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Improving Understanding of Colorectal Cancer Screening Decisional Conflict and Breast Cancer Survivorship Care

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A dissertation submitted in partial fulfillment of the requirements for the degree of Doctor of Philosophy at Virginia Commonwealth University

by

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Abstract

IMPROVING UNDERSTANDING OF COLORECTAL CANCER SCREENING DECISIONAL CONFLICT AND BREAST CANCER SURVIVORSHIP CARE

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A dissertation submitted in partial fulfillment of the requirements for the degree of Doctor of Philosophy at Virginia Commonwealth University.

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Background: Behavioral interventions and evidence based guidelines along the cancer control continuum can reduce the burden of cancer.

Objectives: This dissertation aims to increase our understanding of colorectal cancer screening (CRCS) decisional conflict and breast cancer survivorship care. This project: 1) assesses CRCS decisional conflict in a general population, 2) uses the Theory of Triadic Influence to model and evaluate direct and indirect associations between CRCS decisional conflict and colonoscopy adherence, 3) assesses post-treatment breast cancer care.

Methods: Data from a questionnaire administered to randomly selected adults, 50-75 years, living in six MN communities (N=1,268) and the 2010 Behavioral Risk Factor Surveillance System (BRFSS) (N=1,024, women ages 27-99) were used. Multivariable logistic regression was used to identify characteristics associated with high CRCS decisional conflict; then structural

equation modelling (SEM) was performed to assess direct and indirect associations of CRCS decisional conflict and colonoscopy adherence. Using BRFSS data, multivariable logistic regression was performed to assess the association between years since diagnosis and the type of clinician providing the majority of care for breast cancer survivors after treatment completion.

Results: Greater colonoscopy barriers (OR=1.04; 95% CI: 1.02-1.05) and CRCS-specific confusion (OR=1.12; 95% CI: 1.10-1.15) as well as a healthcare provider not discussing CRCS options (OR=1.67; 95% CI: 1.18-2.37) were associated with increased odds of high CRCS decisional conflict. A similar relationship was found in the SEM analyses: both greater levels of perceived colonoscopy barriers and CRCS confusion were associated with higher decisional conflict (standardized total effects=0.42 and 0.39, respectively, p-values < 0.01). CRCS decisional conflict was associated with increased non-adherence to colonoscopy. This relationship was mediated by CRCS-specific self-efficacy and intention (standardized total effect=0.14, p-value <0.01). Among breast cancer survivors, women 0–1 and 2–3 years since diagnosis were 2.1-2.6 times more likely to have a cancer-related clinician providing the majority of care compared to women 6+ years since diagnosis (95% CIs: 1.0-4.3; 1.4-4.6).

Conclusions: Decreasing colonoscopy barriers and CRCS-specific confusion could decrease CRCS decisional conflict and ultimately increase CRCS uptake. National policies to move breast cancer follow-up care to a primary care provider might be well-received by cancer survivors.

Chapter 1: Background

Cancer is the second leading cause of death in the United States (US) (1). As a result, cancer prevention and control is a top public health priority. The cancer control continuum divides cancer prevention and control and cancer research into distinct segments ranging from prevention to end of life care (2). Scientists use the continuum to identify areas of research to ultimately reduce cancer incidence, mortality, and to reduce the burden of cancer. A cross cutting area of research along the continuum is behavior because behaviors play a central role in both the etiology and progression of cancer outcomes (3). Behaviors that could reduce the burden of cancer include preventive behaviors, screening behaviors, and health care utilization behaviors (3).

Because behaviors have an influence along the entire cancer control continuum, behavioral epidemiology, interventions designed to change behavior, and evidence-based policies/guidelines can be used to impact the burden of cancer. There are multi-level influences on behaviors (individual, psychological, organizational, and environmental) (3), which means that multi-level interventions are needed to help foster changes in behavior. For example, improvements in decision making at the individual level could help people make better cancer screening or treatment decisions. To enhance decision making, constructs that are potentially important to decision making need to be evaluated and addressed in future interventions. Alternatively, policies with implications at an organizational or national level could change

healthcare utilization patterns for cancer survivors. The purpose of this project is to better understand factors associated with two specific behaviors along the cancer control continuum: colorectal cancer screening (CRCS) and breast cancer survivorship care, with a focus on potential applications in future research studies designed to change behaviors and informing evidence-based guidelines.

Colorectal cancer and screening

Colorectal cancer (CRC) is the second leading cause of cancer death in the US with an estimated 49,700 deaths in 2015 (1). However, with early detection and treatment through colorectal cancer screening (CRCS), the morbidity and mortality rates of CRC are significantly reduced (4). Based on the efficacy of CRCS on reducing CRC mortality, the US Preventive Services Task Force currently recommends CRCS via stool test every year, sigmoidoscopy every 5 years, or colonoscopy every 10 years for average-risk men and women, ages 50-75 years (approximately 26% of the US population) (4, 5). Although recommended, CRCS adherence remains low – approximately one out of every three average-risk adults is not screened as recommended (6). This screening rate is below the Healthy People 2020 and National Colorectal Cancer Screening Roundtable 2018 CRCS adherence goals of 70.5% and 80%, respectively (7, 8). While there are multiple reasons why people do not get screened, one reason why CRCS uptake remains low is because people experience barriers to CRCS (9-16). Barriers to CRCS can take many forms, and interventions have attempted to increase CRCS by decreasing barriers (9-11, 13-22).

Decisional conflict

One psychosocial construct that could have an influential role in CRCS is decisional conflict (23-28). Decisional conflict is an emotional state, with affective and effective

components, characterized by feeling uncertain, uninformed, unsupported, having unclear values, being unsatisfied, or having pressure relating to a decision (29, 30). Decisional conflict can occur for any decision, but it is likely to be present for decisions that: 1) have elements of emotion, 2) might be irreversible, 3) have a short decision window, 4) where the pros and cons need to be weighed and preferences taken into account, and 5) importantly, for decisions where there is no best decision based on clinical evidence (31). In 1995, O'Connor developed and validated a scale to measure decisional conflict, which includes five subscales: informed, values clarity, support, uncertainty and effective decision making (32). The scale has been used in many different settings and has been validated in multiple languages (33). There are multiple versions of the scale including 16- (33, 34) and 4-item (33, 34) versions and a low literacy version (33, 34).

Decisional conflict in decision making research

Decisional conflict is often evaluated in decision making research (35) and is included as part of decision making frameworks and interventions (29, 36). For example, the Ottawa Decision Support Framework is designed to help people make informed health decisions (36). It begins by assessing a person's decisional conflict and the goal of a decision making session using the framework is to discuss the decision while re-assessing a person's decisional conflict until it is eliminated and the person makes a decision (36). In intervention studies, decisional conflict has been included as primary or secondary outcomes for a variety of health decisions (23-25, 27-29, 35, 37-48).

Decisional conflict and decision aid research

Decisional conflict is often assessed in trials testing the efficacy of decision aids (35). Decision aids have been used to address decisional conflict and help people make decisions about a variety of medical treatment and cancer screening decisions, including CRCS (35). For

cancer screening decisions, decision aids usually provide information to help someone understand their risk of developing a specific cancer, screening options, the risks and benefits of the options, and ideally an interactive exercise that can help the participant decide what decision is best for them based on their values and preferences (49, 50). In general, decision aids are effective (35); however, little is known about how decision aids work (49, 51), especially the impact that decision aids have on emotional outcomes (51). The most recent Cochrane review of decision aids used for treatment or screening decisions found that of 86 studies, 45.3% measured decisional conflict and in general, decision aids led to a significant reduction in decisional conflict in these studies (35). Thus, it is possible that the decrease in decisional conflict from decision aid interventions could help people make a decision (32). However, from these results it is not clear why decision aids are able to decrease decisional conflict which makes building upon past decision aid interventions difficult. A better understanding of decisional conflict is a first step in creating more effective decision aid interventions and to better understand how decision aids might be impacting this psychosocial aspect of decision making.

To date, the majority of studies that have included a measure of decisional conflict have taken place in patient populations (24, 25, 31, 39, 40, 44-46, 51-55), specific segments of the general population (e.g. only low socio-economic status, only men, only people >75 years of age), or with people recruited for an intervention (23, 27, 28, 37, 38, 42, 43, 47, 56-58). As a result, the people included in the existing decisional conflict research could be systematically different than the larger general population from which they were selected, limiting the generalizability of current research related to decisional conflict.

Predictors of Decisional Conflict

Although used frequently in decision making research, decisional conflict is not completely understood and there is little empirical evidence about the mechanism in which decision making interventions could reduce decisional conflict (29, 52). Understanding the predictors/determinants of decisional conflict is a first step in understanding the mechanisms that could decrease decisional conflict but currently, the predictors of decisional conflict are not fully elucidated (29, 38, 42, 52, 53, 57, 59). To date, two studies have assessed the association between demographic variables and decisional conflict (38, 42). Both of these studies took place within the context of prostate cancer screening. One found that increased age and having a previous prostate specific antigen (PSA) screening test were associated with increased decisional conflict in bivariate analyses (multivariate analyses not performed) (38), while the other found that demographic (e.g., age, education, employment, etc.), lifestyle, or past PSA were not predictors of decisional conflict in multivariate analysis (42). Another study focused on patient shared decision preferences found no bivariate association between decisional conflict and a preference for a shared decision (57).

To date, four studies have taken a closer look at the predictors of decisional conflict using structural equation modeling (SEM) (29, 52, 53, 59); however, none were related to colorectal cancer screening. Stephens et al. examined the effect of a prostate cancer screening decision aid intervention on decisional conflict (N=400) (29). While several variables including, perceived risk of prostate cancer, decisional anxiety about PSA testing, PSA pros (advantages of PSA testing) and cons (disadvantages of PSA testing), and prostate cancer knowledge were modeled, the final model showed that increasing patient knowledge reduced decisional anxiety, which increased the perceived risk of prostate cancer and reduced decisional conflict. Additionally, PSA pros (e.g., believing PSA testing is safe, useful, accurate, etc.) and cons (e.g. believing PSA

testing is embarrassing, intrusive, stressful, etc.), modeled as one latent construct, reduced decisional conflict directly (29). Hall et al. tested the hypothesis that an educational intervention would increase knowledge about microsatellite instability testing which would decrease decisional conflict for microsatellite instability testing among adults previously diagnosed with CRC (N=239) (52). Greater knowledge was hypothesized to decrease decisional conflict through four mediators: pros, cons, self-efficacy and preparedness to make a decision. In the final model, decisional conflict was decreased by increasing preparedness in decision making and knowledge (52). In a cross-sectional study of German integrated health system patients (N=1,913), Hölzel et al. tested a conceptual model study focused on decision involvement preference (53). Their model hypothesized that involvement preference would increase a patients' involvement experience, which would in turn decrease decisional conflict and increase patient satisfaction. The final model found that involvement in decision making was associated with reduced decisional conflict and that higher mental quality of life decreased decisional conflict (53). Miller et al. used SEM to better understand how cancer clinical trial preparedness mediated the effect of both cancer clinical trial self-efficacy and knowledge with decisional conflict within the context of exposure to an informational website (N=105) and found that the relationships of cancer clinical trial self-efficacy and knowledge with decisional conflict was almost entirely mediated by cancer clinical trial preparedness (59).

These four studies give us information about the predictors of decisional conflict, which could also be relevant in the context of CRCS. For example, Stephens et al. and Hall et al. both found that pros and cons related to a specific decision had a direct influence on decisional conflict, and that knowledge had an indirect effect (29, 52). Barriers to CRCS including a lack of knowledge are some of the reasons why CRCS uptake remains low (9-16); thus, similar

associations might be found for CRCS decisional conflict. However, further comparison of their results is difficult as there were few overlapping variables. Also, both studies used very different patient populations and targeted different health behaviors. Miller et al. and Hall et al. both found that self-efficacy did not have a direct effect on decisional conflict (52, 59). However, self-efficacy has been a target in previous CRCS interventions as it is thought to be a very strong predictor of CRCS update (60, 61). Knowing if there is a relationship between self-efficacy and decisional conflict in the context of CRCS will help us better understand the potential importance of CRCS decisional conflict and ultimately CRCS adherence. Hölzel et al. focused on patient decision involvement preference and found that increased patient participation in decision making was associated with decreased decisional conflict (53). However, because this was a cross-sectional study, temporality between patient involvement in decision making and decisional conflict is unknown. In short, while none of these studies focused on CRCS, their findings suggest that important psychosocial characteristics are associated with decisional conflict; thus, similar relationships could exist in the context of CRCS.

Decisional conflict and CRCS

Compared to other cancer screening-related decisions, relatively little is known about decisional conflict for CRCS (23-28). For example, no studies have assessed the distribution of decisional conflict for CRCS in a general population. CRCS is nationally recommended and public health campaigns to increase CRCS across the country are currently underway. By having a better understanding the distribution of decisional conflict, and factors associated with decisional conflict, we would have the ability to potentially enhance the effectiveness of existing national campaigns as well as develop better CRCS campaigns and interventions in the future. Focusing on CRCS is also important because, unlike breast and prostate cancer screening, CRCS

has multiple recommended options (4, 62). Therefore, people must make at least two decisions: (1) if they want to do CRCS and (2) if so by which modality. As a result, decision-making could be more complicated and lead to a person who is considering CRCS having increased feelings of uncertainty, feeling less informed, and having difficulty determining their preferred CRCS test. Specifically, previous research has found that patients who discussed more than one CRCS option with their healthcare provider were 1.6 times more likely to be confused compared to those who had only discussed one CRCS option, and increased confusion reduced CRCS adherence (63). Confusion could be related to decisional conflict yet to date the two have not been assessed together.

To our knowledge, only six CRCS studies have measured decisional conflict and all were testing the efficacy of an intervention related to CRCS (23-28). Three randomized controlled trials included CRCS as an outcome (24-26), and among these studies, the effect of the decision aid interventions on decisional conflict is limited and inconsistent. Further, none of these studies demonstrated a significant increase in CRCS adherence in the intervention compared to the comparison group (24-26). A limitation in the existing CRCS research is that different versions of the decisional conflict scale have been used, making comparisons across studies difficult. Other CRCS decision aid interventions have not measured decisional conflict but have successfully increased CRCS in the intervention group relative to a comparison group (62, 64). Based on these inconsistencies, a better understanding of decisional conflict in the context of CRCS is needed to improve subsequent interventions and ultimately increase CRCS.

Cancer survivorship

Early detection of cancer through screening is an important behavior with the potential to impact one component of the cancer control continuum as early detection can lead to better

treatment success and improved survival (1). As a result of the increased early detection efforts and increasing efficacy of cancer treatments, the 5-year relative survival rate for all cancers has steadily increased over time to 68% from 2004-2010 (1). In tandem with increasing survival rates, the number of cancer survivors has also increased to about 14 million adults with a history of cancer in the US in 2014 (65). Also, the number of cancer survivors is expected to continue to increase because of the aging US population (66). The increasing number of cancer survivors highlights the importance of understanding the survivorship phase of the cancer control continuum, which is characterized by the completion of treatment and the start of long-term surveillance (67). There are many potential opportunities for interventions or policies that could change behavior at the individual, psychological, organizational, and environmental levels to improve cancer survivorship care (3).

In addition to the increasing number of cancer survivors, previous evidence suggests that cancer survivors struggle to maintain their health after completing treatment, as there are both physical and psychological impacts to health after a cancer diagnosis and treatment (68). Cancer survivors can experience late and long-term effects as a result of their cancer treatment (68). Long-term effects are side effects or complications that occur as a result of treatment that persist beyond the end of treatment (69), such as changes to physical functioning (68). Late effects are effects that are not present at the end of cancer treatment, but which appear later and are important for the care of cancer survivors (69). Examples of late effects for adult cancer survivors can be cancer-specific. For example, people who have had cancer are at risk of cancer recurrence or a new primary cancer diagnosis (68). However, late effects can also occur that are not cancer-specific. For example, people who have had cardiovascular cancer are at risk of experiencing congestive heart failure as a result of chemotherapy and radiation therapy (68). In

addition, cancer survivors can experience negative psychological effects as a result of their diagnosis and treatment experience such as fear of recurrence and/or concerns about future health, which can keep cancer survivors from making plans for the future (68). Because cancer survivors have known increased risk for adverse health effects after completing treatment, they need continued follow-up after completing treatment (70-72).

Cancer survivors experience difficulty maintaining their health after completing treatment for several reasons such as: not understanding their cancer-specific or health risks after completing treatment, a lack of coordinated care between different provider types (i.e. cancer-related and primary care), not receiving consistent follow-up care recommendations, and not continuing to receive follow-up care after completing treatment (68). In recognition of the increasing population of cancer survivors and their growing healthcare needs, in 2005, the Institute of Medicine (IOM) published a review of the state of cancer survivorship care (68). The review resulted in 10 specific recommendations to improve the health of cancer survivors. The first recommendation was to define cancer survivorship as a specific period along the cancer control continuum (68). As a result of this recommendation, research to ensure the delivery of high quality cancer survivorship care has been promoted and supported (73).

In addition to defining cancer survivorship as a distinct phase along the cancer control continuum, the 2005 IOM report included a recommendation that all patients completing cancer treatment should receive a written survivorship care plan (68). The basic components of the care plan as described in the report are: a detailed summary of all diagnostic tests performed and cancer treatments received as well as information about when follow-up visits/tests are needed including what medical provider should be seen for follow-up care (68). The content of the survivorship care plan is designed to convey information that the IOM deemed critical for the

long-term care of cancer survivors and it was recommended that the care plan be reviewed during a formal discharge consultation upon treatment completion by a member of the oncology treatment team (68).

The use of survivorship care plans was recommended by the IOM without having empirical evidence about the ability of care plans to change cancer survivorship care, or the impact of care plans on the physical and mental health of cancer survivors. Nevertheless, the recommendation was based on the high face validity of the survivorship care plan (68, 74-76). Further, support for providing care plans and follow-up instructions has been high among cancer survivors and healthcare providers (77). However, while recommended and generally supported, care plans are underused (77). Specifically, a cross-sectional survey by Salz et al. found that out of 53 National Cancer Institute-designated cancer centers treating adult cancer patients, only 43% were using survivorship care plans for their breast and/or colorectal cancer survivors (77). Breast and colorectal cancer survivors are two of the largest groups of all cancer survivors (65), and both have post-treatment care guidelines (70-72), so it is surprising that care plans are not being used more often. Also, the impact of providing survivorship care plans on cancer survivor behavior after completing treatment needs to be assessed.

To implement survivorship care plans, clinical practice guidelines are needed to ensure that all cancer survivors are given adequate information to receive appropriate care. However, the IOM report also found that, at the time of the report, relatively few cancers had clinical practice guidelines, and that the guidelines did not provide enough information to adequately inform cancer survivors with clear next steps (68). This finding resulted in another recommendation from the IOM – that evidence-based clinical practice guidelines be used to monitor for late and long-term effects of cancer treatment (68). Currently, evidence-based

recommendations for post-treatment care for a variety of cancers can be found through the National Comprehensive Care Network (NCCN) and the American Society of Clinical Oncology (ASCO) (70-72). The next section describes the state of cancer survivorship care for breast cancer survivors.

Breast cancer survivorship

Breast cancer survivorship is one of the most extensively studied areas of cancer survivorship (68), because breast cancer is the most common cancer among women (1) and because breast cancer survivors make up the largest sub-group of all cancer survivors (excluding basal and squamous cell skin cancer survivors) (65). Specifically, an estimated 237,840 new cases of invasive breast cancer are expected to occur in women in 2015 (1). As with cancer in general, advances in early detection and treatments have resulted in a reduction in breast cancer mortality (68). The overall 5- and 10-year breast cancer survival rates are currently 89% and 83%, respectively (78). As of January 2014, there were an estimated 3 million female breast cancer survivors in the US (65).

