

Constructing Risky Categories: The Politics of Race, Gender, and Colorectal Cancer Advocacy

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Disease advocacy organizations have emerged in the last four decades in the U.S. as important political actors and knowledge producers (Best, 2012; Brown & Zavestoski, 2004; Epstein, 2016). Following the successes of HIV/AIDS and breast cancer organizations in bringing their diseases of concern to national attention, disease advocacy organizations in the U.S. have continued to play an important role in shaping common assumptions of how diseases should be defined (Diedrich & Boyce, 2007) and how resources to combat these diseases should be mobilized (Best, 2012 Dimock, 2003).

Since the late 1990s, colorectal cancer (CRC) advocacy organizations have emerged as part of a health social movement focused on increasing awareness, support, and research for colorectal cancer. Despite the fact that colorectal cancer (or “colon cancer” -- used interchangeably) has the fourth highest incidence and mortality rate out of all cancer types in the U.S. (CDC, 2012), colorectal cancer remains marginal in analyses of cancer organizations. Analyses of health social movement organizations have often focused on breast (Brown et al., 2006; Klawiter, 2008; Kolker, 2004; Sulik, 2011), prostate (Dimock, 2003; Kedrowski & Sarow, 2007; Wailoo, 2011), and lung cancer and tobacco control advocacy (Nathanson, 2005). And despite increasing awareness surrounding risk factors related to colorectal cancer and the development of new, effective preventive screening technologies, colorectal cancer continues to disproportionately impact African American men more than any other population (CDC, 2015).

By applying a social movement framing perspective to this understudied area of activism, I explore why the disproportionately high rates of colorectal cancer among African Americans and African American men continue to remain neglected in colorectal cancer advocacy circles. Drawing upon interviews with members of colorectal cancer advocacy organizations (n=9), I argue this neglect can be attributed to two processes: colorectal cancer organizations constructing

frames that are more politically and culturally salient than empirically sound (or, more viable than valid) and framing racial and gender differences in health as a result of individual behaviors and misconceptions rather than as a result of structural causes.

The bulk of the social movements and health social movements literatures on framing examine identities and disease constructed through social movement frames (the effects of frames), but limited research examines the processes which account for the construction of frames (P. Brown et al. 2012; Hughey, 2015). By analyzing how ideas of risk shape the construction of social movement frames, I examine why colorectal cancer advocacy organizations do *not* construct identities and disease definitions that could address the disproportionately high rates of CRC among African Americans and particularly African American men. I argue that when these organizations define race and gender as personal problems which can be resolved through reducing behavioral risk factors rather than as social problems, which can be resolved through reducing structural risk factors, these organizations mobilize other categories of difference, such as age and insurance status, as social problems, instead of focusing on race and gender. In this process, differential CRC outcomes based on race and gender are obscured as these organizations construct colorectal cancer as a disease which can be overcome through increased personal responsibility and awareness.

I first introduce the theoretical frameworks, social movements framing and the construction of risk, which guide my analysis. Then, I provide a literature review of the tensions between race, gender, and risk within breast cancer and prostate cancer organizations' movement frames and strategies. Next, I introduce my research questions and the methods I use in order to understand how ideas of race, gender, and risk shape colorectal cancer advocacy organizations' frames. Finally, I analyze the data from interviews with colorectal cancer advocacy organization

leaders and advocates (n=9) and argue that by drawing upon ideas of race, gender, and risk, these organization construct frames which marginalize racial and gender health differences in colorectal cancer. I conclude by discussing how these findings can guide future research on colorectal cancer advocacy organizations and on how ideas race, gender, and risk construct movement frames.

### **Theoretical Framework: Social Movements Framing**

The social movement framing perspective can guide an analysis of how and for what purposes colorectal cancer organizations construct meanings of race, gender, and risk. Framing can be broadly defined as the process by which social movements construct meaning (Benford & Snow, 2000). Social movements construct meaning by crafting frames, which are communicated as the core elements of a phenomenon considered most important (Goffman, 1974). My research will focus on the diagnostic and prognostic' frames that colorectal cancer advocacy organizations construct. *Diagnostic framing* is the process by which social movements define what a problem is and *prognostic framing* is the process by which an intervention or solution to the problem is offered (Benford & Snow, 2000). With respect to health social movements, framing can be understood "as a key strategy used to reach its target audience" (Harris, 2010, p. 10). Health social movement studies of framing examine how movements deliberately craft frames in order to convey a health outcome as a social a problem and direct frames towards actors whom they want to intervene (P. Brown et al., 2012). In this process of defining what the problem is and what should be done about it, health social movements reproduce and create new meanings about what a disease is. Because understandings of diseases are socially constructed, the social process of framing creates meanings and assumptions about what facts matters and don't matter for a given disease.

Health social movements often produce frames that are more viable than valid (Kolker, 2004). Viability describes the extent to which a frame is culturally and politically salient and validity describes the extent to which a frame is empirically true. For example, in the early 1990s, breast cancer organizations drew upon the frame of gender equity in order to advocate for more research dollars for breast cancer (Klawiter, 2008; Kolker, 2004). This frame was viable because it targeted a vulnerable population, women. However, the frame may not have been the most valid frame: for years, breast cancer had been receiving more research funding than other cancer sites. In contrast, it may not have been viable for prostate cancer organizations to employ a gender equity frame to describe the lack of research funding and attention directed to a disease that impacts a majority of men, but it may have been valid since prostate cancer was receiving significantly less funding than breast cancer (Klawiter, 2008). The concept of frame viability versus frame validity can help explain why certain populations (e.g. gender, racial, geographic) are prioritized and other ones overlooked within social movement frames. In order to understand not only the impacts of these frames, but also how exactly these frames are constructed, I incorporate a social constructionist perspective of risk.

