professionals, across areas of specialties, to collaborate and share their expertise. In the Ottawa Cardiac Oncology Program, physicians with expertise in cardiology and oncology collaborate to provide comprehensive cancer care while trying to avoid long-term cardiotoxicity related to cancer treatment (Barros-Gomes et al., 2016). However, the clinic does not have nurses available to respond to patient concerns regarding cardiotoxicity. Therefore, the nurses at The Ottawa Hospital who typically respond to telephone calls from patients experiencing cardiotoxic-related dyspnea are oncology nurses with limited cardiology knowledge. Nurses providing care to patients with cardiotoxic symptoms require additional, evidence-based cardiology knowledge to guide patients in their symptom management. Knowledge tools, like SPGs, can bridge this gap. Although the original COSTaRS Dyspnea SPG offered assessment, medication and self-care items based on oncology evidence, it neglected to include cardiology evidence, thereby overlooking recommendations for dyspnea management in the setting of cancer treatment-related cardiotoxicity. As cardiotoxicity commonly presents itself as HF, the need to safely triage symptoms, such as dyspnea, to the appropriate level of care is of particular importance. HF, regardless of its origin, is the leading cause of hospitalization for those 65 years of age and over, with each hospital admission costing between $6000 and $15,000 (Ratanawongsa et al., 2012). With the additional self-care strategies in the adapted SPG, oncology nurses may safely assist their patients in managing their dyspnea

in their home until they are able to appropriately see their healthcare provider. As oncology nurses may be the first line of contact for cancer patients, it is important that the self-care items they are offering patients are evidence-based, as represented by the adapted SPG.

Moreover, nurses require assistance to differentiate among the various causes of dyspnea in order to triage severity appropriately (Stein-Parbury & Liaschenko, 2007). As a first point of contact, participants in our study indicated the importance of using the assessment questions to assist oncology nurses in differentiating among the various causes of dyspnea, thereby allowing them to appropriately triage their patients. It has been previously described that collaboration between nurses and physicians is strengthened when nurses' concerns are based on case knowledge, the scientifically established knowledge that allows physicians to make medical diagnoses (Stein-Parbury & Liaschenko, 2007). The colour-coding sections specific to *oncology*, *cardiology* and *both*, changed to symbols in the third revision, was highly rated by participants as it allowed clearer guidance with regards to which questions indicated a cardiac cause of dyspnea versus other potential causes of dyspnea (i.e., infection, anemia, pulmonary embolism, etc.). As patients treated for cancer may experience a number of symptoms from a multitude of causes, nurses require support in differentiating among such causes in order to safely triage patients over the phone.

Strengths and Limitations

To improve quality and reduce the risk of bias: (a) the protocol for the systematic review was developed a priori; (b) a comprehensive search of four electronic databases and grey literature was conducted; and (c) two reviewers screened the identified literature and appraised the quality of the included studies (Higgins & Green, 2011; Moher et al., 2015; Shea et al., 2007).

Semi-structured interviews were used to introduce participants to the adapted SPG and offered participants the freedom to respond to questions in their own words with as much detail as they desired (Onwuegbuzie et al., 2009; Polit & Beck, 2008). We were able to interview various healthcare professionals, however were unable to recruit an oncology nurse who specialized in cardio-oncology, given the novelty of this sub-specialty.

Conclusion

Guided by the CAN-IMPLEMENT© methodology, it was possible to adapt the original COSTaRS Dyspnea SPG by adding evidence from seven HF guidelines. User-centered feedback led to the adapted SPG being iteratively revised three times during the interviews. Healthcare professionals found the adapted SPG comprehensive and easy to follow, and believed it would be useful in clinical practice. Further research should focus on evaluating the adapted SPG in clinical practice and on creating a version for patients experiencing cancer treatment-related cardiotoxicity.

Abbreviations

AGREE: Appraisal of Guidelines for Research and Evaluation

APN: advanced practice nurse

COSTaRS: pan-Canadian Oncology Symptom Triage and Remote Support

HF: heart failure

MD: physician

NP: nurse practitioner

PIPOH: Population, Intervention, Professionals/Patients, Outcomes and Health Care Setting

PRISMA: Preferred Reporting Items for Systematic Reviews and Meta-Analyses

RN-cardiac: cardiac registered nurses/advanced practice nurse

RN-onc: oncology registered nurse/advanced practice nurse

RNAO: Registered Nurses' Association of Ontario

SPG: symptom practice guide

Declarations

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Availability of Data and Materials

The datasets used and/or analyzed during the current study are available from the corresponding author on reasonable request.

Authors' Contributions

FK and DS conceived the study. FK and DS wrote the manuscript. RS developed the search strategy. FK and DS performed three levels of screening. FK and JH appraised the included guidelines. FK extracted data from the included guidelines. MC audited the extracted data. FK developed the adapted SPG. FK, DS, SC and MC reviewed the adapted SPG prior to user-centered feedback. FK performed the interviews and analyzed the data. DS audited the qualitative analysis findings. All authors reviewed and approved of the final manuscript.

Ethics Approval and Consent to Participate

Ethics approval was received from the Ottawa Health Science Network Research Ethics Board (20160752-01H) and the University of Ottawa Research Ethics Board (A12-16-02). All participants provided written informed consent.

Consent for Publication

Not applicable.

Competing Interests

The authors declare that they have no competing interest.

References

The ADAPTE Collaboration. (2009). *The ADAPTE process: Resource toolkit for guideline adaptation. Version 2.0.* Retrieved from http://www.g-i-n.net.

American Thoracic Society. (1999). Dyspnea. Mechanisms, assessment, and management: A consensus statement. *American Journal of Respiratory and Critical Care Medicine, 159*(1): 321 – 340. doi: 10.1164/ajrccm.159.1.ats898

Armenian S., Lacchetti C., Barac A., Carver J., Constine L., Denduluri N., Dent S., Douglas P., Durand J., Ewer M., Fabian C., Hudson M., Jessup M., Jones L., Ky B., Mayer E., Moslehi J., Oeffinger K., Ray K., Ruddy K. & Lenihan D. (2016). Prevention and monitoring of cardiac dysfunction in survivors of adults cancers: American society of clinical oncology clinical practice guideline. *Journal of Clinical Oncology, 35*(8): 893 – 911. doi: 10.1200/JCO.2016.70.5400

Barbera L., Seow H., Howell D., Sutradhar R., Earle C., Liu Y., Stitt A., Husain A., Sussman J. & Dudgeon D. (2010). Symptom burden and performance status in a population-based cohort of ambulatory cancer patients. *Cancer, 116*(24): 5767 – 5776. doi: 10.1002/cncr.25681

Barros-Gomes S., Herrmann J., Mulvagh S., Lerman A., Lin G. & Villarraga H. (2016). Rationale for setting up a cardio-oncology unit: Our experience at Mayo Clinic. *BioMed Central, 2*(5): 1 – 9. doi: 10.1186/s40959-016-0014-2

Bashi N., Karunanithi M., Fatehi F., Ding H. & Walters D. (2017). Remote monitoring of patients with heart failure: An overview of systematic reviews. *Journal of Medical Internet Research, 19*(1): e18. doi: 10.2196/jmir.6571

BC Guidelines. (2015). Chronic heart failure – Diagnosis and management. Retrieved from http://www2.gov.bc.ca/assets/gov/health/practitioner-pro/bc-guidelines/chronicheartfailure_full.pdf

Behl D., Hendrickson A. & Moynihan T. (2010). Oncology emergencies. *Critical Care Clinics, 26*(1): 181 – 205. doi: 10.1016/j.ccc.2009.09.004

Brouwers M., Kho M., Browman G., Burgers J., Cluzeau F., Feder G., Fervers B., Graham I., Hanna S., Makarski J. & AGREE Next Steps Consortium. (2010b). Development of the AGREE II, part 2: Assessment of validity of items and tools to support application. *Canadian Medical Association Journal, 182*(10): E472 – E478. doi: 10.1503/cmaj.091716

Brouwers M., Kho M., Browman G., Burgers J., Cluzeau F., Feder G., Fevers B., Graham I., Grimshaw J., Hanna S., Littlejohns P., Makarski J., Zitzelsberger L. & AGREE Next Steps Consortium. (2010a). AGREE II: Advancing guideline development, reporting and evaluation in health care. *Canadian Medical Association Journal, 182*(18): E839 – E42. doi: 10.1503/cmaj.090449

Chen J., Wu P.T., Middlekauff H. & Nguyen K.L. (2016). Aerobic exercise in anthracycline-induced cardiotoxicity: A systematic review of current evidence and future directions. *American Journal of Physiology. Heart and Circulatory Physiology.* doi: 10.1152/ajpheart.00646.2016

Cohen D. & Crabtree B. (2008). Evaluative criteria for qualitative research in health care: Controversies and recommendations. *Annals of Family Medicine, 6*(4): 331 – 339. doi: 10.1370/afm.818

Colorafi K. & Evans B. (2016). Qualitative descriptive methods in health science research. *Health Environments Research & Design Journal, 9*(4): 16 – 25. doi: 10.1177/1937586715614171.

Cox K. & Wilson E. (2003). Follow-up for people with cancer: Nurse-led services and telephone interventions. *Journal of Advanced Nursing, 43*(1): 51 – 61.

Daher I., Daigle T., Bhatia N. & Durand J. (2012). The prevention of cardiovascular disease in cancer survivors. *Texas Heart Institute Journal, 39*(2): 190 – 198.

Ferrante D., Virani S., Macchia A., Soifer S., Badra R., Nul D., Grancelli H., Doval H. & GESICA Investigators. (2010). Long-term results after a telephone intervention in chronic heart failure: DIAL (Randomized Trial of Phone Intervention in Chronic Heart Failure) follow-up. *Journal of the American College of Cardiology, 56*(5): 372 – 378. doi: 10.1016/j.jacc.2010.03.049

GESICA Investigators. (2005). Randomized trial of telephone intervention in chronic heart failure: DIAL trial. *British Medical Journal, 331*(7514): 425.

Harrison M., van den Hoek J. & Graham I. (2014). *Can-Implement©: Planning for best-practice implementation.* Philadelphia, PA: Lippincott Williams & Wilkins.

Henry D., Viswanathan H., Elkin E., Traina S., Wade S. & Cella D. (2008). Symptoms and treatment burden associated with cancer treatment: Results from a cross-sectional national survey in the US. *Supportive Care in Cancer, 16*(7): 791 – 801. doi: 10.1007/s00520-007-0380-2

Hewitt M., Greenfield S. & Stovall E. (Eds.). (2005). *From cancer patient to cancer survivor: Lost in Transition.* Washington, DC: National Academies Press.

Higgins J. & Green S. (Eds.). (2011). *Cochrane handbook for systematic reviews of interventions version 5.1.0 [updated March 2011]*. The Cochrane Collaboration. Available from: www.handbook.cochrane.org.

Keefe D. (2002). Trastuzumab-associated cardiotoxicity. *Cancer, 95*(7): 1592 – 1600.

Lambert V. & Lambert C. (2012). Editorial: Qualitative descriptive research: An acceptable design. *Pacific Rim International Journal of Nursing Research, 16*(4): 255 – 256.

Lewis S., Dirksen S., Heitkemper M., Bucher L. & Camera I. (2014). Medical-Surgical Nursing in Canada. Toronto, Ontario: Elsevier Mosby.

Moher D., Liberati A., Tetzlaff J., Altman D. & The Prisma Group. (2009). Preferred reporting items for systematic reviews and meta-analysis: The PRISMA statement. *Public Library of Science Medicine, 3*(2): 123 – 130. doi: 10.1371/journal.pmed.1000097

Moher D, Shamseer L, Clarke M, et al. Preferred reporting items for systematic review and meta-analysis protocols (PRISMA-P) 2015 statement. *Syst Rev* 2015; *4*(1). doi: 10.1186/2046-4053-4-1

Ontario Local Health Integration Network. (2014). *Champlain LHIN: Introduction.* Retrieved from http://www.champlainlhin.on.ca/AboutUs/Intro.aspx

Onwuegbuzie, A., Dickinson, W., Leech, N. & Zoran, A. (2009). A qualitative framework for collecting and analyzing data in focus group research. *International Journal of Qualitative Methods, 8*(3): 1 – 21. doi: 10.1177/160940690900800301

pan-Canadian Oncology Symptom Triage and Remote Support (COSTaRS). (2015). *Factors influencing nurses using symptom practice guides for remote support of patients undergoing cancer treatments. Baseline survey.* Retrieved from http://www.ktcanada.ohri.ca/costars/docs/Baseline_Barriers_Survey.pdf

Peters M., Godfrey C., Khalil H., McInerney P., Parker D. & Soares C. (2015). Guidance for conducting systematic scoping reviews. *International Journal of Evidence-Based Healthcare, 13*(3): 141 – 146. doi: 10.1097/XEB.0000000000000050

Polit, D. & Beck, C. (2008). *Nursing research: Generating and assessing evidence for nursing practice.* (8th ed.). Philadelphia: Lippincott Williams & Wilkin

Ratanawongsa N., Bhandari V., Handley M., Rundall T., Hammer H. & Schillinger D. (2012). Primary care provider perceptions of the effectiveness of two self-management support programs for vulnerable patients with diabetes. *Journal of Diabetes Science and Technology, 6*(1): 116 – 124. doi: 10.1177/193229681200600114

Registered Nurses' Association of Ontario. (2010). *Strategies to support self-management in chronic conditions: Collaboration with clients.* Retrieved from http://rnao.ca/sites/rnao-ca/files/Strategies_to_Support_Self-Management_in_Chronic_Conditions_-_Collaboration_with_Clients.pdf

Sarna L., Evangelista L., Tashkin D., Padilla G., Holmes C., Brecht M. & Grannis F. (2004). Impact of respiratory symptoms and pulmonary function on quality of life of long-term survivors of non-small cell lung cancer. *Chest, 125*(2): 439 – 445.

Shea B., Grimshaw J., Wells G., Boers M., Andersson N., Hamel C., Porter A., Tugwell P., Moher D. & Bouter L. (2007). Development of AMSTAR: A measurement tool to assess the methodological quality of systematic reviews. *BMC Medical Research Methodology, 15*(7): 10. doi: 10.1186/1471-2288-7-10

Stacey D., Bakker D., Green E., Zanchetta M. & Conlon M. (2007). Ambulatory oncology nursing telephone services: A provincial survey. *Canadian Oncology Nursing Journal, 17*(4): 1 – 5.

Stacey D., Carley M., Ballantyne B., Skrutkowski M., Whynot A., pan-Canadian Oncology Symptom Triage and Remote Support COSTaRS Team. (2015). Perceived factors influencing nurses' use of evidence-informed protocols for remote cancer treatment-related symptom management: A mixed methods study. *European Journal of Oncology Nursing, 19*(3): 268 – 277. doi: 10.1016/j.ejon.2014.11.002

Stacey D., Green E., Ballantyne B., Tarasuk J., Skrutkowski M., Carley M., Chapman K., Kuziemsky C., Kolari E., Sabo B., Saucier A., Shaw T., Tardif L., Truant T., Cummings G. & Howell D. (2016). Implementation of symptom protocols for nurses providing telephone-based cancer symptom management: A comparative case study. *Worldviews on Evidence-Based Nursing, 13*(6): 420 – 431. doi: 10.1111/wvn.12166

Stacey D., Macartney G., Carley M., Harrison M. & The Pan-Canadian Oncology Symptom Triage and Remote Support Group. (2013). Development and evaluation of evidence-informed clinical nursing protocols for remote assessment, triage and support of cancer treatment-induced symptoms. *Nursing Research and Practice, 2013*(171872). doi: 10.1155/2013/171872

Stacey D., Skrutkowski M., Ballantyne B., Carley M., Kolari E. & Shaw T. for the Pan-Canadian Oncology Symptom Triage and Remote Support (COSTaRS) Team. (2014). Translating evidence from guidelines for remote symptom assessment, triage and support: COSTaRS Workshop for Nurses. University of Ottawa School of Nursing and the Ottawa Hospital Research Institute, Ottawa, Ontario, Canada.

Stein-Parbury J. & Liaschenko J. (2007). Understanding collaboration between nurses and physicians as knowledge at work. *Challenges in the Critical Care Workplace, 16*(5): 470 – 477.

