Distribution Agreement

Signature:

________________________________ __________________________

Breanna L. Blaess Date

How Important are Perceptions?
Investigating the Effect of Perceived Care Coordination on Survival among a Stage III Colorectal Cancer SEER Surgical Patient Population

By

Breanna L. Blaess

B.A.
University of Iowa
2016

Faculty Thesis Advisor: Kevin C. Ward, PhD, MPH

An abstract of
A thesis submitted to the Faculty of the
Rollins School of Public Health of Emory University
in partial fulfillment of the requirements for the degree of
Master of Public Health
in Epidemiology
2020

ABSTRACT

How Important are Perceptions?
Investigating the Effect of Perceived Care Coordination on Survival among a
Stage III Colorectal Cancer SEER Surgical Patient Population

By Breanna L. Blaess

Background

Colorectal cancer (CRC) is a major public health burden as the second leading cause of cancer death in the United States. Patients' perceptions regarding their medical care team, quality of treatments, and communication between all providers have an important impact on the patients' confidence and comfortability of their cancer care. We aimed to investigate the relationship between patients' perceptions regarding care coordination and their survival.

Methods

We identified patients ≥21 years of age that underwent surgical resection for pathologic stage III colon or rectal cancer diagnosed between August 2011 and December 2013 in the state of Georgia and Metropolitan Detroit Surveillance, Epidemiology, and End Results (SEER) Registries' catchment areas. Poor perceived care coordination (PCC), our primary exposure, was measured using a composite score from five questions on patients' perceptions of their provider's knowledge of their case and quality of communication between themselves and their providers.

Results

Among the 1,226 patients included in our analysis, 355 (29.0%) had poor PCC and 871 (71.0%) had good PCC. Individuals with perceived care coordination that was poor were more likely to be unmarried ($p<0.001$), have a higher census tract poverty percentage ($p < 0.001$), and be on Medicare and/or Medicaid ($p=0.008$). Univariate analysis found that those with poor PCC had a 24% increased hazard of death compared to those with good PCC (cHR=1.24, 95% CI: (1.00, 1.53)). Multivariate analyses adjusting for age, natal sex, race/ethnicity, marital status, education, and poverty status found that those with poor PCC had a 12% increased hazard of death compared to those with good PCC (aHR=1.12, 95% CI: (0.90, 1.39)). Older patients had an increased hazard than younger patients (aHR=1.45, 95% CI: (1.30, 1.63)) and this effect size increased with increasing age. Males had an increased hazard compared to females (aHR=1.31, 95% CI: (1.06, 1.61)).

Conclusion

Our study results suggest a slightly increased hazard of death for CRC patients with poor PCC, though this is not statistically significant. These results may be able to assist providers as well as hospital administrators and policy makers towards enhancing patient-centered cancer care.

How Important are Perceptions?
Investigating the Effect of Perceived Care Coordination on Survival among a Stage III Colorectal Cancer SEER Surgical Patient Population

By

Breanna L. Blaess

B.A.
University of Iowa
2016

Thesis Committee Chair: Kevin C. Ward, PhD, MPH

A thesis submitted to the Faculty of the
Rollins School of Public Health of Emory University
in partial fulfillment of the requirements for the degree of
Master of Public Health
in Epidemiology
2020

ACKNOWLEDGEMENTS

I would first like to express my gratitude toward Dr. Kevin C. Ward, my thesis faculty advisor, for his guidance during this process: his balance of providing needed clarity while ensuring the integrity of my thesis experience was invaluable.

I would also like to recognize the assistance from the teams at the State of Georgia and Metropolitan Detroit SEER Registries and the work of those who collected and cleaned the data. If not for their exemplary effort in creating the survey, putting in the time to collect a representative sample, and ensure clean data was available for analysis, I would not have been able to complete this study.

I also wish to thank my family. To my mother, Tracey: your determination and persistence toward your own education was an incredibly motivating example to model as I navigated this journey. To my younger brother and sister: you reminded me to live in the moment and not to worry about the future. To my grandmother and grandfather: your faith in my abilities bolstered my confidence and allowed me to fearlessly pursue my master’s degree.

Finally, I would like to thank my partner, Philip. Your unconditional love and unwavering belief were the driving force behind my success during my time at Rollins.

TABLE OF CONTENTS

CHAPTER I: LITERATURE REVIEW

Colorectal cancer (CRC) is a major public health burden as the fourth most common incident cancer in the United States, with an estimated 150,000 new cases in 2020 [1]. Colorectal cancer is characterized by masses of cancerous cells called polyps that grow on the lining of the colon, the rectum, or both. These polyps can extend beyond the colorectal tract into other areas of the body, becoming increasingly dangerous if left untreated. It is the second leading cause of cancer death in the United States among both men and women with an estimated 53,000 deaths in 2020 [1].

There are various treatment options for colorectal cancer, dependent on the stage of cancer at diagnosis. For earlier stage cancers, local therapies such as surgery and radiation therapy are the two most common treatments [2]. The 5-year survival rate is 71% and higher for cancers that have not spread to surrounding lymph nodes or other distant sites, depending on the extent of the tumor [3]. However, for later stage cancers that have spread beyond the site of origin into lymph nodes and distant organs, chemotherapy, targeted drug therapies, and immunotherapy are typically utilized in addition to surgery [4-5]. The 5-year survival rate for cancers that have spread can be as low as 14% [3]. Due to this rapid decrease in 5-year survival, it is important to identify preventable risk factors that can reduce mortality in more advanced-stage colorectal cancer.

Colorectal cancer differs from other types of cancers as there is more known about the effects of individual lifestyle factors that can impact risk. One risk factor that has been identified for colorectal cancer is an individuals’ tobacco and alcohol intake [6]. Tobacco and alcohol introduce carcinogens to the body which can increase the risk of tumor cells forming and growing [7]. Chao et al. studied the impact that cigarette smoking has on cancer-specific mortality among adult cancer patients and found that those who smoked cigarettes 20 years or more had a 33% increased risk for cancer-specific mortality (RR=1.33, 95% CI: (1.10, 1.61)) compared to those who never smoked [8]. In Walter et al.'s study among first incident colorectal cancer patients from the German DACHS study, lifetime heavy drinkers had a 37% increased hazard for disease-free survival (aHR=1.37, 95% CI: (1.09, 1.74) compared to lifetime light drinkers [9].

A second individual risk factor for colorectal cancer is a poor diet and nutrition regimen [6]. To address this, individuals can work to reduce intake of red meat and foods with a high glycemic index and pursue a specific number of hours of physical activity each week [6, 10-12]. McCullough et al. found that among colorectal cancer patients at all stages, those who reported higher than median intake of red and processed meats had a 79% increased risk of colorectal cancer-specific mortality (RR=1.79. 95% CI: (1.11, 2.89)) compared to those with intakes below the median [10]. In Meyerhardt et al.'s study among stage III colon cancer patients, those who consumed the highest quintile of high glycemic index foods had a 74% increased hazard of all-cause mortality (aHR=1.74, 95% CI: (1.20, 2.51)) compared to those in the lowest quintile [11]. Meyerhardt et al. assessed the relationship between metabolic equivalent task (MET) hours and mortality among women with stage I to III colorectal cancer and found that patients who reported more than 18 MET-hours per week had a 61% decreased hazard for cancer-specific mortality (HR= 0.39, 95% CI: (0.18, 0.82)) compared to women who reported less than 3 MET-hours per week [12]. While individual lifestyle factors are important in reducing one's colorectal cancer risk and associated mortality, external factors that can impact an individual's treatment experience are important to assess as well.