### **Theoretical Framework: Constructing Risk**

Health social movements construct meanings of risk when articulating theories of disease causation (Brown et al., 2006; Klawiter, 2008). Phil Brown and colleagues' (2012) concept of the politicized collective illness identity, an identity that is mobilized to transform a personal problem into a social problem, hinges on the articulation of what bodies and identities are at risk and what social problems can be attributed to these risks. This process of articulating a politicized collective illness identity is able to harness the increasing relevance of risk discourses within public health and medicine.

Partially due to therapeutic and diagnostic innovations, expanding epidemiological knowledge, and a desire within the pharmaceutical industry to expand its marketplace, the concept of risk has been increasingly applied to asymptomatic people (Aronowitz, 2009; Clark et al., 2003;). In this process, being at risk for and being diagnosed with a disease have become conflated, affecting how medicine is conducted and how we view “healthy people” (Aronowitz, 2009). For example, as epidemiological knowledge has increasingly identified people with irritable bowel disease as at increased risk for colorectal cancer, these people become a new “risk population” with differential standards applied to them, such as recommended annual colonoscopies and even prophylactic surgery (Aronowitz, 2009). Additionally, because African Americans have higher colon cancer incidences, higher mortality rates, and a younger median age at diagnosis than any other racial or ethnic group in the U.S., organizations such as the American Society for Gastrointestinal Endoscopy have recommended that colorectal cancer screening begin at age 45 for African Americans, as compared to age 50 in the rest of the population (American Society for Gastrointestinal Endoscopy, 2014).

The ways that providers and organizations define risk has consequences for who is framed as responsible for managing those risks and what kinds of interventions are appropriate (Jain, 2013, MacKendrick, 2010). In this research, I will depart from a concept of risk that assumes that a risk can be concretized and should be studied as something pre-existing in the material world. Rather, I draw upon a social constructionist perspective of risk and a “risk society” perspective.

From a social constructionist perspective of risk, “Nothing is a risk in itself – what we understand to be a ‘risk’ (or hazard, threat or danger) is the product of historically, socially contingent ‘ways of seeing’” (Lupton, 2013, p. 50). For example, when health social movements



present theories of individual risk, they encourage a “way of seeing” that lines up with dominant perspectives in which individual behavioral factors (often referred to as lifestyle factors) are attributed to cancer risk. In presenting these theories, these organizations not only articulate the “risk object” (the disease outcome) but also the object that is at risk (specific persons, populations, or environments). In this process, essentialist notions of race and gender may be reified, that is, instead of pointing to structural inequalities which are “fundamental causes” of health disparities (Link & Phelan, 1995; Phelan & Link, 2015), race and gender become framed as *a priori* risk (Brown et al., 2006; Hatch, 2016). The risk society perspective, is concerned with how late modernity creates risks through macro level processes (e.g. industrial pollution, economic meltdown, epidemics) that individuals are then expected to manage at the micro level (Beck, 1990; Lupton, 2013; MacKendrick, 2010;).

By bringing into conversation a social constructionist perspective of risk with a social movements framing perspective, we can analyze under what circumstances risks are constructed and individualized. Furthermore, we can analyze how social movements draw on ideas of risk when constructing frames and how these frames reproduce ideas of risk. Identifying colorectal cancer advocacy organizations’ diagnostic frames, or frames that identify what the problem is, will allow for an understanding of how these organizations define at risk populations and risk factors. Identifying the organizations’ prognostic frames, or frames that identify what the solution is, will allow for an understanding of what these organizations define as actions that can help eliminate or mitigate risk.

## Literature Review

### Disease Advocacy Organizations

Disease advocacy organizations are also referred to as “embodied health social movements” because they are driven by those who are affected by an illness or disease and direct attention to issues such as screening, treatment, access, research, and issues of social inequality that may impact these factors (Brown & Zavestoski, 2004). While research on disease advocacy organizations has often focused on the ways these types of organizations have been too narrowly focused on specific diseases to the detriment of addressing larger issues of social injustice, less research has examined the ways these organizations may look “inward” and “outward” (Epstein, 2016), that is, how they focus at times on specific diseases and at other times on broader health and social issues such as universal health care and racial and gender inequality through building connections with other health social movements (Epstein, 2016). In a recent critical review of the health social movements literature, Epstein (2016) argued that “disease constituencies,” or disease advocacy movements, are not inevitably narrowly focused on one disease, but rather may also look to larger issues of social change which can impact multiple diseases. Analyzing when these organizations look “inward” and “outward” allows for understanding of how the terrain of health and health care acts as a stage upon which political debates are carried out (Epstein, 2016; Nelson, 2011; Rose, 2007).

These political debates are crucial during an era in which critical race scholars in the humanities and social sciences have refuted the concept of race as a biological category, yet at the same time, there is a “resuscitation of race” (Roberts, 2013) as a supposed biological category within the field of genetics and biomedical research. Given this disjuncture between knowledge and practice, it remains critical to examine the extent to which health social

movements are challenging or further bolstering this “resuscitation of race” and other social categories such as gender that are being recast as biological. Disease advocacy organizations have the potential to uphold but also challenge social hierarchies. I now turn to a discussion of the breast and prostate cancer movements in order to provide context of the political and cultural debates in which colorectal cancer advocacy organizations and other disease advocacy organizations are situated.

### **Cancer and Health Social Movements: Breast Cancer and Prostate Cancer**

Since the early 1990s, the prostate cancer and breast cancer movements have taken medicalized and biomedicalized approaches to activism. That is, the main goals of these movements have often been to promote early detection and timely treatment and to fundraise to support biomedical cancer research (Kedrowski & Sarow, 2007; Moffett, 2003; Sulik, 2014). Through their approaches to cause marketing, mobilizing supporters at the grassroots level, and fighting cancer through aesthetic displays of white heteronormative middle class femininity (Sulik, 2011; Sulik, 2014), breast cancer organizations have been able to garner attention from Congress and the media in order to improve funding for breast cancer research (Dimock, 2003; Kolker, 2004, Sulik, 2011). The prostate cancer movement, while less effective at mobilizing grassroots supporters (Dimock, 2003), has also drawn upon gendered narratives through emphasizing a frame of “science as salvation” for men, implying men’s deservingness and an assumed masculinity of science through its ability to come to the rescue (Kedrowski & Sarow, 2007).