Vandyk A., Harrison M., Macartney G., Ross-White A. & Stacey D. (2012). Emergency department visits for symptoms experienced by oncology patients: A systematic review. *Supportive Care in Cancer, 20*(8): 1589 – 1599. doi: 10.1007/s00520-012-1459-y

Virani S., Dent S., Brezden-Masley C., Clarke B., Davis M., Jassal D., Johnson C., Lemieux J., Paterson I., Sebag I., Simmons C., Sulpher J., Thain K., Thavendiranathan P., Wentzell J. & Wurtele N. (2016). Canadian cardiovascular society guidelines for evaluation and management of cardiovascular complications of cancer therapy. *Canadian Journal of Cardiology, 32*(2016): 831 – 841. doi: 10.1016/j.cjca.2016.02.078

Witte K. & Clark A. (2007). Why does chronic heart failure cause breathlessness and fatigue? *Progress in Cardiovascular Diseases, 49*(5): 366 – 384. doi: 10.1016/j.pcad.2006.10.003

Zamorano J., Lancellotti P., Rodriguez Muñoz D., Aboyans V., Asteggiano R., Galderisi M., Habib G., Lenihan D., Lip G., Lyon A., Lopez Fernandez T., Mohty D., Piepoli M., Tamargo J., Torbicki A., Suter T., Authors/Task Force Members, ESC Committee for Practice Guidelines (CPG). (2016). 2016 ESC position paper on cancer treatments and cardiovascular toxicity developed under the auspices of the ESC committee for practice guidelines: The task force for cancer treatments and cardiovascular toxicity of the European Society of Cardiology (ESC). *Eur Heart J* , 37(36): 2768 – 2801. doi: 10.1093/eurheartj/ehw211

Table 4.1. The search strategy used for Medline.

1	Exp Neoplasms/ and Survivors/
2	(cancer adj10 survivor*).tw.
3	1 or 2
4	Cardiotoxicity
5	Exp cardiomyopathies/ci [Chemically Induced]
6	(cardiotoxic* or card* toxic*).tw.
7	4 or 5 or 6
8	3 and 7
9	Guideline/ or practice guideline/
10	Guidelines as topic/ or practice guidelines as topic/
11	(guideline or practice guideline or consensus development conference or consensus development conference, NIH).pt.
12	(position statement* or policy statement* or practice parameter* or best practice*).tw.
13	(standards or guideline or guidelines).ti.
14	((practice or treatment* or clinical) adj guideline*).ab.
15	(CPG or CPGs).ti.
16	Consensus*.ti.
17	((critical or clinical or practice) adj2 (path or paths or pathway or pathways or protocol*)).tw.
18	(care adj2 (standard or path or paths or pathway or pathways or map or maps or plan or plans)).tw.
19	Clinical protocols/
20	Critical pathways/
21	Consensus/
22	(MEDLINE or systematic review).tw. or meta analysis.pt.
23	Or/9-22
24	8 and 23
25	7 and 22

Table 4.2. The eligibility criteria for the symptom practice guide – dyspnea.

	Inclusion	**Exclusion**
Population	Adults, defined as 18 years of age or older, with cardiotoxicity and/or heart failure.	Children aged 17 years of age or younger.
Intervention	Cardiac related symptom intervention to assess, rate severity, or manage dyspnea.	--
Professionals targeted	Nurses and other healthcare professionals working in oncology and/or cardiology services.	--
Outcomes	Appropriate referrals for medical consultation, safe management of symptoms, and patients guided in self-care.	--
Healthcare setting	Telephone patients at home receiving services through an ambulatory oncology program.	--
Methodology	Clinical practice guideline Systematic review	Randomized control trial Cohort study Pre-/post-test study Case-control study Cross-sectional study Case reports and series Editorials, Opinions
Language	Any	--
Publication Dates	2010 or later	Prior to 2010

Figure 4.1. The PRISMA flow diagram.

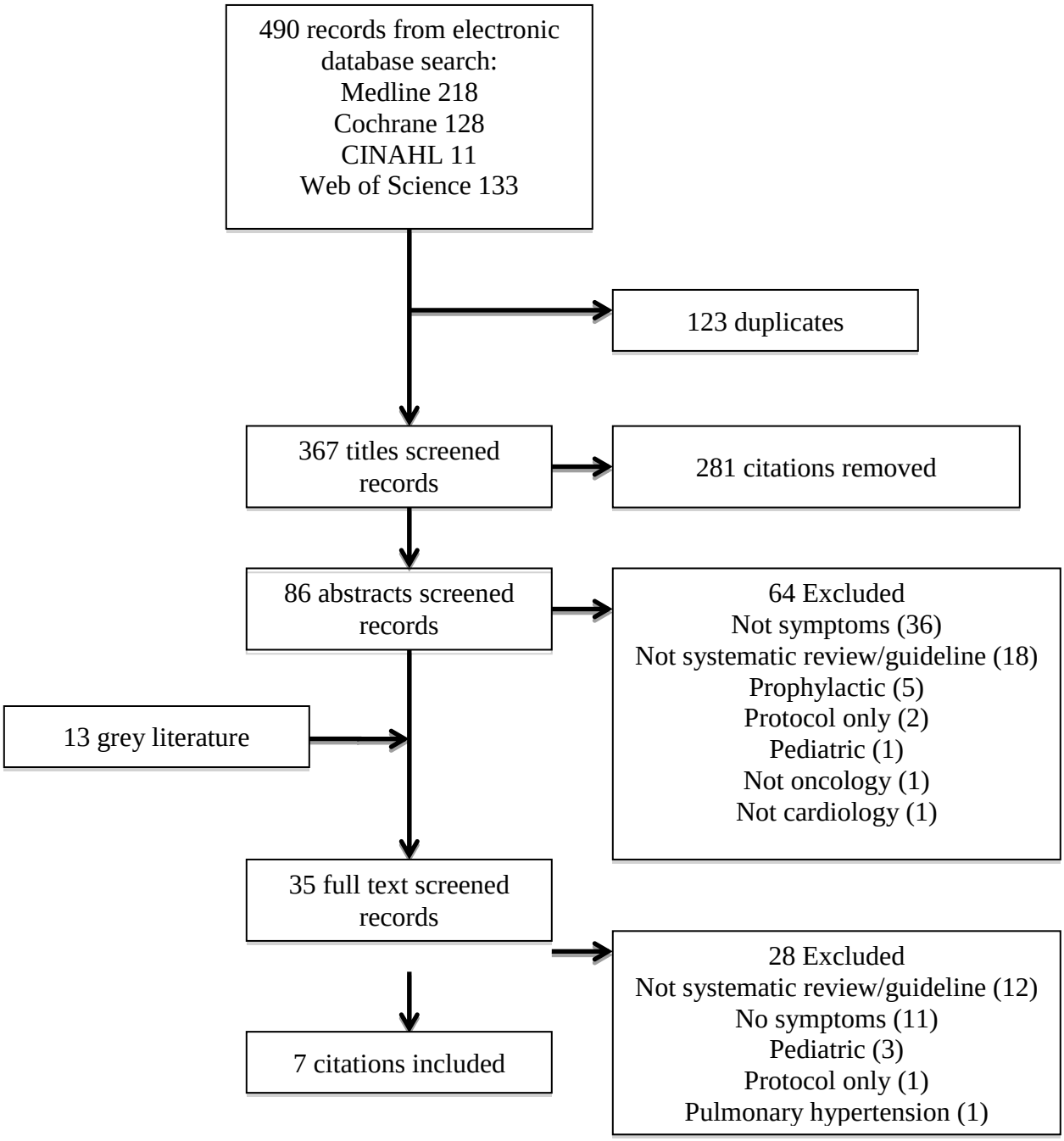


Table 4.3. Characteristics of included guidelines (n=7).

Author	Country	Year	Title	Quality Rating* (%)
British Columbia Guidelines	Canada	2015	Chronic Heart Failure – Diagnosis and Management	23
SIGN	Scotland	2016	Management of Chronic Heart Failure	92
Canadian Cardiovascular Society	Canada	2012	The 2012 Canadian Cardiovascular Society Heart Failure Management Guidelines Update: Focus on Acute and Chronic Heart Failure	71
American College of Cardiology Foundation and the American Heart Association	USA	2013	2013 ACCF/AHA Guideline for the Management of Heart Failure	81
American College of Cardiology, the American Heart Association and the Heart Failure Society of America	USA	2016	2016 ACC/AHA/HFSA Focused Update on New Pharmacological Therapy for Heart Failure: An Update of the 2013 ACCF/AHA Guideline for the Management of Heart Failure.	83
National Heart Foundation of Australia	Australia	2011	Guidelines for the Prevention, Detection and Management of Chronic Heart Failure in Australia	62
European Society of Cardiology	Poland	2016	2016 ESC Guidelines for the Diagnosis and Treatment of Acute and Chronic Heart Failure	54

* Quality rating for AGREE II domain of rigour development.

Table 4.4. Excluded items from the included heart failure guidelines (n=7).

Item	BC, 2015	SIGN, 2016	CCS, 2012	ACCF & AHA, 2013	ACCF & AHA, 2016	NHF, 2011	ESC, 2016	Exclusion Reason
Assessment								
Vomiting/diarrhea	X							Not specific assessment for dyspnea, but rather due to congestion around the liver and intestines due to HF.
Dizziness/Lightheaded	X						X	Not specific assessment for dyspnea, but rather poor circulation to the brain due to HF.
Confused/confusion	X	X					X	Not specific assessment for dyspnea, but rather poor circulation to the brain due to HF; changes in serum sodium.
Syncope/Fainting	X	X					X	Not specific assessment for dyspnea, but rather poor circulation to the brain due to HF
Medications								
Nitrates			X			X		Not specific to dyspnea but rather for heart failure
Angiotensin converting enzyme inhibitor (ACE-I) or angiotensin receptor blockers (ARBs)	X	X	X	X	X	X	X	Not specific to dyspnea but rather for HF.
Beta-blockers (BBs)	X	X	X	X		X	X	Not specific to dyspnea but rather for HF.
Mineralocorticoid receptor antagonists (MRAs)	X	X	X					Not specific to dyspnea but rather for HF.

Item	BC, 2015	SIGN, 2016	CCS, 2012	ACCF & AHA, 2013	ACCF & AHA, 2016	NHF, 2011	ESC, 2016	Exclusion Reason
Digoxin	X		X	X		X		Not specific to dyspnea but rather for HF.
Hydralazine and isosorbide dinitrate				X		X		Not specific to dyspnea but rather for HF.
Omega-3 fatty acids				X		X		Not specific to dyspnea but rather for HF.
Angiotensin receptor-neprilysin inhibitor (valsartan/sacubitril)					X			Not specific to dyspnea but rather for HF.
Self-Care Management								
Annual influenza vaccine	X							Not helpful for patient to self-manage dyspnea they are currently experiencing when they are calling in to nurses.

BC – British Columbia; CCS – Canadian Cardiovascular Society; ACCF – American College of Cardiology Foundation; AHA – American Heart Association; NHF – National Heart Foundation of Australia; ESC – European Society of Cardiology

Table 4.5. Demographic characteristics of participants (n=11).

Characteristics	Oncology Nurses (n=4)	Cardiology Nurses (n=4)	Cardiologists (n=3)
Age (in years)			
30 – 39	0	2	0
40 – 49	1	1	2
50 – 59	1	1	0
60 – 69	0	0	1
Sex			
Female	4	4	2
Male	0	0	1
Highest level of education:			
Undergraduate degree	1	0	0
Graduate degree	3	4	0
Medicinae Doctor	0	0	3
Role			
Physician	0	0	3
Registered nurse	1	1	0
Advanced practice nurse	1	2	0
Nurse educator	2	1	0
Hours worked			
Full time	3	3	2
Regular part-time	1	0	1
Casual	0	1	0
Length in current position			
1 – 2 years	1	2	0
3 – 5 years	0	0	0
6 – 10 years	2	1	0
≥ 10 years	1	1	3

Table 4.6. Revisions to adapted SPG.

Participant Comment	Supporting Quotations	Revision
Revision #1		
Chest pain question appears as two separate questions, rather than linked together.	*"So it's not an automatic question if somebody says no I don't have chest pain, then you're not gonna ask them that question"* RN-onc	Revised to "If you have chest pain, does it go away with rest or medication?"
Language used to assess for patients tachycardia is unclear.	*"And then, I'm not sure how I would answer as a patient 'Do you have a fast heart beat that won't slow down?'"* RN-onc	Revised to "Do you have a fast heartbeat that does not slow down when you rest?"
Self-care strategy for limiting sodium and fluid intake has unfamiliar units (self-care strategies number 11 and 12).	*"I would have no idea as a layperson if I, when I see less than 2000mg a day."* RN-cardiac "*Have you tried limiting your salt intake to, this is a funny number, right? What is 0.4 of a teaspoon of salt?*" MD	Revised to "Have you tried limiting your salt intake to under half a teaspoon (under 2000 mg) per day?" and "Are you aiming for a fluid intake of 6 to 8 cups (1.5 to 2 litres) per day?"
Lacking an assessment of smoking and drinking prior to offering self-care strategy (self care strategy numbers 13 and 14).	*" 'Have you tried to stop, uh, to stop smoking or drinking?' Well how do you know that I do?"* RN-onc	Revised to "If you smoke, have you tried to stop?" and "If you drink more than 1 – 2 standard alcoholic drinks per day, have you tried to reduce your alcohol intake to 1 drink per day?"
Revision #2		
Lacking something in the title to differentiate adapted SPG from original COSTaRS SPG.	*"even just reflecting in the title of the practice guide that this one would be related to cardiotoxicity."* RN-cardiac	Revised to "Breathlessness/Dyspnea Practice Guide: Cardiotoxicity"
Missing a way for the nurse to document whether chest pain has gone away with rest and/or medication, and which medication relieved the pain.	*"so should the clinician be able to, to uh, document whether the pain does subside with medication or with rest?"* RN-cardiac	Revised to "If you have chest pain, does it go away with: ☐ Rest or ☐ Medication?_____"
Missing a way for the nurse to document how many pillows the patient has increased for sleeping.	*"is it important to note the number of pillows that they have increased?"* RN-cardiac	Revised to "Have you increased the number of pillows you need to sleep? Increase in number of pillows:_____"

Participant Comment	**Supporting Quotations**	**Revision**
Missing space for the nurse to document the patient's description of their dyspnea.	*"So is this space intended for the description?"* RN-cardiac	Revised to "Does your shortness of breath interfere with your daily activities at home and/or at work? Describe:"
Unclear what the coloured boxes are.	*"You might even have a little title that says legend"* RN-cardiac	Revised to "**Legend:** ♥ Cardiology ★ Cardiology and Oncology"
Self-care strategy suggesting exercise requires emphasis on symptom stability.	*"And so, perhaps to start the question, uh, state, when breathlessness is stable."* RN-cardiac	Revised to "When breathlessness is stable, have you tried 30 minutes of exercise at least twice a week?"
Lacking space for the nurse to document.	*"I often think of as, the whiteness being paper real-estate"* RN-cardiac	Revised to make margins smaller around document.
Unsure if patient would remember how many pillows they have increased from their baseline.	*"if there was a baseline I like the idea of that"* RN-cardiac	Revised to "Baseline #:_____" and "Current #:_____"
Lacking space in the self-care strategy for weight management to document the patients' weight at the time of the call (self-care strategy number 16).	*"the last time you called your weight was"* RN-cardiac	Revised to "Are you weighing yourself daily (after waking and voiding, before dressing and eating)? Weight_____"
Revision #3		
Missing assessing for paroxysmal nocturnal dyspnea.	*"I notice you don't ask about PND though in here, right?"* MD	Revised to "Are you waking up at night with shortness of breath?"
Lacking space for nurse to document if patient is unsure whether he/she have gained or lost weight at time of the call.	*"I find that unless they know about heart failure and you've had, they've already had teaching on it they're probably not weighing themselves everyday"* MD	Revised to "Have you gained or lost weight in the last week? ☐ Unsure"
Lacking nitrates to assist with dyspnea.	*"nitrates also help heart failure so"* MD	Revised to "Nitrates – Benefits Balanced With Harm"

Participant Comment	**Supporting Quotations**	**Revision**
Printer only prints in black-and-white rather then in colour.	*"and then I saw the colours because this I thought, my first comment was 'What's this?'"* RN-onc	Revised to ♥ for cardiology evidence, and ★ for both cardiology and oncology evidence

RN-onc = oncology registered nurse/advanced practice nurse; RN-cardiac = cardiology registered nurse/advanced practice nurse; MD = physician

Figure 4.2 Breathlessness/Dyspnea Practice Guide: Cardiotoxicity

Breathlessness/Dyspnea: A subjective experience described as breathing discomfort of varying intensities.[1-4] Includes descriptors such as hard to breathe, feeling smothered, tightness in chest, unable to catch breath, panting, gasping.