Among the external factors that can impact a patient's treatment experience is the team of medical professionals providing their care. McDonald et al. have defined care coordination as the organization of patient care between two or more participants involved in patients' care to facilitate the appropriate delivery of health care services [13]. Due to the wide range of needs of cancer patients, involvement of several care providers is necessary and typically includes primary care providers, medical oncologists, chemotherapy doctors, nurses, and administrative personnel. Since the knowledge, expertise, and responsibilities of these providers can be vastly different, there can be challenges that arise in the process of coordinating care for cancer patients.

Several studies have identified communication between care providers as the main challenge in care coordination, especially in care of cancer patients [14-17]. Gorin et al. conducted a systematic literature review on whether more effective care coordination leads to better quality of care and patient outcomes and found that better care coordination significantly reduced hospitalization rates and emergency department visits [14]. Trogdon et al. conducted a study to assess how care coordination impacts adherence to treatment and survival by calculating the proportion of patients who were shared between their surgeon and medical oncologist [15]. They found that patients who belonged to medical oncologists and surgeons with higher "shared volume fractions" were more likely to receive adjuvant chemotherapy and were less likely to visit an emergency room (ME=3.9 percentage points, p=0.001) when compared to patients belonging to providers with lower shared volume fractions [15]. This suggests that with higher proportion of shared patients, providers are inherently going to be communicating more, supporting the hypothesis that better care coordination improves patient outcomes.

The quality of the interaction in addition to the communication itself between providers can also contribute to efficacy of care coordination [15, 16]. Easley et al. conducted a study among 58 health care providers to determine what challenges may arise during care coordination and concluded that communication itself was the biggest problem [16]. The recurring themes within their participants’ responses were delays in medical transcription, difficulties accessing patient information, physicians not being copied on reports, lack of clearly defined and broadly communicated roles, and lack of rapport between family practitioners and cancer specialists [16]. Each of these themes reflect a lack of systematic processes to facilitate care coordination, resulting in a lack of effective communication. Easley et al. recommend that every person on the cancer care team collaborates efficiently to achieve the goal of high-quality care coordination. Thus, collecting patient perspectives in addition to provider perspectives is important in assessing the efficacy and identifying problems with care coordination.

As the individual who is most impacted by care coordination, obtaining patient perceptions on the quality, access, and barriers regarding coordination of care is crucial to improving outcomes. Past research has found that patients who feel their care is fragmented are less likely to adhere to treatment guidelines, more likely to have additional emergency department visits, and have less confidence in their care [14, 15, 18-21]. A variety of factors can impact an individuals’ perceptions including their personal experiences, knowledge, and demographic factors. Any one of these or a combination, whether they are simply perceived or are real obstacles, can act as an additional challenge to achieving effective care coordination.

Several studies have found that comorbidities have a strong impact on a patients' perceptions regarding their care coordination [18, 19, 21]. Hohmann et al. conducted a systematic literature review on patient perspectives related to care coordination for various types of cancer among groups of individuals with comorbidities and identified frequently cited needs that were important for their care coordination [18]. Four areas were: communication with and between providers, defining provider care roles, ease of access to care information, and individualized patient care [18], which matches the goals of providers identified earlier. Hawley et al., in their study of care coordination perceptions among a population of breast cancer patients, found that women with two or more comorbid conditions had lower satisfaction in their care coordination compared to women with no comorbid conditions (OR=1.46, 95% CI: (1.02, 2.11)) [19]. Durcinoska et al. had a similar finding in their study of care coordination patterns and predictors among a population of stage I, II, III, and IV colorectal cancer patients with greater than three comorbid conditions compared to patients with none (beta=-4.51, SE=2.07, p=0.049) [21].

Studies on care coordination have identified other patient characteristics that significantly impacted their perception. Hawley et al.'s study among breast cancer patients (OR=0.98, 95% CI: (0.97, 0.99)) found an inverse association between age and perceptions of care coordination, with younger participants having worse care coordination perceptions [21]. An inverse association was also found for Ayanian et al. and Hawley et al. regarding education and perceptions of care coordination, with less educated participants having worse care coordination perceptions [20, 21]. Ayanian et al. compared those with college degrees to those who did not graduate high school (difference: 10.3, $p < 0.001$) [20], while Hawley et al. compared those with some college education or more to those with a high school education or less (OR=1.20, 95% CI: (0.88, 1.64)) [21]. Ayanian et al. also found a difference in perceived care coordination among various racial and ethnic groups compared to English-speaking whites, with African American (difference: 9.8, $p < 0.001$), Hispanic (difference: 4.4, p=0.06), Asian/Pacific Islander (difference: 13.2, $p < 0.001$) and non-English speaking whites (difference: 21.9, $p < 0.001$) reporting worse care coordination and worse quality of cancer care [20]. We can see that these patient characteristics impact perceived care coordination, but they can also have a significant impact on patient outcomes.

The relationship between patient’s perceived care coordination and survival outcomes has not been extensively studied in general, but especially not among colorectal cancer patients. A 2012 study by Gupta et al. assessed the relationship between patient assessment of quality of care and survival outcomes among 702 colorectal cancer patients across all stages [22]. They utilized a 31-item questionnaire asking patients about their experience within the following domains: hospital operations and services, physicians and staff, and patient endorsements for others on a 7-point Likert scale. For their analysis, they dichotomized their exposure into “completely satisfied (7)” and “not completely satisfied (1-6)” and found in a multivariate analysis of these questions that those who were completely satisfied with their quality of care had better survival outcomes compared to those who were not completely satisfied (HR=0.75, 95% CI: (0.59, 0.95)) [22]. Aside from this study, the research on this topic in this population is scarce.

A 2018 study conducted by Beesley et al. did assess the relationship between perceived care coordination and survival among a population of 110 pancreatic cancer patients in Australia [23]. They utilized 15 questions from a questionnaire developed by Young et al. [24] related to communication and navigation in care coordination. Participants had a median time of 7 months between time of diagnosis and completion of the final questionnaire (range=1-8) [24]. They found that those who did not have chemotherapy reported worse care coordination and that navigation care coordination scores were significantly associated with better quality of life [24]. However, upon survival analysis, they did not find a significant association between perceived care coordination and survival among those who had tumor resection (HR=1.00, 95% CI: (0.95, 1.05)) or those who did not have a tumor resection (HR=0.98, 95% CI: (0.93, 1.02)) [23]. While there was a null finding in this study, the authors do mention that these measures are still important for delivery the best care for cancer patients.