Post-treatment breast cancer care

As with other cancers, women with breast cancer can experience long-term and late effects of treatment, which are monitored after treatment is completed. The long-term and late effects experienced by breast cancer survivors vary by type of treatment(s) received, stage of breast cancer at the time of diagnosis, and the time since diagnosis. Late effects of breast cancer include cancer recurrence, diagnosis of additional primary cancers, lymphedema of the arm, premature menopause, weight gain, cardiovascular disease, fatigue and reduced cognitive functioning (68). Risks of late effects are also attributed for use of tamoxifen, which can increase the risk of endometrial cancer, blood clots and stroke (68). Also, psychosocial distress is

considered a long-term effect and it is particularly high during points of transition, for example at the time of treatment completion and before follow-up visits (68).

For breast cancer, the ASCO and NCCN both provide evidence-based recommendations for post-treatment care (70, 71). The ASCO guidelines have several different intervals for recommend physicals: an examination every 3–6 months for the first 3 years, and every 6–12 months for years 4 and 5 post-treatment, and then annual exams 5 years post-diagnosis (71). Further, if diagnosed with early-stage breast cancer, follow-up care can be transferred to a primary care physician 1 year after diagnosis (71). Compared to ASCO, the NCCN has a more simplistic recommendation. Specifically, the NCCN recommends a physical exam every 6–12 months for 5 years, followed by annual exams 5 years post-diagnosis (70). Further, both sets of guidelines recommend regular mammograms after completing treatment (70, 71). One issue with both sets of guidelines is that the type of clinician (e.g., oncologist or cancer-related provider, primary care provider) responsible for this care is not stated (70, 71, 79). Without a clear designation of the provider who should be responsible for follow-up care, there is the potential for breast cancer survivors to become lost to follow-up after completing treatment. For example, if survivors are uncertain about who they should see or the correct time intervals, they could end up going without any visits, which could increase their risk of a late effect being missed until it is more difficult to manage. Also, currently, the healthcare organization where treatment occurred is recommended as the organization that should be creating the survivorship care plan, which could impact the type of clinician recommended to breast cancer survivors for their continued care.

Evidence-based guidelines do not specify the type of provider who should be responsible for post-treatment care because there is currently little evidence about whether cancer outcomes

differ by the type of clinician providing follow-up care. A specialist (e.g., oncologist) traditionally provides cancer follow-up care (67, 80); however, keeping cancer survivors in oncology follow-up care has resulted in an increased patient burden on outpatient specialty care as the number of survivors has increased (81). Importantly, the burden in oncology care and health-care costs could be lowered if breast cancer follow-up care could be performed in a primary care setting (82). To date, two randomized controlled trials have assessed the potential of primary care follow-up among breast cancer survivors and found that both primary care and oncology follow-up care led to similar outcomes (80, 83). These two studies took place in England (83) and Ontario, Canada (80), and randomized patients to breast cancer follow-up in a cancer center/hospital (e.g., traditional follow-up) or with the patients' own primary care provider (80, 83). One of the studies included women who had been diagnosed with breast cancer in stages I-III (83), while the other only included women with an early-stage diagnosis (80). At the end of the follow-up periods, both studies found that there was no difference in health related quality of life scores among breast cancer survivors between primary care and traditional follow-up (80, 83). There were also no differences in recurrence, death, recurrence-related serious clinical events (80), or time to diagnosis of recurrence (83) between groups. Given the similarities in outcomes between primary care and oncology follow-up, it is reasonable to conclude that a cancer-related clinician or a primary care provider could be responsible for follow-up care of breast cancer survivors. Unfortunately, little work has been done to estimate the prevalence of breast cancer survivors who receive instructions for follow-up care. Further, the impact that receiving a survivorship care plan has healthcare utilization has not been fully assessed.

To date, seven studies have investigated the patterns of follow-up care (e.g. what type(s) of clinicians are providing care) among breast cancer survivors (79, 84-89). These studies have used several different types of study designs and different methods to assess the type of clinician providing care. Four of the seven studies used claims or medical record data. Among these four studies, three found that both primary care providers and cancer-related providers are involved in the follow-up care of breast cancer survivors, while one study found that follow-up care is provided almost exclusively by an oncologist (84-86, 88). Specifically, Grunfeld et al. conducted a retrospective cohort study in Ontario, Canada of women (N=11,219) diagnosed with breast cancer using Ontario Health Insurance Plan records (84). They found that the majority of women had visits with both primary care providers and oncologists during the five year study period and that the average number of visits to an oncologist decreased as the follow-up years increased (84). Keating et al. used Surveillance, Epidemiology, and End Results (SEER)-Medicare linked data to follow a large cohort of women ≥ 65 years of age (N=44,511) who were diagnosed with stage I or II breast cancer for three years (85). A majority of women also had claims for primary care and oncology visits during the three years of follow-up (85). Pollack et al. also used SEER-Medicare linked data to identify cancer survivors (N= 104,895 total, n= 26,972 with breast cancer) who had survived at least five years (88). Similarly to Keating et al. and Grunfeld et al., they found that both oncologists and primary care providers were seen, even though their study assessed care patterns occurring much later – during the 6^{th} through 12^{th} years since diagnosis for these survivors (88). Lastly, Worster et al. assessed primary care provider involvement in breast cancer follow-up care for women (N=183) alive five years after diagnosis who had been diagnosed with stage I breast cancer and who had been seen at the London Regional Cancer

Center during the study period (86). They found that almost 67% of follow-up care was provided by oncologists alone (86).

While these studies provide information on care utilization patterns, they do not shed light on the cancer survivors' perspective of their care after completing treatment. As guidelines and/or policies are developed to guide breast cancer follow-up care, a better understanding of the current experience of women diagnosed with breast cancer is needed (79). For example, given that the current evidence suggests that primary care and oncology follow-up lead to similar outcomes, policies might recommend shifting breast cancer follow-up care to be the responsibility of primary care providers. Three of the seven studies have assessed self- reported measures of the clinician providing care to breast cancer survivors (79, 87, 89). Among these studies, if patterns of care were separated by provider-type (e.g., cancer-related vs. primary care provider) a cancer-related provider was reported more frequently. Specifically, Chuback et al. asked breast cancer survivors (N=230) from an integrated healthcare delivery system who were participating in a randomized control trial of oncology nurse follow-up what type of clinician was providing their cancer follow-up care (89). Almost 93% considered a cancer specialist to be the main doctor for their cancer follow-up care 12 months after the start of the study (89). Also, Friese et al., conducted a longitudinal study of breast cancer survivors from Los Angeles, CA and Detroit, MI identified through SEER registries (N=844) (79) and found that about 65% of women reported that an oncologist was the main provider of their care four years after diagnosis (79). Lastly, Mandelblatt et al. followed a cohort of women (N=558) diagnosed with stage I or II breast cancer for one year and described patterns of care using a healthcare use diary (87). While the average number of medical visits was presented, information about visits by provider type was not provided (87). If these patterns are consistent in a larger, more generalizable population

of breast cancer survivors, policies that recommend moving follow-up care out of oncology and into primary care might not be well-received, regardless of similarities in health outcomes.

These studies provide an initial description of the type of clinician who is providing care to breast cancer survivors, but have limitations that reduce their ability to fully capture the current state of breast cancer survivorship care. For example, some of these studies have only included women diagnosed with early-stage breast cancer (85, 86), or women from Canadian or British healthcare systems that might differ from the US population enough to reduce the generalizability of their findings (84, 86). Also, most of the previous studies have had limited follow-up duration after treatment completion, which means that we are not able to completely understand the care patterns of breast cancer survivors as their time since diagnosis increases (87-89).

Receiving follow-up care instructions could have a large impact on who breast cancer survivors see for their care after treatment completion; however, to date, only one study has examined receiving cancer follow-up instructions using a nationally representative sample (90). Using the 2010 Behavioral Risk Factor Surveillance System (BRFSS), about 82% of breast cancer survivors had received follow-up instructions; however, the patterns of post-treatment care were not described (90). Therefore, the impact of receiving follow-up care instructions on breast cancer survivors' perspectives about the clinician responsible for the majority of their care has yet to be described and examined. It is also possible that the type of clinician providing care could change as survival time increases. For example, breast cancer survivors may move away from oncologist follow-up care to primary care providers over time as their healthcare needs shift away from their cancer treatment, but these changes have not been assessed. Thus, information about who provides the majority of care for breast cancer survivors as time since diagnosis

increases is needed to increase our understanding of current breast cancer follow-up care patterns and also to inform future recommendations and policies. In addition, guidelines that specify a provider-type to be responsible for breast cancer follow-up care has implications with the training needs of clinicians who would ultimately be providing care to breast cancer survivors.

Aims of dissertation

The purpose of this dissertation is to increase our understanding of colorectal cancer screening (CRCS) decisional conflict and breast cancer survivorship care.

The specific aims of this project are:

Paper 1: Assess decisional conflict for CRCS in a general population

a. Describe the distribution of decisional conflict for CRCS in the general population
b. Determine respondent characteristics that are related to decisional conflict

Paper 2: Use the Theory of Triadic Influence to model the direct and indirect associations of decisional conflict and colonoscopy adherence

a. Use the TTI to develop a model to investigate the determinants of CRCS decisional conflict and the relationship between CRCS decisional conflict and colonoscopy adherence
b. Test the model using structural equation modeling

Paper 3: Assess the patterns of breast cancer care after completing treatment

a. Describe the characteristics of breast cancer survivors by years since diagnosis
b. Determine what type of clinician (e.g., primary care, cancer-related, other) is providing the majority of care to breast cancer survivors by years since diagnosis

c. Determine the association between years since diagnosis and a cancer-related clinician providing the majority of care among breast cancer survivors, taking into account whether women received follow-up care instructions.

Chapter 2: Decisional conflict for colorectal cancer screening in a general population

ABSTRACT

There are multiple recommended options for colorectal cancer screening (CRCS); thus people considering CRCS must make multiple decisions, including whether they want to be screened and their preferred test, potentially complicating CRCS decision-making. Experiencing decisional conflict, or difficulty when making a decision, could act as a barrier to decision-making and limit CRCS uptake; however its evaluation for CRCS is limited.

In December 2012, a self-administered questionnaire was sent to N=2,150 randomly selected adults ages, 50-75 years of age, from six MN communities (adjusted response rate=71.2%). Questions ascertained CRCS decisional conflict, CRCS-specific barriers, confusion, intention, self-efficacy, social influence, control preferences, CRCS test preference, CRCS options discussed with a healthcare provider, and socio-demographic characteristics. Among white, non-Hispanic respondents at average-risk for colorectal cancer (N=1,268), total and subscale-specific decisional conflict scores were calculated and dichotomized. Descriptive statistics were calculated and multivariable logistic regression was performed using prediction models with backwards elimination to determine characteristics associated with high total and subscale-specific decisional conflict.

Overall, 56.3% of respondents had high total decisional conflict. In general, greater colonoscopy barriers (OR= 1.04; 95% CI: 1.02-1.05), and CRCS confusion (OR=1.12; 95% CI: 1.10-1.15), and not having a clear CRCS test preference (OR=3.40; 95% CI: 2.11-5.45) were significantly positively associated with increased odds of high total and subscale-specific decisional conflict. Greater CRCS self-efficacy was inversely associated with high total decisional conflict (OR= 0.85; 95% CI: 0.80-0.90) and high subscale-specific decisional conflict (ORs range: 0.82 to 0.88, 95% CIs range: 0.78-0.87 to 0.83-0.92).

Addressing modifiable characteristics could potentially decrease CRCS decisional conflict, but further assessment of CRCS decisional conflict in more generalizable populations is needed.

INTRODUCTION

Colorectal cancer (CRC) is the second leading cause of cancer death in the United States (1). However, early detection through colorectal cancer screening (CRCS) reduces mortality rates of CRC (4). The US Preventive Services Task Force currently recommends multiple options for CRCS (i.e., stool test, sigmoidoscopy, and colonoscopy) (4); thus, people considering CRCS must make multiple decisions, including whether they want to be screened and their preferred test.

Decisional conflict is an emotional state characterized by feeling uncertain, uninformed, unsupported, having unclear values, or being unsatisfied with decisions that have elements of emotion, where pros and cons need to be weighed, or when preferences need to be considered (32). Experiencing decisional conflict could act as a barrier to decision making and inhibit uptake of preventive health behaviors, including CRCS. Likewise, decreasing decisional conflict could help people make a decision (32). While national CRCS recommendations exist, CRCS adherence remains lower (6) than the national target of 80% adherence by 2018 (8). Addressing decisional conflict among those who are non-adherent to recommended CRCS guidelines may help communities reach the 80% target.

To date, six studies have measured CRCS decisional conflict (23-28); two in patient populations (24, 25), and four in other specific segments of the general population (23, 26-28). Additional information about the distribution of CRCS decisional conflict could be gained by measuring this construct in general populations not selected using any additional characteristics. Further, factors associated with high CRCS decisional conflict have not been identified. While not in the context of CRCS, one previous study found that reduced decisional anxiety for prostate specific antigen (PSA) testing, and PSA pros (e.g., believing PSA testing is safe, useful,

accurate, etc.) and cons (e.g. believing PSA testing is embarrassing, intrusive, stressful, etc.) were inversely associated with decisional conflict (29). Further, extensive research has identified correlates of CRCS (9-16, 63), but these studies have not also included CRCS decisional conflict. By knowing factors associated with high decisional conflict, future interventions aiming to increase CRCS adherence could potentially decrease decisional conflict and in return increase CRCS adherence. Therefore, the purpose of this study is to begin to address the existing gaps in the CRCS decisional conflict literature by: 1) describing the distribution of CRCS decisional conflict in a general population and 2) determining characteristics associated with high decisional conflict.

METHODS

Setting and Data Collection

Data for this study come from the Colorectal Cancer Screening With Improved Shared Decision Making (CRCS-WISDM) Project baseline general population questionnaire. The CRCS-WISDM design and data collection have been described elsewhere (91-94). Briefly, in December 2012, a self-administered questionnaire was mailed using a modified Dillman method (95, 96) to a sample of adults, ages 50-75 years, living in six non-urban MN communities (N=2,150). Adults were randomly selected using a probabilistic sampling scheme given the age and gender distribution in each of the six communities. The adjusted response rate after removing respondents who were not part of the target population (i.e., not 50-75 years of age, did not live in the communities at the time of the survey, and duplicates from the sample) was 71.2% (N=1,449). The Virginia Commonwealth University and Allina Health Institutional Review Boards approved all aspects of CRCS-WISDM.

Measures

Decisional conflict

Decisional conflict was measured using the validated 16-item decisional conflict scale with items measured on a 5-point Likert-type scale (32, 34). Average scores for total and subscale-specific (i.e., uncertainty, support, informed, values clarity, and effective decision making) decisional conflict were calculated resulting in scores with a possible range of 0–100 (34). Higher scores (≥25) indicate greater decisional conflict and scores <25 are associated with making a decision (34); thus, the variable was dichotomized accordingly.

Psychosocial characteristics

The following psychosocial characteristics were measured using validated or adapted measures: 1) stool test and colonoscopy barriers (10, 97, 98); 2) CRCS-specific self-efficacy and social influence (99), 3) CRCS-specific confusion (100), 4) CRCS-specific intention (101), and 5) control preferences (102).

Other characteristics of interest

CRCS knowledge, CRCS history for the guaiac stool test, sigmoidoscopy, colonoscopy (103), and the immunological stool test (92), whether a healthcare provider discussed different CRCS options, CRCS test preference, and other preventive screening behaviors were assessed. Lastly, socio-demographic characteristics such as marital status, education, employment status, and whether health insurance covers CRCS were also assessed. Current insurance coverage was not included in the general population questionnaire; thus, age was used as a proxy for health insurance coverage by dichotomizing at age-eligibility for Medicare (i.e. ≥65 years of age).

Study population

White non-Hispanic respondents at average-risk for colorectal cancer (CRC) who answered all of the decisional conflict scale items were included in this study (N=1,268). Specifically, persons reporting a race other than white were excluded (n=60), as well as persons at increased-risk (n=75) due to reporting a personal CRC history, blood in stool more than 1-2 times a week without having hemorrhoids, a first-degree relative (i.e., mother, father, or sibling) diagnosed with CRC before age 60, or two or more first-degree relatives diagnosed with CRC at any age.

Analysis

SAS 9.4 Survey Procedures were used given the sampling methodology. We used: PROC SURVEYFREQ to calculate the prevalence of categorical respondent characteristics overall and by low/high total decisional conflict, and to conduct chi-square tests; PROC SURVEYMEANS to calculate mean values of continuous respondent characteristics (i.e., stool test and colonoscopy barriers, CRCS-specific self-efficacy, social influence, confusion, and CRCS knowledge); and PROC SURVEYREG to conduct t-tests of mean scores of continuous respondent characteristics (i.e., stool test and colonoscopy barriers, CRCS-specific self-efficacy, social influence, confusion, and CRCS knowledge) by low/high total decisional conflict. We used PROC SURVEYLOGISTIC to construct multivariable models to assess the association of psychosocial and other characteristics of interest with high total and subscale-specific decisional conflict (low decisional conflict=outcome referent). Multivariable prediction models were created using backwards elimination until all variables in the final models had p-values ≤ 0.2 (104). Logistic regression models generated adjusted odds ratios (OR) and corresponding 95% confidence intervals (CI).

RESULTS

The majority of respondents were 50-64 years of age (74.8%) and employed (63.5%) (Table 2.1). Approximately half (56.3%) had high total decisional conflict (i.e. score ≥ 25). The prevalence of high subscale-specific decisional conflict was: 62.5% uncertainty, 54.7% informed, 63.5% values clarity, 73.8% support, and 50.3% effective decision making (data not shown). Table 2.1 also presents the descriptive statistics for the psychosocial and other characteristics of interest. Among the continuous psychosocial characteristics, mean stool test and colonoscopy barriers as well as CRCS-specific confusion scores were significantly higher for respondents with high total decisional conflict, while mean CRCS-specific self-efficacy and social influence were significantly lower for adults with high total decisional conflict. About 10% of those with low total decisional conflict and 40% of those with high total decisional conflict did not have a CRCS test preference. The proportion of respondents who had not discussed CRCS options with a healthcare provider was 67.2% for those with high total decisional conflict and 42.7%, for those with low total decisional conflict.

Table 2.2 presents the final multivariable models. Among the continuous psychosocial characteristics, greater colonoscopy barriers and greater CRCS-specific confusion were positively associated with high total decisional conflict (colonoscopy barriers: OR= 1.04; 95% CI: 1.02-1.05, CRCS-specific confusion: OR=1.12; 95% CI: 1.10-1.15), while greater CRCS-specific self-efficacy was inversely associated with high total decisional conflict (OR= 0.85; 95% CI: 0.80-0.90). The odds of high total decisional conflict among respondents without a CRCS test preference was 3.4 times that of respondents who preferred endoscopy (95% CI: 2.11–5.45). Greater CRCS-specific confusion was positively and significantly associated with high subscale-specific decisional conflict, with corresponding ORs ranging from 1.07 to 1.12.

Greater CRCS-specific self-efficacy was inversely and significantly associated with high subscale-specific decisional conflict with ORs ranging from 0.82 to 0.88. Socio-demographic characteristics that remained in the final total and subscale-specific decisional conflict models after backwards elimination varied.