1. Assess severity of the breathlessness (Supporting evidence: 6 guidelines)[2,3,6,7,9,12]

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 [5(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

Which of the following are present or absent						
Patient rating (see ESAS above)[3,5]	1-3	☐	4-6	☐	7-10	☐
Patient rating of worry about shortness of breath (see above)[2]	0-5	☐	6-10	☐		
Do you pause while talking every 5-15 seconds?[3]	No	☐			Yes	☐
Is your breathing noisy, rattily or congested?[3]	No	☐			Yes	☐
Do you wake suddenly with shortness of breath?[3,7,12]	No	☐			Yes	☐
Do you have a fever > 38º C?[3] ☐Unsure	No	☐			Yes, with breathlessness	☐
Do you have chest pain or pain in your chest when you breathe?[3]	No	☐			Yes	☐
♥ If you have chest pain, does it go away with: ☐ Rest or ☐ Medication?[6] _____	Yes	☐			No	☐
♥ With what level of activity do you have shortness of breath?[7,9,12]	Moderate activity	☐	Mild activity	☐	At rest	☐
♥ Do you have any other symptoms? ☐ Fatigue[6,12]	No	☐	Yes, some	☐	Yes, often	☐
♥ Have you gained or lost weight in the last week?[6,7,9,12] ☐ Unsure	No	☐	Gained (≥4 lbs in 2 days; 5lbs in 1 week)	☐	Gained or lost (≥5lbs in 2 days)	☐
♥ Do you have a cough?[6, 7,12]	No	☐	Yes (dry)	☐		☐
♥ Are you waking up at night with shortness of breath?[6,7,11,12]	No	☐	Yes	☐		
♥ Have you increased the number of pillows you need to sleep?[6,7,12] Baseline #:_____Current #:_____	No	☐	Yes	☐	Need to sleep in a chair	☐
♥ Do you have swelling in your hands, ankles, feet, legs or stomach?[6,7,12]	No	☐	Yes, some		Yes, significantly	☐
♥ Do you have a fast heartbeat that does not slow down when you rest?[6, 7,12]	No	☐			Yes	☐
♥ Does your shortness of breath interfere with your daily activities at home and/or at work?[6] Describe:	No	☐	Yes, some	☐	Yes, significantly	☐
	1 **Mild** (Green)		2 **Moderate** (Yellow)		3 **Severe** (Red)	
2. Triage for symptom management based on highest severity (Supporting evidence: 2 guidelines)[3,6]	☐ Try self-care strategies ☐ Ensure medication use is appropriate.		☐ Try self-care strategies ☐ Ensure medication use is appropriate ☐ Contact healthcare provider if symptom worsens, new symptoms occur, or no improvement in 12-24 hours.		☐ Seek medical attention immediately.	

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

Additional comments:

Legend: ♥ Cardiology ★ Cardiology and Oncology

3. Review medications for shortness of breath, including prescribed, over the counter, and/or herbal supplements (Supporting evidence: 8 guidelines)[1-3, 6-9, 11]

Current use	Examples of medications for shortness of breath*	Notes (e.g. dose, suggest to use as prescribed)	Evidence
☐	Oxygen[1,2]		Expert Opinion
☐	★ Immediate-release oral or parenteral opioids[2,3, 7]		Effective
☐	♥ Diuretics[6-9, 11]		Recommended for Practice
☐	♥ Nitrates[8,13]		Benefits Balanced With Harm

* Palliative oxygen is not recommended[1,7-9]

† Patient may be prescribed other medications for his/her heart failure[6-12]

4. Self-care strategies (Supporting evidence: 8 guidelines)[1,3,4,6,7,9,11,12]

Patient already uses	Strategy suggested/ education provided	Patient agreed to try	**Self-care strategies**
1.			★ What is your goal for managing when you feel short of breath?
2. ☐	☐	☐	★ What helps when you are short of breath? Reinforce as appropriate. Specify:
3. ☐	☐	☐	Have you tried to use a fan or open window to increase air circulation directed at your face?[1]
4. ☐	☐	☐	Have you tried to turn down the temperature in your house?[1,3]
5. ☐	☐	☐	Are you trying to rest in upright positions that can help you breath?[1,3]
6. ☐	☐	☐	Are you trying different relaxation and breathing exercises (e.g. diaphragmatic breathing, pursed lip breathing)?[1,3,4]
7. ☐	☐	☐	If you have a wheelchair, portable oxygen or walking aids, are you trying to use them to help with activities that cause your shortness of breath?[1,4]
8. ☐	☐	☐	If you have difficulty eating, are you taking nutrition supplements[1]
9. ☐	☐	☐	Would more information about your symptoms help you to manage them better? If yes, provide appropriate information or suggest resources. [1,3]
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)
11. ☐	☐	☐	♥Have you tried limiting your salt intake to under 1/2 tsp. (under 2000 mg) per day?[6,9,11,12]
12. ☐	☐	☐	♥ Are you aiming for a fluid intake of 6 to 8 cups (1.5 – 2 litres) per day?[6,9,11,12]
13. ☐	☐	☐	♥ If you smoke, have you tried to stop?[6,7,11,12]
14. ☐	☐	☐	♥ If you drink more than 1 – 2 standard alcoholic drinks per day, have you tried to reduce your alcohol intake to 1 drink per day? [6,7,11,12]
15. ☐	☐	☐	♥ When breathlessness is stable, have you tried 30 minutes of exercise at least twice a week?[6,11,12]
16. ☐	☐	☐	♥ Are you weighing yourself daily (after waking and voiding, before dressing and eating)?[6,7,9, 12] Weight_____
17. ☐	☐	☐	♥ Have you been referred to the Ottawa Cardiac Oncology Program?

5. Summarize and document plan (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:
☐	Advise to call back in 12-24 hours if no improvement, symptom worsens, or new symptoms occur

Name	**Signature**	**Date**

Legend: ♥ Cardiology ★ Cardiology and Oncology

Figure 4.2 References

Oncology Guidelines
1. Oncology Nursing Society (ONS). Putting evidence into practice (PEP): Dyspnea. 2014. PEP Topic updated August 25, 2014: https://www.ons.org/practice-resources/pep/dyspnea

2. Dy SM, et al. Evidence-based recommendations for cancer fatigue, anorexia, depression, and dyspnea. J Clin Oncol 2008 Aug 10;26(23):3886-95.

3. Cancer Care Ontario. Symptom Management Guide-to-Practice: Dyspnea. Toronto, Ontario, Canada; 2010.

4. Bausewein C, et al. Non-pharmacological interventions for breathlessness in advanced stages of malignant and non-malignant diseases. Cochrane Database Syst Rev 2008;(2):CD005623.

5. Bruera E, et al. The Edmonton Symptom Assessment System (ESAS): a simple method for the assessment of palliative care patients. J Palliat Care 1991;7(2):6-9.

Cardiology Guidelines
6. BC Guidelines. (2015). Chronic heart failure – Diagnosis and management. Retrieved from http://www2.gov.bc.ca/assets/gov/health/practitioner-pro/bc-guidelines/chronicheartfailure_full.pdf

7. SIGN. (2016). Management of chronic heart failure. Retrieved from http://www.sign.ac.uk/pdf/SIGN147.pdf

8. Canadian Cardiovascular Society. (2012). The 2012 Canadian cardiovascular society heart failure management guideline update: Focus on acute and chronic heart failure. *Canadian Journal of Cardiology 29*(2013): 168 – 181.

9. American College of Cardiology Foundation & American Heart Association. (2013). 2013 ACCF/AHA guideline for the management of heart failure. *Journal of the American College of Cardiology, 26*(16): e147 – e239.

10. American College of Cardiology, American Heart Association & Heart Failure Society of American. (2016). 2016 ACC/AHA/HFSA focused update on new pharmacological therapy for heart failure: An update of the 2013 ACCF/AHA guideline for the management of heart failure. *Circulation, 134*. doi: 10.1161/CIR.0000000000000435

11. National Heart Foundation. (2011). Guidelines for the prevention, detection and management of chronic heart failure in Australia. Retrieved from https://www.heartfoundation.org.au/images/uploads/publications/Chronic_Heart_Failure_Guidelines_2011.pdf

12. European Society of Cardiology. (2016). 2016 ESC guidelines for the diagnosis and treatment of acute and chronic heart failure. *European Heart Journal, 2016*(37): 2129 – 2200. doi: 10.1093/eurheartj/ehw128

Table 4.7. Participant acceptability of the adapted SPG based on profession (n=11).

		RN-onc N=4	RN-cardiac N=4	MD N=3
How comfortable would you be using the SPG?	Not very comfortable	-	-	-
	Uncomfortable	-	-	-
	Neutral	-	-	-
	Comfortable	4	4	3
	Very comfortable	-	-	-
How comfortable would you be telling someone?	Not very comfortable	-	-	-
	Uncomfortable	-	-	-
	Neutral	-	-	-
	Comfortable	2	2	3
	Very comfortable	2	2	-
Information on the SPG	Too much information	-	-	-
	Just right	3	4	3
	Not enough information	1	-	-
Is the SPG understandable?	Yes	4	3	3
	No	-	1	-
Were any guidelines missed?	Yes	-	-	-
	No	4	4	3

RN-onc = oncology registered nurse/advanced practice nurse; RN-cardiac = cardiology registered nurse/advanced practice nurse; MD = physician

Table 4.8. Participant acceptability of the adapted SPG based by revision (n=11).

		Revision 1 N=4	Revision 2 N=3	Revision 3 N=4
How comfortable would you be using the SPG?	Not very comfortable Uncomfortable Neutral Comfortable Very comfortable	- - - 4 -	- - - 3 -	- - - 4 -
How comfortable would you be telling someone?	Not very comfortable Uncomfortable Neutral Comfortable Very comfortable	- - - 3 1	- - - 2 1	- - - 2 2
Information on the SPG	Too much information Just right Not enough information	- 3 1	- 3 -	- 4 -
Is the SPG understandable?	Yes No	4 -	2 1	4 -
Were any guidelines missed?	Yes No	- 4	- 3	- 4

Chapter Five

Integrated Discussion and Conclusion

Integrated Discussion

Summary of Thesis

The overall aim of this thesis was to examine evidence-based interventions for nurses to use when supporting cancer survivors self-manage their symptoms. Guided by the Chronic Care Model (CCM), productive interactions between the informed and activated patient, and the prepared and proactive practice team lead to improved outcomes, such as clinical care, health status, satisfaction, healthcare use, and cost (Wagner et al., 1999). This thesis consisted of two studies: a systematic review of shared medical appointments (SMAs) (Chapter Three) and a descriptive study to adapt and evaluate the acceptability of an evidence-based symptom practice guide (SPG) for dyspnea due to cancer treatment-related cardiotoxicity (Chapter Four). According to the CCM, productive interactions between patients and their healthcare providers are improved when attention is given to delivery system designs and self-management support (Wagner et al., 1999). Suitable delivery system designs focus on support for self-management and behavior change, and offer close follow-up to assess response to treatment and self-management ability (Wagner et al., 2001). SMAs are an example of a delivery system design whereby cancer survivors are booked in groups to self-manage their cancer treatment-related symptoms (Fiandt, 2006; Kirsh et al., 2007). The CCM also describes self-management support as tools that allow patients and their healthcare providers to define issues, set priorities, establish goals, create treatment plans and solve problems (Wagner et al., 1999). It is often a challenge to separate the effect of self-management support from other elements of the model, such as delivery system design (Johnston, Liddy, Ives & Soto, 2008). Therefore, both SMAs and SPGs are examples of such self-management support tools. This chapter will offer a summary of the

findings from the two studies performed for this thesis, provide an integrated discussion with implications for nursing, and areas for future research.

The systematic review examined the effect SMAs had on patients with a physical chronic illness (excluding diabetes), their healthcare providers, and the healthcare system. Of nine included randomized trials, SMAs were used for cardiac illnesses (4 studies), breast cancer, chronic kidney disease, Parkinson disease, stress urinary incontinence and carpal tunnel syndrome. Compared to usual care, there were no negative effects on patient quality of life, knowledge and satisfaction. One study reported no difference in healthcare provider satisfaction. Another study showed fewer hospital admissions for patients who attended SMAs. Specific to oncology, there was only one small pilot trial with 69 breast cancer survivors, which demonstrated feasibility (Visser et al., 2015). However, the sample size was too small to measure effectiveness outcomes or equivalence of SMAs versus individual appointments (Visser et al., 2015). This pilot trial further used an experienced chronic disease nurse to lead the SMAs (Visser et al., 2015). Using an experienced nurse to lead SMAs is supported by the CCM, as they are healthcare professionals who often have the appropriate knowledge and time to lead such delivery system designs (Wagner et al., 2001).

The descriptive study was conducted to adapt and evaluate the acceptability of an evidence-informed SPG for use by nurses over the telephone for the assessment, triage, and management of patients experiencing dyspnea due to cancer treatment-related cardiotoxicity. Guided by the CAN-IMPLEMENT© methodology, the original COSTaRS Dyspnea SPG was adapted by integrating seven guidelines for heart failure (HF) identified in a systematic search. Acceptability of the adapted SPG was evaluated by means of collecting user-centered feedback from 11 healthcare professionals, including nurses/advanced practice nurses (APNs) with an

expertise in oncology and/or cardiology, and cardiologists with an expertise in cardio-oncology from the Ottawa Cardiac Oncology Program (OCOP). The adapted SPG was iteratively revised four times during the interviews. The original SPG was adaptable, and participants indicated the adapted SPG was comprehensive, easy to follow, and would be useful in clinical practice. The CCM promotes use of self-management tools, such as the adapted SPG, that encourage and support effective approaches for patients to self-manage their chronic illness (Wagner et al., 2001).

Integrated Discussion

From the systematic review, and the adaptation and evaluation of the acceptability of a SPG, there were three important areas for consideration: (1) self-management interventions are more limited when disease-specific; (2) nurses must have improved access to resources to support patients in their self-management; and (3) cancer survivors require guidance for self-managing their cancer treatment-related symptoms.

Self-management interventions are more limited when disease-specific. Many interventions for guiding patients in self-management are targeted as disease-specific care with few dealing with issues of comorbidity (Lorig et al., 1999). For example, the systematic review (Chapter Three) was limited to SMAs used for adults with a homogenous chronic illness, based on Noffsinger's (2009) definition of a Specialty cooperative healthcare clinic. Nonetheless, it was not uncommon that patients attending SMAs may also experience other chronic health issues (Noffsinger, 2009). Two of the included randomized controlled trials in our systematic review evaluated SMAs for HF, but also reported having participants with co-existing diabetes, 48% and 15%, respectively (Smith et al., 2014; Yehle, Ssands, Rhynders & Newton, 2002). Nevertheless, neither study elaborated on what additional support was offered to those patients

with respect to diabetes management. This is significant as those diagnosed with HF have an increased risk of death when they have diabetes (Aguilar et al., 2004; MacDonald et al., 2008; Pfeffer et al., 1992; Solomon et al., 2002). Specific to oncology, the pilot trial for SMAs for breast cancer survivors did not report any patient comorbidities (Visser et al., 2015). It is therefore important those with multiple chronic illnesses be offered additional support included in the SMA programming, or supplementary counseling for self-management strategies.

The SPGs were another example of single disease specific focus. The development of the original COSTaRS SPGs consisted solely of systematic reviews and clinical guidelines from the oncology setting (Stacey et al., 2013). Although the SPGs transformed evidence into user-friendly formats for clinical use by nurses, they did not include evidence from other diseases, such as cardiovascular disease, that may be relevant during cancer therapies (Larsen & Mulvagh, 2017). As a result of the systematic search for cardiology evidence, supplementary assessment questions, medications and self-care strategies were subsequently added to the adapted dyspnea SPG. The additional questions has allowed for a more detailed assessment of the patient, allowing the nurse to suitably triage the patient to the appropriate level of care, and perhaps indicate the need for a cardio-oncology healthcare professional to be involved in the patients' care.

Nurses must have improved access to resources to support patients in their self-management. Nurses require access to evidence-based resources to provide self-management support to their patients. Evidence-based practice gives guidance and helps generate the best possible client outcomes, either by supporting current practice or advocating for change (Bosse, Breuer & Spies, 2006; Youngblut & Brooten, 2001). Protocols and guidelines based on evidence decrease differences in the care provided across different healthcare sites (Youngblut & Brooten,

2001). The RNAO therefore developed evidence-based best practice guidelines for registered nurses working in Ontario to support the quality of service that nurses are dedicated to administering in their daily practice (RNAO, 2007). One best practice guideline is *Strategies to Support Self-Management in Chronic Conditions: Collaboration with Clients* (RNAO, 2010). It stresses that self-management support approaches are an essential part of nursing practice, and that nurses should enhance their knowledge and skill in offering self-care management strategies (RNAO, 2010).