Due to the lack of research in this area, our study investigated this relationship among a large colorectal cancer population. The questionnaire utilized in this study was adapted from the validated scale by Young et al. developed to measure cancer care coordination. The questionnaire items were developed from focus groups and semi-structured interviews that resulted in identification of eight crucial components to cancer care coordination, which included: organization of patient care, access to and navigation through the healthcare system, the allocation of a “key contact” person, recognition and understanding of medical team roles, effective communication and cooperation amongst the multidisciplinary team and other health service providers, delivery of services in a complementary and timely manner, needs assessment, and sufficient and timely information for the patient [24]. Our study differed from others in that we measured perceptions of care coordination as well as survival outcomes up to seven years post-diagnosis. We hypothesized that patients with worse perceived care coordination would have worse survival outcomes.

The aim of our study was to assess the relationship between patients' perceptions regarding care coordination and survival among a cohort of stage III colorectal cancer patients from the Georgia and Metropolitan Detroit Surveillance, Epidemiology, and End Results (SEER) Registries diagnosed between August 2011 and December 2013. Utilizing questionnaire responses from the adapted survey by Young et al. and linking survey responses with SEER clinical data, we investigated the research question on whether or not having better perceived care coordination is associated with better survival outcomes. We also assessed which of the factors mentioned previously have an impact on this relationship meaningfully.

This study addressed how patients' perceptions regarding their care coordination impacted their survival outcomes, which has clinical and public health implications in several arenas. Results from this study may provide clinicians with improvements they can make to enhance patient outcomes. Specifically, the area of care coordination that needs the most improvement identified in our study is clarification on the roles that each medical professional provides toward their care as well as helping reduce the feeling of needing to be assertive and remind their doctor about things to get their needs met (Figure 1). These specific areas as identified by patients are a major contribution of our study to this field as they can help inform clinicians the importance of being transparent with their patients regarding their cancer care. It can also inform policy on best-practices for patient-centered cancer care, with a focus on including patients in the decision-making progress. Finally, it can empower patients to voice their concerns and ask questions during their cancer care to improve their perceptions regarding care coordination, which may be able to improve their outcomes.

CHAPTER II: MANUSCRIPT

INTRODUCTION

Colorectal cancer is the fourth most common incident cancer and second leading cause of cancer death in the United States, with an estimated 150,000 new cases and estimated 53,000 deaths in 2020 [1]. While there are various treatment options dependent on the stage of cancer at diagnosis, local therapies such as surgery and radiation are the two most common treatments across all stages [2]. For later stage cancers, targeted drug therapies, immunotherapy, and chemotherapy are commonly used [4-5]. The five-year survival rate for stage III and IV cancers can be as low as 14% with these treatment guidelines, highlighting the importance of identifying preventable risk factors to reduce colorectal cancer-associated mortality [3].

There are risk factors for colorectal cancer at both the individual and interpersonal levels. At the individual level, one can reduce their risk for colorectal cancer-associated mortality by reducing their alcohol and tobacco intake [6-9], maintaining a healthy diet [6, 10-11], and maintaining a healthy exercise routine [12]. Among the interpersonal factors that can impact cancer-associated mortality, one of the most important may be the team of medical professional providing their care. McDonald et al. have defined care coordination as the organization of patient care between two or more participants involved in patients' care to facilitate the appropriate delivery of health care services [13]. Due to the wide range of needs of cancer patients, involvement of several care providers is necessary and typically includes primary care providers, medical oncologists, chemotherapy doctors, nurses, and administrative personnel. Since the knowledge, expertise, and responsibilities of these providers can be vastly different, there can be challenges that arise in the process of coordinating care for cancer patients.

Studies have identified communication and quality of interactions between care providers as the main barriers to effective care coordination in the care of cancer patients [14-17]. Among health care providers, lack of clearly defined and broadly communicated roles, and lack of rapport between family practitioners and cancer specialists were identified as two of the main issues in care coordination [16]. Patients belonging to care providers that have high quality care coordination have had lower hospitalization and emergency room visit rates [14, 15] and had more confidence in their care compared to those with lower quality care coordination [14, 15, 18-21]. We can see that these characteristics impact perceived care coordination, but they may also have a significant impact on patient outcomes.

The relationship between patient's perceived care coordination and survival outcomes has not been studied extensively in general, but especially not among colorectal cancer patients. A 2012 study among colorectal cancer patients from one of three Cancer Treatment Centers of America hospitals assessing quality of care and survival concluded that those who were completely satisfied with their quality of care had better survival outcomes compared to those who were not completely satisfied (HR=0.75, 95% CI: (0.59, 0.95)) [22]. A study among Australian pancreatic cancer patients in the Queensland Pancreatic Cancer Study, however, did not find an association among care coordination and survival (Tumor resection patients' [HR=1.00, 95% CI: (0.95, 1.05)], non-resection patients' [HR=0.98, 95% CI: (0.93, 1.02)]) [23].

Due to the lack of research in this area, our study aimed to assess the relationship between patients' perceptions regarding care coordination and survival among a large cohort of stage III colorectal cancer patients from the Georgia and Metropolitan Detroit Surveillance, Epidemiology, and End Results (SEER) Registries who had surgical resection for stage 3 colorectal cancer between August 2011 and December 2013. We also assessed the impact of covariates that were significant in the literature, such as age, natal sex, race/ethnicity, comorbidities, and socioeconomic status.

METHODS

Study Population

We identified patients ≥21 years of age that underwent surgical resection for pathologic stage III colon or rectal cancer between August 2011 and December 2013 and were reported to the state of Georgia or Metropolitan Detroit Surveillance, Epidemiology, and End Results Registries. Patients were identified through rapid case ascertainment at the registries utilizing real-time pathology reports and were eligible for recruitment starting 3 months after resection for colorectal cancer. Exclusion criteria included patients later identified to have stage IV colon or rectal cancer, change in diagnosis upon final histology, death before survey deployment, residence change outside the catchment areas of the registries, or lack of response data for the exposure variable. This analysis was nested within a broader survey and included 1,226 patients.

Data Collection

We identified physicians of record from pathology reports and notified them of our intention to contact the study patients. After allowing a brief response period from physicians, subjects were contacted by mail and invited to participate in the survey. Following initial patient and physician contact, 55 (4.5%) patients were excluded due to either stage IV disease, change in diagnosis upon final histology, or residence outside the catchment area. A modified Dillman approach was used for recruitment, including sequential follow-up steps in the event of non-response. Upon receipt of surveys, extensive data checks were performed for logic, errors, and omissions, and patients were re-contacted as necessary for correct information. Survey responses were accepted up to one year from the date of surgery; the last day to accept survey responses was December 31, 2014. Clinical data was collected from the Surveillance, Epidemiology, and End Results (SEER) registries and were added to a de-identified dataset with survey responses, linked by a unique study ID. Patients were surveyed on average nine months after surgery and were followed for a median of 1,932 days (range: 5 to 2,899 days).