DISCUSSION

This study assessed total and subscale-specific CRCS decisional conflict in a large general population sample of white, non-Hispanic adults ages 50-75, living in six MN communities. A majority of respondents had decisional conflict scores above levels associated with delaying decisions (34). Further, CRCS-specific psychosocial characteristics colonoscopy barriers, CRCS-specific confusion, and not intending to have CRCS were positively associated with high total and subscale-specific decisional conflict, while greater CRCS-specific self-efficacy was inversely associated with high total and subscale-specific decisional conflict.

The level of decisional conflict in our population was consistently higher than that reported in previous CRCS research (23-28). Specifically, compared to our population, mean decisional conflict scores have been ≤25 (25-28) and when dichotomized, a smaller proportion of participants had high decisional conflict (20%-49% (23, 24, 26) vs. 56.3% in this study). There are several potential explanations for these disparate results. First, there were differences between our study population and the populations included in the previous studies. The previous studies were limited to specific sub-groups of the general population such as patient populations (24, 25), adults ≥75 years (23), adults with low socioeconomic status (26), or adults included as part of an online panel maintained by Survey Sampling International from the US and Australia (28). Thus, it is possible that CRCS decisional conflict is more prevalent in the general

population when not selected on any additional characteristics. It is also possible that the particular characteristics of the people included in the previous studies contributed to the low prevalence of decisional conflict. For example, patient populations might be more accustomed to making health decisions and as a result, have lower levels of decisional conflict. While it may seem counterintuitive for people in lower socioeconomic status to have lower levels of decisional conflict, a previous study found that higher education was associated with higher levels of CRCS confusion (63). This similar finding could be a consequence of decisional conflict and confusion both consisting of affective and cognitive components. (32). Thus, it could be that similar to CRCS confusion, adults with lower socioeconomic status also have lower decisional conflict. Interestingly, the majority of previous studies were intervention studies that only included adults non-adherent to CRCS guidelines (24-27). Thus, if experiencing decisional conflict is associated with delaying CRCS decision making, it is surprising that the level of CRCS decisional conflict was so much higher in our population. In *post hoc* analyses, of the 24.4% (n=302) who were non-adherent to CRCS, 80% had total decisional conflict scores ≥25 – higher than the prevalence in the overall sample. A second potential explanation of the high level of decisional conflict found in this study could be artifactual differences in coding of the decisional conflict scale. Previous CRCS studies dichotomizing decisional conflict included a score of 25 to indicate low decisional conflict (23, 24, 26); however, the most recent decisional conflict scale user guide drove our coding decisions (34). In *post hoc* analyses, including a score of 25 with low decisional conflict (rather than high decisional conflict) resulted in an absolute reduction in high decisional conflict prevalence of 3.2% (n = 36 respondents) to 53.1% but remained higher than previously reported results (23, 24, 26). Therefore, regardless of coding, the majority of adults in this study had decisional conflict scores previously associated with

delaying decision making. Lastly, the frame of reference used in this study for the decisional conflict scale is not necessarily the same as what was used in the previous studies which could result in differences in levels of decisional conflict (23-28)..

Before developing interventions to reduce CRCS decisional conflict and ultimately increase CRCS adherence, modifiable respondent characteristics to potentially target need to be identified. Modifiable psychosocial characteristics, colonoscopy barriers, CRCS-specific confusion, intention, and self-efficacy, as well as CRCS test preference, and a healthcare provider discussing CRCS options were significantly associated with high total decisional conflict and most of the decisional conflict subscales. As these characteristics are associated with all aspects of decisional conflict (i.e. total and subscale-specific), changing these characteristics has the greatest potential to decrease decisional conflict scores. Some previous CRCS interventions have aimed to increase self-efficacy (60, 61), and CRCS intention (105-109), while others have attempted to change how health care providers discuss CRCS options (64, 108) and help people determine their preferred CRCS test (25, 28, 64, 110). Therefore, existing intervention materials could potentially be adapted and used to decrease CRCS decisional conflict. However, decreasing CRCS confusion and addressing test-specific barriers are only starting to be included in CRCS interventions (91, 111); thus, additional materials to adapt and use to decrease CRCS decisional conflict might become available over time.

There were some characteristics that were only associated with specific subscales, which still provides useful information on characteristics associated with decisional conflict. The characteristics that are associated with some, but not all, of the decisional conflict subscales can help identify additional potential targets to decrease decisional conflict, but which might have a lesser impact compared to the characteristics associated with all of the subscales. For example,

education only remained in the final model after backwards elimination for the informed and effective decision-making subscales. In both final models, the odds of high subscale-specific decisional conflict was significantly lower among respondents with some college compared to those with at least a college degree. While not a modifiable factor at the time of CRCS decision-making, this information can help identify groups that might need to be targeted to ensure that decisional conflict is addressed.

In addition to assessing associations between CRCS decisional conflict and modifiable factors, the association between CRCS decisional conflict and CRCS adherence needs to be evaluated. From the prediction model that initially included all respondent characteristics, the only multivariable model that retained CRCS adherence after backwards elimination was the model for total decisional conflict. While respondents who were overdue or never screened for CRCS had a higher odds of high total decisional conflict, these associations were not statistically significant. These findings differ from Brenner et al. who found that mean values clarity CRCS decisional conflict was significantly higher for people who had never completed CRCS compared to those who had previously completed CRCS (28). Three of the six previous studies to measure CRCS decisional conflict also measured CRCS adherence (24-26).Decisional conflict was the primary outcome in only one of these studies (25). This randomized control trial in a patient population used a multicriteria decision analysis intervention as a potential way to implement shared decision making for CRCS. The primary outcome of interest was “decision process” which was measured using the decisional conflict scale, and CRCS adherence was measured 2-3 months after intervention administration. After the intervention, levels of decisional conflict were significantly lower in the intervention group but there was no difference in CRCS uptake (25). The lack of a significant increase in CRCS adherence could indicate that

decreasing decisional conflict does not lead to an increase in CRCS. In some medical practices, there can be a several month wait between scheduling and completing a colonoscopy; thus, CRCS adherence might have been higher if measured after a longer amount of time. However, measuring CRCS adherence after a longer period might not have made a large difference in CRCS uptake in this study because at the immediate post-intervention assessment, only one patient had selected colonoscopy as their "screening plan". Another potential explanation of their findings is that levels of decisional conflict in this study were at or below levels associated with making a decision (34); thus, a significant reduction in decisional conflict between groups might not have led to a change in CRCS behavior.

Limitations

This study has several limitations. First, cross-sectional data were used; therefore, the temporality of associations are unknown. However, data from this study comes from an ongoing longitudinal study; thus, these associations can also be examined over time as data collection continues. Second, decisional conflict was dichotomized, which reduces the information available about decisional conflict and also assumes that all respondents with scores below or above 25 are similar enough to be collapsed together. While some information is lost when categorizing continuous measures, the goal of this study was to identify characteristics associated with levels of decisional conflict that might inhibit decision-making. Also, the threshold chosen was based on the available evidence. Third, this study is a secondary data analysis and other potential variables of interest were not included. For example, people who have had a high-risk polyp diagnosis might have lower levels of decisional conflict. Unfortunately, details regarding history of polyps were not obtained; therefore, respondents with a history of polyps were not excluded from this average-risk population. In *post hoc* analyses, after excluding the 32.9% of

respondents who reported any history of colorectal polyps, the prevalence of high total decisional conflict increased to 62.7%; therefore, it is likely that the level of decisional conflict in our population is underestimated. Fourth, generalizability is limited because of our racially homogeneous population from non-urban MN communities. Fifth, analyses were weighted for gender and five-year age group because of inclusion in the stratification variable but we were unable to estimate the independent association of both with decisional conflict. However, age was used as a proxy for Medicare coverage by creating a dichotomous variable representing age-eligibility for Medicare. Because the distribution of gender and age in our study population was fixed to be the same as the distributions in our six target communities, while our findings represent adults from the six communities, they are not generalizable to populations with different distributions of age and gender. Lastly, recall errors are possible in self-reported data; however, many of the characteristics assessed are opinions measured with validated instruments and it is unlikely that errors are differential by level of decisional conflict.

Conclusions

Decisional conflict could be a potential new target to increase CRCS but has not been fully assessed. This study described total and subscale-specific CRCS decisional conflict in a large, general population sample of adults 50-75 years of age from six MN communities, and assessed respondent characteristics associated with high total and subscale-specific decisional conflict. Given the high prevalence of decisional conflict in this study compared to previous research, continued assessment of decisional conflict in increasingly generalizable populations is warranted. Knowing the distribution of decisional conflict in the general population can help us determine if decisional conflict needs to be addressed in future public health campaigns. Importantly, characteristics most strongly associated with high CRCS decisional conflict include

modifiable psychosocial characteristics such as colonoscopy barriers, and CRCS-specific confusion, intention, and self-efficacy. Further evaluation is needed to understand how decisional conflict and other well-established psychosocial variables influence each other and CRCS adherence to facilitate intervention planning and development.

Table 2.1. Characteristics of interest overall and by total decisional conflict status

Variable	Overall (N=1268)	Total Decisional Conflict <25 (n=554)	Total Decisional Conflict ≥25 (n=714)	
Continuous variables	**Mean, (Standard Error)**	**Mean, (Standard Error)**	**Mean, (Standard Error)**	**p-value[a]**
Psychosocial characteristics				
FOBT barriers	39.85 (0.43)	32.30 (0.56)	45.67 (0.55)	<0.001
Colonoscopy barriers	41.88 (0.49)	32.05 (0.56)	49.47 (0.63)	<0.001
CRCS self-efficacy	27.87 (0.13)	30.38 (0.13)	25.93 (0.17)	<0.001
CRCS social influence	11.33 (0.09)	12.15 (0.13)	10.70 (0.11)	<0.001
CRCS confusion	22.51 (0.23)	17.81 (0.34)	26.12 (0.23)	<0.001
Other characteristic of interest				
CRCS knowledge	4.42 (0.02)	4.54 (0.03)	4.33 (0.03)	<0.001
Categorical variables	**N (Weighted Percent)**	**n (Weighted Percent)**	**n (Weighted Percent)**	**p-value[a]**
Psychosocial characteristics				
Control preferences[b,c]				
Mostly patient decisions	596 (48.8)	232 (43.3)	364 (53.1)	0.005
Shared decisions	535 (41.6)	260 (46.5)	275 (37.8)	
Mostly MD decisions	131 (9.6)	61 (10.2)	70 (9.1)	
CRCS intention[b]				
Strongly agree	586 (48.6)	384 (71.7)	202 (30.6)	<0.001
Agree	481 (37.5)	127 (22.4)	354 (49.3)	
Disagree[d]	186 (13.9)	38 (5.9)	148 (20.1)	
Other characteristics of interest				
CRCS adherence[e]				
Adherent	966 (75.6)	496 (88.8)	470 (65.3)	<0.001
Overdue	98 (7.4)	26 (4.2)	72 (9.8)	
Never screened	204 (17.0)	32 (7.0)	172 (24.9)	
Provider discussed CRCS options[b,f]				
Yes	559 (43.6)	321 (57.3)	238 (32.8)	<0.001
No	699 (56.4)	231 (42.7)	468 (67.2)	
CRCS test preference[b,g]				
Stool test	222 (18.1)	80 (14.3)	142 (21.1)	<0.001
Endoscopy[h]	710 (55.2)	420 (76.0)	290 (39.0)	
Don't know	331 (26.7)	53 (9.7)	278 (39.9)	
Other preventive screenings[i]				
Yes	1044 (82.0)	490 (87.9)	554 (77.4)	<0.001
No	224 (18.0)	64 (12.1)	160 (22.6)	
Socio-demographic characteristics				
Age eligible for				

Medicare				
No[j]	896 (74.8)	355 (68.2)	541 (79.9)	<0.001
Yes[k]	372 (25.2)	199 (31.8)	173 (20.1)	
Education[b]				
≤ High school	301 (21.5)	115 (19.0)	186 (23.4)	0.055
Some college	492 (38.0)	213 (36.6)	279 (39.1)	
≥ College degree	452 (40.5)	218 (44.4)	234 (37.5)	
Married[b,l]				
Yes	1020 (82.1)	463 (84.2)	557 (80.4)	0.111
No	224 (17.9)	83 (15.8)	141 (19.6)	
Employed				
Yes	769 (63.5)	308 (58.7)	461 (66.7)	0.003
No	499 (36.5)	246 (41.3)	253 (33.3)	
Insurance covers CRCS[b,m]				
Yes	958 (76.2)	480 (87.2)	478 (67.7)	<0.001
No	306 (23.8)	73 (12.8)	233 (32.3)	

Note: CRCS = Colorectal cancer screening

a. P-value from t-tests for continuous variables and chi-square tests for categorical variables

b. Sum does not add to total due to missing

c. Control preferences scale assesses how much input the respondent wants with their medical provider when making a health decision. Mostly patient decisions= make the final selection about what I will receive, and make the final selection after seriously considering my doctor's opinion; Shared decisions = have my doctor and I share the responsibility for deciding what is best; Mostly MD decisions = have my doctor make the final decision but consider my opinion, and leave all decisions to my doctor.

d. Disagree or strongly disagree

e. Adherent = stool test in last year, sigmoidoscopy in last 5 years or colonoscopy in last 10 years; Overdue = stool test >1 year ago, sigmoidoscopy >5 years ago, or colonoscopy >10 years ago; Never screened = never had colorectal cancer screening

f. Healthcare provider discussed colorectal cancer screening options

g. Question worded: "If you were to get screened for colorectal cancer, either again or for the first time, which test would you prefer?"

h. Respondent prefers sigmoidoscopy or colonoscopy. Overall, 4.8% (34/710) of endoscopy is sigmoidoscopy preference and 95.2% is colonoscopy preference.

i. Ever had a mammogram or prostate-specific antigen test

j. 50-64 years of age

k. 65-75 years of age

l. Married or in a marriage like relationship

m. Respondents' opinion on whether their health insurance covers colorectal cancer screening

Table 2.2. Associations between characteristics of interests with total and subscale-specific decisional conflict

Variable	Total Decisional conflict (N=1,198[a]) OR (95% CI)	Uncertainty subscale (N=1,210[a]) OR (95% CI)	Support subscale (N=1,215[a]) OR (95% CI)	Informed subscale (N=1,195[a]) OR (95% CI)	Effective decision making subscale (N=1,197[a]) OR (95% CI)	Values clarity subscale (N=1,223[a]) OR (95% CI)
Psychosocial characteristics						
Colonoscopy barriers[b]	1.04 (1.02–1.05)	1.04 (1.03–1.06)	1.05 (1.03–1.06)	1.02 (1.01–1.03)	1.03 (1.01–1.04)	1.03 (1.01–1.04)
CRCS self-efficacy[b]	0.85 (0.80–0.90)	0.85 (0.80–0.90)	–	0.87 (0.83–0.92)	0.82 (0.78–0.87)	0.88 (0.83–0.92)
CRCS social influence[b]	–	1.04 (0.98–1.11)	–	–	–	–
CRCS confusion [b]	1.12 (1.10–1.15)	1.07 (1.05–1.10)	1.12 (1.09–1.14)	1.09 (1.06–1.11)	1.07 (1.04–1.09)	1.09 (1.07–1.12)
Control preferences[c]						
Mostly patient decisions	–	1.00 (ref)	1.00 (ref)	–	–	–
Shared decisions	–	0.68 (0.48–0.97)	0.68 (0.47–0.99)	–	–	–
Mostly MD decisions	–	0.83 (0.47–1.49)	0.63 (0.37–1.10)	–	–	–
CRCS Intention						
Strongly agree	1.00 (ref)	1.00 (ref)	1.00 (ref)	1.00 (ref)	1.00 (ref)	1.00 (ref)
Agree	1.85 (1.25–2.74)	1.40 (0.95–2.07)	1.69 (1.13–2.52)	1.81 (1.26–2.60)	2.15 (1.50–3.09)	2.23 (1.55–3.22)
Disagree[d]	0.96 (0.47–1.96)	0.66 (0.35–1.25)	0.66 (0.33–1.31)	1.15 (0.65–2.04)	0.92 (0.48–1.77)	1.84 (1.03–3.30)
Other characteristics of interest						
CRCS Knowledge[b]	–	0.87 (0.69–1.08)	–	–	–	–
CRCS adherence[e]						
Adherent	1.00 (ref)	–	–	–	–	–
Overdue	1.39 (0.62–3.12)	–	–	–	–	–
Never screened	1.70 (0.96–3.02)	–	–	–	–	–
Provider discussed CRCS options[f]						
Yes	1.00 (ref)	1.00 (ref)	1.00 (ref)	1.00 (ref)	1.00 (ref)	–
No	1.67 (1.18–2.37)	1.55 (1.12–2.15)	1.33 (0.94–1.89)	1.60 (1.17–2.17)	1.64 (1.18–2.29)	–
CRCS test preference[g]						
Stool test	1.28 (0.79–2.07)	1.18 (0.72–1.94)	1.19 (0.73–1.95)	0.67 (0.44–1.02)	1.27 (0.81–1.97)	0.78 (0.50–1.21)
Endoscopy[h]	1.00 (ref)	1.00 (ref)	1.00 (ref)	1.00 (ref)	1.00 (ref)	1.00 (ref)
Don’t know	3.40 (2.11–5.45)	2.69 (1.68–4.33)	2.22 (1.27–3.88)	2.09 (1.40–3.13)	2.59 (1.71–3.91)	1.30 (0.85–1.97)
Other preventive screening[i]						

Yes	–	–	–	–	1.00 (ref)	–
No	–	–	–	–	1.34 (0.88–2.02)	–
Socio-demographic characteristics						
Age eligible for Medicare						
No[j]	1.52 (1.01–2.29)	–	–	1.56 (1.11–2.20)	2.02 (1.38–2.97)	–
Yes[k]	1.00 (ref)	–	–	1.00 (ref)	1.00 (ref)	–
Education						
≤ High school	0.65 (0.40–1.06)	–	–	0.68 (0.45–1.01)	0.50 (0.31–0.79)	–
Some college	0.78 (0.52–1.15)	–	–	0.69 (0.48–0.98)	0.56 (0.39–0.82)	–
≥ College degree	1.00 (ref)	–	–	1.00 (ref)	1.00 (ref)	–
Married[l]						
Yes	–	–	–	–	1.00 (ref)	–
No	–	–	–	–	0.75 (0.49–1.15)	–
Employed						
Yes	–	1.00 (ref)	–	–	–	–
No	–	1.38 (0.98–1.94)	–	–	–	–
Insurance covers CRCS[m]						
Yes	–	–	1.00 (ref)	1.00 (ref)	–	–
No	–	–	1.55 (0.95–2.52)	1.38 (0.90–2.10)	–	–

Note: Modeling assessed likelihood of having high decisional conflict (score of ≥25, ranges: total: 0–78.1, uncertainty: 0–100, support: 0–91.7, informed: 0–100, effective decision making: 0–100, values clarity: 0–100). Variables not included in the final models after backwards elimination denoted with "–".