Support of patient self-management is a key aspect of the CCM and nurses have previously been identified as the most likely professional group to offer both formal and informal patient education (Coleman et al., 2005; Coster & Norman, 2009). Self-management support reduces hospitalizations, emergency department use, overall cost of care management, and improves self-care behavior and symptom management (Coleman et al., 2005; Lorig et al., 1999; Lorig et al., 2001; Smeulders et al., 2010; Sochalski et al., 2009). Nonetheless, few high quality studies have assessed the impact nurses have in offering self-management support (Coster & Norman, 2009). In this thesis, the systematic review showed that SMAs were a safe and effective evidence-based delivery system design that nurses can use for supporting groups of patients, such as cancer survivors, with the self-management of their chronic illnesses. In addition, the original SPG was easy to adapt, integrating evidence from cardiology to be able to provide nurses with access to a resource to support cancer survivors self-manage their dyspnea due to cancer treatment-related cardiotoxicity.

Cancer survivors require guidance for self-managing their cancer treatment-related symptoms. As patients transition from active oncology treatment to the survivorship phase of the cancer trajectory, the need for self-management becomes even more apparent. Compared to the

active treatment phase, differences in self-management during the cancer survivorship phase include less frequent oncology visits, need to understand the signs and symptoms of disease recurrence, more emphasis on self-managing the late- and long-term effects of cancer and its treatment, re-establishing ordinary routines and social roles, and coping with psychological distress (McCorkle et al., 2011).

The systematic review identified one randomized controlled trial that evaluated the effectiveness of SMAs for breast cancer survivors, which did not evaluate self-management as an outcome (Visser et al., 2015). A systematic review of patients with diabetes who attend SMAs reported improved self-management skills (Housden et al., 2013). Therefore, it is likely that SMAs improve self-management in cancer survivors but this outcome needs to be measured in subsequent studies.

Although the COSTaRS SPGs were intended for nurses to guide adults undergoing cancer treatment in self-managing their symptoms, patients have also requested having their own version of COSTaRS SPGs (Stacey et al., 2015). Furthermore, patients would like more guidance on self-care strategies, both at discharge and during phone calls made to the support line (Stacey et al., 2016). Patients who have the appropriate information, skills and confidence to engage in self-management interventions feel more empowered, are better able to make informed decisions, and are able to cope with treatment and treatment-related late- and long-term effects (Hibbard et al., 2007; Howell et al., 2016).

Implications for Nursing

The results from the systematic review, and the adaptation and evaluation of the acceptability of the adapted SPG have several implications for nurses, particularly within the role of the APN (see Table 5.1). APNs are considered experts in their respective fields, and their

practice involves the innovative use of knowledge and skills. There are four core competencies of the APN as outlined by the Canadian Nurses Association (CNA) (2008): (1) clinical, (2) consultation and collaboration, (3) leadership, and (4) research. The Ottawa Hospital further uses education as a key component of the APN role (De Grasse & Nicklin, 2001). Although not currently a role within Canada, these core competencies provide a clear link between cancer treatment-related symptom self-management and the need for an APN role requiring this level of expertise.

Table 5.1. Implications of findings for APNs.

APN Competency	**Implications of thesis findings for APNs**
1. Direct Clinical Practice	• Assessing individual cancer survivors experiencing cancer treatment-related symptoms using evidence from both oncology and cardiology (e.g. assessment section of the adapted SPG) • Offering self-management strategies to individual cancer survivors who have had cancer treatment using evidence from both oncology and cardiology (e.g. self-care section of the adapted SPG) • Using SMAs and SPGs to engage cancer survivors in self-managing their cancer treatment-related symptoms and understanding cancer surveillance guidelines
2. Consultation and Collaboration	• Participating as a knowledge user on a research team. For example, a randomized controlled trial comparing SMAs to individualized visits for transitioning care from oncologists to primary care providers
3. Leadership (clinical, professional, systems)	• Identifying strategies for more resource-efficient discharges of cancer survivors • Incorporating cardiology evidence into other oncology SPGs that have been implemented for use by oncology nurses for symptom management
4. Research	• Assessing barriers and facilitators to implementing the adapted SPG • Using the systematic review for SMAs to support justification of conducting a randomized controlled trial to evaluate SMAs compared to individual visits for transitioning cancer survivors from oncologists to primary care providers • Disseminating systematic review findings of SMAs at a national conference and publishing in a peer-reviewed journal • Disseminating findings of the adapted SPG at an international summit and publishing in a peer-reviewed journal
5. Education	*Patients and Families* • Providing education to cancer survivors and their families to enhance their ability to self-manage their chronic illness

	Healthcare Professionals • Acting as a role model and clinical expert in SMAs and adapting SPGs

Direct clinical practice. The foundation of advanced nursing practice involves an expertise in a specialized area of nursing. Through a unified and holistic approach, the APN can work together with the client and other members of the healthcare team to provide comprehensive care (CNA, 2008). The APN may develop numerous innovative assessment and intervention strategies within a client-centered framework for individual clients. The clinical competency also engages clients in problem solving at the individual level. This thesis focuses on the APN role in developing assessment and self-management strategies for cancer survivors with cancer treatment-related cardiotoxicity based on evidence from both oncology and cardiology, as seen in the assessment and self-care sections of the adapted SPG. The APN may further use SMAs and SPGs to engage cancer survivors in self-managing their cancer treatment-related symptoms and understanding cancer surveillance guidelines.

Consultation and collaboration. The APN can demonstrate the ability to consult and collaborate with colleagues across clinical divisions and at the organizational, provincial, national and international level (CNA, 2008). As well, the APN partakes in collaborative projects with academic institutions by working on a research team as a knowledge user. Collaborating with expert researchers, the APN may, for example, provide justification and background for a grant application to the Canadian Institutes of Health Research to perform a randomized controlled trial comparing SMAs to individualized discharges from their oncologist to their primary care provider.

Leadership. The leadership competency aims at describing the APN as an agent of change, always looking for effective new ways to improve the delivery of care, to benefit their

community, and to influence health policy (CNA, 2008). The APN identifies the learning needs of members of the healthcare team, and finding programs and resources to best meet those needs. The APN may assist a cancer survivorship program that had identified a need for better resource-efficient discharges. The evidence-based findings of the systematic review for SMAs met those needs by offering an alternative appointment type that had no patient-specific negative effects. The APN may also incorporate new nursing knowledge and develop or participate as a knowledge user on establishing new standards of care, such as incorporating cardiology evidence into previously implemented COSTaRS SPGs.

Researcher. The APN generates, synthesizes and uses evidence-based findings (CNA, 2008). This also involves implementing research-based innovations for improving client care. Based on the findings from this thesis, an example research project for the APN is to assess the barriers and facilitators to implementing the adapted SPG into the healthcare system. Currently, oncology nurses are using the original dyspnea SPG and it would be helpful to better understand barriers to using the adapted SPG such that appropriate interventions can be selected to overcome the identified barriers (Graham et al., 2006). Moreover, the APN may collaborate with other members of the healthcare team to identify, conduct and support research that enhances nursing practice. The use of the findings from the systematic review for SMAs could be used to support a grant application to the Canadian Institutes of Health Research to perform a randomized controlled trial to evaluate the current practice of individualized discharges compared to SMAs for cancer survivors being transitioned to primary care providers. The APN can also disseminate evidence-based findings, for example, through the presentation of the findings from the research studies conducted within this thesis at conferences, summits, and in peer-reviewed journal publications.

***Areas for future research*.** The results from this thesis have provided directions for future research relating to self-management for cancer survivors with cancer treatment-related symptoms. First, although SMAs have been studied extensively among patients with diabetes mellitus and have shown no negative effects, few trials have measured SMAs for other chronic illnesses. This systematic review is the first to assess SMAs versus usual care for patients with a homogeneous physical chronic illness, other than diabetes mellitus, and included nine trials reporting no negative effects on patient outcomes. In particular, further studies evaluating the use of SMAs for cancer survivors with cancer treatment-related symptoms should be conducted. Only one randomized controlled trial evaluated the use of SMAs for breast cancer survivors (Visser et al., 2015). Unfortunately, this pilot trial also did not evaluate the effect their SMA had on patient self-management, one of the main goals of SMAs (Edelman et al., 2012). As self-management is a combination of knowledge and self-efficacy, it is an important outcome that should be further assessed (Yehle et al., 2009).

Home-care nurses and cancer patients have also suggested the need to develop a patient version of the COSTaRS SPGs (Nichol et al., 2015; Stacey et al., 2013). The adapted SPG is established in such a way that it could easily be adapted for patients. Transformed into a "Stoplight" tool, it may be more suitable for cancer survivors to use in the home setting when they are no longer patients of The Ottawa Hospital Cancer Centre. Previously used in the Diabetes Zones for Management guide and the Heart Failure Zones, the Stoplight tool divides various signs and symptoms into green, yellow and red management zones (BC Guidelines, 2015; Coleman & Newton, 2005). As indicated with the stoplight on the COSTaRS SPGs, green indicates stability and good control over the condition; yellow indicates caution and suggests steps for self-care; and red indicates a medical crisis that requires a physician's attention (Stacey

et al., 2013). Tools such as these may be especially important when community resources are limited (Coleman & Newton, 2005). Although no trials have been performed to evaluate the success of Stoplight tools in improving patient self-management of their symptoms, self-management tools often lead to a reduction in symptoms and distress, and allow for better communication between the patient and their healthcare provider (Lorig & Holman, 2003).

Education. The APN educates patients, families and healthcare professionals, and promotes the development of evidence-based nursing practice (Ervin, 2005; Hamric, Spross & Hanson, 2009). Through the use of both SMAs and SPGs, the APN may provide education to cancer survivors and their families to enhance their knowledge, and thereby increase their ability to self-manage symptoms of their chronic illness. The APN can also act as a role model and clinical expert in their area of expertise (DeGrasse & Nicklin, 2001). This includes having a good knowledge base of the potential to use SMAs versus individual appointments. It also includes adapting evidence-based SPGs, particularly as it relates to the assessment, triage and suggestion of self-care strategies to patients with dyspnea due to cancer treatment-related cardiotoxicity.

Conclusion

This thesis has sought to examine evidence-based interventions (i.e. SMAs and SPGs) for nurses to use when supporting cancer survivors self-manage their symptoms. The systematic review (Chapter Three) revealed no patient harm when SMAs were used versus individual appointments. The descriptive study (Chapter Four) revealed that the adapted SPG was comprehensive and easy to follow, and would be helpful for handling symptom calls from patients on cancer treatment. Guided by the CCM, the thesis findings suggest that SMAs are suitable delivery system designs, and both SMAs and SPGs are appropriate self-management

support tools used to enhance productive interactions between the informed and active patient, and the prepared and proactive practice team. With evidence-based interventions, such as SMAs and SPGs, oncology nurses may be able to better support cancer survivors with the self-management of their cardiotoxic-related symptoms.

References

Aguilar D., Solomon S., Køber L., Rouleau J.L., Skali H., McMurray J., Francis G., Henis M., O'Connor C., Diaz R., Belenkov Y., Varshavsky S., Leimberger J., Velazquez E., Califf R. & Pfeffer M. (2004). Newly diagnosed and previously known diabetes mellitus and 1-year outcomes of acute myocardial infarction. The valsartan in acute myocardial infarction (VALIANT) trial. *Circulation, 110*(12): 1572 – 1578. doi: 10.1161/01.CIR.0000142047.28024.F2

BC Guidelines. (2015). *Chronic heart failure – Diagnosis and management*. Retrieved from http://www2.gov.bc.ca/assets/gov/health/practitioner-pro/bc-guidelines/chronicheartfailure_full.pdf

Bodenheimer T., MacGregor K. & Stothart N. (2005). Nurses as leaders in chronic care. Their role is pivotal in improving care for chronic diseases. *BioMed Journal, 330*(7492) : 612 – 613. doi : 10.1136/bmj.330.7492.612

Bodenheimer T., Wagner E. & Grumbach K. (2002). Improving primary care for patients with chronic illness. *Innovations in Primary Care, 288*(14) : 1775 – 1779.

Bosse G., Breuer J. & Spies C. (2006). The resistance to changing guidelines – What are the challenges and how to meet them. *Best Practice and Research Clinical Anaesthesiology, 20*(3): 379 – 395. doi: 10.1016/j.bpa.2006.02.005

Burke R., Ferrara S., Fuller A., Kelderhouse J. & Ferrara L. (2011). The effectiveness of group medical visits on diabetes mellitus type 2 (dm2) specific outcomes in adults: A systematic review. *JBI Library of Systematic Reviews, 9*(23): 833 – 885.

Canadian Institutes of Health Research. (2015). *CBPHC objectives and priority areas.* Retrieved from http://www.cihr-irsc.gc.ca/e/44765.html

Canadian Institutes of Health Research, Natural Sciences and Engineering Research Council of Canada, and Social Sciences and Humanities Research Council of Canada. (2014). *Tri-council policy statement: Ethical conduct for research involving humans.* Retrieved from http://www.pre.ethics.gc.ca/pdf/eng/tcps2-2014/TCPS_2_FINAL_Web.pdf

Canadian Nurses Association. (2008). *Advanced nursing practice: A national framework.* Retrieved from https://www.cna-aiic.ca/~/media/cna/page-content/pdf-en/anp_national_framework_e.pdf

Coleman M. & Newton K. (2005). Supporting self-management in patients with chronic illness. *American Family Physician, 72*(8): 1503 – 1510.

Coster S. & Norman I. (2009). Cochrane reviews of educational and self-management interventions to guide nursing practice: A review. *International Journal of Nursing Studies, 46*: 508 – 528. doi: 10.1016/j.ijnurstu.2008.09.009

DeGrasse C. & Nicklin W. (2001). Advanced nursing practice: Old hat, new design. *Canadian Journal of Nursing Leadership, 14*(4): 7 – 12.

Edelman D., McDuffie J., Oddone E., Gierisch J., Nagi A. & Williams W. (2012). *Shared medical appointments for chronic medical conditions: A systematic review.* Washington, DC: Department of Veterans Affairs.

Ederhy S., Izzedine H., Massard C., Dufaitre G., Spano J., Milano G., Meuleman C., Besse B., Boccara F., Kahyat D., Cohen A. & Soria J. (2011). Cardiac side effects of molecularly targeted therapies: Toward a better dialogue between oncologist and cardiologist. *Oncology/Hematology, 80*(3): 369 – 379. doi: 10.1016/j.critrevonc.2011.01.009

Ervin N. (2005). Clinical coaching: A strategy for enhancing evidence-based nursing practice. *Clinical Nurse Specialist, 19*(6): 296 – 301.

Fiandt K. (2006). The chronic care model: Description and application for practice. *Topics in Advanced Practice Nursing eJournal, 6*(4): 1 – 7.

Graham I., Logan J., Harrison M., Straus S., Tetroe J., Caswell W. & Robinson N. (2006). Lost in knowledge translation: Time for a map? *Journal of Continuing Education in the Health, 26*(1): 13 – 24. doi: 10.1002/chp.47

Hamric A., Spross J. & Hanson C. (2009). *Advanced practice nursing: An integrative approach.* (4th ed.). Toronto: Saunders.

Harrison M.B., van den Hoek J., for the Canadian Guideline Adaptation Study Group. (2012). *CANIMPLEMENT©: A Guideline Adaptation and Implementation Planning Resource.* Kingston, Ontario: Queen's University School of Nursing and Canadian Partnership Against Cancer.

Hewitt M., Greenfield S. & Stovall E. (2005). *From cancer patient to cancer survivor: Lost in transition.* The National Academies Press.

Hibbard J., Mahoney E., Stock R. & Tusler M. (2007). Do increases in patient activation result in improved self-management behaviors? *Health Serv Res, 42*: 1443 – 1463.

Higgins J. & Green S. (Eds). (2011). *Cochrane handbook for systematic reviews of interventions, version 5.1.0.* The Cochrane Collaboration. Retrieved from www.handbook.cochrane.org

Housden L., Wong S. & Dawes M. (2013) Effectiveness of group medical visits for improving diabetes care: A systematic review and meta-analysis. *Canadian Medical Association Journal, 185*(13): E635 – E644. doi: 10.1503/cmaj.130053

Howell D., Harth T., Brown J., Bennett C., Boyko S. & the Patient Education Program Committee. (2016). *Self-management education for patients with cancer: Evidence summary.*

Toronto, Ontario: Cancer Care Ontario. Program in Evidence-based care evidence summary No.: 20-3.