In a departure from individualized and narrowly biomedical notions of cancer prevention and survivorship, organizations within the environmental breast cancer movement have looked to structural and environmental causes of cancer and in the process, have challenged the Dominant

Epidemiological Paradigm (Brown et al., 2006). The environmental breast cancer movement, which also emerged during the early 1990s, drew upon the traditions of the Civil Rights Movements, the ACT UP movement, and the environmental justice movement in order to confront social justice issues, such as race, class, gender, and environmental inequality, as they relate to breast cancer (Klawiter, 2008). Brown and colleagues (2006) define the Dominant Epidemiological Paradigm (DEP) as "...an embedded set of institutional structures, beliefs, and actions of academia, government, industry, nonprofit organizations, health voluntaries (e.g., American Cancer Society), and the media" (p. 500). The DEP within the U.S. focuses on individual factors, or downstream factors, such as diet, exercise, and reproductive choices, in seeking to understand breast cancer risk. The environmental breast cancer movement challenges the DEP of breast cancer by seeking to provide data and knowledge of more upstream and environmental factors, such as exposure to toxins, which highlight the importance of structures rather than individuals in understanding breast cancer risk (Brown et al. 2006; Klawiter, 2008; Ley, 2009).

The environmental breast cancer movement not only challenges the narrow epidemiological focus that the mainstream breast cancer movement employs, but also the gender and racial ideologies of "pink ribbon culture" (Sulik, 2011). Their critique of "pink ribbon culture" asserts that use of the color pink perpetuates images of white, middle class femininity. These images marginalize the experiences of poor women and women of color impacted by the disease and frame breast cancer survivors as at risk of losing their femininity and in need of rescuing by the biomedical community (Sulik 2011, 2014). Furthermore, when corporate sponsors take up the pink ribbon to "support the cause," they obscure their culpability in perpetuating breast cancer risk (Sulik, 2014).

The ongoing tension between medicalized and environmental approaches to cancer activism is a clear example of how conflicting theories of disease causation are a manifestation of different “hidden arguments” (Hatch, 2016; Shim, 2014; Tesh, 1981). Within the context of disease activism, these political arguments center on who or what is responsible for a disease, and as a result, what role individuals and policy interventions ought to play. Genetic and lifestyle theories (which often emphasize the importance of individuals in making the choice to get themselves screened) tend to reify social hierarchies by assuming that individuals must take control of their own risk. Environmental theories tend to call into question social hierarchies, either explicitly or implicitly, by calling into questions theories that place disproportionate burden on individuals to mitigate risk (Klawiter, 2008). By examining the theories of disease causation and risk that colorectal cancer advocacy organizations draw upon, I am able to parse out the hidden arguments that these organizations make with respect to racial and gender differences in CRC outcomes. For example, when organizations apply the lifestyle theories which are commonly used within the Dominant Epidemiological Paradigm to a population experiencing high rates of CRC without considering structural factors, the ‘hidden’ argument is that this population is responsible for managing their own risk. As they do in the case of breast cancer, hidden arguments shape assumptions of who or what is responsible for managing colorectal cancer risk and ultimately how the disease should be defined.

### **Research Questions**

In order to understand how the hidden arguments of colorectal cancer advocacy organizations might challenge or reproduce the way racial and gender differences in colorectal cancer outcomes are framed, I ask the following: (1) in what ways do colorectal cancer advocacy organizations’ diagnostic and prognostic frames draw upon and reproduce concepts of individual

and structural risk?; (2) what implications do these diagnostic and prognostic frames have for addressing and/or mitigating racial and gender health differences in colorectal cancer? I find that by operating within the Dominant Epidemiological Paradigm, in a similar fashion to the mainstream breast and prostate cancer movements, colorectal cancer advocacy organizations reproduce ideas of individual responsibility and risk. These ideas of individual responsibility and risk elide structural causes of differential colorectal cancer outcomes based on race and gender. In this process, colorectal cancer advocacy organizations construct colorectal cancer as a disease that can be addressed largely through screening and awareness.

### **Colorectal Cancer Outcomes and Advocacy Organizations**

African American men experience the highest colorectal cancer (CRC) incidence and mortality rates and lowest survival rates out of all sex by racial/ethnic groups in the United States (CDC, 2015; Valeri et al., 2015). This disproportionate burden of CRC among African American men is a trend that has occurred since the late 1970s, when new screening technologies were introduced (Soneji et al., 2010; Valeri et al., 2015). Before then, whites experienced the highest rates of CRC. This new trend indicates that social and environmental factors likely explain or at least contribute to this differential health outcome, rather than genetic factors (Soneji et al., 2010; Saldana Ruiz et al., 2013). Once diagnosed, African American men experience the lowest CRC survival rates as well. Epidemiological studies of racial disparities in CRC have primarily focused on disparities in stage of diagnosis, tumor biology, SES factors, comorbidities, diet, exercise, type of treatment, and quality of treatment as potential reasons for the persistence of this disparity (Berry et al., 2009; Soneji et al., 2010). While environmental factors have been studied less often, a paucity of studies utilize census tract data to highlight key geographic risk factors when it comes to CRC survivorship (Hao et al., 2011; Hines & Markossian, 2012).

Despite the persistence of CRC as a major cause of mortality and the persistence of CRC disparities, national level sustained activism for colorectal cancer has only emerged in the late 1990s and early 2000s. I focus my study on three national-level colorectal cancer advocacy organizations who advocate for CRC patients and those at risk for CRC. While these organizations do not represent the totality of social movement and extra-social movement actors focused on colorectal cancer, they have had strong national presence in patient advocacy for over a decade. These organizations work in the realms of research, patient education, and advocacy.