OR = Odds ratio, CI = Confidence interval, CRCS = colorectal cancer screening

a. Sample size varies due to missing data on predictors

b. Continuous predictor

c. Control preferences scale assesses how much input the respondent wants with their medical provider when making a health decision. Mostly patient decisions= make the final selection about what I will receive, and make the final selection after seriously considering my doctor's opinion; Shared decisions = have my doctor and I share the responsibility for deciding what is best; Mostly MD decisions = have my doctor make the final decision but consider my opinion, and leave all decisions to my doctor.

d. Disagree or strongly disagree

e. Adherent = Stool test in last year, sigmoidoscopy in last 5 years or colonoscopy in last 10 years; Overdue = stool test >1 year ago, sigmoidoscopy >5 years ago, or colonoscopy >10 years ago; Never screened = never had colorectal cancer screening

f. Healthcare provider discussed colorectal cancer screening options

g. Question worded: "If you were to get screened for colorectal cancer, either again or for the first time, which test would you prefer?"

h. Respondent prefers sigmoidoscopy or colonoscopy. Specifically, for total decisional conflict 4.8% (34/710) of endoscopy is sigmoidoscopy preference and 95.2% is colonoscopy preference.
i. Ever had a mammogram or prostate-specific antigen test
j. 50-64 years of age
k. 65-75 years of age
l. Married or in a marriage like relationship
m. Respondent's opinion on whether their health insurance covers colorectal cancer screening

Chapter 3: Psychosocial determinants of decisional conflict and its relationship to colonoscopy adherence

ABSTRACT

Background: There are multiple recommended colorectal cancer screening (CRCS) options; each with specific barriers that impact uptake. Also, the multiple CRCS options could increase decisional conflict about which modality to choose – impacting CRCS adherence. Therefore, decreasing decisional conflict may be a potential target for interventions aimed at increasing CRCS.

Objective: This study aimed to: 1) develop a model using the Theory of Triadic Influence to understand the determinants of CRCS decisional conflict and the relationship between CRCS decisional conflict and colonoscopy adherence 2) test the model using structural equation modeling

Methods: Data come from a probabilistic cross-sectional survey (adjusted response rate: 72.1%), administered in December 2012 among adults 50-75 years of age living in six MN communities. Among white, non-Hispanic respondents, at average-risk for colorectal cancer (N=1,268), the Theory of Triadic influence was used to develop a structural equation model . The model was developed to examine the interrelationships between CRCS decisional conflict, psychosocial and other characteristics specific to CRCS such as, confusion and self-efficacy regarding testing, and CRCS knowledge. Next, structural equation modeling was used to examine the direct and indirect effects between CRCS decisional conflict, psychosocial characteristics and colonoscopy adherence.

Results: Both greater levels of CRCS confusion and greater perceived colonoscopy barriers were associated with greater levels of decisional conflict (standardized total effects=0.39 and 0.42, respectively, p-values < 0.01). A greater number of CRCS options discussed and greater knowledge about CRCS were associated with lower levels of decisional conflict (standardized

total effects=-0.17 and -0.11, respectively, p-values < 0.01). Greater levels of CRCS decisional conflict were associated with increased non-adherence to colonoscopy and this effect was mediated by CRCS self-efficacy and intention (standardized total effect =0.14, p-value <0.01). The final model explained 40.5% of the variance in total decisional conflict, and 45.9% of the variance in colonoscopy adherence.

Conclusions: Decisional conflict is related to other important aspects of CRCS, such as colonoscopy barriers, CRCS-specific confusion, and the number of CRCS options discussed with healthcare provider. Interventions aimed at addressing these characteristics could decrease decisional conflict and ultimately increase colonoscopy uptake.

INTRODUCTION

Colorectal cancer screening (CRCS) via colonoscopy, stool test or flexible sigmoidoscopy reduces the morbidity and mortality rates of colorectal cancer (CRC) (4) and is nationally recommended for average-risk men and women, ages 50-75 years (4). Many CRCS interventions have attempted to increase CRCS uptake by capitalizing on recognized correlates of CRCS such as increasing self-efficacy, intention, and CRCS knowledge and reducing logistical/structural barriers to CRCS (60, 61, 64, 105-107, 109, 112). Despite these efforts, CRCS adherence remains below national goals (6, 8) and there is a continued need for interventions to promote CRCS (113). Because of the multiple recommended CRCS options, perhaps more so than for other types of cancer screening decisions, the decision-making process about whether to undergo CRCS, and by which testing modality, may be particularly impacted by feelings of uncertainty and ambiguity. Therefore, decisional conflict about CRCS may be an under-recognized target for interventions aimed at increasing CRCS uptake.

Decisional conflict is an emotional state characterized by effective (e.g., feeling uninformed about decision options) and affective (e.g., feeling unsupported in decision making, having unclear values) qualities (32). While decisional conflict is often a central theme of decision-making conceptual frameworks and is often evaluated in decision-making research (35), it has only rarely been considered as part of CRCS decision making (23-28). Relatively little is known about the determinants of CRCS decisional conflict or how it is related to CRCS behaviors and other characteristics (i.e., test-specific barriers, confusion, CRCS test-preference, self-efficacy, intention, CRCS knowledge, CRCS test-preference, number of CRCS options discussed with a healthcare provider, and CRCS adherence) (28, 114). A robust understanding of

the factors that contribute to CRCS decisional conflict is needed to understand whether this construct should be a target for interventions aimed at increasing CRCS adherence.

A handful of previous studies have examined the correlates of CRCS decisional conflict. Brenner et al. found that prior completion of CRCS was inversely associated with levels of decisional conflict compared to never having completed CRCS (28). Our prior work found that greater levels of CRCS-specific confusion and colonoscopy barriers were significantly associated with high CRCS decisional conflict, while greater CRCS-specific self-efficacy was associated with lower decisional conflict (114). However, unlike Brenner et al., our study did not observe a significant association between CRCS adherence and decisional conflict (114). In sum, both the determinants of CRCS decisional conflict, and the implications of decisional conflict for CRCS adherence, need further evaluation.

However, CRCS decision conflict is only one component of the broader framework for investigating the factors that impact individual's adherence to preventive screening behaviors. Understanding the interrelationships between CRCS decisional conflict, psychosocial characteristics, CRCS-specific characteristics, and CRCS adherence can help us identify the pathways that contribute to decisional conflict in the context of cancer screening. Also, this information can help determine whether reducing CRCS decisional conflict might be a viable approach to increase CRCS uptake. Further, understanding the potential mediating pathways between decisional conflict and CRCS adherence will inform the development of interventions that reflect these complex relationships. For example, it is possible that the relationship between decisional conflict and CRCS adherence is mediated through other health behaviors or psychosocial characteristics, which may explain the mixed research to date on the relationship between decisional conflict and CRCS adherence (28, 114).

One way to systematically evaluate these potential mediating pathways is through testing specific pathways within the lens of a theory of health behavior. The macro-level Theory of Triadic Influence (TTI) is one of few theories to include a focus on multiple predictors of health behaviors (115) and is one of several health behavior theories that have been used in CRCS promotion research (91, 113). The TTI proposes that there are many influences of behaviors that act from very distal tiers to very proximal tiers in relation to a health behavior (115). As the tiers move from distal to proximal, they become more focused on the specific behavior of interest. The influences on behavior go through three "streams of influence": environmental, interpersonal and intrapersonal, which allows researchers to better understand the inter-relatedness of health behavior constructs (115). The most proximal constructs in each "stream of influence" leads to behavioral intention, which is considered the immediate pre-cursor of behavior and directly impacts uptake of a health behavior (115). Because the TTI specifies inter-stream and inter-tier effects, it can be used to conceptualize direct and indirect effects and helps bridge the distal and proximal factors to describe how they work together to motivate and influence behavior.

Structural equation modeling (SEM) is an analytic framework that is well-suited for testing theory-derived hypotheses. SEM is a tool that builds upon traditional regression modelling by allowing for the simultaneous estimation of several regression equations (116). By using SEM, direct and indirect pathways between several variables of interest can be estimated simultaneously and independently of each other (116). In this manner, SEM is an appropriate analytic approach for examining both the interrelationships among multiple determinants of CRCS decisional conflict, as well as the direct (and indirect) pathways connecting decisional conflict to screening outcomes. To date, four studies have examined the determinants of

decisional conflict using SEM; however, these reports have not been specific to CRCS (29, 52, 53, 59). These studies indicate that knowledge is indirectly associated with decisional conflict, mediated through decisional anxiety, and perceived risk of cancer for prostate specific antigen testing (29), and preparedness in decision making for microsatellite instability testing (52). Decisional conflict is also correlated with feelings of cancer treatment self-efficacy (17), indicating an additional indirect pathway linking CRCS decision conflict with decision-making outcomes. An important limitation of this extant research is that these SEM analyses have generally not been derived from an existing health behavior theory.

While interventions are needed to increase adherence to all of the recommended CRCS tests, barriers to CRCS are test-specific. Therefore, evaluation of potential barriers to CRCS needs to assess test-specific adherence. As an initial step, this study focuses on colonoscopy adherence, the most widely used CRCS test in the U.S. (6). The goals of this study are to 1) use the TTI to develop a model to investigate the determinants of CRCS decisional conflict and the relationship between CRCS decisional conflict and colonoscopy adherence 2) test the model using structural equation modeling.

METHODS

Setting and data collection

This study uses data from the Colorectal Cancer Screening With Improved Shared Decision Making (CRCS-WISDM) baseline general population questionnaire. The CRCS-WISDM project and questionnaire has been described elsewhere (91-94). Briefly, a mailed, self-administered survey was sent to adults 50-75 years of age randomly selected proportionate to the age and gender distribution in six non-urban MN communities in December 2012 (N=2,150).

Phone follow-up was performed with initial non-responders. The adjusted response rate for the baseline questionnaire among eligible respondents was 71.2% (N=1,449). The Virginia Commonwealth University and Allina health Institutional Review Boards have approved all aspects of CRCS-WISDM.

Study population

The analytic sample for this study (N=1,268) includes white, non-Hispanic respondents 50-75 years of age, at average-risk for CRC, who responded to all 16 decisional conflict scale items. Therefore there were no missing values for our two main outcome variables of interest, decisional conflict and colonoscopy adherence. Specifically, people who reported a race other than white (n=60), or who were at high-risk for CRC (n=75) (i.e., self-reported a personal CRC history, having a 1st-degree relative (i.e., mother, father, sibling) diagnosed with CRC before age 60 or ≥2 1st-degree relatives diagnosed with CRC at any age; or having blood in their stool >1-2 times a week without having hemorrhoids) were excluded. Among the 1,268 adults included in this study, 52.8% were female, 74.8% were 50-75 years of age, and 21.5% had a high school education or less. Other respondent characteristics for this sample have been described in more detail elsewhere (114).

Study measures

Main outcomes of interest

Decisional conflict was measured using the validated 16-item decisional conflict scale with a 5-point Likert-type responses where 1 is strongly agree and 5 is strongly disagree (32). The scale includes five subscales (uncertainty, support, informed, values clarity, and effective decision making). Each item was coded from 0 to 4, so that a higher score indicates higher decisional conflict and five subscale scores were calculated by summing subscale items, dividing

by the number of items and multiplying by 25, resulting in a possible range of 0 to 100 (34). Total decisional conflict was included as an observed variable using a continuous factor score obtained from a one-factor model using the five subscale scores as indicators ($\chi^2_{(21)}$= 42.22, CFI=0.98, TLI=0.94, RMSEA=0.09, 90% CI: 0.06-0.11). Colonoscopy history was measured using a National Cancer Institute-recommended CRCS history question (103), and was coded dichotomously as adherent (i.e. colonoscopy in the last 10 years, referent group) or non-adherent to current CRCS guidelines (4).

Psychosocial characteristics

Colonoscopy barriers were measured using a validated 21-item scale using 5-point Likert-type responses where 1 is strongly agree and 5 is strongly disagree to assess a range of test-specific barriers (10, 97). Each item was coded from 1 to 5, so that higher score indicates more barriers to colonoscopy. A total barrier score was calculated by multiplying the average score by the total number of items answered for people who responded to at least 20 of the 21 items, otherwise responses were set to missing for a possible range of 21 to 105 (10, 97). CRCS confusion was measured using an adapted 8-item scale with 5-point Likert-type responses where 1 is strongly agree and 5 is strongly disagree (100). Each item was coded from 1 to 5, so that higher scores indicates more confusion. A confusion score was calculated by summing the score of each item for a possible range of 8-40 (100). CRCS intention was measured by asking respondents to respond to the statement, “I intend to undergo colorectal screening” with four response options ranging from strongly agree to strongly disagree, (101). Intention to have CRCS was coded dichotomously as intends to have CRCS (i.e., strongly agree or agree, referent group) and does not intend to have CRCS (i.e., strongly disagree or disagree). CRCS self-efficacy was measured using an 8-item scale with 4-point Likert-type responses where 1 is not at

all confident and 4 is very confident (101). Each item was coded from 1 to 4, so that higher scores indicates more self-efficacy. A self-efficacy score was calculated by summing each item for a possible range of 8-32 (99). Control preference was measured using the validated control preferences scale, with 5 response options ("make the final selection about what I will receive", "make the final selection after seriously considering my doctor's opinion", "have my doctor and I share the responsibility for deciding what is best"," have my doctor make the final decision but consider my opinion", and "leave all decisions to my doctor") (102). Control preference was coded into three categories (i.e., mostly patient decisions, shared medical decisions, and mostly healthcare provider decisions).

Other CRCS-behavior characteristics

CRCS options discussed with a healthcare provider was measured using two items, if different CRCS options had ever been discussed with a healthcare provider and if so, which CRCS options had been discussed. The number of CRCS options discussed with a healthcare provider was summed (0, 1, 2, 3, 4). CRCS knowledge was measured using five factual questions about CRC risk and CRCS (e.g., "Colorectal cancer risk is higher in people over the age of 50", "Early detection does not make colorectal cancer easier to treat", etc.). CRCS knowledge was calculated by summing the total number of answered correctly for a potential range of 0 to 5. CRCS test preference was measured using one item, "If you were to get screened for colorectal cancer, either again or for the first time, which test would you prefer?" Response options were, "FOBT (or stool blood test)", "Sigmoidoscopy", "Colonoscopy", and "Don't know/Not sure". CRCS test preference was dichotomized into any CRCS preference (referent group), or an unsure CRCS preference. Lastly, socio-demographic variables included were age, which was used as a proxy for Medicare coverage (dichotomized to 50-64 and 65-75 years,

based on age-eligibility for Medicare coverage) and education (coded as ≤ high school, some college, and ≥ a college degree).

Statistical analyses

Initial development of TTI model

Appendices 3.1 to 3.4 show the progression of model development that began with an original comprehensive model of all potential influences and ended in the initial SEM model that is shown in Figure 3.1. The initial model was developed using the TTI and existing evidence from CRCS and other studies to conceptualize the direct and indirect associations between decisional conflict, psychosocial directly observed influences, and colonoscopy adherence. In the TTI, factors in more distal tiers flow through each of the more proximal tiers along each stream of influence. In this study, colonoscopy barriers and CRCS-specific confusion were considered to be part of the distal tier related to a persons' sense of self and sense of control, while CRCS decisional conflict and CRCS test preference were considered to be part of a more proximal tier related to self-determination. Thus, all pathways from colonoscopy barriers and CRCS-specific confusion flowed directly through CRCS decisional conflict and CRCS preference. Also, because of the strong association between colonoscopy barriers and colonoscopy adherence (10), a direct pathway from colonoscopy barriers to colonoscopy adherence was included in the initial model. Experiencing previous health behaviors can have a feedback loop on the more distal tiers in the TTI, however, no feedback loops were incorporated into the initial model. To ensure that there would be enough power to estimate the associations most relevant to addressing the study aims, all potential associations between colonoscopy adherence and more distal influences were not included. The initial model also included pathways from CRCS decisional conflict directly to CRCS intention and colonoscopy adherence and from CRCS test preference to CRCS intention.

While these direct associations are not within the guidance of the TTI, understanding the indirect associations between CRCS decisional conflict and colonoscopy adherence was a primary aim of this study; thus, these potential pathways were included. To simplify model estimation and interpretation, all pathways were conceptualized as being unidirectional, moving from more distal to more proximal influences.

Model estimation

To maximize the number of potential determinants that could be included in the model, all variables were treated as observed variables. The model was initially tested and then refined using Mplus with diagonally weighted least squares (WLSMV) that took into account the probabilistic sampling using weighting and stratification statements. Mplus is able to handle missing values with the full information maximum likelihood method; however, we purposefully restricted our study population to include only respondents with no missing values for our two main outcomes of interest (decisional conflict and colonoscopy adherence) so that these values would not be imputed. Model fit indices (Chi-square (χ^2), comparative fit index (CFI), non-normed fit index (TLI), root-mean-square approximation (RMSEA)) were used to assess model fit (116). After testing the initial model, the modification indices were examined to look for possible pathways to add to improve model fit while staying true to the TTI framework in several rounds of model building. Non-significant path estimates were also considered for removal from the model. Nested models were compared using the χ^2 difference test (116). In the final model, the magnitude and significance of standardized path coefficients for direct and indirect effects were calculated (116). Path coefficients for categorical variables are derived from a probit regression model; thus, the coefficients represent the probability of a binary event occurring

(117). Finally, the total variance in decisional conflict and colonoscopy adherence explained by the model was assessed using R^2 (116).

RESULTS

Model estimation

The fit indices of the initial theorized model (Figure 3.1) were unacceptable ($\chi^2_{(21)}$=321.84, p<0.01, CFI=0.84, TLI=0.48, RMSEA=0.11). This indicated that relying solely on the pathways guided by the TTI did not adequately describe the relationships between these variables in this sample. To achieve acceptable model fit we began an iterative process of adding and testing additional paths that, while consistent with TTI, were not directly hypothesized by this framework. In our data, an additional pathway from colonoscopy barriers to CRCS self-efficacy resulted in acceptable model fit ($\chi^2_{(22)}$=214.53, p<0.01, CFI=0.90, TLI=0.68, RMSEA=0.08), and therefore this was the model used for interpretation.

Determinants of CRCS decisional conflict and colonoscopy adherence

Figure 3.2 shows the final model with standardized path coefficients, and Table 3.1 shows the estimates of total, direct, and indirect effects for the determinants of CRCS decisional conflict and the association between CRCS decisional conflict and colonoscopy adherence. Greater CRCS confusion and colonoscopy barriers were associated with greater decisional conflict (standardized total effects=0.39 and 0.42 and, respectively, p-values <0.01). A greater number of CRCS options discussed with a healthcare provider and greater knowledge about CRCS were associated with lower levels of decisional conflict (standardized total effects=-0.17 and -0.11, respectively, p-values < 0.01). CRCS confusion mediated the associations between number of CRCS options discussed by a medical provider and decisional conflict (standardized

indirect effect=-0.08, p-value < 0.01), as well as colonoscopy barriers and decisional conflict (standardized indirect effect=0.13, p-value < 0.01). The model explained 40.5% of the variance in total decisional conflict.

CRCS decisional conflict and colonoscopy adherence

Greater decisional conflict was associated with increased probability of non-adherence to colonoscopy recommendations (i.e., not having colonoscopy in the last 10 years) indirectly through decreasing CRCS self-efficacy and an increase in the probit of not intending to have CRCS compared to intending to have CRCS (standardized total effect=0.14. p-value < 0.01). The model explained 45.9% of the variance in colonoscopy adherence.