Johnston S., Liddy C., Ives S.E. & Soto E. (2008). *Literature review on chronic disease self-management*. Retrieved from https://www.livinghealthychamplain.ca/documents/pages/ReviewChronicDisease.pdf

Kirsh S., Watts S., Pascuzzi K., O'Day M., Davidson D., Strauss G., O'Kern E. & Aron D. (2007). Shared medical appointments based on the chronic care model: A quality improvement project to address the challenges of patients with diabetes with high cardiovascular risk. *Quality & Safety in Health Care, 16*(5): 349 – 353. doi: 10.1136/qshc.2006.019158

Knackstedt T. & Samie F. (2015). Shared medical appointments for the preoperative consultation visit of Mohs micrographic surgery. *Dermatologic surgery, 72*(2): 340 – 344. doi: 10.1016/j.jaad.2014.10.022

Larsen C. & Mulvagh S. (2017). Cardio-oncology: What you need to know now for clinical practice and echocardiography. *Echo Research and Practice, 4*(1): R33 – R41. doi: 10.1530/ERP-17-0013

Lorig K. & Holman H. (2003). Self-management education: History, definition, outcomes, and mechanisms. *Annals of Behavioral Medicine, 26*(1): 1 – 7.

Lorig K., Ritter P., Stewart A., Sobel D., Brown B., Bandura A., Gonzalez V., Laurent D. & Holman H. (2001). Chronic disease self-management program: 2-year health status and health care utilization outcomes. *Medical Care, 39*(11): 1217 – 1223.

Lorig K., Sobel D., Stewart A., Brown B., Bandura A., Ritter P., Gonzalez V., Laurent D. & Holman H. (1999). Evidence suggesting that a chronic disease self-management programs can

improve health status while reducing hospitalization: A randomized trial. *Medical Care, 37*(1): 5 – 14.

MacDonald M., Petrie M., Varyani F., Östergren J., Michelson E., Young J., Solomon S., Granger C., Swedberg K., Yusuf S., Pfeffer M. & McMurray J. (2008). Impact of diabetes on outcomes in patients with low and preserved ejection fraction heart failure: An analysis of the candesartan in heart failure: Assessment of reduction in mortality and morbidity (CHARM) programme. *European Heart Journal, 29*(11): 1377 – 1385. doi: 10.1093/eurheartj/ehn153

McCorkle R., Ercolano E., Lazenby M., Schulman-Green D., Schilling L., Lorig K. & Wagner E. (2011). Self-management: Enabling and empowering patients living with cancer as a chronic illness. *CA Cancer J Clin, 61*(1): 50 – 62. doi: 10.3322/caac.20093

Moher D., Liberati A., Tetzlaff J., Altman D. & The Prisma Group. (2009). Preferred reporting items for systematic reviews and meta-analysis: The PRISMA statement. *Public Library of Science Medicine, 3*(2): 123 – 130. doi: 10.1371/journal.pmed.1000097

Nichol K., Stacey D., Kuziemsky C., Gifford W. & Mackenzie S. (2015). Knowledge tools for cancer treatment? Related symptom management by home care nurses: A mixed methods study. *Home Health Care Management & Practice.* doi: 10.1177/1084822315607231

Noffsinger E. *Running group visits in your practice.* New York, NY: Springer, 2009.

Patnaik J., Byers T., Diguiseppi C., Denberg T. & Dabelea D. (2011). The influence of comorbidities on overall survival among older women diagnosed with breast cancer. *J Natl Cancer Inst, 103*(14): 1101.

Pfeffer M., Braunwald E., Moyé L., Basta L., Brown E., Cuddy T., Davis B., Geltman E., Goldman S., Flaker G., Klein M., Lamas G., Packer M., Rouleau J., Rouleau J., Rutherford J., Wertheimer J. & Hawkins M. (1992). Effect of captopril on mortality and morbidity in

patients with left ventricular dysfunction after myocardial infarction – Results of the survival and ventricular enlargement trial. *N Engl J Med, 327*: 669 – 677. doi: 10.1056/NEJM199209033271001

Prescott L., Dickens A., Guerra S., Tanha J., Phillips D., Patel K., Umberson K., Lozano, M., Lowe, K., Brown, A., Taylor, J., Soliman, P., Garcia, E., Levenback, C. & Bodurka, D. (2016). Fighting cancer together: Development and implementation of shared medical appointments to standardize and improve chemotherapy education. *Gynecologic Oncology, 140*(1): 114 – 119. doi: 10.1016/j.ygyno.2015.11.006

Raschi E. & De Ponti F. (2012). Cardiovascular toxicity of anti-cancer targeted therapy: Emerging issues in the era of cardio-oncology. *Internal and Emergency Medicine, 7*: 113 – 131.

Registered Nurses' Association of Ontario. (2007). *Healthy work environments best practice guidelines: Professionalism in nursing*. Retrieved from http://rnao.ca/sites/rnao-ca/files/Professionalism_in_Nursing.pdf

Registered Nurses' Association of Ontario. (2010). *Strategies to support self-management in chronic conditions: Collaboration with clients.* Retrieved from http://rnao.ca/sites/rnao-ca/files/Strategies_to_Support_Self-Management_in_Chronic_Conditions_-_Collaboration_with_Clients.pdf

Risendal B., Dwyer A., Seidel R., Lorig K., Coombs L. & Ory M. (2014). Meeting the challenge of cancer survivorship in public health: Results from the evaluation of the chronic disease self-management program for cancer survivors. *Front Public Health, 2*(24): 214. doi: 10.3389/fpubh.2014.00214

Shea B., Hamel C., Wells G., Bouter L., Kristjansson E., Grimshaw J., Henry D. & Boers M. (2009). AMSTAR is a reliable and valid measurement tool to assess the methodological quality of systematic reviews. *Journal of Clinical Epidemiology, 62*(10): 1013 – 1020. doi: 10.1016/j.jclinepi.2008.10.009

Smeulders E., van Haastregt J., Ambergen T., Usko-Lencer N., Janssen-Boyne J., Gorgels A., Stoffers H., Lodewijks-van der Bolt C., van Eijk J. & Kempen G. (2010). Nurse-led self-management group programme for patients with congestive heart failure: Randomized controlled trial. *Journal of Advanced Nursing, 66*(7): 1487 – 1499. doi: 10.1111/j.1365-2648.2010.05318.x

Smith C., Piamjariyakul U., Wick J., Spertus J., Russell C., Dalton K., Elyachar A., Vacek J., Reeder K., Nazir N. & Ellerbeck E. (2014). Multidisciplinary group clinic appointments: The self-management and care of heart failure (SMAC-HF) trial. *Circ: Heart Fail, 7*(6): 888-894. doi: 10.1161/CIRCHEARTFAILURE.113.001246

Sochalski J., Jaarsma T., Krumholz H., Laramee A., McMurray J., Naylor M., Rich M., Rigel B. & Stewart S. (2009). What works in chronic care management: The case of heart failure. *Health Affairs 28*(1): 179 – 189. doi: 10.1377/hlthaff.28.1.179.

Solomon S., St John Sutton M., Lamas G., Plappert T., Rouleau J., Skali H., Moyé L., Braunwald E. & Pfeffer M. (2002). Ventricular remodelling does not accompany the development of heart failure in diabetic patients after myocardial infarction. *Circulation, 106*(10): 1251 – 1255. doi: 10.1161/01.CIR.0000032313.82552.E3

Stacey D., Carley M., Ballantyne B., Skrutkowski M., Whynot A., pan-Canadian Oncology Symptom Triage and Remote Support COSTaRS Team. (2015). Perceived factors influencing nurses' use of evidence-informed protocols for remote cancer treatment-related symptom

management: A mixed methods study. *European Journal of Oncology Nursing, 19*(3): 268 – 277. doi: 10.1016/j.ejon.2014.11.002

Stacey D., Green E., Ballantyne B., Skrutkowski M., Whynot A., Tardif L., Tarasuk J., Carley M., pan-Canadian Oncology Symptom Triage and Remote Support (COSTaRS) Team. (2016). Patient and family experiences with accessing telephone cancer treatment symptom support: A descriptive study. *Support Cancer Care, 24*(2): 893 – 901. doi: 10.1007/s00520-015-2859-6

Stacey D., Macartney G., Carley M., Harrison M. & the pan-Canadian Oncology Symptom Triage and Remote Support Group. (2013). Development and evaluation of evidence-informed clinical nursing protocols for remote assessment, triage and support of cancer treatment-induced symptoms. *Nursing Research and Practice, 2013*(171872). doi: 10.1155/2013/171872

Stull V., Snyder D. & Demark-Wahnefried W. (2007). Lifestyle interventions in cancer survivors: Designing programs that meet the needs of this vulnerable and growing population. *J Nutr, 137*(1 Suppl): 243S-248S.

Trotter K., Schneider S. & Turner B. (2013) Group appointments in a breast cancer survivorship clinic. *Journal of Advanced Practitioner in Oncology, 4*(6): 423-431.

Visser A., van Laarhoven H., Govaert P., Schlooz M., Jansen L., van Dalen T. & Prins J. (2015). Group medical consultations in the follow-up of breast cancer: A randomized feasibility study. *Journal of Cancer Survivorship, 9*(3): 450 – 461. doi: 10.1007/s11764-014-0421-z

Widakowich C., De Castro G., De Azambuja E., Dinh P. & Awada A. (2007). Review: Side effects of approved molecular targeted therapies in solid cancers. *The Oncologist, 12*: 1443 – 1455. doi: 10.1634/theoncologist

Yehle K., Sands L., Rhynders P. & Newton G. (2009). The effect of shared medical visits on knowledge and self-care in patients with heart failure: A pilot study. *Heart Lung, 38*(1): 25-33. doi: 10.1016/j.hrtlng.2008.04.004

Youngblut J. & Brooten, D. (2001). Evidence-based nursing practice: Why is it important? *AACN Clinical Issues, 12*(4): 468 – 476.

Zamorano J., Lancellotti P., Rodriguez Muñoz D., Aboyans V., Asteggiano R., Galderisi M., Habib G., Lenihan D., Lip G., Lyon A., Lopez Fernandez T., Mohty D., Piepoli M., Tamargo J., Torbicki A., Suter T., Authors/Task Force Members, ESC Committee for Practice Guidelines (CPG). (2016). 2016 ESC position paper on cancer treatments and cardiovascular toxicity developed under the auspices of the ESC committee for practice guidelines: The task force for cancer treatments and cardiovascular toxicity of the European Society of Cardiology (ESC). *European Heart Journal*, 37(36): 2768 – 2801. doi: 10.1093/eurheartj/ehw211

Appendices

Appendix A

Breathlessness/Dyspnea Practice Guide

Breathlessness/Dyspnea: A subjective experience described as breathing discomfort of varying intensities.[1-4] Includes descriptors such as hard to breathe, feeling smothered, tightness in chest, unable to catch breath, panting, gasping.

Study ID
Month and Year of Birth
Sex

Date and Time

1. Assess severity of the breathlessness **(Supporting evidence: 2 guidelines)**[2,3]

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 [5(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)[3,5]	1-3	☐	4-6	☐	7-10	☐
Patient rating of worry about shortness of breath (see above)[2]	0-5	☐	6-10	☐		
With what level of activity do you experience this shortness of breath?	Moderate activity	☐	Mild activity	☐	At rest	☐
Do you pause while talking every 5-15 seconds?[3]	No	☐			Yes	☐
Do you have pain in your chest when you breathe?[3]	No	☐			Yes	☐
Is your breathing noisy, rattily or congested?[3]	No	☐			Yes	☐
Did you wake suddenly with shortness of breath?[3]	No	☐			Yes	☐
Do you have a fever > 38º C?[3] ☐U	No	☐			Yes, with breathlessness	☐
Does your shortness of breath interfere with your daily activities at home and/or at work? Describe.	No	☐	Yes, some	☐	Yes, significantly	☐
	1 **Mild** (Green)		2 **Moderate** (Yellow)		3 **Severe** (Red)	
2. Triage patient for symptom management based on highest severity (Supporting evidence: 1 guideline)[3]	☐ Review self-care. ☐ Verify medication use, if appropriate.		☐ Review self-care. ☐ Verify medication use, if appropriate. ☐ Advise to call back if symptom		☐ Refer for medical attention immediately.	

		worsens, new symptoms occur, or no improvement in 12-24 hours.	

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

Additional comments:

Study ID_____

3. Review medications patient is using for shortness of breath, including prescribed, over the counter, and/or herbal supplements **(Supporting evidence: 3 guidelines)**[1-3]

Current use	Examples of medications for shortness of breath*	Notes (e.g. dose, suggest to use as prescribed)	Evidence
☐	Oxygen[1,2]		Expert Opinion
☐	Immediate-release oral or parenteral opioids - morphine (Statex®), hydromorphone (Dilaudid®), fentanyl[1,2,3]		Effective

* Palliative oxygen is not recommended.[1]

4. Review self-care strategies **(Supporting evidence: 3 guidelines)**[1,3,4]

Patient already uses	Strategy suggested/ education provided	Patient agreed to try	**Self-care strategies**
1.			What is your goal for managing when you feel short of breath?
2. ☐	☐	☐	What helps when you are short of breath? Reinforce as appropriate. Specify:
3. ☐	☐	☐	Have you tried to use a fan or open window to increase air circulation directed at your face?[1]
4. ☐	☐	☐	Have you tried to turn down the temperature in your house?[1,3]
5. ☐	☐	☐	Are you trying to rest in upright positions that can help you breath?[1,3]
6. ☐	☐	☐	Are you trying different relaxation and breathing exercises (e.g. diaphragmatic breathing, pursed lip breathing)?[1,3,4]
7. ☐	☐	☐	If you have a wheelchair, portable oxygen or walking aids, are you trying to use them to help with activities that cause your shortness of

			breath?[1,4]
8. ☐	☐	☐	If you have difficulty eating, are you taking nutrition supplements[1]
9. ☐	☐	☐	Would more information about your symptoms help you to manage them better? If yes, provide appropriate information or suggest resources. [1,3]
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:
☐	Advise to call back in 12-24 hours if no improvement, symptom worsens, or new symptoms occur

References: 1. ONS-PEP Dyspnea (2014); 2. Dy SM, et al. (2008); 3. Cancer Care Ontario (2010); 4. Bausewein C, et al. (2008); 5. Bruera E, et al. (1991). (See pages 36-39 for complete references).

Appendix B

Adapting the COSTaRS Breathlessness/Dyspnea Practice Guide, Informed by Cardiac-Oncology and Heart Failure Clinical Practice Guidelines

Interview/Focus Group Questions

Introduce SPG and indicate that we have taken the original COSTaRS Breathlessness/Dyspnea Practice Guide and incorporated evidence from heart failure guidelines. Cardiotoxity, defined as the direct effects of the cancer treatment on heart function and structure, is a common side effect of herceptin. As you can see, in this version of the guide, the white is the same as the original COSTaRS Breathlessness/Dyspnea Practice Guide, purple indicates evidence from heart failure guides, and blue overlaps with both. Work through with the participant.