## **Methods**

### **Recruitment**

I conducted qualitative semi-structured interviews (n= 9) in the fall of 2016 and winter of 2017 with present and past national and local leaders and advocates of colorectal cancer advocacy organizations. Participants represented leaders and advocates from three colorectal cancer advocacy organizations. I selected these organizations because they have had a prominent voice in cancer advocacy for at least 10 years and they have engaged in diverse forms of advocacy and education about colorectal cancer (e.g., legislative, patient care, research). I contacted leaders and advocates through accessing public contact information available on organizations' websites. Then, I used snowball sampling to identify additional leaders and advocates who may qualify for the study and who may be interested in being interviewed. In order to protect confidentiality, I use pseudonyms for individuals in this study.

### **Interview Protocol**

I conducted all interviews over the phone. These interviews lasted approximately 45 minutes and followed a semi structured interview guide. In these interviews, I asked participants about the main goals their organization seek to address and in what ways. I also asked how and

why certain goals are prioritized over others and what populations are targeted for advocacy work and for interventions. Furthermore, I asked about what types of language and slogans are used, and how participants understand the advocacy work of their organizations as it relates to other health advocacy organizations and health politics more broadly in the U.S. (see Appendix A for interview guide). This study, interview guide, and protocols were approved by Vanderbilt University's Institutional Review Board.

### **Data Analysis**

After digitally audio recording the interviews, I transcribed and uploaded excerpts from the interviews alongside field notes onto a secure storage system. I then uploaded the excerpts onto a qualitative data analysis software package, DeDoose.

I applied the process of labeling (Richards, 2015) to these transcripts. Labeling is the process whereby the researcher identifies portions of the data related to key topics and/or themes that are being studied. In this case, I labeled the data with the following themes - diagnostic frames, prognostic frames, and risk – and analyzed them separately. I then conducted analytical coding (Richards, 2015) to generate specific codes that describe the phenomenon of study. I then re-coded all portions of labeled data with the selected analytical codes in order to ensure reliability. I closely analyzed these analytical codes to identify how and under what circumstances participants discussed – or avoided discussion of – race, gender, and risk. I then used the analytical codes to describe the predominant diagnostic frames and prognostic frames that colorectal cancer advocacy organizations draw upon.

I approached the data through an “abductive analysis” approach (Tavory & Timmermans, 2014): an analytical approach in which the researcher remains immersed in the relevant literature



while analyzing data in order to generate novel findings that emerge from the data and which contribute to the literature. In this case, I drew primarily on the literatures on frames of race, gender, and risk in embodied health social movements and the sociology of risk; and social movements' frames and science and technology studies more broadly.

## **Results**

I interviewed nine organizational leaders and advocates. Six participants work at the national level and three at the local level. In terms of gender, two of the participants identified as male and seven identified as female. In terms of race and/or ethnicity, seven identified as white, one as white and Hispanic, and one as black. The average age of participants was 47 years (the youngest was 24 years and the oldest was 82 years).

### **Diagnostic Frames**

The predominate frames that participants utilized in the interviews to describe why colorectal cancer persists as a major health issue were lack of awareness, delayed screening, access, and to a lesser extent, uncertain causes.

**Lack of awareness.** Many participants drew upon a frame that describes lack of awareness as a major problem. Within this frame, participants stressed the general lack of awareness of the urgency and magnitude of colorectal cancer: *“The more we can talk about prevention and risk factors and keep them in front of mind with people I think that would be beneficial”* (Charlotte, patient educator). Similar to Charlotte’s perspective, but also hinting towards the problem of embarrassment regarding discussing rectums and colons, Rene, a medical adviser, offered an explanation for the lack of attention colorectal cancer receives, stating that: *“People don’t want to talk about colons, rectums. I mean they just don’t want to talk about it.”*

Also, participants discussed African Americans and populations served by Federally Qualified Health Centers as the specific populations who have a lack of awareness. For example, when discussing the low screening and high incidence rates among African Americans, Marie, a legislative advocate, claimed that after the passing and implementation of the Affordable Care Act, access is less of an issue and now the priority is spreading information to African Americans about the importance of being screened. Allison, a local level advocate, when discussing potential reasons for poor health outcomes among people served by Federally Qualified Health Centers, described how she thinks the causes of these health outcomes are related to healthy behaviors being discussed and prioritized less in regions where people are served by Federally Qualified Health Centers.

**Delayed screening.** Participants described later stage colorectal cancer diagnoses caused by delayed colorectal cancer screening as a major cause of colorectal incidence and mortality. Within this frame, there was variation in terms of who or what participants framed as responsible for the delayed screening. Participants attributed the cause of delayed screening to patients' behaviors and beliefs, lack of health care provider awareness, and a recommended screening age of 50 that does not attend to the entirety of the at risk population.

*Patient behaviors and beliefs.* Rene, a medical adviser, described people in their early 50s as putting off screening until a later age since the average age at diagnosis is in the mid-60s. Rene also described African Americans delaying screening because of fears of past discrimination.

*R: "I think we're also working on the African American community because unfortunately the African Americans [sic] when they're diagnosed they are*

*usually diagnosed at a later stage and also they tend not to live as long white people, even when they are diagnosed at the same disease stage.”*

*I: “What do you think some of those leading causes and leading factors are that is contributing to that. Because that is a consistent trend right?”*

*R: Yes, it is. It is. And I think that part of it is failure to get treatment. You know, uh, fear of doctors. Just because of what happened in the past...*

Rene, among others, also described men’s delayed screening as caused by their fear of undergoing colonoscopies.

*Lack of health care provider awareness.* While participants attributed behaviors and beliefs among people in their early 50s, African Americans, and men as a cause of delayed screening, participants also discussed a lack of awareness on behalf of health care providers, especially with respect to colorectal cancer in the under 50 population: *“We hear often times that, you know, these younger people had been presenting symptoms and it was years before they were even offered a colonoscopy”* (Charlotte, patient education).