DISCUSSION

This study is the first, to our knowledge, to apply and test the predictions of a theoretical framework to investigate the determinants of CRCS decision conflict. We also evaluated and compared a set of correlated constructs linking decisional conflict to colonoscopy adherence. There are three important findings from this study. First, while we aimed to derive our model solely from guidance based on the TTI, this framework was not, in and of itself, able to adequately explain the relationships between the determinants of decisional conflict. These findings can inform the refinement of TTI and related health behavior theories as part of the iterative process of theory development and testing. Second, CRCS decisional conflict is impacted by a range of psychosocial and other CRCS-specific characteristics, including colonoscopy barriers, CRCS confusion, and the number of CRCS options discussed with a healthcare provider. Finally, CRCS decisional conflict is associated with colonoscopy adherence, but this relationship is mediated by two factors that are recognized to impact screening

behaviors: CRCS-specific self-efficacy and intention. These latter two findings are discussed in detail below.

Determinants of decisional conflict

Colonoscopy barriers had the largest impact on CRCS decisional conflict. Specifically, greater colonoscopy barriers were significantly associated with greater decisional conflict directly and indirectly through CRCS-specific confusion. None of the previous studies evaluating determinants of decisional conflict using SEM have included a measure of test specific barriers which limits our ability to compare to other's findings; however, Stephens et al. found that prostate specific antigen testing schema, which included positive and negative items, was associated with decisional conflict directly and indirectly through decisional anxiety (29). Therefore, we are beginning to see that there are several potential ways that decisional conflict could be decreased if barriers are decreased

A greater number of CRCS options discussed with a healthcare provider was significantly associated with decreasing decisional conflict directly and also indirectly through CRCS-specific confusion. The association between the number of CRCS options discussed and CRCS decisional conflict could mean that knowing about more of the recommended options decreases decisional conflict, but, if we consider the variable more broadly, it could also indicate that increased patient-provider involvement in healthcare discussions decreases CRCS decisional conflict.

CRCS-specific confusion was associated with CRCS decisional conflict, and was also the mediator in the associations between colonoscopy barriers and CRCS decisional conflict as well as the number of CRCS options discussed with a healthcare provider and CRCS decisional conflict. Confusion has not been included in the previous studies examining simultaneous effects

with decisional conflict so we are unable to compare this finding to those of the previous studies. While there were significant indirect effects between colonoscopy barriers and the number of CRCS options discussed with a healthcare provider through CRCS confusion, the direct effects of all three variables had higher standardized estimates. Regardless, our results show the potentially prominent influence that CRCS confusion has on CRCS decisional conflict.

While our previous work showed that all these of these factors were associated independently with high CRCS decisional conflict (114), this study was able to build upon our previous results by beginning to clarify the interrelationships of all three factors. Our findings also suggest that interventions specifically designed to help people understand their CRCS options might be well suited to address CRCS decisional conflict. Shared decision making promotes having a discussion about possible decision options between two people (typically a healthcare professional and a patient), and is designed to help people come to a decision that is most in line with their preferences and values (118). This type of discussion-based intervention has the potential to address CRCS confusion, decrease test-specific barriers, and increase the number of options discussed, making it a promising avenue to reduce decisional conflict and potentially increase CRCS uptake.

CRCS decisional conflict and colonoscopy adherence

This study found that CRCS decisional conflict is associated with colonoscopy adherence, but that this relationship is mediated by two factors recognized to impact screening behaviors: lower CRCS-specific self-efficacy and reduced CRCS intention This finding highlights the benefit of choosing to use SEM as an alternative modeling strategy because when this relationship was assessed using traditional logistic regression modelling, a significant association between CRCS decisional conflict and CRCS adherence was not found. Our finding

that greater decisional conflict was inversely associated with self-efficacy differs from Miller et al. and Hall et al., neither of which found a significant direct relationship between these constructs (52, 59). However, these two studies focused on very different types of decisions. Miller et al. examined the decision to participate in cancer clinical trials (59), while Hall et al. examined the decision of getting a microsatellite instability test to determine cancer risk (52). It is possible that self-efficacy is less important for these types of decisions where the risk/benefit ratio is less clear, or where there is less responsibility on the person to follow through with the decision.

In this study, intention was most strongly associated with colonoscopy adherence as it had the highest standardized direct effect. This finding is consistent with the conceptualization of this variable in the TTI as the most proximal predictor of behavior. Self-efficacy and intention have already been included as targets in previous interventions aimed at increasing CRCS adherence (60, 61, 105-109, 113). Therefore, it is possible that existing intervention materials could be enhanced by including material designed to decrease CRCS decisional conflict.

The role of test preference

Unexpectedly, the indirect association between decisional conflict and colonoscopy adherence via CRCS test preference was not statistically significant. Further exploring this null relationship showed that in the indirect path from decisional conflict to colonoscopy adherence, test preference was unrelated to self-efficacy. Prior studies have not examined the intersection of decisional conflict, CRCS test preference and . Preferring a colonoscopy is independently associated with increased colonoscopy adherence (92), but this prior study did not also take into account decisional conflict or CRCS-self-efficacy. Further, in the final model, CRCS test

preference was only significantly associated with decisional conflict. Thus, additional research is needed to better understand the interplay between these important variables.

The final model explained a large amount of the variance in both CRCS decisional conflict and colonoscopy adherence, which indicates that the variables included and their specified relationships are able to explain our two outcomes of interest. However, over 50% of the variance of both of these variables remains to be explained. Potential feedback loops between experiencing CRCS and the distal influences were not included in this study, and not all potential variables of interest were able to be included in the initial model. Including feedback loops and additional characteristics in future models is needed to better refine our understanding of these constructs.

Strengths and limitations

This study has several limitations that need to be considered. First, in this study adherence to colonoscopy recommendations, not overall CRCS was assessed. Because barriers to CRCS options are test-specific (9, 10) separate models needed to be created for each of the recommended screening tests. However, in this sample, the prevalence of adherence to the stool test was so low that a stable model could not be created using only this outcome (75.6% adherent to CRCS overall, 73.4% adherent to colonoscopy, and 3.2% adherent to stool test). It is possible that the patterns of associations could be different for the other recommended tests; thus, future studies are needed to specifically investigate the interrelationships between CRCS decisional conflict, psychosocial factors and other characteristics related to CRCS, and stool test adherence. Second, because all of the psychosocial characteristics of interest were included as observed variables, we were unable to incorporate measurement error into our model. Third, because this is a secondary data analysis, not all potential psychosocial constructs relevant to

CRCS decisional conflict or CRCS adherence were included. However, we were able to include constructs that were not included in the previous literature (i.e., CRCS-specific confusion, CRCS test preference, and CRCS-specific intention) that were found to be very important constructs in our model. Fourth, because of the need to maximize power, CRCS decisional conflict was not able to be included as a latent variable but instead was included as a factor score. Fifth, because of the size of our study population and the complexity of the associations of interest, we were not able to model all potential direct and indirect pathways. However, since our initial model was built using guidance from the TTI, the pathways most relevant to answering the aims of this study were initially included. Fifth, this was a cross-sectional survey; thus, the temporality of associations are unknown; however, again, the TTI was used as the framework for the development of the initial model and the directionality of included pathways. Also, data from this study are from an ongoing longitudinal study; therefore we will have the ability to assess these associations over time after remaining data collection is completed. Lastly, we have limited generalizability since our study population consists of only white, non-Hispanic adults from six non-urban MN communities. However, this study also has several strengths as SEM models were able to exploit complex relationships and tested theory driven hypotheses using a large, population-based sample.

Conclusion

To our knowledge, this study was the first to apply a health-behavior theory to understand determinants of CRCS decisional conflict and to test a model assessing the relationship between CRCS decisional conflict and colonoscopy adherence. Because of the multiple recommended CRCS options, the decision-making process about whether to undergo CRCS is potentially more complicated than for other screening decisions. Interventions

developed to increase CRCS adherence need to capitalize on improving decision making, potentially by reducing decisional conflict. Future studies are recommended to continue to investigate the intersection of psychosocial and health-related behaviors using health-behavior theory in increasingly generalizable populations. Shared decision making interventions have the potential to impact all of the factors found to be important for CRCS decisional conflict and could also increase CRCS uptake. More effective CRCS interventions could ultimately increase CRCS in the general population which would significantly reduce the morbidity and mortality of CRC.

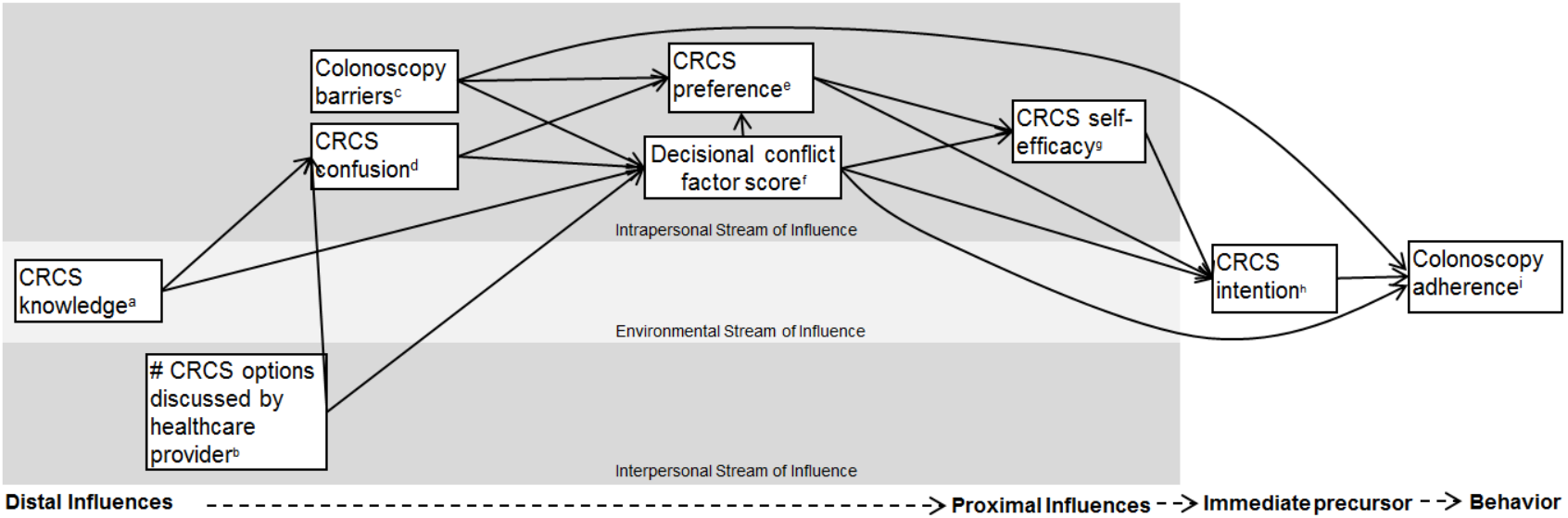
Table 3.1. Coefficients of direct and indirect associations of health behavior and psychosocial determinants for decisional conflict and colonoscopy adherence (N=1,268)

	Estimate	Standard error	p-value	Standardized estimate
Total decisional conflict				
Number of CRCS options discussed with healthcare provider				
Indirect	-1.07	0.16	< 0.01	-0.08
Specific indirect associations				
Number of CRCS options discussed → CRCS confusion → Total decisional conflict	-1.07	0.16	< 0.01	-0.08
Direct	-1.36	0.32	< 0.01	-0.10
Total	-2.43	0.35	< 0.01	-0.17
Colonoscopy barriers				
Indirect	0.11	0.01	< 0.01	0.13
Specific indirect associations				
Colonoscopy barriers → CRCS confusion → Total decisional conflict	0.11	0.01	< 0.01	0.13
Direct	0.25	0.02	< 0.01	0.29
Total	0.36	0.02	< 0.01	0.42
CRCS knowledge				
Indirect	–	–	–	–
Specific indirect associations	–	–	–	–
Direct	-2.09	0.46	< 0.01	-0.11
Total	-2.09	0.46	< 0.01	-0.11
CRCS confusion				
Indirect	–	–	–	–
Specific indirect associations	–	–	–	–
Direct	0.70	0.04	< 0.01	0.39
Total	0.70	0.04	< 0.01	0.39

Colonoscopy adherence				
Total decisional conflict				
Indirect	0.01	< 0.01	< 0.01	0.14
Specific indirect associations				
Total decisional conflict → CRCS intention → Colonoscopy adherence	0.01	< 0.01	< 0.01	0.09
Total decisional conflict → CRCS self-efficacy → CRCS intention → Colonoscopy adherence	0.01	< 0.01	< 0.01	0.05
Total decisional conflict → CRCS preference → CRCS self-efficacy → CRCS intention → Colonoscopy adherence	0.00	< 0.01	0.72	0.00
Direct	–	–	–	–
Total	0.01	< 0.01	< 0.01	0.14

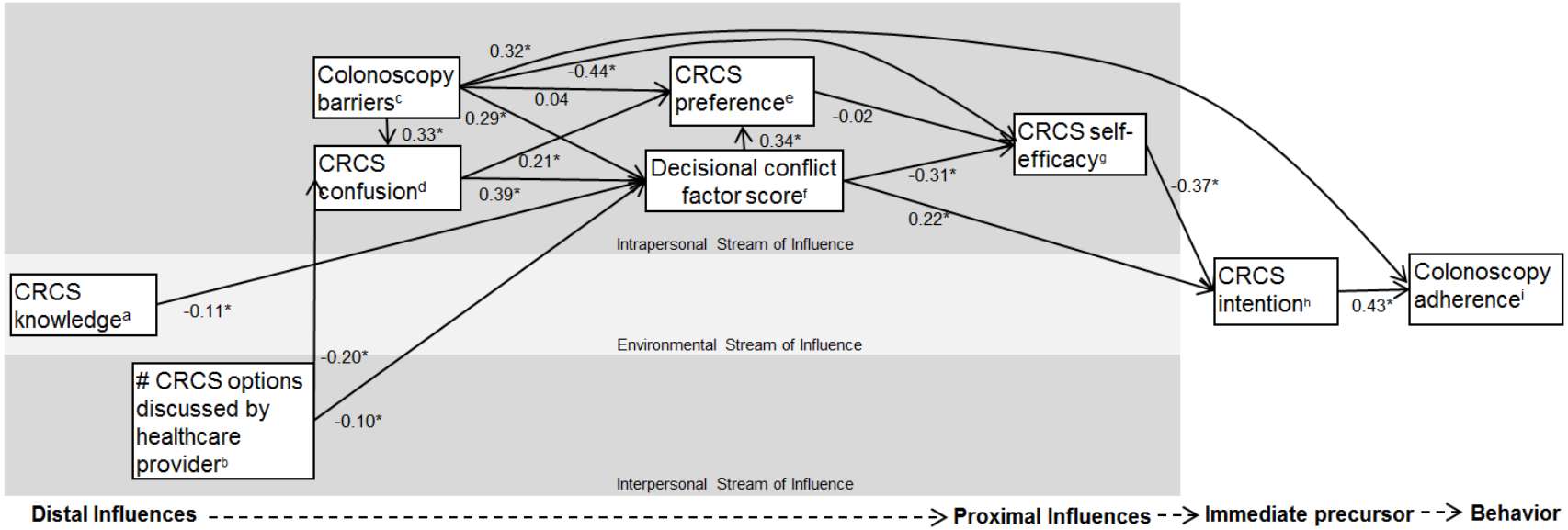
Note: CRCS = colorectal cancer screening. Pathways not included in the final model labelled with "–".

Figure 3.1. Initial SEM model: Health behavior and psychosocial determinants of decisional conflict and colonoscopy adherence using the Theory of Triadic Influence



Note: CRCS = colorectal cancer screening. Age eligibility for Medicare, education, and control preferences included as covariates in the model
a. CRCS knowledge measured using five knowledge questions. Range: 0-5, higher score indicates more questions answered correctly
b. Number of CRCS options discussed measured using two questions. One asked respondents if a healthcare provider had ever discussed different CRCS options. The second question asked which CRCS tests had been discussed. Variable coded as the total number of tests discussed. Range: 0-4 tests discussed
c. Colonoscopy barriers measured using a 21-item scale. Range: 21-105, higher score indicates more barriers to colonoscopy
d. CRCS confusion measured using an 8-item scale. Range: 8-40, higher score indicates more confusion relating to CRCS
e. CRCS preference measured by asking respondents, "If you were to get screened for colorectal cancer, either again or for the first time, which test would you prefer?" Responses options were, "FOBT (or stool blood test)", "Sigmoidoscopy", "Colonoscopy", "Don't know/Not sure". Responses dichotomized as a CRCS preference or unsure CRCS preference. Referent = CRCS preference
f. Total decisional conflict measured using a factor score. Higher score indicates more decisional conflict
g. CRCS self-efficacy measured using an 8-item scale. Range: 10-32, higher score indicates more self-efficacy
h. CRCS intention measured by asking respondents to respond to the statement, "I intend to undergo colorectal screening". Responses dichotomized as strongly agree or agree and strongly disagree or disagree. Referent = strongly agree or agree
i. Baseline colonoscopy adherence. Adherent = colonoscopy within the last 10 years), non-adherent = colonoscopy >10 years ago or never had colonoscopy. Referent = adherent to colonoscopy

Figure 3.2. Final SEM model: Health behavior and psychosocial determinants of decisional conflict and colonoscopy adherence using the Theory of Triadic Influence



Note: CRCS = colorectal cancer screening. All path coefficients are standardized. Age eligibility for Medicare, education, and control preferences included as covariates in the model

* Indicates a p-value < 0.05

a. CRCS knowledge measured using five knowledge questions. Range: 0-5, higher score indicates more questions answered correctly

b. Number of CRCS options discussed measured using two questions. One asked respondents if a healthcare provider had ever discussed different CRCS options. The second question asked which CRCS tests had been discussed. Variable coded as the total number of tests discussed. Range: 0-4 tests discussed

c. Colonoscopy barriers measured using a 21-item scale. Range: 21-105, higher score indicates more barriers to colonoscopy

d. CRCS confusion measured using an 8-item scale. Range: 8-40, higher score indicates more confusion relating to CRCS

e. CRCS preference measured by asking respondents, “If you were to get screened for colorectal cancer, either again or for the first time, which test would you prefer?” Responses options were, “FOBT (or stool blood test)”, “Sigmoidoscopy”, “Colonoscopy”, “Don’t know/Not sure”. Responses dichotomized as a CRCS preference or unsure CRCS preference. Referent = CRCS preference

f. Total decisional conflict measured using a factor score. Higher score indicates more decisional conflict

g. CRCS self-efficacy measured using an 8-item scale. Range: 10-32, higher score indicates more self-efficacy

h. CRCS intention measured by asking respondents to respond to the statement, “I intend to undergo colorectal screening”. Responses dichotomized as strongly agree or agree and strongly disagree or disagree. Referent = strongly agree or agree

i. Baseline colonoscopy adherence. Adherent = colonoscopy within the last 10 years), non-adherent = colonoscopy >10 years ago or never had colonoscopy. Referent = adherent to colonoscopy

Chapter 4: Survivorship care plans and time since diagnosis: factors that contribute to who breast cancer survivors see for the majority of their care

ABSTRACT[1]

Purpose: The study purpose is to describe who breast cancer survivors see for their care by years since diagnosis and determine the association between time since diagnosis and the type of clinician providing the majority of care, taking into account receipt of follow-up care instructions.

Methods: The 2010 Behavioral Risk Factor Surveillance System was used to identify a sample (N=1024) of women with a self-reported history of breast cancer. Descriptive characteristics were calculated and stratified by years since diagnosis. Multivariate logistic regression adjusting for age, income, and receiving follow-up care instructions was performed to evaluate the association between years since diagnosis and clinician providing the majority of care.