1. What are your first impressions of the revised symptom practice guide?

2. Do you think this will be helpful for handling symptom calls from patients on cancer treatments?

3. What other changes could be made to ensure the symptom practice guide is more useful?

4. Are there any guidelines that were missed?

Guidelines:

a) BC Guidelines (2015)
b) SIGN (2016)
c) Canadian Cardiovascular Society (2012)
d) American College of Cardiology Foundation & American Heart Association (2013)
e) American College of Cardiology Foundation & American Heart Association (2016)
f) National Heart Foundatiomn (2011)
g) European Society of Cardiology (2016)

Modified from: Stacey, Carley, Ballantyne, Strutkowski & Whynot. (2015b). Perceived factors influencing nurses' use of evidence-informed protocols for remote cancer treatment-related symptom management: A mixed methods study. *European Journal of Oncology Nursing, 19*(3): 268 – 277. doi: 10.1016/j.ejon.2014.11.002

Appendix C

Adapting the COSTaRS Breathlessness/Dyspnea Practice Guide, Informed by Cardiac-Oncology and Heart Failure Clinical Practice Guidelines

Acceptability Survey Questions

1. Have you reviewed the breathlessness symptom practice guide?
   - ○ Yes
   - ○ No

2. How comfortable would you be using the symptom practice guide?
   - ○ Not very comfortable
   - ○ Uncomfortable
   - ○ Neutral
   - ○ Comfortable
   - ○ Very Comfortable

3. How likely are you to tell someone about the symptom practice guide as a resource to assist adults on cancer treatment with self-management of their breathlessness?
   - ○ Not very comfortable
   - ○ Uncomfortable
   - ○ Neutral
   - ○ Comfortable
   - ○ Very comfortable

4. Information on the symptom practice guide
   - ○ Too much information
   - ○ Just right
   - ○ Not enough information

5. Is the symptom practice guide understandable?
   - ○ Yes
   - ○ No
   - ○ If no, please explain why not?

6. What changes need to be made to the symptom practice guide to make it more relevant to you?

7. Do you have any further comments, questions or suggestions?

Please tell us a little about yourself…

1. What is your position?
   - ○ Staff registered practical nurse (RPN)
   - ○ Staff registered nurse (RN)
   - ○ Supervisor/manager
   - ○ Advanced practice nurse (APN)
   - ○ Educator
   - ○ Other:_____
2. How long have you been working within this position?
   - ○ 6 or fewer months
   - ○ 7 to 12 months
   - ○ 1 to 2 years
   - o 3 to 5 years
   - o 6 to 10 years
   - o More than 10 years
3. Are you currently working: o Full time o Regular part-time o Casual
4. Your birth year: _____
5. Your sex: o Female o Male o Other
6. What education programs have you completed (check all that apply)?
   - ○ College diploma
   - ○ Undergraduate university degree
   - ○ Graduate university degree
   - ○ Specialty certification in oncology nursing
   - ○ Other: _____
7. How long have you been working in your position?
   - ○ Less than 2 years
   - ○ 2 to 5 years
   - ○ 6 to 10 years
   - o 11 to 15 years
   - o 16 to 20 years
   - o 20 to 25 years
   - o 26 to 30 years
   - o More than 30 years
8. Today's date: _____

Modified from: Pan-Canadian Oncology Symptom Triage and Remote Support (COSTaRS). (n.d.). *Factors influencing nurses using symptom practice guides for remote support of patients undergoing cancer treatments. Baseline survey.* Retrieved from http://www.ktcanada.ohri.ca/costars/docs/Baseline_Barriers_Survey.pdf and Stacey, D., Carley, M., Ballantyne, B., Skrutkowski, M. & Whynot, A. for the Pan-Canadian Oncology Symptom Triage and Remote Support (COSTaRS) Team. Perceived factors influencing nurses' use of evidence-informed protocols for remote cancer treatment-related symptom management: A mixed methods study. *European Journal of Oncology Nursing, 19*(3): 268 – 277. doi: 10.1016/j.ejon.2014.11.002

Appendix D

Letter of Invitation

April 25, 2017

Title of Study: Adapting the COSTaRS Breathlessness/Dyspnea Practice Guide, Informed by Cardiac-Oncology and Heart Failure Clinical Practice Guidelines
(Original Title of Thesis: Supporting Cancer Survivors in Self-Management: A Study Protocol)

Principal Investigator: Dawn Stacey, Full professor, School of Nursing, School of Epidemiology, University of Ottawa

Student Principal Investigator: Freya Kelly, Student, School of Nursing, University of Ottawa

You are being asked to participate in a research project being done by Freya Kelly, from the School of Nursing, University of Ottawa.

You must be able to read and understand English in order to participate in the study.

The purpose of this research project is to adapt the COSTaRS symptom practice guide for breathlessness when used with adults on cancer treatment with co-existing cardiac toxicity and assess its usability. Should you choose to participate, you will be asked to participate in an interview and complete an acceptability survey.

The expected duration is 30 to 45 minutes.

If you have any questions, please feel free to contact us (see below for contact information).

Thank you,

[Insert Principal Investigator's Signature]

Dawn Stacey
Full Professor
School of Nursing
School of Epidemiology
University of Ottawa

Freya Kelly
Master's of Science in Nursing Student
School of Nursing, Faculty of Health Sciences
University of Ottawa

Appendix E

PARTICIPANT INFORMED CONSENT FORM

Title of Study: Adapting the COSTaRS Breathlessness/Dyspnea Practice Guide, Informed by Cardiac-Oncology and Heart Failure Clinical Practice Guidelines
(Original Title of Thesis: Supporting Cancer Survivors in Self-Management: A Study Protocol)

Principal Investigator: Dawn Stacey, Full Professor, School of Nursing, School of Epidemiology, University of Ottawa
Student Principal Investigator: Freya Kelly, Master's of Science in Nursing Student, University of Ottawa

Participation in this study is voluntary. Please read this Participant Informed Consent Form carefully before you decide if you would like to participate. Ask the principal investigator and study team as many questions as you like.

Why am I being given this form?

You are being asked to participate in this research study because you are a healthcare provider with an expertise in oncology and/or cardiology.

You must be able to read and understand English in order to participate in the study.

Why is this study being done?

Cancer-related breathlessness is commonly experienced by adults on cancer treatment, particularly those who have simultaneously experienced cardiac toxicity. Although there are evidence-based interventions available in the literature, there are no symptom practice guides specific to this patient population. The overall objective of the proposed research project is therefore to adapt one Pan-Canadian Oncology Symptom Triage and Remote Support (COSTaRS) symptom practice guide for adults with cardiotoxicity and test its usability for self-management of long-term symptoms (e.g. breathlessness).

We estimate that thirteen participants will be enrolled in the study.

What is expected of me?

You will be asked to complete one acceptability survey and participate in an interview at a time and location convenient for you. The survey will be conducted to collect your feedback regarding the symptom practice guides' acceptability and usability. It will take approximately

thirty minutes to complete. You may skip any questions that make you uncomfortable or that you do not wish to answer.

You will also be asked to participate in an interview. The interview will be conducted to collect your feedback regarding the symptom practice guides' acceptability and usability. The interview will be approximately sixty minutes long. You may skip any questions that make you uncomfortable or that you do not wish to answer. The session will be digitally recorded to allow for verbatim transcription. If you do not want it to be recorded, you have the choice at the end of this form. This will not affect your participation in the study.

How long will I be involved in the study?

The entire study will last approximately twelve months. Your participation in the study will last approximately 30 to 45 minutes. Over this time, you will meet with the student principal investigator once.

Your participation in the study may be stopped for any of the following reasons:

- The researcher feels it is in your best interest.
- You do not follow the researcher's instructions.

What are the potential risks I may experience?

This study has risks, as most studies do.

However, there is always a chance of risks that we do not know about. The risks we know about are listed below.

Interview and Acceptability Survey:
You might find the interview and acceptability survey upsetting. You might not like all of the questions that you are asked. You do not have to answer any questions that make you feel uncomfortable.

Can I expect to benefit from participating in this research study?

You may not receive any direct benefit from your participation in this study. Your participation may allow the researchers to develop and evaluate one symptom practice guides for helping adults with cardiotoxicity to self-manage their cancer-treatment related breathlessness. This may benefit future adults with cardiotoxicity.

Do I have to participate? What alternatives do I have? If I agree now, can I change my mind and withdraw later?

Your participation in this study is voluntary. The alternative to this study is not to participate.

You may decide not to be in this study, or to be in the study now, and then change your mind later without affecting the medical care or other services to which you are entitled or are presently receiving at this institution.

If you withdraw your consent, the study team will no longer collect your personal identifying information for research purposes. You will also be given the choice of having your data withdrawn from the study completely.

How is my personal information being protected?

- All information collected during your participation in this study will be identified with a unique study number, and will not contain information that identifies you.
- The link between your unique study number and your name and contact information will be stored securely and separate from your study records, and will not leave this site.
- Any documents leaving The Ottawa Hospital will only contain your unique study number.
- The data will be stored and analyzed at The Ottawa Hospital
- For audit purposes only, your original study records may be reviewed under the supervision of Dawn Stacey and her staff by representatives from:
    - The Ottawa Health Science Network Research Ethics Board (OHSN-REB),
    - The Ottawa Hospital Research Institute.
- Information that identifies you will be released only if it is required by law.
- Research records will be kept for 10 years, after this time they will be destroyed.

Will I be informed about any new information that might affect my decision to continue participating?

You will be told in a timely fashion of any new findings during the study that could affect your willingness to continue in the study. You may be asked to sign a new consent form.

Who do I contact if I have any further questions?

If you have any questions about this study, or if you feel that you have experienced a study-related injury or illness, please contact Dawn Stacey.

The Ottawa Health Science Network Research Ethics Board (OHSN-REB) has reviewed this protocol. The Board 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 study participant, you may contact the Chairperson at 613-798-5555, extension 16719.

Supporting Adults in Cancer-Related Symptom Self-Management

Consent to Participate in Research

- I understand that I am being asked to participate in a research study about adapting one symptom practice guide for adults with cardiotoxicity and test its usability for self-management of long-term symptoms (e.g. breathlessness)
- This study was explained to me by _____.
- I have read, or have had it read to me, each page of this Participant Informed Consent Form.
- All of my questions have been answered to my satisfaction.
- If I decide later that I would like to withdraw my participation and/or consent from the study, I can do so at any time.
- I voluntarily agree to participate in this study.
- I will be given a copy of this signed Participant Informed Consent Form.

I agree to be digitally recorded Yes ☐ No ☐ Initials ___

_____	_____	_____
Participant's Printed Name	Participant's Signature	Date

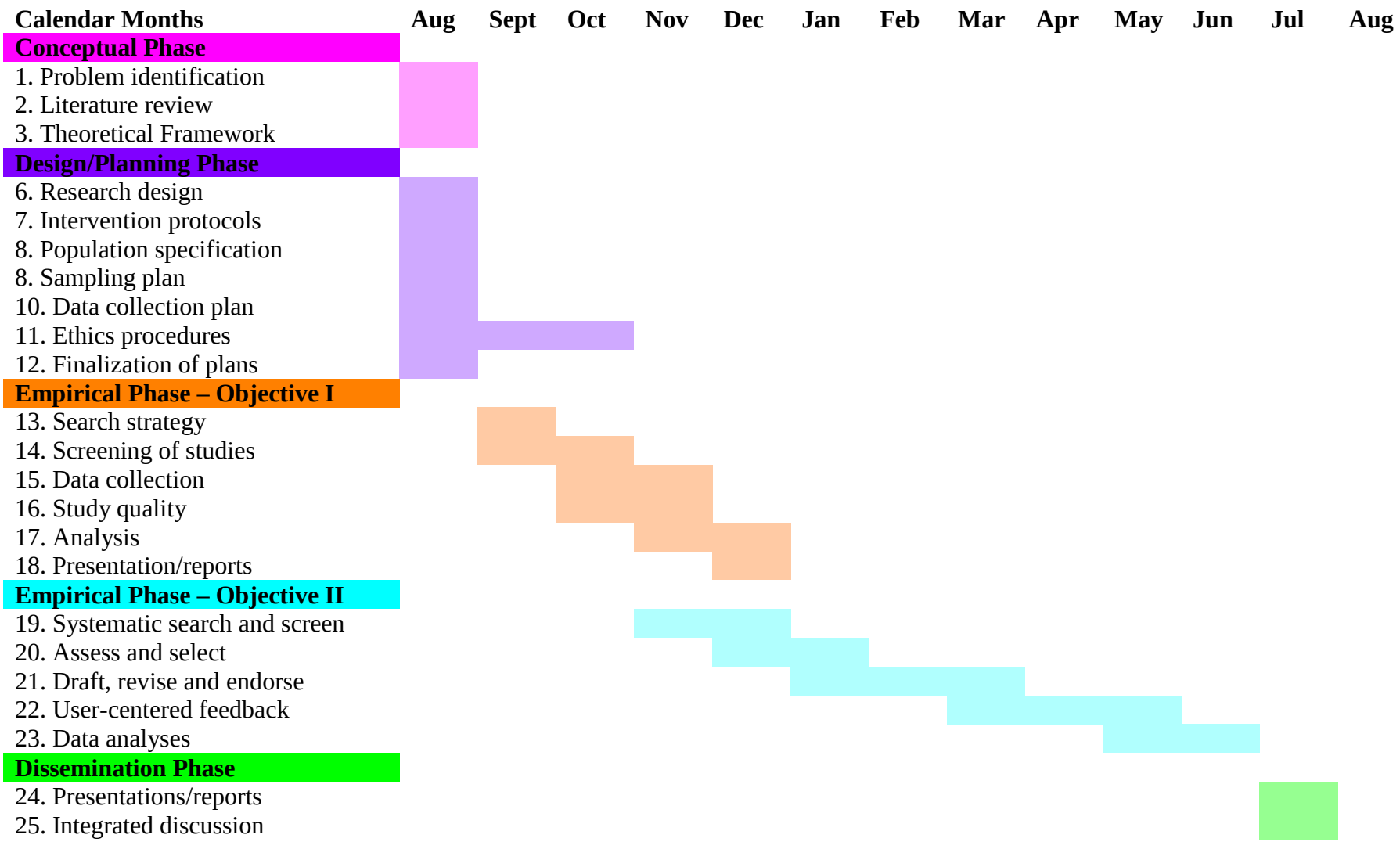
Investigator or Delegate Statement

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

_____	_____	_____
Investigator/Delegate's Printed Name	Investigator/Delegate's Signature	Date

Appendix F

In calendar months, the proposed research project over a thirteen-month period.



26. Defense

Calendar Months	**Aug**	**Sep**	**Oct**	**Nov**	**Dec**	**Jan**	**Feb**	**Mar**	**Apr**	**May**	**Jun**	**Jul**	**Aug**

Modified from Polit, D. & Beck, C. (2008). *Nursing research: Generating and assessing evidence for nursing practice.* (8th ed.).

Philadelphia: Lippincott Williams & Wilkin

Appendix G

The three major group visit models compared (the cooperative healthcare clinic, the drop-in group medical appointment and the physicals shared medical appointment) (Noffsinger, 2009).

	Cooperative Healthcare Clinic	Drop-in Group Medical Appointment	Physicals Shared Medical Appointment
Primary Focus	Follow-up visits	Follow-up visits	Physical examinations
Target Patients	Same 15 – 20 high-utilizing, multi-morbid geriatric patients	Patients in a provider's practice or chronic illness program requiring a follow-up visit	Patients in a provider's practice or chronic illness program requiring a private, physical examination
Same or Different Patients	Same	Different	Different
Formal Educational Lecture	Yes	No	No
Typically a Series of Individual Office Visits	No	Yes	Yes
Timing of Patients Attendance	Regularly	Only when medically necessary	Only when medically necessary
Ideal Group Size	15 – 20 patients	10 – 16 patients	10 – 13 patients (medical and surgical subspecialties)
SMA Team Members	Physician, nurse/medical assistant, guest speakers	Physician, nurse, documenter, behaviorist, assistant	Physician, documenter, behaviorist, assistant
Frequency of Sessions	Monthly	Weekly	Weekly
Typical Length of Sessions	2.5 hours (1.5 hours group, 1 hour optional individual consultation)	90 minutes	90 minutes
Care Provided in Front of Others	No	Yes	Yes
Limitations	Not being seen as a lecture; Regular attendance by patients	Maintaining an ideal group size; operational challenges	Maintaining an ideal group size; Operational challenges
Unique benefits	Reduced nursing home, emergency, and hospital costs; patient bonding	Increased productivity, access to care and disease management	Increased productivity, access to care and practice management

Appendix H

Excluded studies from Chapter Three. All citations listed below were reviewed in their full-text version and excluded for the reason indicated. An alphabetical reference list follows the table.