One advocate, Marissa, the only African American participant I spoke with, described how health care providers’ lack of cultural competency could lead to delayed colonoscopies for African Americans. To illustrate this problem, Marissa shared the story of her father who died of colorectal cancer. Her father, whom she identified as black, was originally offered a sigmoidoscopy, but not a colonoscopy. A colonoscopy, which searches the entire length of the colon, likely would have detected the cancer earlier, which was in the right side of his colon, a location which sigmoidoscopies do not reach. Marissa said that more providers need to be aware that African Americans are diagnosed with colorectal cancer in the right side of the colon more

often than other populations. She also tried to advocate for a state level cultural competency bill, but the bill did not pass after a nurses' organization decided not to support it. Marissa, in contrast with other participants I spoke with, strongly emphasized the need for better provider awareness when it comes to caring for racial and ethnic minority patients.

*Screening age.* Related to the discussion of colorectal cancer in the under 50 population, participants described the difficulty that the generally recommended and health insurance-supported screening age of 50 poses. Participants recognize that lowering the screening age would not be cost effective nor is it scientifically justified; but at the same time, they realize that keeping the screening age at 50 could put people under 50 at risk for not being recommended for screening even when they have symptoms. Because of the disconnect between the recommended screening age and those who become diagnosed under the age 50, medical adviser Rene described under 50 colorectal cancer diagnoses as the 10% of colorectal cancer diagnoses that are not preventable.

The main argument made by participants within the delayed screening frame is that delayed screening leads to later stage diagnoses and higher incidence and mortality rates. Most often, participants described individuals as needing to be more responsible and aware in order to overcome "misconceptions." The logic of this argument works within an information deficit model in which individuals' perspectives on screening are seen as the problem that needs to be tackled. However, participants did put some of the focus on health care providers within the context of describing a need for greater cultural competency (expressed by the one African American participant I spoke with) and to be aware of under age 50 colorectal cancers. Notably, participants did not mention African Americans in conversations about under 50 colorectal

cancer, even though African Americans are disproportionately represented in under 50 colorectal cancer incidences (Abdelsattar et al., 2016).

**Access.** Participants discussed spatial and economic disparities in access to colorectal cancer screening and treatment as a major issue.

*Spatial disparities.* The main argument made by participants with respect to spatial disparities is that people in inner city and rural areas are at disproportionate risk of not having access to adequate prevention and treatment. James, medical adviser and patient advocate, attributed these disparities to clinics closing down because of federal reimbursement policies:

*“One of the big drivers we see in access issues are federal reimbursement policies, changes in Medicare, that maybe favor hospitals over local clinics, that kind of thing, so you are seeing local clinics close pretty rapidly and be consolidated pretty rapidly with bigger systems. That’s a big problem for rural service and also for inner cities.”*

*Economic disparities.* The main argument participants made with respect to economic disparities is that the uninsured and underinsured don’t have access to the best centers and affordable care. For example, participants discussed the issues of the receipt of outdated treatments and being negatively impacted by the Medicare Loophole, an insurance billing loophole in which patients on Medicare are billed a co-pay for their colorectal cancer screening when precancerous polyps are found and removed during the screening process. Medical adviser Rene described economic disparities related to colorectal cancer:

*“I think that it’s still unfortunately the haves and the have nots. Those with good insurance, those with access to...university centers, centers of excellence,*

*National Cancer Institute, comprehensive cancer centers, those are the ones that are going to get the best treatment. If you live outside of that and if you don't have good insurance, you have less of a likelihood to live [strong emphasis on live]."*

Within the frame of access, the concepts of risk discussed most prevalently by participants were geographical and insurance status risks. Also, very notably, participants did not discuss gender in this frame and only one participant discussed racial and ethnic minorities. None discussed the need to consider the unique barriers faced by African American men.

**Uncertain Causes.** Two participants I spoke with discussed the challenge of addressing a disease that has many different causal and risk factors. James, who works in patient navigation and advocacy, described how screening is so strongly emphasized because it is a single solution that puts the majority of responsibility on people at risk for a disease that has many causes:

*One reason we emphasize prevention and screening so much is no matter what the cause, if you get screened and follow the guidelines, there is a good chance you will never get colon cancer. In terms of causes, there is a genetic, we don't seem to have a firm number...But then, tobacco use contributes to colon cancer, as does alcohol, and then, uh, diet...We try to do a lot in terms of helping people understanding the role that exercise and diet can play in prevention of colon cancer and then preventing a recurrence because most of the people who have had colon cancer want to find out how they don't get it again. Then there is stuff that comes and goes about, does aspirin help prevent colon cancer? Does calcium help prevent colon cancer? And aspirin, it's pretty solid that it might help...We usually look at tobacco, alcohol use, diet, and exercise, those are the biggies."*

James recognizes the value of tracking the complex set of risk factors that contribute to colorectal cancer, but also places a heavy value on screening mechanisms that can detect precancerous polyps, irrespective of what caused them to develop. Here, James seems to recognize the *viability* of emphasizing screening: it is a rather clear message compared to the uncertainty he associates with other topics (e.g. aspirin, genetics, lifestyle).

Chris, a former organizational board member, discussed the multiple potential causes of the disease, stating that because there so many different factors, it is really difficult to predict who will get cancer and when. In my interview with Chris, he overall seemed more enthusiastic about screening and treatment than research, perhaps because of his view that energy spent tracking risk factors may ultimately be better spent caring for those who already have the disease.

The difficulty in tracking the relative strength of different causal factors may explain why colorectal cancer organizations focus heavily on screening, a solution that does not tackle root causes, but is able to help prevent the development of colorectal cancer “no matter what the cause” was.

Race, gender, and risk come up in various ways within the diagnostic frames of lack of awareness, delayed screening, access, and uncertain causes. Participants discussed racial disparities briefly in conversations about access, but at the same time, participants framed racial disparities as a problem of lack of knowledge among racial and ethnic minorities and the need for them to overcome fear of past discrimination, not larger structural factors. Participants also discussed gender within the awareness and delayed screening frames and understood gender difference in outcomes as a problem of individual behaviors and beliefs of patients. With respect to risk, participants strongly emphasized behavioral risk factors, but also mentioned spatial and

economic risk factors. Only two participants discussed discrimination. One participant discussed discrimination in terms of lack of cultural competency among providers leading to delayed screening and another participant discussed African Americans' fear of past discrimination leading to delayed screening.