The study protocol was approved by the institutional review boards of the University of Michigan, Wayne State University, Emory University, the State of Michigan, and the State of Georgia Department of Public Health. The research information sheet in the survey packet included a statement of purpose, risks and benefits of participation, and information regarding patient confidentiality.

Measures

The primary outcome in this study was patient survival, measured from date of diagnosis until death or date of last contact collected from the state of Georgia and Metropolitan Detroit SEER Registries. The earliest surgical resection occurred on August 8, 2011, with our follow-up potentially beginning retrospectively from date of diagnosis depending on if the patient was diagnosed prior to surgical resection or if they were diagnosed pathologically during surgery. Follow-up was until either death or loss to follow-up with a study end date of December 31, 2017.

The primary exposure in this study was patient's perceived care coordination. This measure was determined by development of a composite score from a selection of questions in the section of the survey titled "Coordinating Your Care". The questions selected passed collinearity tests and were informative of the patient's care coordination perceptions, including the following: "I felt like my doctors did not seem up to date on my health status", "I was often confused about the roles of different health professionals involved in my care", "I had to remind my doctors about things to get my needs met", "I had to be assertive to get my needs met", and "I felt like I got lost in the system". All five included questions were on the same 5-point Likert scale (1="strongly disagree", 2="disagree", 3="neither agree nor disagree", 4="agree", 5="strongly agree").

The care coordination composite score was created by taking the reverse valence and mean for all items to give a score from 1-5 (1="strongly agree", 2="agree", 3="neither agree nor disagree", 4="disagree", 5="strongly disagree"). Care coordination was categorized as "good" if the mean composite score was greater than or equal to 4, which was the equivalent of "disagree" and "strongly disagree" in the survey. Care coordination was categorized as "poor" if the mean composite score was less than 4, which was the equivalent of "strongly agree", "agree", and "neither agree or disagree" in the survey. For statistical analysis, the "poor" care coordination group was coded as the exposed group.

Statistical Analyses

Univariate analyses between perceived care coordination and survival were conducted utilizing Kaplan-Meier curves and Log-Rank testing. Adjusted survival curves for perceived care coordination, survival, and other covariates were constructed with Cox Proportional Hazards models. Graphical, goodness-of-fit, and time-dependent variables methods were utilized to assess the proportional hazards assumption for our exposure variable, and the care coordination variable did not violate any of them. We ran these same tests with our covariates of interest and found that the proportional hazards assumption was met for all potential covariates. Thus, Cox Proportional Hazards procedures were utilized for interaction and confounding assessments as well as for our final model analysis.

We determined from the literature that age, race/ethnicity, natal sex, marital status, poverty, and education would act as our *a priori* criteria for model inclusion. Data for age, race/ethnicity, natal sex, marital status, and education were extracted from survey responses. We were missing a large proportion of income data from the survey (20.5%), so we opted to utilize an area-based measure of poverty, as a proxy variable. Census tract data from each patient's residential address at the time of diagnosis was matched to area-based census level poverty data from the Census Bureau, with the percent of those living below the federal poverty level categorized into four groups: 0-4%, 5-9%, 10-19%, and 20+%. Patients who lived in areas with 20% or more of the residents living below the federal poverty level were defined as Federal Poverty Areas [25]. A chunk test as well as backwards elimination tests were run to determine which variables had statistically significant interaction with our exposure variable, and four models were run to determine if there was evidence of confounding by any covariates of interest. In addition to the *a priori* variables above, we further identified insurance coverage and comorbidities as additional covariates to test in the confounding assessment for improvement in precision of the 95% confidence interval associated with the full model. Our final model included our *a priori* variables of interest but did not include our additional covariates of insurance coverage and comorbidities. All statistical tests were two-sided and p-values < 0.05 were considered statistically significant. All analyses were conducted using the SAS version 9.4 software package (SAS Institute, Inc., Cary, NC).

RESULTS

We identified 1,913 patients in the state of Georgia and Metropolitan Detroit Surveillance Epidemiology and End Results Registries with stage III colorectal cancer that received surgery as a form of treatment and distributed the survey to these participants via mailed questionnaire. From those who were mailed the survey, 1,301 (68%) responded to the survey. There were 26 patients (2.0%) that did not respond to the questions used to create the composite score and were removed. From the remaining 1,275 patients, we removed an additional 49 (3.8%) who were missing data on covariates of interest. After removal of these patients, 1,226 were included in our sample for analysis.

The perceived care coordination composite score was created utilizing five questions from the survey as listed above. Most patients had low scores for the questions utilized to create the composite score and the histograms for each question were right skewed, indicating that their care was mostly positive (Figure 1). When taking the inverse valence and mean for each question to get the care composite score, we see that most patients had a positive PCC with a histogram having a left-skewed distribution (Figure 2).

Among our patients included in analysis, 355 (29.0%) had poor perceived care coordination and 871 (71.0%) had good perceived care coordination (Table 1, Figure 2). The average age was 63.3 years for the poor perceived care coordination group and 66.2 years for the good perceived care coordination group ($p=0.02$) (Table 1). Persons with poor perceived care coordination were more likely to be unmarried ($p<0.001$), have a higher census tract poverty percentage ($p < 0.001$), and be on Medicare and/or Medicaid ($p=0.008$) (Table 1). Natal sex, race/ethnicity, education, and comorbidity were similarly distributed between groups.

The univariate model investigating this relationship yielded a 24% increased hazard for death among those with poor perceived care coordination compared to those with good perceived care coordination (Log-Rank χ^2=3.71, $p=0.05$) (Figure 3). Our final multivariate model yielded a 12% increased hazard for mortality among those who have poor perceived care coordination compared to those who have good perceived care coordination (aHR=1.12, 95% CI: (0.90, 1.39)) (Table 2). The final model controlled for age, race/ethnicity, marital status, education, census tract poverty percentage, and natal sex.

Multivariate analysis with Cox Proportional Hazards investigated the effect of covariates when controlling for all other variables in the model (Table 3). Those who were 50-64 years old had a 45% increased hazard for death compared to those who were 25-49 years of age. (HR=1.45, 95% CI: (1.30, 1.63)). The effect size increased with increasing age, with 65-74 year-olds having twice the hazard compared to 25-49 year-olds (HR=2.11, 95% CI: (1.69, 2.64)), and those 75 and older having triple the hazard compared to 25-49 year-olds (HR=3.07, 95% CI: (2.19, 4.29)). Males with poor care coordination had a 31% increased hazard compared to females (HR=1.31, 95% CI: (1.06, 1.61)). Individuals with a high school diploma had a 17% decreased hazard for death compared to those with some high school education or less (HR=0.87, 95% CI: (0.78, 0.96)). This effect increased with increasing education disparity, with individuals with some college education having a 25% decreased hazard for death compared to those with some high school education or less (HR=0.75, 95% CI: (0.61, 0.92)). Those with a 4-year college or graduate degrees and poor perceived care coordination had a 35% decreased hazard for death compared to individuals with some high school or less education (HR=0.65, 95% CI: (0.0.48, 0.89)).