Citation	Not RCT	Not chronic	Not available	Abstract only	No individual consultation	No group segment	Not 1 chronic illness	Not peer-reviewed	Protocol
AARC Times 2004	X								
AHRQ Research Activities 2007	X								
Albert 2014	X								
American Family Physician 2007	X								
Anonymous 2001	X								
Anonymous 2001	X								
Anonymous 2001	X								
Anonymous 2002	X								
Anonymous 2002	X								
Anonymous 2002	X								
Anonymous 2003	X								
Anonymous 2004	X								
Anonymous 2007	X								
Anonymous 2009	X								
Anonymous 2010	X								
Anonymous 2013	X								
Antonucci 2008	X								
Ayoub 2009	X								
Barnett 2015	X								
Barud 2006	X								
Beck 1997		X							
Block 2010	X								
Blunt 2014	X								
Brower 2009	X								
Buppert 2009			X						
Butcher 2016	X								
Carlson 2003	X								
Coleman 2001		X							
Colon-Rivera 2016	X								
Côté 2001			X						

Citation	Not RCT	Not chronic	Not available	Abstract only	No individual consultation	No group segment	Not 1 chronic illness	Not peer-reviewed	Protocol
Crane 2012		X							
Desai 2014	X								
Donovan 1985	X								
Dreffer 2004	X								
Dyer 2012	X								
Escobar 2001		X							
Griffin 2009							X		
Grotjahn 1972	X								
Heimoff 2000	X								
Hofmann 2010	X								
Houck 2003	X								
Inlander 2013	X								
Irlich 2015	X								
Jaber 2006	X								
Khandelwal 2015	X								
Kirsh 2008	X								
Knopf 2015	X								
Koren 1994	X								
Kuiken 2005	X								
Levine 2010		X							
Lyons 2005			X						
Magdic 2006	X								
Marcus 2015	X								
Masley 2001					X				
May 2006	X								
McGee 1974	X								
Moberly 2010	X								
Morrison 1974	X								
NASPE News 2003			X						
Nilsson 1970	X								
Nitzsche 1985	X								
Painter 2014	X								
Palaniappan 2011	X								
Pennachio 2003	X								
Peterson 2007	X								

Citation	Not RCT	Not chronic	Not available	Abstract only	No individual consultation	No group segment	Not 1 chronic illness	Not peer-reviewed	Protocol
Reeder 2016				X					
Reich 2011	X								
Resneck 2010	X								
Rhee 2011	X								
Romeo 2016				X					
Rubenstein 2014	X								
Salanave 2008						X			
Scheet 1994			X						
Scott 2004		X							
Seesing 2014					X				
Seesing 2015					X				
Self 2007	X								
Sherwen 1983	X								
Shlosser 2012								X	
Sikon 2010	X								
Singrey 2015	X								
Stevens 2016	X								
Tanner 1997		X							
Thompson 2000	X								
Trott 2016				X					
Trotter 2009	X								
Trotter 2013				X					
van Eijk 2001		X							
Vickery 1988							X		
Visser 2011									X
Westheimer 2009	X								
Yehle 2007								X	

List of Excluded Studies

1. AARC Times. Group medical appointments becoming commonplace. *AARC Times* 2004.

2. Agency for Healthcare Research and Quality. Studies examine medication adherence and group medical visits among persons with high blood pressure. AHRQ Research Activities. 2007;(326): 16-17.

3. Albert N. Shared appointments in heart failure: Team model value add or not ready for prime time? *Circ Heart Fail* 2014; *7*(6): 871-873. doi: 10.1161/CIRCHEARTFAILURE.114.001779

4. American Family Physician. Americans in motion assists physicians with conducting, billing for group visits. *Am Fam Physician* 2008; *78*(2): 173-174.

5. Anonymous. DIGMAs (drop-in group medical appointments): Satisfaction Rx for doctors and patients. *Hosp Peer Rev* 2001; *26*(6): 81-82. doi: 10.1370/afm.1660

6. Anonymous. Researchers find new value in group visit concept among chronically ill adults. *Disease Management Advisor* 2001; *7*(8): 121-125.

7. Anonymous. Take steps to ensure group visits are successful: Start with chronic patient groups. *Patient Education Management* 2001.

8. Anonymous. Group appointments create opportunities for education. *Patient Education Management* 2002; *9*(7): 73-76.

9. Anonymous. Group appointments for seniors continue to prove their worth. *Senior Care Management* 2002; *5*(4): 57-59.

10. Anonymous. Group visits encouraged for chronically ill. *Clin Resour Manag* 2002; *3*(1): 1-5.

11. Anonymous. Shared medical appointments save money for capitated groups. Capitation Manag Rep 2003; *10*(2): 20-24, 17.

12. Anonymous. Group visits are effective use of case managers' time. *Case Manage Advis* 2004; *15*(11): 121-123.

13. Anonymous. Indian group visits midwifery services in Netherlands, Sweden. *Nursing Journal of India* 2007; *98*(1): 23

14. Anonymous. 'Shared' appointments improve patient satisfaction, access. *Urology Times* 2009; *37*(12): 6.

15. Anonymous. It takes a village: Shared medical appointments increase patient satisfaction and quality of care. *The Joint Commission Benchmark* 2010.

16. Anonymous. Shared visits offer benefits for patient and provider. *Harv Dent Bull* 2013; *73*(2): 27, 34.

17. Antonucci J. A new approach group visits: Helping high-need patients make behavioral change. *Fam Pract Manag* 2008; *15*(4): A6-A8

18. Ayoub W, Newman E, Blosky M, et al. Improving detection and treatment of osteoporosis: Redesigning care using the electronic medical record and shared medical appointments. *Osteoporosis International* 2009; *20*(1): 37-42. doi: 10.1007/s00198-008-0635-x

19. Barnett K. Group medical visits: The future of healthcare? *Glob Adv Health Med* 2015; *4*(6): 6-7. doi: 10.7453/gahmj.2015.110

20. Barud S, Marcy T, Armor B, et al. Development and implementation of group medical visits at a family medicine center. *Am J Health Syst Pharm* 2006; *63*(15): 1448-1452.

21. Beck A, Scott J, Williams P, et al. A randomized trial of group outpatient visits for chronically ill older HMO members: The cooperative health care clinic. *JAGS* 1997; *45*(5): 543-549.

22. Block J. Outcomes research in review. Group visits for the treatment of hypertension among diabetics: Success without a pill? *Journal of Clinical Outcomes Management* 2010; *17*(8): 343

23. Blunt A. Practice Pearls. Correctly billing for group visits. *Fam Pract Manag* 2014; *21*(2): 28.

24. Brower A. Shared medical appointments. *RN* 2009; *72*(9): 28-31.

25. Buppert C. Let's talk money. May NPs bill group visits? *Nurse Practitioner World News* 2009; *14*(5-6): 1-6

26. Butcher L. Weigh your options: Shared medical appointments vs. standard practice. *Oncology Times* 2016; *38*(5): 1, 7, 9. doi: 10.1097/01.COT.0000481865.02544.93

27. Carlson B. Shared appointments improve efficiency in the clinic. *Manag Care* 2003; *12*(5): 46-48.

28. Coleman E, Eilertsen T, Kramer A, et al. Reducing emergency visits in older adults with chronic illness. A randomized, controlled trial of group visits. *Eff Clin Pract* 2001; *4*(2): 49-57.

29. Colon-Rivera H, Daum A and Nykiel S. The impact of sharing: The use of shared medical appointments to allow providers to increase treatment access for substance use and related disorders. *Subst Abus* 2016; *37*(1): 7-8. doi: 10.1080/08897077.2015.1129021

30. Côté J, Bowie D, Robichaud P, et al. Evaluation of two different educational interventions for adult patients consulting with an acute asthma exacerbation. *Am J Respir Crit Care Med* 2001; *163*(6): 1415-1419. doi: 10.1164/ajrccm.163.6.2006069

31. Crane S, Crollins L, Hall J, et al. Reducing utilization by uninsured frequent users of the emergency department: Combining case management and drop-in group medical appointments. *J Am Board Fam Med* 2012; *25*(2): 184-191. doi: 10.3122/jabfm.2012.02.110156

32. Desai K and Bragg S. Group medical visits for chronic diseases. *Am Fam Physician* 2014; *90*(11): 794.

33. Donovan C. Joint or shared appointments. Clinical nurse specialist practice in an acute care setting. *Annu Symp Nurs Fac Pract* 1985; (2): 111-118.

34. Dreffer D. Group visits hit the road. *Fam Pract Manag* 2004; *11*(8): 39-42.

35. Dyer N, Sorra J, Smith S, et al. Psychometric properties of the consumer assessment of healthcare providers and systems (CAHPS®) clinician and group adult visit survey. *Med Care* 2012; *50*(Suppl): S28-S34. doi: 10.1097/MLR.0b013e31826cbc0d

36. Escobar G, Braveman P, Ackerson L, et al. A randomized comparison of home visits and hospital-based group follow-up visits after early postpartum discharge. *Pediatrics* 2001; *108*(3): 719-727.

37. Griffin B, Burkiewicz J, Peppers L, et al. International normalized ratio values in group versus individual appointments in a pharmacist-managed anticoagulation clinic. *Am J Health Syst Pharm* 2009; *66*(13): 1218-1223. doi: 10.2146/ajhp080278

38. Grotjahn M. Learning from dropout patients: A clinical view of patients who discontinued group psychotherapy. *Int J Group Psychother* 1972; *22*(3): 306-319.

39. Heimoff S. Waiting room crowded? Put a few people in the examining room at once. *Manag Care* 2000; *9*(6): 34-37.

40. Hofmann M, Rodriguez J and Shearer B. Are group visits effective for the treatment of obesity? *Evidence-Based Practice* 2010; *13*(2): 6-7

41. Houck S, Kilo C and Scott J. Improving patient care. Group visits 101. *Fam Pract Manag* 2003; *10*(5): 66-68.

42. Inlander C. When to book a group medical appointment. *Bottom Line Health* 2013.

43. Irlich J, Kaufman S and Ganetsky, V. Group medical visits as a tool for interprofessional team practice and implementation of the pharmacy practice model initiative. *Am J Health-Syst Pharm* 2015; *72*: 1172-1173. doi: 10.2146/ajhp150012

44. Jaber J, Braksmajer A and Trilling J. Group visits for chronic illness care: Models, benefits and challenges. *Fam Pract Manag* 2006; *13*(1): 37-40.

45. Khandelwal C, Prentice A, Fisher J, et al. Treating dementia with shared group visits. *Fam Prac Manag* 2015; *22*(3): 16-21.

46. Kirsh S and Aron D. Integrating the chronic-care model and the ACGME competencies: Using shared medical appointments to focus on systems-based practice. *Qual Saf Health Care* 2008; *17*: 15-19. doi: 10.1136/qshc.2006.020925

47. Knopf A. CleanSlate's bupe clinics use part-time doctors, group visits to maximize access. *Alcoholism & Drug Abuse Weekly* 2015; *27*(6): 1-3. doi: 10.1002/adaw.30156

48. Koren M, Bartel J and Corliss J. Interventions to improve patient appointments in an ambulatory care facility. *J Ambul Care Manage* 1994; *17*(3): 76-80.

49. Kuiken S and Seiffert D. Thinking outside the box! Enhance patient education by using shared medical appointments. *Plast Surg Nurs* 2005; *25*(4): 191-195.

50. Levine M, Ross T, Balderson B, et al. Implementing group medical visits for older adults at group health cooperative. *J Am Geriatr Soc* 2010; *58*(1): 168-172. doi: 10.1111/j.1532-5415.2009.02628.x

51. Lyons K. Randomized study of an early intervention palliative care program comprising a phone-based nurse educator and shared medical appointments versus a standard care program in improving end-of-life care of patients with advanced lung, gastrointestinal, genitourinary, or breast cancer. *AJMC* 2005; *6*.

52. Magdic K. Acute care billing: Shared visits. *Nurse Pract* 2006; *31*(11): 9-10

53. Marcus M. Are shared medical appointments the future for cancer care? *Oncology Times* 2015; *37*(15): 1, 10-11. doi: 10.1097/01.COT.0000470859.19234.97

54. Masley S, Phillips S and Copeland J. Group office visits change dietary habits of patients with coronary artery disease – The dietary intervention and evaluation trial (D.I.E.T.). *J Fam Pract* 2001; *50*(3): 235-239.

55. May M. Groups visits for chronic illness care. *Fam Prac Manag* 2006; *13*(2): 16-22.

56. McGee T, Schuman B and Racusen F. Termination in group psychotherapy. *Am J Psychother* 1974; 521-532.

57. Moberly T. Practices trial nurse-led group appointments for dermatology. *Independent Nurse* 2010.

58. Morrison P. Group visits help T and A patients. *AORN Journal* 1974; *20*(2): 323-326.

59. NASPE News. Coding corner. Shared visits: What are they, how can they benefit your practice? *NASPE News* 2003; *24*(4): 1.

60. Nilsson C. Group appointments under further education. *Lakartidningen* 1970; *67*(18): 2011-2014.

61. Nitzsche M. Experiences from group visits made within the framework of a sociopsychiatric rehabilitation program. *Z Gesamte Hyg* 1985; *31*(3): 179-180.

62. Painter R and Painter M. How to bill for shared medical appointments. *Urology Times* 2014; *42*(9): 31, 32

63. Palaniappan L, Muzaffar A, Wang E, et al. Shared medical appointments: Promoting weight loss in a clinical setting. *J Am Board Fam Med* 2011; *24*(3): 326-328. doi: 10.3122/jabfm.2011.03.100220

64. Pennachio D. Should you offer group visit? You can't beat shared medical appointments for patient education and compliance, say proponents. *Med Econ* 2003; *80*(15): 70.

65. Peterson C, Chicano K, Capone-Swearer D, et al. Shared medical appointments. *Nurse Practitioner World News* 2007; *12*(6): 16.

66. Reeder K, Smith C, Piamjariyakul U, et al. Outcomes of a multidisciplinary heart failure self-management group clinic appointments intervention. *Heart & Lung* 2016; *45*(4): 372-373. doi: 10.1016/j.hrtlng.2016.05.004

67. Reich S and Weiner W. Group visits for Parkinson disease: “The doctor will see all of you now”. *Neurology* 2011; *76:* 1538-1539.

68. Resneck J and VanBeek M. Shared medical appointments: Will changes in health care delivery and financing promote increased use of nonphysician clinicians in dermatology patient counseling? *Arch Dermatol* 2010; *146*(4): 434-436. doi: 10.1001/archdermatol.2010.49

69. Rhee E. Group visits deliver efficiency, patient satisfaction. *Urology Times* 2011; *39*(2): 1.

70. Romeo J, Roy D and Newmyer J. Increased cost-effectiveness and efficiency utilizing shared medical appointments for cardiac rehabilitation program enrollment. *JACC* 2016; *67*(13): 1938.

71. Rubenstein J. Shared medical appointments in urology. *Rev Uro* 2014; *16*(3): 136-138.

72. Salanave B, Bertin N, Vernay M, et al. Evaluation de l'impact de visites confraternelles avec ou sans examen conjoint sur le comportement des maladies hypertendus exonérés du ticket modérateur. *Pratiques et Organisation des Soins* 2008; *39*(2): 87 – 94.

73. Scheet N. The shared visit. *Home Health Focus* 1994; *1*(5): 2-3.

74. Scott J, Connor D, Venohr I, et al. Effectiveness of a group outpatient visit model for chronically ill older health maintenance organization members: A 2-year randomized trial of the Cooperative Health Care. *J Am Geriatr Soc* 2004; *52*(9): 1463 – 1470. doi: 10.1111/j.1532-5415.2004.52408.x

75. Seesing F, Drost G, Groenewoud J, et al. Shared medical appointments improve QOL in neuromuscular patients: A randomized controlled trial. *Neurology* 2014; *83*(3): 240-246. doi: 10.1212/WNL.0000000000000588

76. Seesing F, Groenewoud H, Drost G, et al. Cost-effectiveness of shared medical appointments for neuromuscular patients. *Neurology* 2015; *85*(7): 619-625. doi: 10.1212/WNL.0000000000001857

77. Self D. Medicare matters. Shared visit denotes service billed under a physician's number. *Geriatrics* 2007; *62*(10): 32.

78. Sherwen L and Salvio K. The teacher/practitioner shared appointment making it work. *Nurs Educ* 1983; *8*(2): 30-33.

79. Shlosser H. Hypertension group healthcare visits. University of Virginia; 2012.

80. Sikon A and Bronson D. Shared medical appointments: Challenges and opportunities. *Ann Intern Med* 2010; *152*(11): 745-746. doi: 10.7326/0003-4819-152-11-201006010-00012

81. Singrey A, Mehta B and Casper K. Management of heart failure patients through integrative medical group visits. *Am J Health Syst Pharm* 2015; *72*(5): 349-351. doi: 10.2146/ajhp140294

82. Stevens J, Dixon J, Binns A, et al. Shared medical appointments for Aboriginal and Torres Strait Islander men. *Aust Fam Physician* 2016; *45*(6): 425-429.

83. Tanner E and Feldman R. Strategies for enhancing appointment keeping in low-income chronically ill clients. *Nurs Res* 1997; *46*(6): 342-344.

84. Thompson E. The power of group visits. Improved quality of care, increased productivity entice physicians to see up to 15 patients at a time. *Mod Healthc* 2000; *30*(23): 54, 56, 62.

85. Trott N, Kurien M, Branchi F, et al. Comparing dietitian-led group clinics to individual appointments for newly diagnosed patients with coeliac disease (CD). *Gut* 2016; 65: A292.

86. Trotter K. Group visits for survivor care: An innovative multi-disciplinary approach. *Oncol Nurs Forum* 2009; *36*(3): 25.

87. Trotter K, Schneider S and Turner B. Group appointments in a breast cancer survivorship clinic. *J Adv Pract Oncol* 2013; *4*(6): 423-431.

88. van Eijk M, Avorn J, Porsius A, et al. Reducing prescribing of highly anticholinergic antidepressants for elderly people: Randomised trial of group versus individual academic detailing. *BMJ* 2001; *322*(7287):654-657.