### **Prognostic Frames**

The most common prognostic frames that participants utilized in the interviews were awareness, screening and prevention, access, and to a lesser extent, research and move beyond a disease specific approach.

**Awareness.** Participants described the need to increase knowledge and awareness of the disease in order to decrease incidence and mortality. Participants spoke of the importance of raising awareness about colorectal cancer in the under 50 population, educating patients on risk factors and treatment options, raising awareness among men, and raising awareness in order to overcome racial disparities in screening and treatment.

*Under 50 population.* Charlotte, patient educator, and Rene, medical adviser and patient navigator, both discussed the need to spread awareness of the incidence of colon cancer in the under 50 population. Charlotte specifically identified providers as targets for awareness campaigns:

*"I mentioned that a lot of people come... [to our organization] ...diagnosed at late stage. We also see a lot people who are diagnosed under age 50. So, sharing that story is very important. We hear often times that these younger people had been presenting symptoms and it was years before they were even offered a colonoscopy. So the more that they can share their story, the more it can get out*



*to primary care, different providers to let them know that...just because traditional it's been an over 50 diagnosis, you know, there are increases in the under 50 [age group]."*

In contrast to emphasizing awareness among health care providers, Rene and Charlotte both emphasized the need for people to be aware of symptoms, and for people to undergo screening if they have symptoms, no matter what age they are despite the fact that insurance is not likely to be willing to pay for such tests.

*Patient education.* Charlotte, patient educator, discussed in depth why improving patient education should be an important initiative. She described how because their organization works with many colorectal cancer patients, one major focus is to provide information on various treatment options and on how to manage side effects of cancer drug treatments. Charlotte also discussed the importance of educating people on risk factors, such as what her organization calls risk factors "beyond our control" such as genetics and family history and risk factors "within our control" such as screening and lifestyle.

*Raising awareness among men.* James, patient navigator and advocate, spoke on the importance of directing awareness towards men. However, there are no specific programs in place. Instead, James, as a patient navigator, deals with this issue on a case-by-case basis:

*"Field Note: When I asked James about addressing screening in men, he emphasized that he tries to work with them by telling them that if they are asymptomatic, there are other screening options besides the colonoscopy. But, if they are symptomatic, they should get a colonoscopy: 'If you are having*

*symptoms...it is something you need to get your hands on [...] Extend the picture: do you want to die of colon cancer? The answer is probably no.’”*

In contrast, Belinda, a local level advocate, spoke of the importance of speaking with people at health fairs about how colon cancer is “not just an old’s man’s disease,” thus directing awareness to people who don’t identify as older men.

*Raise awareness to overcome racial disparities.* Two participants discussed the importance of increasing knowledge and clearing up “misconceptions” among African Americans, Patient educator Charlotte discussed disparities in clinical trial participation:

*“We do talk about clinical trials in underserved populations, specifically the African American community, because there is a lower rate, I think a lower rate, of clinical trial participation. And it’s not, I mean my understanding is that a lot of that has to do with some preconceived ideas of people that are recruiting, so we touch on it in a variety of different ways.”*

Similarly, as mentioned in my discussion of diagnostic frames, legislative advocate Marie talked about how after ACA, access is less of an issue and now the issue is getting the information out that people need to get screened. Marie also emphasized how teaming up with the CDC in order to carry out this awareness campaign is crucial.

**Screening and Prevention.** In the prognostic frame of screening and prevention, participants focused on increasing individual awareness of the importance of screening, increasing screening rates across the population, and reducing barriers to screening.

*Individual awareness.* Two participants who work in patient navigation emphasized that no matter what the age and no matter what the cause, screening is crucial. For example:

*“So first of all, when you turn 50, you need to be screened, but even more important is, if you have any symptoms you need to have a colonoscopy -- but regardless of the age --because we are seeing a rise in people under the age of 50, especially with rectal cancer, I mean I was 43 when I was diagnosed” (Rene, medical adviser).*

*Increase screening rates.* Participants from all organizations discussed how their colorectal cancer advocacy organizations are part of the 80 by 2018 campaign led by National Colorectal Cancer Roundtable. This campaign constitutes a major campaign within the colon cancer movement with a goal to have the up-to-date on screening rate in the US reach 80% by 2018.

*Reduce barriers to screening.* All organizations involved in this study support the removal of the Medicare Loophole, which describes the process by which people on Medicare are billed a co-pay when a polyp is found and removed. That is, a screening test becomes a diagnostic test and falls into a different billing category once precancerous polyps are found:

*“The Medicare patient has no cost as long as nothing is found [...]. For our seniors it really does have that potential that they put off such a preventive service because the potential that they wake up with a bill. Studies have shown that colon cancer is one of the most treatable cancers as long as it's caught early, which is the reason for of course nationally the big push for making sure people get screened, which is the reason why we focus on getting that Medicare loophole closed” (Allison, local colon cancer advocate).*

Additionally, Marie, a legislative advocate, described to me how their organization looks for interventions that will decrease screening costs and screening distance.

Despite generally enthusiasm for screening awareness campaigns, Chris, a former organization board member, was skeptical of the effectiveness of this approach since people can be reluctant to undergo invasive screening tests:

*“What I found is that no matter how much advocacy people try to put out there, unless a person has a direct connection to a friend or family member who has been through colon cancer or had a colonoscopy, it is almost doesn’t matter how much advocacy you do, they’re probably not going to do it.”*

He also expressed skepticism towards mass screening campaigns, implying that they can be ineffective if not carried out with care:

*“At a lot of organizations especially in the colon cancer field, some of the people that are a part of the organization not necessarily as employees but as volunteers they are really zealous about colonoscopies, and unfortunately you can turn people the wrong way if you are overzealous about colonoscopies [...]. I’ve went out and done a few things and one of them was the Navajo Reservation in Arizona. I knew they were underserved and they asked me to come out there and speak, so we were able to turn that into a little bit of an event where some volunteers came out. And I just observed it, and I was like okay, you guys got to go a little lightly here, especially with the Native American population, they are a little hesitant still with white people”*

Chris was the only advocate I spoke with who argued that screening campaigns can do more harm than good if not carried out properly.