Results: The type of clinician reported most frequently was a primary care provider. Women 0–1 year since diagnosis had the highest proportion reporting a cancer-related clinician for their care. After adjustment, women 0–1, 2–3, and 4–5 years since diagnosis were respectively 2.1, 2.6, and 1.7 times more likely to have a cancer-related clinician providing the majority of care compared to women 6+years since diagnosis (respective 95 % confidence intervals (CIs) 1.0–4.3; 1.4–4.6; 0.9–3.1).

Conclusions: Breast cancer survivors receive the majority of their care from primary care providers, and years since diagnosis has a significant impact on who survivors see for their care. Breast cancer survivors have nationally recommended follow-up guidelines; however, the type of clinician that should provide care is not specified. Information regarding who provides the majority of care can be used for future planning and policy development.

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INTRODUCTION

The American Cancer Society (ACS) estimates that 237,840 new cases of invasive breast cancer will occur in women in 2015 (1). Due to advances in early detection and treatments, the mortality associated with breast cancer has been reduced (68). Currently, the overall 5- and 10-year breast cancer survival rates are 89 % and 83 %, respectively (78), which equates to approximately 2.5 million female breast cancer survivors in the USA (119), the largest sub-group of all cancer survivors (68).

After completing treatment, women with breast cancer are monitored for long-term and late effects of treatment. The long-term and late effects experienced by breast cancer survivors vary by treatment, stage of diagnosis, and length of survival time and include recurrence of breast cancer, additional primary cancers, reduced physical and cognitive functioning, premature menopause, lymphedema, weight gain, fatigue, and increased risk of cardiovascular disease (68). Based on a 2005 Institute of Medicine (IOM) recommendation, all patients completing cancer treatment should receive a written survivorship care plan, which, among other things, should provide information about when follow-up visits are needed and what medical provider should be seen for follow-up care (68). While the National Comprehensive Care Network (NCCN) (70) and the American Society of Clinical Oncology (ASCO) (71) evidence-based guidelines detail the type and frequency of follow-up care to ensure the long-term health of breast cancer survivors, the type of clinician responsible for this care is not explicitly stated (70, 71, 79). As such, survivorship care plans and related instructions could impact the type of clinician breast cancer survivors see for their care following treatment completion.

Historically, follow-up care is traditionally provided by a specialist (e.g., oncologist) (67, 80); however, this model of care puts a large burden on outpatient specialty care (81).

Alternatively, follow-up care could be performed in a primary care setting, which could reduce the burden in oncology care and lower health-care costs (82). For example, two randomized controlled trials among breast cancer survivors found that primary care follow-up and oncology follow-up lead to similar outcomes (80, 83). Therefore, it is reasonable that a cancer related clinician or a primary care provider could be responsible for follow-up care of breast cancer survivors.

Unfortunately, little is known about the prevalence of who actually receives instructions and the potential impact on health-care demand and delivery. To date, seven studies have described the patterns of who is providing follow-up care among breast cancer survivors(79, 84-89), but these studies are limited. For example, the studies have examined patterns focusing only on women diagnosed with early-stage breast cancer (85, 86), Canadian women who have a different health-care system that is not entirely generalizable to the US population (84), and women with limited follow-up duration after treatment completion (87-89). Further, the majority of these studies used registry, claims, or medical records data, which does not capture survivors' views of who is responsible for their care (84-88). One study has examined receiving cancer follow-up instructions using a nationally representative sample from the 2010 Behavioral Risk Factor Surveillance System (BRFSS); however, the patterns of post-treatment care were not described (90). In short, to our knowledge, no previous studies have examined the patterns of breast cancer survivors' perspectives about the clinician responsible for the majority of their care among a large population of US breast cancer survivors with varying time since treatment completion.

As guidelines and policies for cancer follow-up care are refined, it is important to gain a better understanding of the current experience of women diagnosed with breast cancer

(79). For example, if breast cancer survivors perceive care to be largely the responsibility of an oncologist, policies moving follow-up care out of oncology and into primary care might not be well-received, regardless of similarities in health outcomes. Further, changes in who provides care as survival time increases are unknown. It is possible that breast cancer survivors move away from oncologist follow-up care to primary care providers over time as their health-care needs shift away from their cancer treatment. Thus, information about who provides the majority of care for breast cancer survivors as time since diagnosis increases not only would facilitate our understanding of current breast cancer follow-up care patterns but also could help inform future recommendations and policies, particularly those related to the training needs of clinicians ultimately providing care to cancer survivors.

Using a large, national sample of female breast cancer survivors who have completed breast cancer treatment, this study aims to (1) describe the characteristics of survivors by years since diagnosis, (2) determine what type of clinician (e.g., primary care, cancer-related, other) is providing the majority of care by years since diagnosis, and (3) determine the association between years since diagnosis and a cancer-related clinician providing the majority of care among survivors, taking into account whether women received follow-up care instructions. We hypothesize that women with fewer years since diagnosis will be more likely to report that a cancer-related clinician is providing the majority of their care compared to those with more years since diagnosis.

METHODS

Data collection and target population

This study is a secondary data analysis using the 2010 BRFSS questionnaire, administered by the Centers for Disease Control and Prevention (CDC). The sampling methodology, data collection procedures, and response rate of the 2010 BRFSS have been described elsewhere (120). Briefly, BRFSS is an annual telephone-administered questionnaire designed to assess behavioral risk factors in the US adult population (120). The Council of American Survey Research Organizations (CASRO) response rate for the core 2010 BRFSS questionnaire was 54.6 % (121). While all respondents are asked the BRFSS core module, only respondents from nine states (AL, CT, IN, MA, MO, NM, OH, SD, and WI) and Guam participated in the optional cancer survivorship module (122). For this study, female breast cancer survivors living in the nine US states who reported having a breast cancer diagnosis (and no other type of cancer) at ≥18 years of age and were no longer receiving treatment for cancer were included in the sample (N=1024; 21 women were excluded—17 had insufficient age-related data and 4 respondents from Guam were breast cancer survivors and excluded due to this study's focus on US survivor plan recommendations).

Measures

Measures selected from the core module were age at time of interview, race, annual household income, employment status, health insurance status, marital status, education, cardiovascular disease (CVD) status, body mass index (BMI), whether the respondent had a primary care provider, and whether the respondent had a routine physical in the last year (122). Measures relating to breast cancer survivorship were type of cancer diagnosis, age at cancer diagnosis, number of cancers diagnosed, current treatment status, receiving follow-up instructions about routine cancer checkups after completing treatment, and type of clinician who provides the majority of the respondent's care.

Primary outcome and independent variables

The clinician providing the majority of care after treatment completion was recoded into three categories: cancer-related (i.e., gynecologic oncologist, medical oncologist, radiation oncologist, general surgeon, plastic surgeon, or cancer surgeon), primary care (i.e., family practitioner or internist), or other clinician (i.e., urologist, other). Years since diagnosis was calculated by subtracting age at time of breast cancer diagnosis from age at time of interview. Years since diagnosis was further categorized to reflect transition points in care after cancer diagnosis based on ASCO and NCCN breast cancer follow-up guidelines (70, 71). The ASCO guidelines state that, depending on stage of diagnosis, follow-up care can be transferred to a primary care physician 1 year after diagnosis (71). ASCO also recommends physical examinations every 3–6months for the first 3 years, and every 6–12 months for years 4 and 5 post-treatment, while NCCN recommends an exam every 6–12 months for 5 years (70, 71). Also, both ASCO and NCCN recommend annual exams 5 years post-diagnosis (70, 71). Thus, years since diagnosis categories were 0–1, 2–3, 4–5, and 6+years.

Covariates

Possible confounders were recoded into the following categories: age (27–49 years of age, 50–64 years of age, 65–97 years of age), race (white, other), annual household income (<$25,000, $25,000–<$75,000, ≥$75,000), employment status (employed for pay, not employed for pay, retired), health insurance coverage (yes, no), marital status (married, not married), education (≤high school, some college, college degree), receiving instructions for cancer follow-up care (yes, no), BMI (underweight/normal, <25 kg/m2; overweight, 25 to ≤30 kg/m2; obese, >30 kg/m2), diabetes (yes, no), and CVD (any history of heart attack, stroke, angina, or coronary

heart disease; no history). A three-level variable was created to assess how regularly breast cancer survivors access care in general, which could be a function of the number of providers a woman sees. This variable was created by combining whether a woman had a routine checkup in the last year and the number of providers the respondent considered to be their primary provider (checkup in the last year with ≥2 providers, checkup in the last year with 1 provider, no checkup in the last year).

Statistical analysis

SAS/STAT® software (version 9.2; SAS Institute Inc.) procedures PROC FREQ and PROC LOGISTIC were used to perform the statistical analysis. Although it is common to take into account the BRFSS probabilistic sampling scheme, this was not done for these analyses as the population weights are not representative of the selected sample of breast cancer survivors given that the cancer survivorship module was only administered in nine states. Descriptive characteristics were calculated for all respondents and stratified by categories of years since diagnosis.

To assess the associations between years since diagnosis and a cancer-related clinician providing the majority of care, multivariate logistic regression was performed. Provider type was limited to cancer-related clinician versus primary care (referent) since these two provider types are most likely to be caring for women with breast cancer (n=132 excluded) (79). Age was also restricted to only include those who were 50 years of age or older at time of diagnosis because the prognosis of those diagnosed before 50 years is different than the prognosis of those who are diagnosed at an older age (123, 124) and due to the small sample size (n=44 excluded). Race and age were assessed for effect modification as they are common effect modifiers in cancer survival (1, 123), but neither was found to modify the association between years since

diagnosis and provider type. Potential differences by state were also assessed (e.g., health insurance coverage, health-care utilization); however, since no significant differences existed, analyses did not include state as a covariate. After assessing confounding, the final multivariate model adjusted for age, annual household income, and receiving instructions for cancer follow-up care.

RESULTS

Overall respondent characteristics

Respondent characteristics are presented in Table 4.1. The majority of respondents were 65 years of age or older (65.4 %) and reported having had a routine checkup in the last year with only one provider who they felt was their primary doctor (77.8 %), and receiving cancer follow-up instructions after completing cancer-related therapy (77.8 %). The prevalence of comorbidities such as diabetes (14.1 %) and CVD (16.0 %) was relatively low; however, about two thirds of respondents were overweight or obese (59.0 %). A primary care provider was reported most frequently as the type of clinician providing the majority of care (75.0 %).

Respondent characteristics by years since diagnosis

The proportion of women in each age category varied greatly across years since diagnosis. The unadjusted proportion of women who reported being employed was highest among those 0–1 year since diagnosis (42.8 %) while the proportion of women who were retired was highest among those 6+years since diagnosis (54.1 %). The proportion of women who reported having a routine checkup in the last year with ≥2 providers as their primary doctor was higher for women who were more recently diagnosed (~12 % for women 0–1 year and 2–3 years since diagnosis). While a primary care provider reportedly provided the majority of care, the

proportion of women reporting seeing a cancer-related clinician for their care was highest for women 0–1 year since diagnosis.

Years since diagnosis and type of clinician providing care

After adjusting for confounders, all women 3 years or less since diagnosis were significantly more likely to report that a cancer-related clinician provided the majority of their care compared to women 6+years since diagnosis (0–1 year, odds ratio (OR)=2.11, 95 % confidence interval (CI) 1.04–4.30; 2–3 years, OR=2.55, 95 % CI 1.43–4.55; see Table 4.2). Women who were 50–64 years of age were 2.00 times more likely to have a cancer-related clinician providing the majority of their care (95 % CI 1.30–3.06) compared to those 65+years of age. Compared to women who reported not receiving follow-up cancer care instructions, women who reported receiving instructions were 3.72 times more likely to have a cancer-related clinician providing the majority of their care (95 % CI 1.75–7.95).

DISCUSSION

To our knowledge, this is the first study investigating the patterns of post-treatment care among short- and long-term US female breast cancer survivors in a general population. We found that the majority of female cancer survivors reportedly received the majority of their care after completing treatment from a primary care clinician. In addition, as hypothesized, women who were 3 years or less since diagnosis were significantly more likely to see a cancer-related clinician for their care compared to their counterparts (i.e., women 6+years since diagnosis) as were younger women (50–64 years of age) in relation to those 65+years of age. Further, women who received follow-up care instructions were more than 3 times as likely to see a cancer-related clinician for the majority of their care.

Type of clinician providing care

In our study, the type of clinician women reported as providing the majority of their care was a primary care provider, which is different than the findings of others who found that follow-up care for breast cancer survivors was largely provided by oncologists or cancer specialists (79, 86, 89). Patients in previous studies were significantly younger than the women in our study population (mean ages 56.5 (79) and 60.7 (89) versus 69.4 in the current study), which could partially explain this difference, as women 50–64 years of age in this study were more likely to report cancer-related care compared to women 65 and older. Further, previous study populations differed from those of our study in that they included women from specific health systems (84, 86), participants in intervention studies (87, 89), or women in SEER-Medicare-linked data, which only included women who were 60 years of age or older (85, 88). Interestingly, breast cancer survivors have reported a preference for their cancer follow-up to be with a cancer-related specialist (89, 125), which appears contrary to our findings since most women were receiving the majority of their care in primary care. However, the time since treatment completion is longer in this study than in previous studies (79, 84, 87, 89), which could be related to this finding. Also, while the question, "What type of doctor provides the majority of your health care?", was only asked within the cancer survivorship module of respondents who reported a cancer diagnosis and were no longer receiving treatment, it did not specifically ask about cancer follow-up care. Thus, there is the potential for misinterpretation and misclassification of our outcome of interest. For example, people with comorbidities might see their primary care provider often, which could change their response regardless of the cancer-related context of the questions. However, no measures of comorbidities (e.g., diabetes, CVD, and BMI) were confounders or substantially changed the model estimates in the multivariate

models; thus, we present more parsimonious models. Also, having multiple providers (i.e., ≥2 providers) as a primary provider was not a confounder.

Years since diagnosis and type of clinician providing care

Among a large sample of breast cancer survivors, women three or less years since diagnosis were significantly more likely to report that a cancer-related clinician provided the majority of their care, which was consistent with our original hypothesis that women with fewer years since diagnosis would be more likely to report that a cancer-related clinician is providing the majority of their care compared to those with more years since diagnosis. To our knowledge, no studies have investigated the association between time since diagnosis and the type of physician providing the majority of care. However, most breast cancer recurrences occur during the second year after diagnosis (126), and women with recurrence would most likely return to oncology care for treatment, which could explain this pattern of physician care. Information on cancer recurrence was not included in the BRFSS cancer module, nor was data on the type of clinician breast cancer survivors would prefer to see for their follow-up care. The majority of the research on follow-up care patterns among breast cancer survivors has been described using data collected before the publication of the IOM survivorship report—approximately 5 years before the 2010 BRFSS data collection (84-88)—and follow-up patterns seen today could therefore be different. Thus, we examined a multivariate model excluding women 6+years since diagnosis so that the IOM guidelines would have been in place for all women in the sample. We found that the patterns of associations were similar with women 0–1 and 2–3 years since diagnosis being more likely to report that a cancer-related clinician provided the majority of their care compared to women 4–5 years since diagnosis. Thus, it appears that as of the time of BRFSS 2010 data collection, the patterns of care had not changed significantly since the IOM report publication.

Follow-up care patterns of breast cancer survivors have the potential to change more drastically as time since the IOM report publication increases and as new policies directing the post-treatment care of breast cancer survivors are established.

Recommendations for follow-up care

Although originally a variable included as a covariate for adjustment, receiving follow-up care instructions had the largest impact on the type of clinician providing the majority of care. Our finding could indicate that cancer-related clinicians using survivorship care plans are recommending that patients stay in cancer-related care. This finding is similar to that of Jabson et al. who found that survivors who received follow-up care instructions were more likely to see an oncologist for their follow-up care (90), and is not surprising given the Potosky et al. finding, using a nationally representative survey of oncologists, that only 23 % believe primary care providers have the skills needed for breast cancer follow-up (127). Because of the potential impact of the IOM report on the utilization of follow-up guidelines, we again considered examining breast cancer survivors diagnosed since the publication of the IOM report. When women 6+years since diagnosis were removed, with only one exception, all women who reported receiving follow-up instructions also reported that a cancer-related clinician provided the majority of their care (data not shown). Thus, it seems that since the publication of the IOM guidelines, cancer follow-up instructions result in cancer-related care immediately after treatment completion. Regardless of the potential limited capacity and cost-related issues of oncology follow-up care, without clear recommendations about the type of provider who should participate in care as survival time increases, it is unclear whether cancer-related care physicians will promote transitions to primary care. The format of follow-up care instructions (i.e., written or verbal) can cause differences in recommended and received cancer surveillance (128);

therefore, we explored whether the format of the follow-up instructions received impacted the outcome. The same pattern of association was found; however, almost 10 % of respondents were missing (n=100) since the question about format of follow-up care instructions was only asked of respondents who reported receiving follow-up instructions. Thus, our final models include receipt of follow-up care instructions, not format.

Limitations

Our study has several limitations which need to be considered. First, some relevant information about breast cancer survivors was not collected in the 2010 BRFSS questionnaire. For example, stage of breast cancer diagnosis and the use of adjuvant therapies like tamoxifen were not captured. Stage and the use of adjuvant therapies could impact the type of provider breast cancer survivors see for their care. Also, we do not know the exact time since treatment completion and instead used years since diagnosis, similar to other studies examining the patterns of cancer follow-up (79, 84, 85, 88, 89). All women had completed treatment, and years since diagnosis was calculated by subtracting age at time of interview from age at cancer diagnosis. Both ages were captured as whole numbers; thus, people could be misclassified into the wrong category for years since diagnosis. However, this method was used by the Centers for Disease Control and Prevention to classify cancer survivors in a recent publication (119). Also, the question ascertaining the type of clinician providing the majority of care did not include response categories for nurse practitioner or other types of non-physician provider. Recall bias is possible since all data are self-reported. While BRFSS is generally representative of the entire US population, generalizability is limited in this study because only nine states chose to administer the optional cancer survivorship module and the care patterns for one type of cancer diagnosis are assessed. Further, while the survivorship module response rate was similar

to the core questionnaire (~57 % of the total eligible sample in the participating states answered the first survivorship module question to determine if they were ever diagnosed with cancer), we do not know the prevalence of survivorship among non-responders. Lastly, while the temporality of associations is generally unknown in cross-sectional studies, we used a time dependent independent variable, which preceded the outcome, so temporality is less of a concern for this study.

Conclusions

Similar cancer-related outcomes exist for those who see a primary care clinician versus those who see a cancer-related clinician (80, 83), and the IOM report, From Cancer Patient to Cancer Survivor: Lost in Transition, recommends post-treatment follow-up care but does not detail the type of physician who should provide this care (68). This comprehensive examination of the post-treatment care patterns of female breast cancer survivors provides relevant information for future planning and policy development. In general, survivors report receiving the majority of their care from primary care providers; however, those with follow-up care instructions are more apt to receive care from cancer-related clinicians. Thus, to address capacity issues as the number of US cancer survivors increases, women would likely be very accepting of policies that promote post-treatment care in a primary care setting particularly if primary care continues to lead to similar outcomes as cancer-related care for breast cancer survivors. Further, a shared model of care that includes transitioning from cancer-related care to primary care (129, 130) has promise for ensuring appropriate care as survivors live longer.