89. Vickery D, Golaszewski T, Wright E, et al. The effect of self-care interventions on the use of medical service within a Medicare population. *Med Care* 1988; *26*(6): 580-588.

90. Visser A, Prins J, Hoogerbrugge N, et al. Group medical visits in the follow-up of women with a BRCA mutation: Design of a randomized controlled trial. *BMC Womens Health* 2011; *11*(39). doi: 10.1186/1472-6874-11-39

91. Westheimer J, Capello J, McCarthy C, et al. Employing a group medical intervention for hypertensive male veterans: An exploratory analysis. *Journal for Specialists in Group Work* 2009; *34*(2): 151-174.

92. Yehle K. A comparison of standard office visits and shared medical appointments in adults with heart failure. Touro University International; 2007.

Appendix I

The recommendation matrix of the included guidelines (n=7).

Author	Year	Assess	Triage	Medications	Management
6. BC Guidelines	2015	Weight gain (2kg over 2 days or 2.5kg in one week) (p. 2) No chest discomfort, pressure or pain (p. 4) You have a dry hacking cough (p. 4) You have chest pain that does not go away with rest or medication (p. 4) See "Heart Failure Zones" (p. 4)	See "Heart Failure Zones" (p. 4)	Furosemide (p. 5, 6) Angiotensin converting enzyme inhibitor (ACE-I) (or angiotensin receptor blocker [ARB], if ACE-I intolerant) (p. 5) Beta-blocker (BB) (p. 6) Mineralocorticoid receptor antagonists (MRA) (p. 6) Digoxin is no longer considered a first-line therapy for heart failure (HF) patients even though it has been shown to relieve symptoms (p. 7)	Record daily weight (p. 4) Limit sodium intake to <2000mg per day (p. 4) The recommended total amount of fluid intake per day is 1.5-2L (p. 4) Limit alcohol consumption to no more than 1 drink per day (p. 4) Stop smoking (p. 4) If stable symptoms and volume status, the goal is 30 minutes of continuous moderate exercise, and weight-bearing/resistance and flexibility activities at least twice a week (p. 4) Annual influenza vaccine (p. 4)
7. SIGN	2016	The NYHA classification (p. 8) Weight gain (>2kg/week) (p. 14) Paroxysmal nocturnal dyspnea/orthopnea (p. 14) Nocturnal cough/wheezing (p. 14) Ankle swelling, bloated feeling, peripheral edema (p. 14) Confusion (especially in older people) (p. 14) Syncope (p. 14) Tachycardia (p. 14)	N/R	Opioids (p. 42) No evidence was identified that oxygen at rest or when ambulatory is beneficial in patients with HF (p. 42) Diuretic or BB (p. 70) ACE-I (p. 25) Intolerant of ACE-I, give ARB (p. 26) Ongoing symptoms (NYHA class II-IV) with BB and ACE-I, add MRA (p. 31)	Strongly advise not to smoke and should be offered smoking cessation advice and support (p. 22) Refrain from excessive alcohol consumption (p. 22) Encourage patient to weigh themselves daily (after waking, before dressing, after voiding, before eating) (p. 70)
8. Canadian Cardiovascular Society Heart Failure Management (Acute and Chronic Heart	2012	N/R	N/R	Loop diuretic (p. 176) Nitrates can be useful to relieve dyspnea or angina but continuous use should	N/R

Author	Year	Assess	Triage	Medications	Management
Failure)				be avoided because of risk tolerance development (p. 176) Diuretics + ACE-I (if intolerant to ACE-I then ARB) + BB (p. 174) MRAs (p. 174) Digoxin (p. 174, p. 176)	
9. American College of Cardiology/American Heart Association	2013	NYHA (p. e155) Rapid weight gain (p. e162). Cachexia (p. e162)	N/R	Diuretics (p. e173) Combination of hydralazine and isosorbide dinitrate who cannot be given an ACE-I or ARB (p. e179) ACE-Is (p. 174) ARBs who are ACE-I intolerant (p. 175) BB (p. 176) Omega-3 polyunsaturated fatty acid (PUFA) supplementation (p. 181)	Fluid restriction (1.5 – 2L/day). Sodium and fluid balance recommendations are best implemented in the context of weight and symptom monitoring programs (p. 190)
10. American College of Cardiology/American Heart Association	2016	N/R	N/R	ACE-I (p. 9) ARBs who are intolerant to ACE-I (pg. 9) Replacement of ACE-I and ARB by an angiotensin receptor-neprilysin inhibitor (ARNI) (p. 10)	N/R
11. National Heart Foundation of Australia (prevention, detection and management)	2011	N/R	N/R	Diuretics (p. 6) Hydralazine-isosorbide dinitrate combination reserved for patients intolerant of ACE-Is and angiotensin II receptor antagonists (p. 31) ACE-Is (p. 31) BBs (pg. 31) ARBs with spironolactone	Fluid management (p. 22) Excessive dietary sodium intake should be avoided (p. 22) Alcohol intake should not exceed 1 – 2 drinks/day (p. 23) Patients should not smoke or chew tobacco (p. 23) Exercise/conditioning program (p. 32)

Author	Year	Assess	Triage	Medications	Management
				(p. 31) Fish oil as a second-line agent (p. 31) Nitrates (p. 44) Digoxin (p. 29)	
12. European Society of Cardiology – Acute and Chronic Heart Failure	2016	Breathlessness, orthopnea, paroxysmal nocturnal dyspnea, reduced exercise tolerance, fatigue, tiredness, increased time to recover after exercise, ankle swelling, nocturnal cough, wheezing, bloated feeling, loss of appetite, confusion (especially in the elderly), depression, palpitations, dizziness, syncope, weight gain, weight loss, peripheral edema, tachycardia, irregular pulse (p. 2140)	N/R	ACE-I, in addition to a BB (pg. 2192) MRA (p. 2192) Diuretics (p. 2192) Sacubitril/valsartan as a replacement for ACE-I (p. 2192)	Regular aerobic exercise (p. 2193) Stop smoking and taking recreational substances (p. 2188) Monitor body weight and prevent malnutrition (p. 2188) Eat healthily, avoid excessive salt intake (>6g/day) and maintain a healthy body weight (p. 2188) Fluid restriction of 1.5-2L/day (p. 2188) Immunization against influenza and pneumococcal disease (p. 2188)

Appendix J

Excluded studies from Chapter Four. All citations listed below were reviewed in their full-text version and excluded for the reason indicated. An alphabetical reference list follows the table.

Citation	Not Systematic Review/Guideline	No Symptoms	Paediatric	Protocol Only	Pulmonary Hypertension
Armenian 2015		X			
Armenian 2016		X			
Barac 2015	X				
Barthel 2016			X		
Bovelli 2010		X			
Chen 2016		X			
Conway 2015		X			
Demirci 2010	X				
Galiè 2015					X
Harrison 2016	X				
Howlet 2013		X			
Kenyon 2014	X				
Lainscak 2011	X				
Lenneman 2016	X				
Mishra 2012		X			
Moe 2013		X			
Nathan 2016	X				
National Heart Foundation of Australia 2011	X				
Okada 2012			X		
Rushton 2015				X	
Schmitz 2012	X				
Steingart 2013		X			
Valachis 2015	X				
Virani 2016		X			
Walsh 2010	X				
Wong 2014	X				
Yun 2015			X		
Zamorano 2016		X			

List of Excluded Studies

1. Armenian S., Hudson M., Mulder R., Chen M., Constine L., Dwyer M., Nathan P., Tissing W., Shankar S., Sieswerda E., Skinner R., Steinberger J., van Dalen E., van der Pal H., Wallace W., Levitt G., Kremer L. & International Late Effects of Childhood Cancer Guideline Harmonization Group. (2015). Recommendations for cardiomyopathy surveillance for survivors of childhood cancer: A report from the international late effects of childhood cancer guideline harmonization group. *The Lancet Oncology, 16*(3): e123 – e136. doi: 10.1016/S1470-2045(14)70409-7

2. Armenian S., Lacchetti C., Barac A., Carver J., Constine L., Denduluri N., Dent S., Douglas P., Durand J., Ewer M., Fabian C., Hudson M., Jessup M., Jones L., Ky B., Mayer E., Moslehi J., Oeffinger K., Ray K., Ruddy K. & Lenihan D. (2016). Prevention and monitoring of cardiac dysfunction in survivors of adults cancers: American society of clinical oncology clinical practice guideline. *Journal of Clinical Oncology, 35*(8): 893 – 911. doi: 10.1200/JCO.2016.70.5400

3. Barac A., Murtagh G., Carver J., Chen M., Freeman A., Herrmann J., Iliescu C., Ky B., Mayer E., Okwuosa T., Plana J., Ryan T., Rzeszut A. & Douglas P. (2015). Council clinical perspective: Cardiovascular health of patients with cancer and cancer survivors: A roadmap to the next level. *Journal of the American College of Cardiology, 65*(25): 2739 – 2746. doi: 10.1016/j.jacc.2015.04.059

4. Barthel E., Spencer K., Banco D., Kiernan E. & Parsons S. (2016). Is the adolescent and young adult cancer survivor at risk for late effects? It depends on where you look. *Journal of Adolescent and Young Adult Oncology, 5*(2): 159 – 173. doi: 10.1089/jayao.2015.0049

5. Bovelli D., Plataniotis G. & Roila F. (2010). Cardiotoxicity of chemotherapeutic agents and radiotherapy-related heart disease: ESMO clinical practice guidelines. *Annals of Oncology, 21*(Supplementary 5): v277 – v282. doi: 10.1093/annonc/mdq200

6. Chen J., Wu P.T., Middlekauff H. & Nguyen K.L. (2016). Aerobic exercise in anthracycline-induced cardiotoxicity: A systematic review of current evidence and future directions. *American Journal of Physiology. Heart and Circulatory Physiology.* doi: 10.1152/ajpheart.00646.2016

7. Conway A., McCarthy A., Lawrence P. & Clark R. (2015). The prevention, detection and management of cancer treatment-induced cardiotoxicity: A meta-review. *BioMed Central Cancer, 15*(366): 1 – 16. doi: 10.1186/s12885-015-1407-6

8. Demirci U., Benekli M., Buyukberber S. & Coskun U. (2010). Late side effects of cancer therapy. *International Journal of Hematology and Oncology, 4*(20): 250 – 261.

9. Galiè N., Humbert M., Vachiery J.L., Gibbs S., Lang I., Torbicki A., Simonneau G., Peacock A., Noordegraaf A., Beghetti M. & Ghofrani A. (2015). 2015 ESC/ERS guidelines for the diagnosis and treatment of pulmonary hypertension. *European Heart Journal, 37*(1): 67 – 119. doi: 10.1093/eurheartj/ehv317

10. Harrison J., Pressler S. & Friese C. (2016). Cardiotoxic heart failure in breast cancer survivors: A concept analysis. *Journal of Advanced Nursing, 72*(7): 1518 – 1528. doi: 10.1111/jan.12988

11. Howlett J. & MacFadyen J. (2013). Treatment of diabetes in people with heart failure. *Canadian Journal of Diabetes, 37*(2013): S126 – S128. doi: 10.1016/j.jcjd.2013.01.036

12. Kenyon M., Mayer D. & Owens A. (2014). Late and long-term effects of breast cancer treatment and surveillance management for the general practitioner. *Journal of Obstetric, Gynecologic & Neonatal Nursing, 43*(3): 382 – 398. doi: 10.1111/1552-6909.12300

13. Lainscak M., Blue L., Clark A., Dahlström U., Dickstein K., Ekman I., McDonagh T., McMurray J., Ryder M., Stewart S., Strömberg A. & Jaarsma T. (2011). Self-care management of heart failure: Practical recommendations from the patient care committee of the heart failure association of the European society of cardiology. *European Journal of Heart Failure, 13*(2): 115 – 126. doi: 10.1093/eurjhf/hfq219

14. Lenneman C. & Sawyer D. (2016). Cardio-oncology: An update on cardiotoxicity of cancer-related treatment. *Circulation Research, 118*(6): 1008 – 1020. doi: 10.1161/CIRCRESAHA.115.303633

15. Mishra S., Scherer R., Geigle P., Berlanstein D., Topaloglu O., Gotay C. & Snyder C. (2012). Exercise interventions on health-related quality of life for cancer survivors (review).*Cochrane Database of Systematic Reviews, 8*: CD007566. doi: 10.1002/14651858.CD007566.pub2

16. Moe G., Ezekowitz J., O'Meara E., Howlett J., Fremes S., Al-Hesayen A., Heckman G., Ducharme A., Estrella-Holder E., Grzeslo A., Harkness K., Lepage S., McDonald M., McKelvie R., Nilgam A., Rajda M., Rao V., Swiggum E., Virani S., Van Le V. & Zieroth S. (2013). The 2013 Canadian cardiovascular society heart

failure management guidelines update: Focus on rehabilitation and exercise and surgical coronary revascularization. *Canadian Journal of Cardiology, 30*(2014): 249 – 263. doi: 10.1016/j.cjca.2013.10.010

17. Nathan P., Amir E., Abdel-Qadir H. (2016). Cardiac outcomes in survivors of pediatric and adult cancer. *Canadian Journal of Cardiology, 32*(2016): 871 – 880. doi: 10.1016/j.cjca.2016.02.065

18. National Heart Foundation of Australia. (2011). Diagnosis and management of chronic heart failure. Retrieved from https://www.heartfoundation.org.au/images/uploads/publications/CHF-QRG-updated-2014.pdf

19. Okada M., Meeske K., Menteer J. & Freyer D. (2012). Exercise recommendations for childhood cancer survivors exposed to cardiotoxic therapies: An institutional clinical practice initiative. *Journal of Pediatric Oncology Nursing, 29*(5): 246 – 252. doi: 10.1177/1043454212451525

20. Rushton M., Clark R., Brideson G. & Damarell R. (2015). The effectiveness of non-pharmacological interventions for the management of cancer treatment-induced cardiotoxicity: A systematic review protocol. *The Joanna Briggs Institute Database of Systematic Reviews & Implementation Reports, 13*(5): 53 – 73. doi: 10.11124/jbisrir-2015-2011

21. Schmitz K., Prosnitz R., Schwartz A. & Carver J. (2012). Prospective surveillance and management of cardiac toxicity and health in breast cancer survivors. *Cancer, 118*(8 suppl): 2270 – 2276. doi: 10.1002/cncr.27462

22. Steingart R., Yadav N., Manrique C., Carver J. & Liu J. (2013). Cancer survivorship: Cardiotoxic therapy in the adult cancer patient; cardiac outcomes with recommendations for patient management. *Seminars in Oncology, 40*(6): 690 – 708. doi: 10.1053/j.seminoncol.2013.09.010

23. Valachis A. & Nilsson C. (2015). Cardiac risk in the treatment of breast cancer: Assessment and management. *Breast Cancer (Dove Medical Press), 2015*(7): 21 – 35. doi: 10.2147/BCTT.S47227

24. Virani S., Dent S., Brezden-Masley C., Clarke B., Davis M., Jassal D., Johnson C., Lemieux J., Paterson I., Sebag I., Simmons C., Sulpher J., Thain K., Thavendiranathan P., Wentzell J. & Wurtele N. (2016). Canadian cardiovascular society guidelines for evaluation and management of cardiovascular complications of cancer therapy. *Canadian Journal of Cardiology, 32*(2016): 831 – 841. doi: 10.1016/j.cjca.2016.02.078

25. Walsh M. (2010). Impact of treatment-related cardiac toxicity on lymphoma survivors: An institutional approach for risk reduction and management. *Clinical Journal of Oncology Nursing, 14*(4): 505 – 507. doi: 10.1188/10.CJON.505-507

26. Wong D. & Hurvitz S. (2014). Cardiotoxicity of targeted agents in oncology: A medical oncology perspective. *Oncology (Williston Park), 28*(6): 490 – 492.

27. Yun S., Vincelette N. & Abraham I. (2015). Cardioprotective role of ß-blockers and angiotensin antagonists in early-onset anthracyclines-induced cardiotoxicity in adult patients: A systematic review and meta-analysis. *Postgraduate Medical Journal, 91*(1081): 627 – 633. doi: 10.1136/postgradmedj-2015-133535

28. Zamorano J., Lancellotti P., Muñoz D., Aboyans V., Asteggiano R., Galderisi M., Habib G., Lenihan D., Lip G., Lyon A., Fernandez T., Mohty D., Piepoli M., Tamargo J., Torbicki A. & Suter T. (2016). 2016 ESC position paper on cancer treatments and cardiovascular toxicity developed under the auspices of the ESC committee for practice guidelines. *European Heart Journal, 2016*(37): 2768 – 2801. doi: 10.1093/eurheartj/ehw211