DISCUSSION

In our study, individuals with poor perceived care coordination had a 24% increased hazard for mortality compared to individuals with good perceived care coordination (cHR=1.24, 95% CI: (1.00, 1.47)) (Table 2). Upon adjusting for age, natal sex, race/ethnicity, marital status, education, and poverty status, these results were attenuated to a statistically nonsignificant 12% increased hazard for the poor perceived care coordination group (aHR=1.12, 95% CI: (0.90, 1.39)) (Table 2). Comorbidities and insurance coverage were tested in the model to determine if there was an improvement in precision of the estimate. These variables did not show a change in the hazard ratios, nor an improvement in the precision of the estimate, and were not included in the final model.

Our findings were consistent with previous research on factors that impact patients' perceptions regarding care coordination. Consistent with past literature on health care in general, we found that marital status, poverty status, and insurance coverage also had an impact on patients' perceptions [26-28]. Individuals who were not married were more likely to have poor perceived care coordination compared to those who were married or living with a partner ($p < 0.001$) (Table 1). Those who had a higher poverty percentage from their census tract data were more likely to have poor perceived care coordination compared to those who had a lower poverty percentage. Our multivariate analysis was consistent with an observational study among 2,268 breast cancer patients in Michigan that suggested women with comorbid conditions have worse perceived care coordination compared to women without comorbid conditions [19] when controlling for all other covariates (HR= 1.16, 95% CI: (1.05, 1.28)) (Table 2).

We also had some inconsistencies with past research. Past literature has suggested that age inversely impacts how patients perceive their care [19-21]. There was a statistically significant difference in age distribution in our sample, with older persons being more likely to have poor perceived quality of care which is inconsistent with past literature ($p=0.02$) (Table 1). While studies among colorectal and breast cancer patients have found that race/ethnicity and natal sex have a strong impact on how patients perceive their care [18-21], we did not find a significant difference in these between our exposed and unexposed groups. While we did find that patients who were Black/African American or other minority races were more likely to have poor perceived care coordination compared to White patients, this was a small effect and was not statistically significant $p=0.23$) (Table 1).

While there is not extensive research on the topic of patient perceptions on their health care and their outcomes, we were able to compare our findings to the two studies investigating the same topic. Our findings were not consistent with previous research on patients perceptions regarding their care and its impact on their outcomes. While our model estimate was in the hypothesized direction, it was not statistically significant, contrast to the findings from the 2012 Gupta study among 702 colorectal cancer patients at three Cancer Treatment Centers of America locations. Gupta that found that patients who were completely satisfied with their quality of care had better survival outcomes compared to patients who were not completely satisfied with their quality of care (HR=0.75, 95% CI: (0.59, 0.95)) [22]. The similarities between the methods of our study and the Gupta study involve the population of colorectal cancer patients and use of survival analysis as the analytic technique. One of the main differences in our study from Gupta's lie in our exposure measurement. The Gupta study's exposure was satisfaction of quality of care, where ours was care coordination. While the differences in these may seem slight, the methods for measuring these and wording of questions can reach a different conclusion. Another difference in our studies are our source populations; our sample included participants who had different forms of insurance and some who had no insurance, where the Gupta study used patients from a treatment center where they may only accept certain forms of insurance.

Our findings differed slightly from the 2018 Australian study by Beesley that found no effect of perceived care coordination on survival among 110 pancreatic cancer patients [23]. Our study found a slightly increased hazard for the poor perceived care coordination group, though it was not statistically significant. While these studies were studying the same research question using the same validated scale, there were a number of differences between them. The most obvious difference between them are their source populations. While our study studied colorectal cancer patients from registry data in the United States, Beesley studied pancreatic cancer patients in Australia. One reason that these studies reached slightly different conclusions could be attributed to the difference in survival rates between pancreatic and colorectal cancer. Pancreatic cancer has one of the lowest survival rates, which may result in survivor bias in studies with too long of follow-up.

This study had several strengths to it, with the foremost being our means of data collection and recruiting methods. Since patients were identified using SEER data, we can assume that the likelihood of misclassification is low. We were also able to supplement our survey responses with information in patients' SEER data profiles, as well as from the US Census Tract data based on their geographic location. This allowed us to utilize the most complete and accurate variables between these data sources for our analysis. We also had a large sample size with a low percentage of exclusions for our analytic sample. Another strength of our study is the amount of follow-up time for patients. We had a median follow-up time of 1,932 days, or 5.3 years, which allowed for a robust dataset for analysis. A third strength of our study was the novelty of the research question. This topic has not been frequently studied, especially in a colorectal cancer patient population. Despite its null finding, our study can contribute to this growing field of research to increase understanding of patient perceptions' impact on outcomes and to enhance patient-centered cancer care.

Our study was not without limitations. One limitation to our study was the measurement of comorbidities. While the survey did ask individually about specific comorbidities, our data condensed these into a number. Specific diseases can impact how individuals perceive their care and can also impact their health outcomes, especially while they are also navigating the cancer treatment process. Thus, we suggest that future research focus on how specific comorbidities impact this relationship. A second limitation could have been the questions utilized to create the care coordination variable. While these were chosen to represent patient perceptions while avoiding collinearity issues, only five questions from the section of twelve on care coordination were used to create the variable. Thus, there could be some pieces of care coordination that were not involved in our exposure.

We investigated the relationship between perceived care coordination and survival among a population of stage III colorectal cancer patients that received surgery as a form of intervention, collected from SEER registries. Moving forward, we suggest that more studies be done on this in a geographically diverse area with a racial and ethnically representative sample. Our study was conducted in the state of Georgia as well as Metropolitan Detroit, where 73% of our respondents identified as white or Caucasian. Since it is well understood that racial and ethnic minorities experience worse health outcomes and can experience worse perceptions regarding their health care, it is important to investigate further to improve minority health outcomes.

This study can contribute to the literature by suggesting to clinicians that patient perspectives can impact their outcomes, despite our effect not being statistically significant. The questions included in our care coordination composite score suggest that patient perceptions regarding cancer care coordination are still poor for some persons, specifically as it relates to patients being confused about the roles of the professionals involved in their care, feeling like they need to be assertive to get their needs met, and having to remind doctors about things to get their needs met (Figure 1). The other two questions that constructed the perceived care coordination variable, relating to patients feeling as though doctors were up to date on their health status and like they got lost in the system, were less of a concern in our study population (Figure 1). These can signal to clinicians that being transparent to their patients regarding their cancer care is important for their patients' comfortability and confidence. These results can also be used for health care policy and administrative staff as they are looking to implement policy in their facilities to improve cancer patient outcomes.

CHAPTER III: CONCLUSION, PUBLIC HEALTH IMPLICATIONS, AND POTENTIAL FUTURE STEPS

Colorectal cancer is the second leading cause of cancer death worldwide and will be responsible for an estimated 53,000 in the United States in 2020 [1]. Both intra- and interpersonal factors can impact the risk for colorectal cancer incidence and associated mortality. Among the interpersonal factors that can impact one's risk, one of the most important may be the team of medical care professionals providing this care and the coordination of services among them. The patient's perspective on their providers' care coordination can be an added layer to the impact that can be had on their outcomes.