Table 4.1. Breast cancer survivor respondent characteristics, BRFSS[a] 2010

		Years since diagnosis			
	Total N = 1,024	**0–1 n = 70**	**2–3 n = 104**	**4–5 n = 113**	**6+ n = 737**
Variable	Percent	Percent	Percent	Percent	Percent
Years since diagnosis: Mean (standard error)	12.3 (0.31)	0.71 (0.05)	2.47 (0.05)	4.58 (0.05)	16.0 (0.35)
Clinician providing majority of care					
Oncologist/cancer related care[b]	16.0	30.0	29.8	21.2	11.9
Primary care[c]	75.0	58.6	62.5	70.8	79.0
Other[d]	9.0	12.4	7.7	8.0	9.1
Age					
27–49[e]	4.3	12.9	6.7	8.9	2.4
50–64	30.3	40.0	35.6	34.5	28.0
65–99[f]	65.4	47.1	57.7	56.6	69.6
Race					
White	90.2	88.6	86.5	89.4	91.0
Other	9.8	11.4	13.5	10.6	9.0
Annual household income					
<$25,000	33.8	35.1	36.1	33.0	33.4
$25,000–<$75,000	45.5	42.1	43.0	45.1	46.3
≥$75,000	20.7	22.8	20.9	21.9	20.3
Employment status					
Not employed	18.3	22.9	20.2	18.6	17.5
Employed	31.3	42.8	36.5	38.1	28.4
Retired	50.5	34.3	43.3	43.4	54.1
Health insurance					
Yes	96.9	97.1	98.1	97.3	96.6
No	3.1	2.9	1.9	2.7	3.4
Marital status					
Married	41.0	43.5	42.3	46.4	39.8
Not married	59.0	56.5	57.7	53.6	60.2
Education					
≤High school	38.7	40.0	36.5	32.1	39.8
Some college	28.2	20.0	27.9	35.8	27.9
College degree	33.2	40.0	35.6	32.1	32.3
Routine check-up in the last year					
Yes, has ≥2 providers	8.6	12.9	12.5	8.0	7.7
Yes, has 1 provider	77.8	77.1	74.0	81.4	77.9
No	13.6	10.0	13.5	10.6	14.4
Instructions for cancer follow-up care[g]					
Yes	77.8	91.4	85.6	92.0	73.1
No	22.2	8.6	14.4	8.0	26.9
BMI					
Underweight/Normal[h]	41.0	38.5	27.1	36.9	43.7
Overweight[i]	35.0	32.3	47.9	32.0	33.9
Obese[j]	24.0	29.2	25.0	31.1	22.4

Diabetes					
Yes	14.1	10.0	16.4	11.5	14.6
No	85.9	90.0	83.6	88.5	85.4
Cardiovascular disease[k]					
Yes	16.0	11.4	10.6	22.1	16.3
No	84.0	88.6	89.4	77.9	83.7

a. BRFSS = Behavioral Risk Factor Surveillance System
b. Gynecologist oncologist, medical oncologist, radiation oncologist, general surgeon, cancer surgeon or plastic surgeon
c. Family practitioner, internist
d. Urologist, other
e. Age of youngest survivor
f. Age of oldest survivor
g. Instructions given to patient upon completion of cancer treatment about cancer follow-up care
h. Body mass index <25 Kg/m2
i. Body mass index 25 to ≤30 Kg/m2
j. Body mass index >30 Kg/m2
k. Any history of heart attack, stroke, angina or coronary heart disease

Table 4.2. Association between years since diagnosis and a cancer-related clinician providing the majority of care, BRFSS[a] 2010

	Clinician providing majority of care		
	Cancer-related[b] n =146	Primary care[c] n= 746	
Variable	**Percent**	**Percent**	**OR[d] (95% CI)[e]**
Age			
50–64	48.0	28.7	2.00 (1.30–3.06)
65–99[f]	52.0	71.3	1.00 (ref)
Annual household income			
<$25,000	29.8	34.7	1.15 (0.63–2.08)
$25,000–<$75,000	47.6	45.7	1.08 (0.64–1.83)
≥$75,000	22.6	19.6	1.00 (ref)
Instructions for cancer follow-up care[g]			
Yes	92.5	74.9	3.72 (1.75–7.95)
No	7.5	25.1	1.00 (ref)
Years since diagnosis			
0–1	11.0	5.0	2.11 (1.04–4.30)
2–3	17.8	8.4	2.55 (1.43–4.55)
4–5	14.4	10.2	1.68 (0.93–3.06)
6+	56.8	76.4	1.00 (ref)

a. BRFSS = Behavioral Risk Factor Surveillance System
b. Gynecologist oncologist, medical oncologist, radiation oncologist, general surgeon, cancer surgeon or plastic surgeon
c. Family practitioner, internist
d. OR = Odds ratio and
e. 95% CI = 95% confidence interval
f. Age of oldest survivor
g. Instructions given to patient upon completion of cancer treatment about cancer follow-up care

Chapter 5: Summary

The purpose of this dissertation was to increase our understanding of CRCS decisional conflict and breast cancer survivorship care with a focus on potential applications in future research studies designed to change behaviors and evidence-based guidelines along the cancer control continuum. Specifically, this dissertation: 1) assessed CRCS decisional conflict in a general population by describing the distribution of CRCS decisional conflict and determining respondent characteristics associated with high total and subscale-specific decisional conflict, 2) used the Theory of Triadic Influence as a framework to model the determinants of CRCS decisional conflict and assess the relationship between CRCS decisional conflict and colonoscopy adherence, and 3) assessed the patterns of post-treatment breast cancer care.

Colorectal cancer screening decisional conflict

The first two studies of this project examined CRCS decisional conflict using a general population sample of adults from six non-urban communities in MN. The study population included white, non-Hispanic respondents at average-risk for CRC who answered all 16 items of the decisional conflict scale (N=1,268). In the first study, total and subscale-specific CRCS decisional conflict was dichotomized into high (≥25) and low (<25) decisional conflict. Over half of respondents had high total or subscale-specific decisional conflict. Several respondent characteristics were associated with total and subscale specific decisional conflict. For example, greater colonoscopy barriers (OR= 1.04; 95% CI: 1.02-1.05) and greater CRCS-specific confusion (OR=1.12; 95% CI: 1.10-1.15) were positively associated with high total decisional

conflict, while greater CRCS-specific self-efficacy was inversely associated with high total decisional conflict (OR= 0.85; 95% CI: 0.80-0.90). A healthcare provider not discussing CRCS options was associated with a greater likelihood of high decisional conflict (OR=1.67; 95% CI: 1.18–2.37). Education, Medicare eligibility, and control preferences were associated with high total or some of the decisional conflict subscales.

In the second study, the Theory of Triadic Influence was used as a framework to guide the development of a model describing the interrelationships between the previously described psychosocial factors and other CRCS-specific characteristics with CRCS decisional conflict and colonoscopy adherence. Decisional conflict was included as an observed continuous variable using a factor score obtained from a one-factor model using the five subscale scores as indicators. After refining the model, several respondent characteristics were found to be associated with CRCS decisional conflict. Specifically, greater CRCS confusion and greater colonoscopy barriers were associated with higher decisional conflict (standardized total effects=0.39 and 0.42, respectively; p-values <0.01). A greater number of CRCS options discussed with a healthcare provider was associated with lower levels of decisional conflict (standardized total effect=-0.17, p-value < 0.01). CRCS confusion mediated the association between colonoscopy barriers and decisional conflict (standardized indirect effect=0.13, p-value <0.01) as well as the association between the number of CRCS options discussed with a healthcare provider and decisional conflict (standardized indirect effect=-0.08, p-value <0.01). Greater decisional conflict was associated with increased probability of non-adherence to colonoscopy recommendations (i.e., not having colonoscopy in the last 10 years) indirectly through decreasing CRCS self-efficacy and an increase in the probit of not intending to have CRCS compared to intending to have CRCS (standardized total effect=0.14. p-value < 0.01). The

model explained 40.5% of the variance in total decisional conflict and 45.9% of the variance in colonoscopy adherence.

The findings from these first two studies are directly applicable to future CRCS intervention studies. In a large, general population not restricted based on any additional characteristics, levels of CRCS decisional conflict were consistently higher than what has been found in previous CRCS studies (23-28). The high levels of CRCS decisional conflict found in this study warrants that future studies continue to measure and assess associations with CRCS decisional conflict in increasingly generalizable populations. Including more generalizable populations would provide the opportunity to investigate the association between race/ethnicity and culture and decisional conflict, which we were not able to do in our racially homogenous population. While the data used for the first two studies was cross-sectional, the data come from an ongoing longitudinal study; thus, these associations can subsequently be evaluated over time.

The results of the first study also provided new information about respondent characteristics associated with total and subscale-specific decisional conflict. Respondent characteristics colonoscopy barriers, CRCS-specific confusion, self-efficacy, and intention, and CRCS test preference were associated with total decisional conflict as well as subscale-specific decisional conflict, while other characteristics control preferences, education, and Medicare age-eligibility were only significantly associated with total or a some of the decisional conflict subscales. While a bigger impact might be expected by addressing factors associated with all aspects of decisional conflict (i.e. total and all subscales), the additional significant relationships that were identified can also be considered in future studies aimed at decreasing decisional conflict and ultimately increasing CRCS adherence.

Also, to our knowledge, this is the first time that the interrelationships of CRCS-specific psychosocial and other health behaviors have been assessed with CRCS decisional conflict and colonoscopy adherence. For the determinants of CRCS decisional conflict, while we found that greater colonoscopy barriers, and greater confusion as well as a healthcare provider not discussing CRCS options were associated with an increased odds of high decisional conflict in the predictive models, our understanding of the interrelationships of these three characteristics was refined using SEM. Colonoscopy barriers, CRCS confusion and discussing CRCS options are modifiable factors and hold great promise as potential constructs to target in future intervention studies aimed at increasing CRCS both at the individual- and practice-level. Intervention studies to decrease test-specific barriers and CRCS-specific confusion have recently started (91, 111), and there are a few clinic-based interventions designed to change patient-provider conversations about CRCS, which could ultimately change the number of CRCS options that are discussed (64, 108). Of particular note is the potential promise of shared decision interventions in decreasing CRCS decisional conflict. Shared decision making interventions promote a discussion of the possible options in a health decision between two people (typically a healthcare professional and a patient), to help people make a decision that is most in line with their preferences and values (118). Because this type of intervention promotes discussion of options, it has the potential to address CRCS confusion, decrease test-specific barriers, and increase the number of options discussed.

An important needed next step for improving our understanding of CRCS decisional conflict is to include a measure of CRCS decisional conflict in studies with even larger sample sizes so that alternative modeling techniques can continue to be used to understand the complex interrelationships between CRCS decisional conflict and CRCS adherence. While we were able

to expand our understanding of the interrelationships between decisional conflict, psychosocial and other CRCS-specific characteristics, and colonoscopy adherence more work is still needed to fully understand these associations. For example, due to sample size and the complexity of our initial model, not all potential pathways or variables of interest could be tested. Even without these pathways and variables, the final model was still able to explain a large amount (40-45%) of the variance in CRCS decisional conflict and colonoscopy adherence, but more than 50% of the variance in both remains to be explained. Adding specific feedback loops as specified in the TTI and additional variables to the model could help increase the amount of variance explained. For example, experiencing CRCS in the past could feedback to impact someone's CRCS test preference, test-specific barriers, and decisional conflict so at least three feedback loops could be added to improve our model. A previous study that examined decisional conflict included pros and cons schema, decisional anxiety, and perceived risk of prostate cancer (29), which were all associated with decisional conflict for prostate specific antigen testing. These constructs might also impact CRCS decisional conflict but measures were not included on the CRCS-WISDM general population questionnaire. Therefore, future models could be enhanced by including these variables.

Previous interventions related to CRCS that also included a measure of CRCS decisional conflict were not able to significantly increase CRCS adherence in the intervention compared to the control group, even if decisional conflict was significantly reduced in the intervention groups (24-26), calling into question the utility of decreasing CRCS decisional conflict in future intervention studies. Importantly, while the first study of this project did not find a significant association between CRCS decisional conflict and CRCS adherence, the second study of this project found that greater decisional conflict was significantly associated with reduced

colonoscopy adherence; however, the association was completely mediated through CRCS-specific self-efficacy and intention. It may seem like these findings are discrepant; however when thinking about the unique aspects of the first and second studies these seemingly discrepant findings can be explained.

One explanation is related to the finding that decisional conflict was only indirectly associated with colonoscopy in the second study. In a mediation model, the crude association between an exposure and outcome of interest provides an estimate of the total effect. Then, the crude association is reduced after a mediator is added to the model. The remaining association after adding the mediator to the model is the direct effect between the exposure and outcome of interest (the indirect effect is adjusted away because of inclusion of the mediator). In the first study, it is not surprising that no significant direct association was found between decisional conflict and CRCS adherence in the final total decisional conflict model because the mediators of that association (as identified in the second study) were also included in the final model. Including the mediators in the final model for a completely mediated effect would have removed a significant association between decisional conflict and CRCS adherence.

Another explanation relates to statistical power. In both studies, CRCS and colonoscopy adherence was fairly high (~75% for both). In the first study, we considered a three-level variable of CRCS adherence while in the second study, a dichotomous variable was used for colonoscopy adherence. However, because of the small number of respondents who were overdue or never screened for CRCS, it is possible that there was not enough power to detect statistically significant direct relationships. Specifically, in the first study, the point estimates for CRCS adherence were 1.39 and 1.70 for respondents who were overdue and never screened,

respectively. These large point estimates suggest that given a larger sample size, a direct association between CRCS adherence and high decisional conflict might have been found.

By extrapolating our findings of the significant association between decisional conflict and colonoscopy adherence to overall CRCS adherence, it is reasonable to think that existing intervention materials already shown to impact CRCS-specific self-efficacy and intention could be enhanced by including material designed to decrease CRCS decisional conflict to have the largest impact. Further, intervention studies aiming to increase CRCS by reducing CRCS decisional conflict might benefit by also measuring CRCS self-efficacy and CRCS intention. This information could be used to investigate potential reasons why future decisional conflict interventions are or are not successful at increasing CRCS adherence and would contribute to increasing our understanding of the mechanisms that impact colonoscopy adherence.

Lastly, future interventions aiming to increase CRCS adherence should include components to decrease CRCS decisional conflict to see if decreasing decisional conflict is able to increase CRCS adherence. By developing and testing interventions at multiple levels specifically designed to decrease decisional conflict, we can better understand its potential for increasing CRCS uptake.

Breast cancer survivorship care

The third study of this project assessed the patterns of breast cancer survivorship care using a population of breast cancer survivors from the 2010 BRFSS who responded to specific questions about cancer survivorship. The majority of breast cancer survivors, regardless of years since diagnosis, reported that a primary care clinician provided the majority of their care. In the multivariable logistic regression model, women who had fewer years since diagnosis and women who had received post-treatment follow-up instructions were more likely to report that a cancer-

related clinician provided the majority of their care. These findings suggest that breast cancer survivors might be open to policies or organizational-level guidelines that promote post-treatment follow-up care in primary care settings, as opposed to oncology-only based follow-up. In addition, models of care where primary care and cancer-related clinicians use a shared approach for cancer follow-up care might be acceptable to survivors.

Given the strong association between post-treatment follow-up care instructions and the type of clinician reportedly responsible for the majority of survivors' care, it appears that instructions have a large potential to be successful in guiding the care patterns of breast cancer survivors in the future. Also, because of the large impact that receiving post-treatment plans had on perceived healthcare utilization behaviors, additional research is needed to evaluate the barriers and facilities of creating care plans in the oncology setting so that these important resources can continue to be used by cancer survivors.

More work is needed to better understand the intersection of perceived and actual healthcare utilization patterns to continue to guide policy development. For example, our study was able to assess the perception of the clinician responsible for the majority of care, but we were unable to compare perception to actual use. While previous studies using claims data were able to see that both primary care and cancer-related clinicians were seen after treatment completion, but were not able to evaluate survivors' perception. Future studies assessing post-treatment care among breast cancer survivors should consider bridging both areas by assessing survivors' perception of who is responsible for their care and actual follow-up care patterns. Further, continued research is needed to evaluate the health-related outcomes including satisfaction with post-treatment care by different types of provider follow-up.

Conclusion

In short, this dissertation provides information to improve our understanding of factors associated with two specific behaviors along the cancer control continuum: CRCS adherence and breast cancer survivorship care. Findings can inform future research studies and evidence-based guidelines to change behaviors at multiple levels. By changing behaviors, the burden of cancer can be reduced across the cancer control continuum.

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List of References

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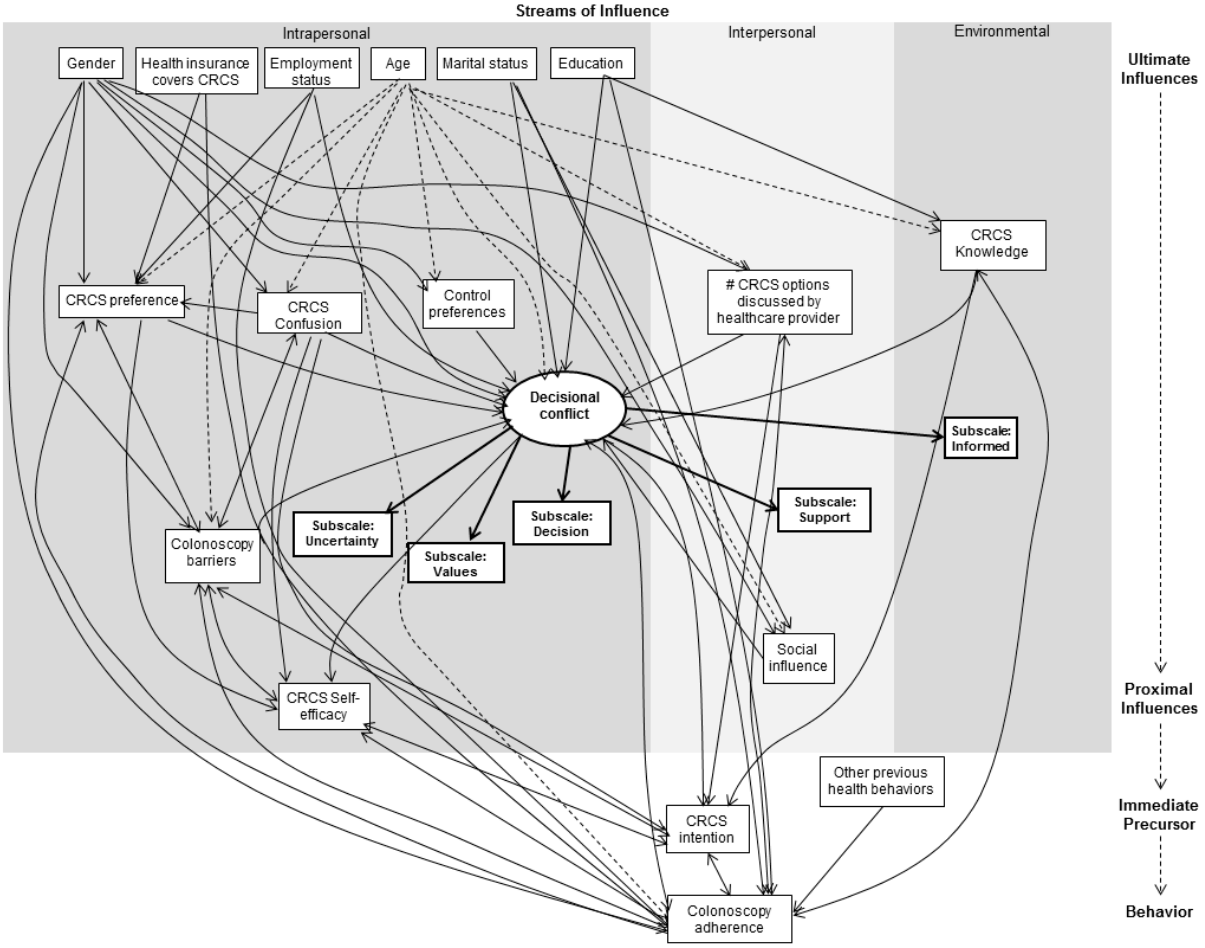
Appendix 3.1