**Access.** Participants described the importance of improving access, which they largely defined in terms of affordable care and spatial access.

*Affordable Care.* Participants discussed the importance of having access to low cost colorectal cancer screenings and more affordable care overall. Patient educator Charlotte described the importance of having access to screening:

*“There are some disparities, and we do try to, we do mention, we do touch upon those. But, I would say mostly in the form of reducing barriers...I mean we provide a link to various resources to help with free low cost colonoscopy [sic]. You can find links to different organizations that help get you to and from your appointment.”*

Similarly, Allison, a local advocate, described how in her circle of advocacy, making care more affordable for people served by Federally Qualified Health Centers is commonly discussed.

*Spatial access.* Participants also described the need to make centers and clinics where screening and treatment take place more geographically accessible. For example, a legislative advocate said that their organization looks to support policies that decrease screening distance. Similarly, a patient navigator and advocate with another organization described how their organization is working across disease specific categories and forming coalitions to address spatial access, and a local advocate with another organization described an effort to improve geographical access for those served by Federally Qualified Health Centers.

Within the prognostic frame of access, participants' main argument is that improving access will increase screening rates and help expand the reach of timely and affordable treatment. Participants discussed access mainly in terms of space and class, but not explicitly in terms of race and gender.

**Research.** Two participants - one who works in partnership management and the other in patient education - described the importance of improving the research process and expanding research on CRC. For example,

*“Research advocacy, it infuses the patient perspective into research, which helps make the scientific and medical advances more timely and effective for the people that are affected with cancer, so it really helps to put a face to the science. It allows patient advocates so their able to sit at the table with some of the researchers, the doctors, the folks that are you know are working to advance science and research so that the patient perspective is always included... We partner with academic institutions and other organizations to provide training for the advocates so they are well informed when they go onto to do other various advocacy opportunities like we have some advocates that DoD – part of the DoD review board. People are part of IRB boards, they help inform local community cancer screening programs and different things, but we provide the training so they can think critically, they are lifelong learners and they can really contribute to the process”* (Charlotte, patient educator).

The main argument shared by the two participants who emphasized research is that finding a cure and getting patients more involved with the drug development process can help decrease colorectal cancer burden across the population.

Despite some participants expressing enthusiasm for directing money and efforts toward research, Chris, a former board member, expressed concern that directing attention to research could ultimately serve to detract from caring for patients who have already been diagnosed. One of the legacies/projects that he wanted to put in place was a fund that would provide \$100,000 in patient support each year. Despite Chris's excitement, the fund was not able to gain very strong traction. The stipulations that he originally envisioned for the fund were not being met, so when he left the organization, he took the name of fund with him. Now, another fund exists, but it does not provide as much financial support as Chris's plan did.

**Move beyond Disease-Specific Approach.** Despite most prognostic frames addressing colorectal cancer specifically, one leader described how moving past disease specific interventions can provide important results:

*"We're in an interesting time with cancer advocacy in general in that, for years, there is American Cancer Society, they were it. And then we kind of saw these disease specific groups. And for a while, it was like breast cancer was sucking all the air out of the room and getting all the attention. But, I mean, I hope I don't sound bitter towards them because they earned every bit of attention they got. But, I feel like we're starting to catch up with them. We're starting to learn how to do it and to make a difference. And there are other cancers that are getting organized. So people kind of see that hey, it's not just cancer its lots of different things, but we all have similar things in common. You can have colon cancer or pancreatic cancer, or whatever, and still, if your local health clinic closed, now you driving 30 miles to the doctor, that's still a problem. So we're starting to come together over certain issue in terms of patient access, in terms of palliative*

*care, the availability of palliative care is another big one. So people are starting to come together and work together, instead of being in, you know, all these separate individual issue groups, we're coalescing on certain issues"* (James, patient navigator and advocate).

James, like many others who work in health advocacy, is not constrained to the disease-specific paradigm. Rather, he seems to acknowledge and act upon the importance of addressing the disease itself, but also larger issues that are shared by people who are at risk for and already diagnosed with colon cancer.

Within the prognostic frames of awareness, screening and prevention, access, research, and move beyond a disease-specific approach, participants recognized that there are no interventions to address racial disparities, but rather discussed how racial disparities are largely addressed by way of awareness campaigns and removing barriers to screening. Similarly, participants discussed how there are no structural level interventions to address gender differences in CRC, but rather they discussed gender as being addressed on a case-by case basis. This lack of broad based, structural-level interventions can lead to overlooking African American men, the racial and gender population with the lowest screening, highest incidence, and highest mortality rates of colorectal cancer. With respect to risk, participants discussed the under 50 population with no mention of race even though African Americans are over – represented in incidences of under 50 colorectal cancers (Abdelsattar et al., 2016). Participants discussed both behavioral risk factors and structural risk factors, but they emphasized structural risk factors related to treatment less than those related to screening.



## Discussion

The predominant diagnostic frames that participants drew upon were lack of awareness, delayed screening, access, and to a lesser extent, uncertain causes. The predominant prognostic frames that participants drew upon were awareness, screening and prevention, access, and to a lesser extent, research and move beyond a disease specific approach. In the diagnostic frames and prognostic frames, participants briefly touched upon racial disparities in their conversations about access. However, participants mainly described racial disparities as caused by a lack of knowledge among racial and ethnic minorities and the need for racial and ethnic minorities to overcome fear of past discrimination. Similarly, participants described gender difference in CRC mainly in terms of gender-shaped, individually behaviors and beliefs of patients. With respect to risk, participants mainly emphasized behavioral risk factors, but did not also discuss spatial and economic risk factors, such as distance to clinics and health insurance statuses. Also, participants emphasized the under 50 population as an at risk population but did not mention African Americans when discussing this age group, even though African Americans are disproportionately represented in under 50 colorectal cancer incidences.