Few studies have assessed whether or not patient perceptions impact their long-term outcomes. This study aimed to investigate the relationship between patient's perceived care coordination and survival among a pathologic stage III colorectal cancer patient population. Our study contributed to a small, but growing field of research on reducing cancer-associated mortality. The strengths of this study lie in their patient recruitment methods, ability to link survey data to SEER and U.S. Census Tract data, and robust sample size. This study highlights that patients perceiving that their providers are invested in their care is important for their outcomes. It also highlights that to improve patient perceptions, providers need to work to enhance the quality and efficiency of cancer care services such as surgery, chemotherapy, immunotherapy, and targeted drug therapies. Without the collaboration between providers, patients may feel confusion or frustration toward processes during an already trying time in their life.

There are a couple of recommendations that we make for future research on this topic. First, we recommend future research focus on recruiting a more geographically and racially/ethnically diverse sample of patients to ensure the results are generalizable.

While these patient populations may have been representative for the source populations they were drawn from, they would not have well represented racial and ethnic minorities well to generalize to populations with high proportions of minority populations. Future research can also focus on which aspect of care coordination is the most important for patient outcomes. The existing validated scale utilized for this study has two domains of care coordination: navigation, which focuses on helping the patient with systems and processes as they are receiving care, and communication, which focuses on the communication between the providers as well as the communication between the patient with their providers [24]. If there is an impact of one more than the other, that could be helpful in tailoring processes and policies toward cancer care with the goal of improving patient outcomes.

REFERENCES

1. American Cancer Society: Cancer Facts and Statistics. *American Cancer Society*. Retrieved from: https://cancerstatisticscenter.cancer.org/.
2. Surgery for Colon Cancer. *American Cancer Society*. Retrieved from: https://www.cancer.org/cancer/colon-rectal-cancer/treating/colon-surgery.html
3. American Cancer Society: Cancer Survival by Stage *American Cancer Society*. Retrieved from: https://www.cancer.org/cancer/colon-rectal-cancer/detection-diagnosis-staging/survival-rates.html
4. Chemotherapy for Colorectal Cancer. *American Cancer Society*. Retrieved from: https://www.cancer.org/cancer/colon-rectal-cancer/treating/chemotherapy.html.
5. Immunotherapy for Colorectal Cancer. *American Cancer Society.* Retrieved from https://www.cancer.org/cancer/colon-rectal-cancer/treating/immunotherapy.html.
6. Simon S. Six Ways to Lower Your Risk for Colorectal Cancer. *American Cancer Society.* 2020. Retrieved from https://www.cancer.org/latest-news/six-ways-to-lower-your-risk-for-colon-cancer.html.
7. NTP (National Toxicology Program). Alcoholic Beverage Consumption. *Report on Carcinogens*. 2016;14. Retrieved from https://ntp.niehs.nih.gov/ntp/roc/content/profiles/alcoholicbeverageconsumption.pdf.
8. Chao A, Thun MJ, Jacobs EJ, Henley SJ, Rodriguez C, Calle EE. Cigarette smoking and colorectal cancer mortality in the cancer prevention study II. *J Natl Cancer Inst*. 2000;92(23):1888–1896. doi:10.1093/jnci/92.23.1888

9. Walter V, Jansen L, Ulrich A, et al. Alcohol consumption and survival of colorectal cancer patients: a population-based study from Germany. *Am J Clin Nutr*. 2016;103(6):1497–1506. doi:10.3945/ajcn.115.127092
10. McCullough ML, Gapstur SM, Shah R, Jacobs EJ, Campbell PT. Association between red and processed meat intake and mortality among colorectal cancer survivors. *J Clin Oncol*. 2013;31(22):2773–2782. doi:10.1200/JCO.2013.49.1126
11. Meyerhardt JA, Sato K, Niedzwiecki D, et al. Dietary glycemic load and cancer recurrence and survival in patients with stage III colon cancer: findings from CALGB 89803. *J Natl Cancer Inst*. 2012;104(22):1702–1711. doi:10.1093/jnci/djs399
12. Meyerhardt JA, Giovannucci EL, Holmes MD, Chan AT, Chan JA, Colditz GA, Fuchs CS. Physical Activity and Survival After Colorectal Cancer Diagnosis. *J Clin Oncol*. 2006;22(24):3527-3534. doi: 10.1200/JCO.2006.06.0855.
13. McDonald KM, Sundaram V, Bravata DM, et al. Closing the Quality Gap: A Critical Analysis of Quality Improvement Strategies (Vol. 7: Care Coordination). Rockville (MD): Agency for Healthcare Research and Quality (US); 2007 Jun. (Technical Reviews, No. 9.7.) 3, Definitions of Care Coordination and Related Terms. Available from: https://www.ncbi.nlm.nih.gov/books/NBK44012/
14. Gorin SS, Haggstrom D, Han PKJ, Fairfield KM, Krebs P, Clauser SB. Cancer Care Coordination: a Systematic Review and Meta-Analysis of Over 30 Years of Empirical Studies. *Ann Behav Med*. 2017;51(4):532–546. doi:10.1007/s12160-017-9876-2

15. Trogdon JG, Chang Y, Shai S, et al. Care Coordination and Multispecialty Teams in the Care of Colorectal Cancer Patients. *Med Care*. 2018;56(5):430–435. doi:10.1097/MLR.0000000000000906
16. Easley J, Miedema B, Carroll JC, et al. Coordination of cancer care between family physicians and cancer specialists: Importance of communication. *Can Fam Physician*. 2016;62(10):e608–e615.
17. Bickell NA, Young GJ. Coordination of care for early-stage breast cancer patients. *J Gen Intern Med*. 2001;16(11):737–742. doi:10.1111/j.1525-1497.2001.10130.x
18. Hohmann NS, McDaniel CC, Mason SW, et al. Patient perspectives on primary care and oncology care coordination in the context of multiple chronic conditions: A systematic review [published online ahead of print, 2019 Nov 26]. *Res Social Adm Pharm*. 2019;S1551-7411(19)30905-2.
19. Hawley ST, Janz NK, Lillie SE, et al. Perceptions of care coordination in a population-based sample of diverse breast cancer patients. *Patient Educ Couns*. 2010;81 Suppl:S34–S40. doi:10.1016/j.pec.2010.08.009
20. Ayanian JZ, Zaslavsky AM, Guadagnoli E, et al. Patients' perceptions of quality of care for colorectal cancer by race, ethnicity, and language. *J Clin Oncol*. 2005;23(27):6576–6586. doi:10.1200/JCO.2005.06.102
21. Durcinoska I, Young JM, Solomon MJ. Patterns and predictors of colorectal cancer care coordination: A population-based survey of Australian patients. *Cancer*. 2017;123(2):319–326. doi:10.1002/cncr.30326