Initially conceptualized comprehensive model with all potential influences:



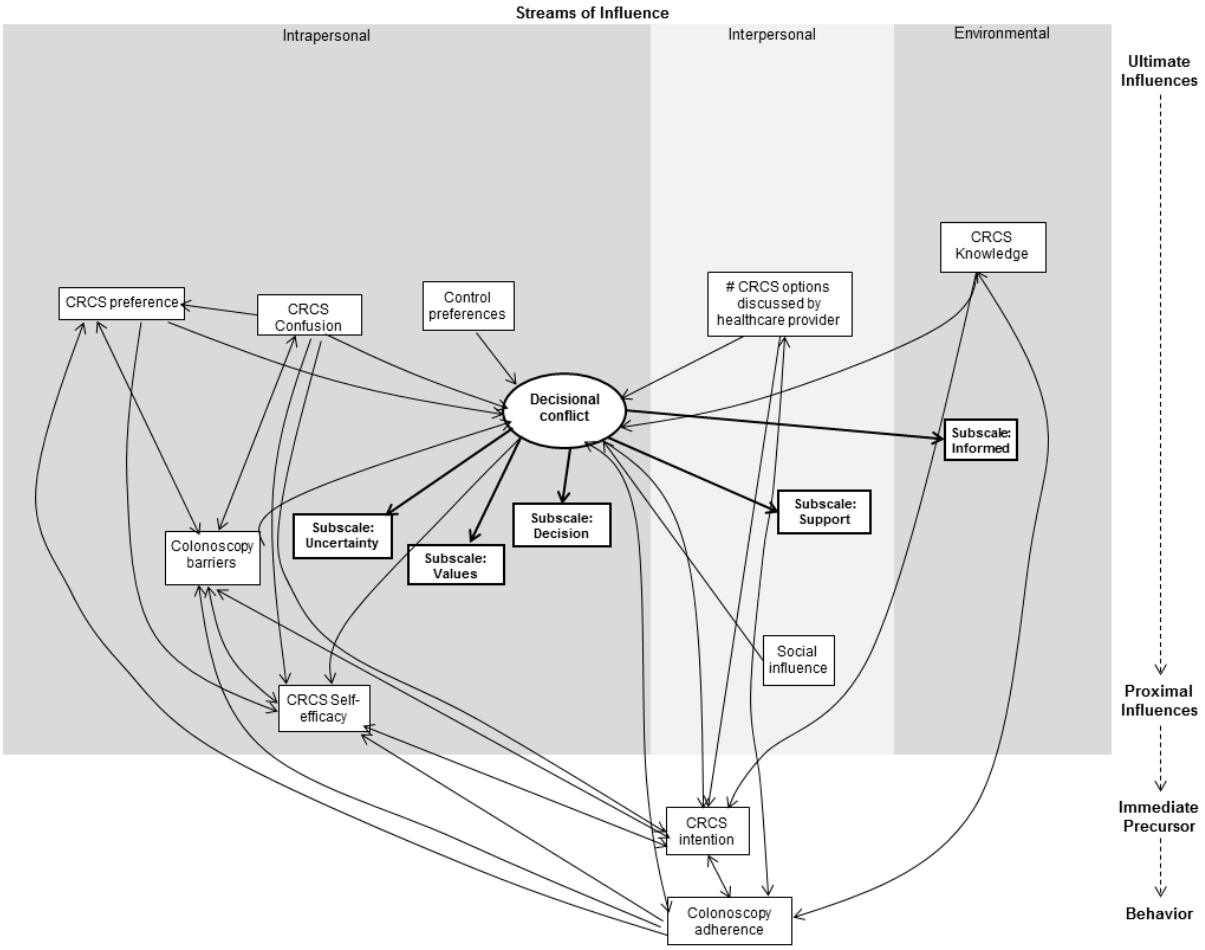
Note: CRCS = colorectal cancer screening. Age in the above model represents age eligibility for Medicare.

The first step in the development of the initial structural equation model (SEM) was to create a comprehensive model that contained all of the possible influences beyond just the

determinants of decisional conflict and potential associations between decisional conflict and colonoscopy adherence. Model development began by organizing all of the potential influences of behavior by the three streams of influence and identifying the immediate precursors of behavior and our behavior of interest. For the intrapersonal stream of influence, the ultimate influences were the socio-demographic characteristics (gender, age eligibility for Medicare, employment status, marital status, education, and if health insurance covered colorectal cancer screening (CRCS)). More proximal influences for the intrapersonal stream were: CRCS test preference, CRCS-specific confusion, control preferences, colonoscopy barriers, and decisional conflict. The most proximal influence in the intrapersonal stream was CRCS-specific self-efficacy. The number of CRCS options discussed with a healthcare provider and social influence were conceived as being part of the interpersonal stream of influence. CRCS knowledge was conceived as being part of the environmental stream of influence. CRCS-specific intention was treated as the immediate precursor of the behavior of interest and other previous screening behaviors (mammogram and prostate-specific antigen testing) were conceptualized as representing other previous health behaviors. Lastly, colonoscopy adherence was the behavior of interest. In this comprehensive conceptual model, decisional conflict was treated as a latent variable with the five subscale scores acting as the indicators. All relevant associations between any of the influences were included whether or not they were directly related to the study aims. Feedback loops (shown as bi-directional arrows) from colonoscopy adherence back to the more distal tiers were also included.

Appendix 3.2

First reduction to the conceptual model



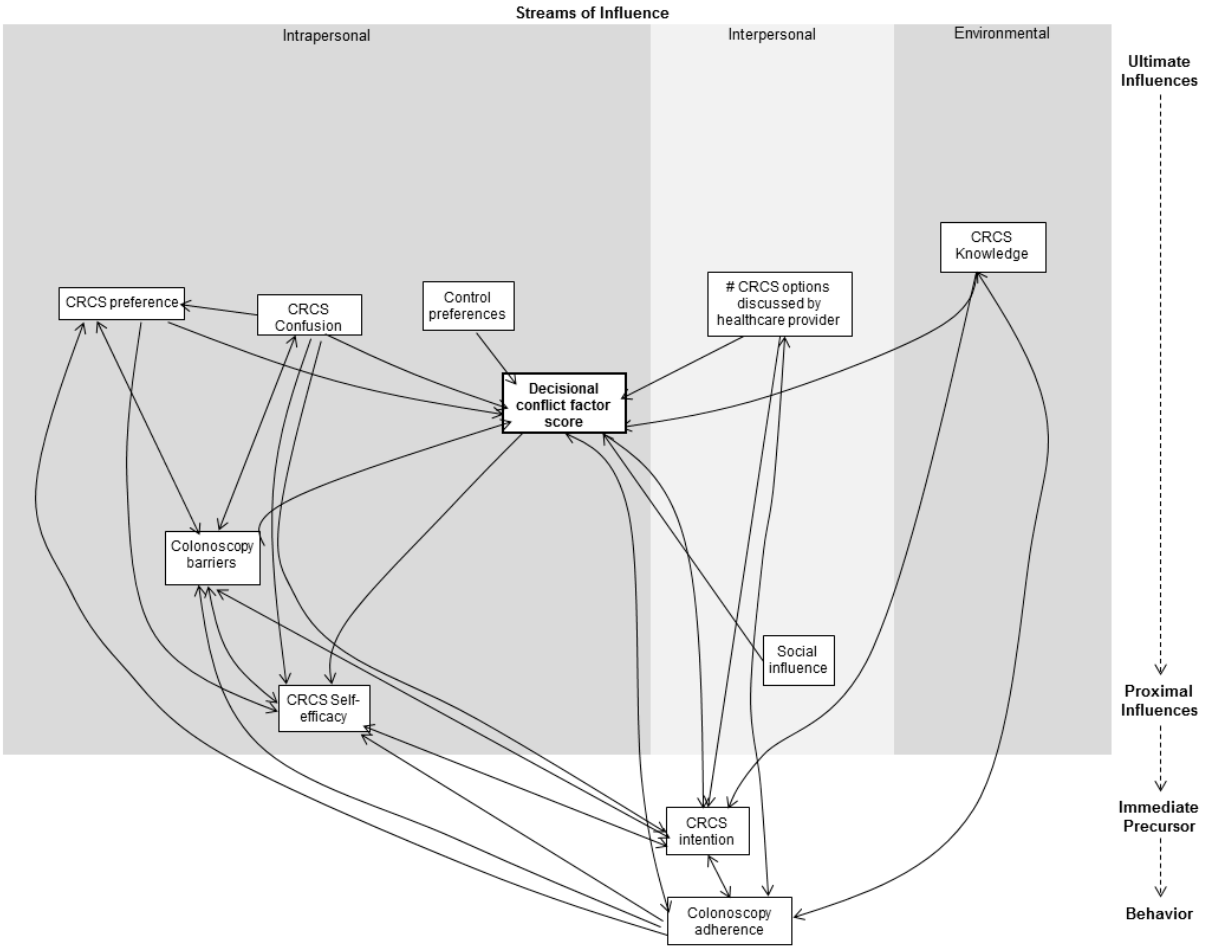
Note: CRCS = colorectal cancer screening. Ultimate intrapersonal influences gender, employment, age eligibility for Medicare, marital status, education, and if health insurance covers CRCS will be adjusted for in analyses. Previous health behaviors will also be adjusted for in analyses. Path coefficients will not be estimated

Because of the complexity of the conceptual model containing all potential influences, potential influences or pathways needed to be removed so that the initial model could be

estimated given a sample size of N =1,268. The first reduction made was to remove the estimation of the effects of the ultimate distal influences from the intrapersonal stream of influence as well as other previous health behaviors and instead include them as covariates to adjust for in the final model. This allowed us to focus on the modifiable influences that would be most relevant to future intervention development.

Appendix 3.3

Decisional conflict as a factor score



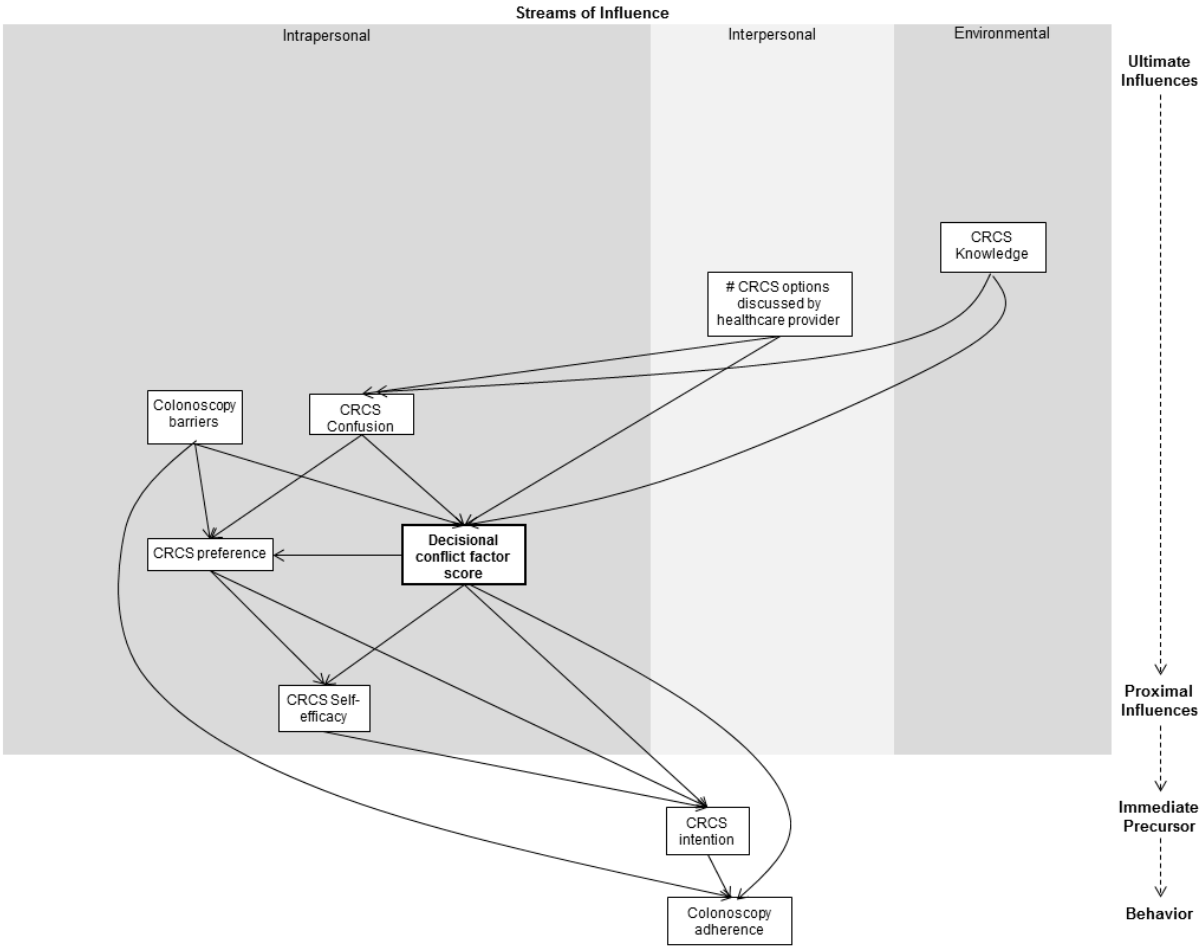
Note: CRCS = colorectal cancer screening. Ultimate intrapersonal influences gender, employment, age eligibility for Medicare, marital status, education, and if health insurance covers CRCS will be adjusted for in analyses. Previous health behaviors will also be adjusted for in analyses. Path coefficients will not be estimated

After removing the ultimate intrapersonal influences and previous health behaviors from the conceptual model, the remaining model was still too complex to estimate. To maximize the

number of influences and pathways that could be included in the initial model, we decided to use decisional conflict as a factor score instead of a latent variable. Using a factor score resulted in no longer needing to include the five subscale scores in the initial model.

Appendix 3.4

Initial SEM model



Note: CRCS = colorectal cancer screening. Age eligibility for Medicare, education, and control preferences included as covariates in the model

After changing decisional conflict from a latent variable to an observed factor score, additional reductions in the number of influences and pathways were still needed to have an

initial model that would be able to converge and be estimated. To reduce the total number of influences included in the initial model, we first considered the socio-demographic and other health behavior characteristics that we had previously decided to use only as covariates in the initial model. In the first study, only age eligibility for Medicare and education were significantly associated with total decisional conflict; thus, these were the socio-demographic variables that were included as covariates in the initial model. For the remaining influences, in the first study we found that CRCS-specific confusion, colonoscopy barriers, CRCS-specific self-efficacy, intention, a healthcare provider discussing CRCS options and CRCS test-preference were all significantly associated with total decisional conflict; thus, these variables were prioritized and remained in the initial SEM model. Control preferences and social influence were the only two influences left to be considered. Social influence was found not to be associated with total or subscale-specific decisional conflict and so it was removed from the initial model. While control preferences was significantly associated with the uncertainty and support subscales, there was not enough power to include this characteristic in the initial model; however, it was able to be included as an additional covariate. Once the final influences to be included in the model were determined, the pathways most pertinent to addressing the aims of the study were added as explained in the methods section of Chapter 3.

Vita

Kara Phillips Wiseman was born October 29, 1985, in Alexandria, Virginia and she is an American citizen. She graduated from Herndon High School, Herndon, Virginia in 2004. She received her Bachelor of Arts in Biology from the University of Virginia, Charlottesville, Virginia in 2008. She received a Master of Public Health from Virginia Commonwealth University, Richmond, Virginia in 2011.

Honors and Awards

2015, Phi Kappa Phi Nomination Award
2015, MCVAA Scholarship Award for the Advanced Degree Program in the School of Medicine
2014, Graduate Student Travel Grant Award
2014, Phi Kappa Phi Nomination Award
2013, CC Clayton Award, Virginia Commonwealth University, Richmond, Virginia
2012, Graduate Student Travel Grant Award
2011, First place, Virginia Commonwealth University Department of Epidemiology and Community Health Fall 2011 Student Research Day. Poster titled, "Impact of a Workplace Colorectal Cancer Screening Awareness Program".
2010, Third Place, Virginia Public Health Association Spring Meeting Student Poster Session. Poster titled, "Family history of colorectal cancer and barriers to colonoscopy screening: implications for screening promotion"

Professional and Research Positions

Evaluation/Analysis Coordinator, CRCS-WISDM (PI: Jones), (October 2014 – Present).
Division of Epidemiology, Department of Family Medicine and Population Health, Virginia Commonwealth University School of Medicine, Richmond, Virginia.

Research Assistant, CRCS-WISDM (PI: Jones), (July 2013 – October 2014).
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Interim Research Coordinator, MyCRCS (PI: Jones), (March 2013 – June 2013).
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Research Assistant (January 2011 – September 2011).
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Student Intern (May 2011 – August 2011).
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Emergency Medical Technician (July 2008 – July 2009).
Sterling Volunteer Fire and Rescue Squad, Sterling, Virginia.

Teaching Assistant (August 2006 – May 2008).
Organic Chemistry, Chemistry Department, University of Virginia, Charlottesville, Virginia.

Publications

Wiseman KP, Bishop DL, Shen Q, Jones RM. Survivorship care plans and time since diagnosis: Factors that contribute to who breast cancer survivors see for the majority of their care. Support Care Cancer. 2015. In press.

Presentations

National

2011, March – Jones RM, Wiseman KP, Aggarwal A, Lafata JE. Colorectal cancer screening among adults with physical disabilities. Presented at the 35th American Society of Preventive Oncology Annual Meeting, Las Vegas, NV.

2012, March – Wiseman KP, Woolf SH, Jones RM. Family history of colorectal cancer and barriers to colonoscopy screening: Implications for screening promotion. Presented at the 38th American Society for Preventive Oncology Annual Meeting. Washington, DC.

2012, October – Wiseman KP, Jones RM. Confusion about colorectal cancer screening options decreases screening adherence. Presented at the 140th American Public Health Association Annual Meeting. San Francisco, CA.

2013, March – Jones RM, Kramer JJ, Bishop DL, Wiseman KP, Shen Q. Optimizing a shared decision making intervention for community-based primary care practice. Presented at the 34th Society of Behavioral Medicine Annual Meeting. San Francisco, CA.

2014, November – Wiseman KP, Mink PJ, Jones RM. Predictors of colorectal cancer screening-related decisional conflict in a general population. Presented at the 142nd American Public Health Association Annual Meeting. New Orleans, LA.

2015, April – Jones RM, Mink PJ, Shen Q, Wiseman KP, Bishop DL. Colorectal cancer screening options: Are people having the conversations they want to make the decision that is right for them? To be presented at the 36th Annual Meeting and Scientific Sessions of the Society of Behavioral Medicine. San Antonio, TX.

International

2015, July – Jones RM, Mink PJ, Shen Q, Hansberger R, Wiseman KP, Orr J. Shared decision making with nurse clinicians in primary care practice increases colorectal cancer screening. To be presented at the 2015 Joint International Shared Decision-Making and International Society for Evidence Based Health Care Conference, Sydney, New South Wales, Australia.