22. Gupta D, Lis CG, Rodeghier M. Can patient experience with service quality predict survival in colorectal cancer?. *J Healthc Qual*. 2013;35(6):37–43. doi:10.1111/j.1945-1474.2012.00217.x
23. Beesley VL, Janda M, Burmeister EA, et al. Association between pancreatic cancer patients' perception of their care coordination and patient-reported and survival outcomes. *Palliat Support Care*. 2018;16(5):534–543. doi:10.1017/S1478951517000608
24. Young JM, Walsh J, Butow PN, Solomon MJ, Shaw J. Measuring cancer care coordination: development and validation of a questionnaire for patients. *BMC Cancer*. 2011;11:298. Published 2011 Jul 15. doi:10.1186/1471-2407-11-298
25. United States Census Bureau: How the Census Bureau Measures Poverty. *United States Census Bureau.* Retrieved from: https://www.census.gov/topics/income-poverty/poverty/guidance/poverty-measures.html.
26. Robards, J., Evandrou, M., Falkingham, J., & Vlachantoni, A. (2012). Marital status, health and mortality. *Maturitas*, *73*(4), 295–299. https://doi.org/10.1016/j.maturitas.2012.08.007
27. Arpey, N. C., Gaglioti, A. H., & Rosenbaum, M. E. (2017). How Socioeconomic Status Affects Patient Perceptions of Health Care: A Qualitative Study. *Journal of primary care & community health*, *8*(3), 169–175. https://doi.org/10.1177/2150131917697439
28. Chung, G. K., Dong, D., Wong, S. Y., Wong, H., & Chung, R. Y. (2020). Perceived poverty and health, and their roles in the poverty-health vicious cycle: a qualitative study of major stakeholders in the healthcare setting in Hong

Kong. *International journal for equity in health*, *19*(1), 13. https://doi.org/10.1186/s12939-020-1127-7

TABLES

Table 1. Participant Characteristics

	All Participants n (%)	Poor Perceived Care Coordination n (%)	Good Perceived Care Coordination n (%)	p-value
n	1226	355	871	
Age				0.02
25-49	206 (16.8)	44 (12.4)	162 (18.6)	
50-64	442 (36.1)	125 (35.2)	317 (36.4)	
65-74	297 (24.2)	90 (25.4)	207 (23.8)	
75+	281 (22.9)	96 (27.0)	185 (21.2)	
Natal Sex				0.61
Male	656 (53.5)	194 (54.7)	462 (53.0)	
Female	570 (46.5)	161 (35.3)	409 (47.0)	
Race/Ethnicity				0.23
White/Caucasian	891 (72.7)	246 (69.3)	645 (74.1)	
Black/African-American	312 (25.4)	102 (28.7)	210 (24.1)	
Other	23 (1.9)	7 (2.0)	16 (1.8)	
Marital Status				< 0.001
Not married	298 (24.3)	105 (29.6)	193 (22.2)	
Married/Living with a partner	738 (60.2)	183 (51.5)	555 (63.7)	
Widowed	190 (15.5)	67 (18.9)	123 (14.1)	
Education				0.09
Some High School or Less	201 (16.4)	71 (20.0)	130 (14.9)	
High School Graduate or G.E.D.	304 (24.8)	92 (25.9)	212 (24.3)	
Some College or Technical School	397 (32.4)	110 (31.0)	287 (33.0)	
4-Year College or Graduate Degree	324 (26.4)	82 (23.1)	242 (27.8)	
Census Tract Poverty Percentage				< 0.001
0-4	231 (18.8)	68 (19.2)	163 (18.7)	
5-9	323 (26.4)	69 (19.4)	254 (29.2)	
10-19	331 (27.0)	93 (26.2)	238 (27.3)	
20+	341 (27.8)	125 (35.2)	216 (24.8)	
Insurance Coverage (select all that apply)				0.008
No insurance	69	21	48	
Employer provided insurance	364	89	275	
Self-purchased or Spouse's insurance	351	96	255	
Medicaid or Medicare	770	255	515	
Other	199	53	146	
Comorbidities				0.22
0	299 (24.4)	93 (26.2)	206 (23.6)	
1	378 (30.8)	97 (27.3)	281 (32.3)	
2	264 (21.5)	73 (20.6)	191 (21.9)	
3+	285 (23.3)	92 (25.9)	193 (22.2)	

Table 2. Model Selection

	Model 1[a] HR (95% CI)	Model 2 [b] HR (95% CI)	Model 3 [c] HR (95% CI)	Model 4 [d] HR (95% CI)	Model 5 [e] HR (95% CI)
Care Coordination	1.24 (1.00, 1.47)	1.12 (0.90, 1.39)	1.13 (0.91, 1.40)	1.13 (0.91, 1.41)	1.11 (0.90, 1.39)

[a] Model 1 is the crude model

[b] Model 2 controls for perceived care coordination, age, race/ethnicity, marital status, census tract poverty percentage, and natal sex. Chosen as the final model.

[c] Model 3 controls for perceived care coordination, age, race/ethnicity, marital status, and census tract poverty percentage.

[d] Model 4 controls for perceived care coordination, age, race/ethnicity, marital status, census tract poverty percentage, natal sex, and comorbidities.

[e] Model 5 controls for perceived care coordination, age, race/ethnicity, marital status, census tract poverty percentage, natal sex, and insurance coverage.

Table 3. Multivariate Analysis with Cox Proportional Hazards

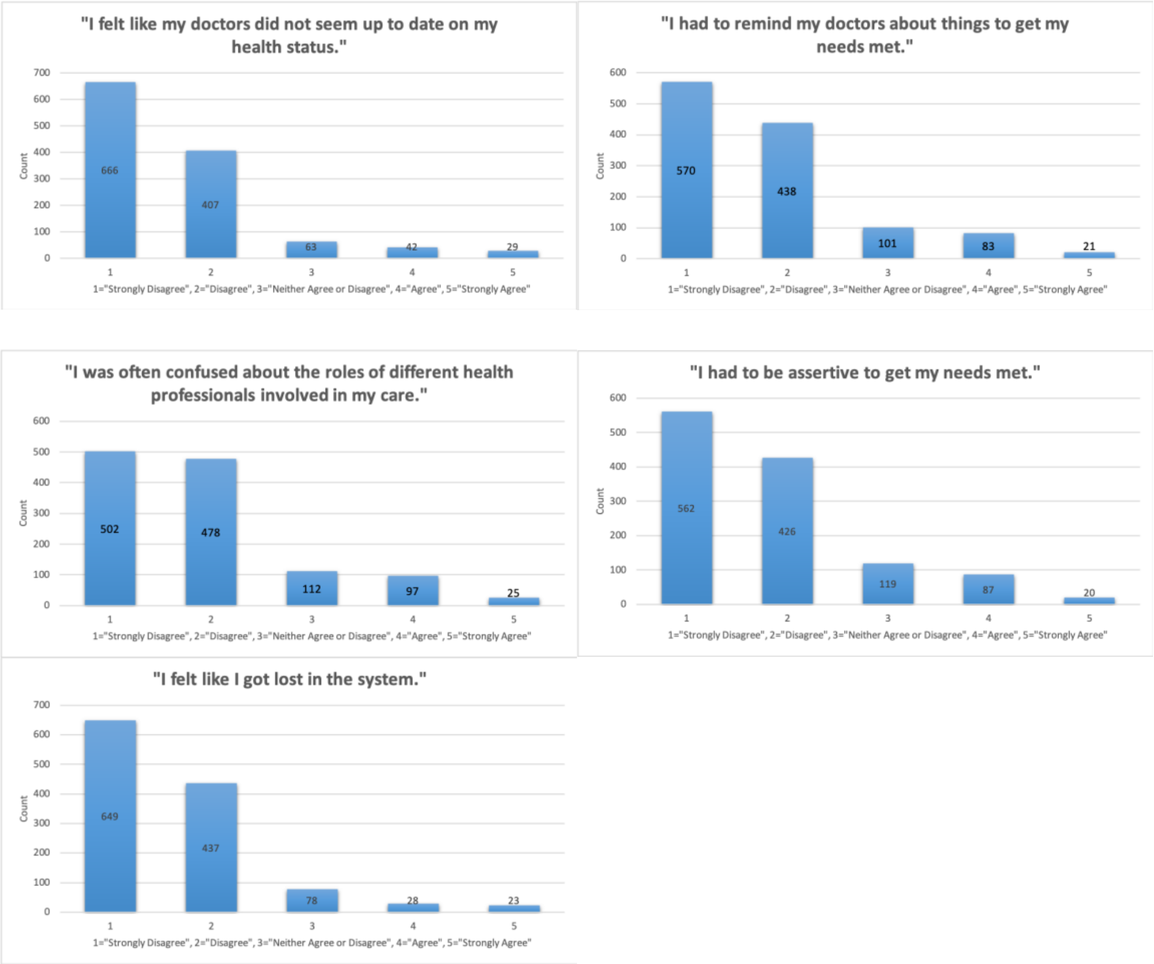
Variable	Hazard Ratio	95% Confidence Interval	p-value
Perceived Care Coordination [a]			
Good	Ref	Ref	Ref
Poor	1.12	0.90, 1.39	0.30
Age			
25-49	Ref	Ref	Ref
50-64	1.45	1.30, 1.63	< 0.001*
65-74	2.11	1.69, 2.64	< 0.001*
75+	3.07	2.19, 4.29	< 0.001*
Race/Ethnicity			
White/Caucasian	Ref	Ref	Ref
Black/African-American	0.96	0.77, 2.21	0.76
Other	0.93	0.60, 1.46	0.76
Natal Sex			
Female	Ref	Ref	Ref
Male	1.31	1.06, 1.61	0.01*
Marital Status			
Married/Living with Partner	Ref	Ref	Ref
Not Married	1.04	0.94, 1.16	0.44
Widowed	1.09	0.88, 1.35	0.44
Census Tract Poverty %			
0-4	Ref	Ref	Ref
5-9	1.02	0.92, 1.12	0.76
10-19	1.03	0.84, 1.26	0.76
20+	1.05	0.78, 1.41	0.76
Education			
Some High School or Less	Ref	Ref	Ref
High School Diploma/G.E.D.	0.87	0.78, 0.96	0.01*
Some College or Tech School	0.75	0.61, 0.92	0.01*
College or Graduate Degree	0.65	0.48, 0.89	0.01*

* p-value < 0.05

[a] Perceived Care Coordination was the main exposure variable.

FIGURES

Figure 1. Distribution of Questions Utilized in Creating the Care Coordination Composite Score



"I felt like my doctors did not seem up to date on my health status."

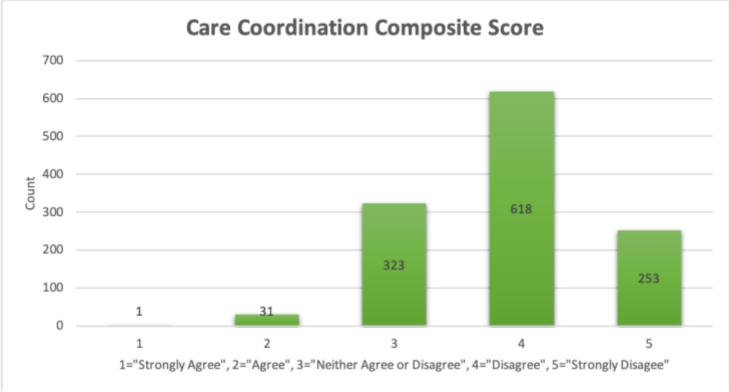
"I had to remind my doctors about things to get my needs met."

"I was often confused about the roles of different health professionals involved in my care."

"I had to be assertive to get my needs met."

"I felt like I got lost in the system."

Figure 2. Distribution of Composite Score Variable



Care Coordination Composite Score

Figure 3. Kaplan-Meier Plot for Perceived Care Coordination and Survival

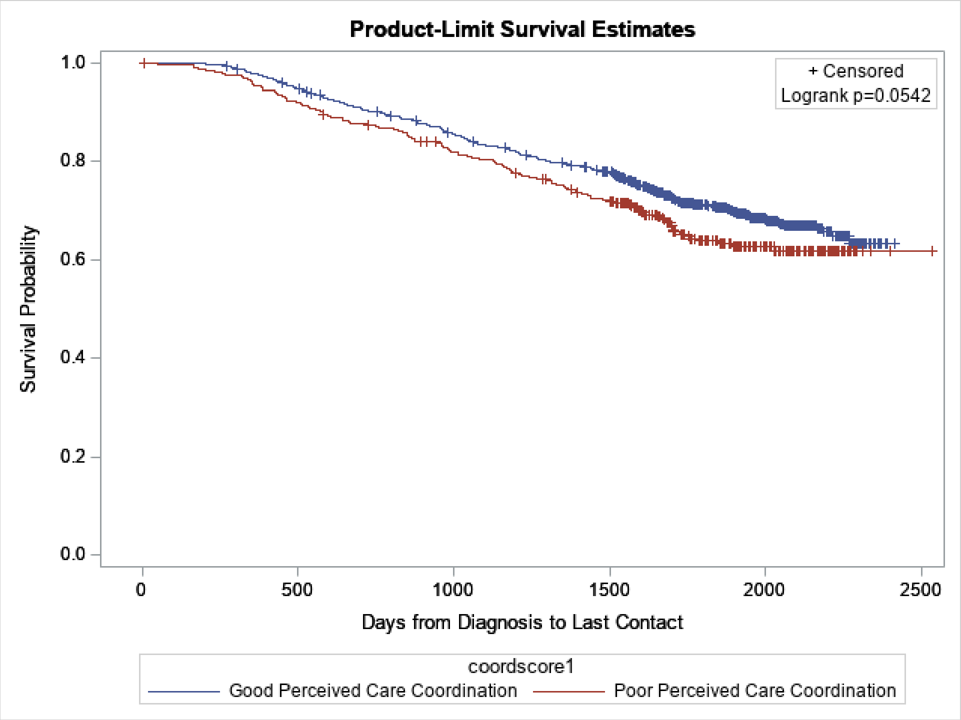


Figure 4. Adjusted Survival Plot