Examining the intersections of race, gender, and risk within the diagnostic and prognostic frames of colorectal cancer organizations can provide explanations of why differential racial and gender health outcomes in colorectal cancer remain minimally addressed. In the diagnostic and prognostic frames, organizations framed African Americans as largely to blame for the higher rates of CRC that they experience. In the diagnostic frames, while some participants acknowledged structural barriers, they generally framed these structural barriers as problems of the past without being explicit about how these problems continue today. Furthermore, participants framed African Americans as responsible for overcoming these structural barriers

through overcoming their own misperceptions. For example, when I asked Rene, who works in patient navigation and medical advising, about the reasons for the high rates of CRC among African Americans, Rene responded: *“I think that part of it is failure to get treatment. You know, uh, fear of doctors. Just because of what happened in the past.”* Moreover, Charlotte, who works in patient education, described how African Americans have “preconceived ideas of people” who are doing clinical trial recruiting without mentioning ongoing forms of discrimination.

In the prognostic frames related to race and risk, organizations focused on increasing awareness among racial and ethnic minorities in order to overcome disparities. Participants primarily described awareness-based initiatives and recognized that there are no programs in place to address racial disparities in treatment or survivorship. When participants discussed awareness, they focused on improving awareness among racial and ethnic minority target populations and not among health care providers. Furthermore, in frames related to screening, participants focused more on increasing awareness of screening options and screening locations rather than removing structural barriers to equitable screening, treatment, and survivorship. For example, only one person I spoke with explicitly mentioned the problem of disparities in treatment. Another advocate I spoke with hinted towards disparities in treatment and survivorship but did not provide an explicit explanation of why they are taking place. Furthermore, advocates described inequalities in access as a problem of the past. For example, a legislative advocate I spoke with asserted that in the wake of the passing of Affordable Care Act, disparities in access and treatment are less of an issue. Now, she argued, the focus should be on educating at risk populations on the importance of getting screened.

By framing discrimination and structural barriers as problems of the past, colorectal cancer organizations frame current CRC racial disparities as caused by lack of awareness among

African Americans. That is, participants discussed behavioral risk factors and racial differences out of context with the ongoing structural factors that shape them (e.g. racial residential segregation, disparities in access). In this process, colorectal cancer organizations effectively construct racial disparities in colorectal cancer as a personal problem that can be overcome through more individually responsible behavior, rather than as a social problem which can be overcome through social change.

Similarly, participants largely framed differential CRC outcomes based on gender as personal problems that can be addressed on a case-by-case basis. Participants mainly described gender as an individual identity and mostly only discussed it in terms of men's fears of getting screened. Participants described how there are no gender-specific interventions in place to address gender differences in CRC outcomes, but rather patient navigators I spoke with discussed how they counsel men on overcoming fears of screening. Furthermore, participants did not discuss gender and race together, as one would if seeking to specifically address the high rates of CRC among African American men.

The findings from this thesis further support the argument that social movements' frames are often more viable than valid (Kolker, 2004). Moreover, the findings from this thesis further extend this argument by providing an explanation of how taken for granted ideas of risk shape the construction of movement frames. The goal of social movement frames is not always to be empirically valid, but rather for the frames to be politically and culturally resonant with target audiences. Diagnostic and prognostic frames that focus on screening and awareness more than treatment and transforming structural contexts may be more viable than valid with regards to addressing differential CRC outcomes based on race and gender. Focusing on screening and awareness without focusing on differences in access and others structural factors may not yield

the best results since significant racial and gender differences remain after screening rates and stage at diagnosis are controlled for (Berry et al., 2009; Link & Phelan, 1995; Soneji et al., 2010). While screening is a very important procedure and one that should be available regardless of race, class, gender, geography, citizenship status, and insurance status, a consistent focus on screening may also be a result of this intervention's cultural salience.

Since the 1930s, screening has been a central focus of cancer advocacy organizations in the US. These screening campaigns have often targeted individuals to be more vigilant in managing their risk (Kolker, 2004; Wailoo, 2011) and have often focused on cancer risk among younger women (Wailoo, 2011). Thus, emphasizing the under 50 population may be a culturally viable frame for colorectal cancer organizations to draw upon. However, colorectal cancer organizations' reference to the under 50 population without reference to race and class may not be the most valid frame: this framing can create the image that the under 50 population is among those in need of the most intervention. When organizations do not bring race up as an important factor, the fact that African Americans are over-represented in the under 50 colorectal cancer population can be elided (Abdelsattar et al., 2016).

Similar to prostate cancer organizations, colorectal cancer advocacy organizations may not employ a gender equity frame because of its lack of viability. While men, and especially African American men, experience disproportionately high rates of CRC, a gender equity frame may be more valid than viable to describe this health difference. Although people under 50 (without reference to race, gender, or class) are not at higher risk of CRC than African American men, focusing on people under 50 as being neglected may be more viable than focusing on African American men, a population that is often blamed for their own poor health outcomes.

In addition to providing further empirical support to the concept of frame viability versus frame validity, I argue that commonly shared ideas of risk help explain why frames are constructed which are more viable than valid. While there is limited research which examines exactly how social movement frames are constructed (P. Brown et al., 2012; Hughey, 2015) this thesis suggest that commonly shared ideas of race, gender, and risk may be major factors which shape the construction of health social movement frames. The diagnostic and prognostic frames described by representatives of colorectal cancer organizations were most often situated within the Dominant Epidemiological Paradigm (DEP) (P. Brown et al., 2012), in which personal responsibility and behavioral risk factors are emphasized over larger political-economic approaches to understanding health outcomes. Surprisingly, organizations challenged the DEP when it came to discussing colorectal cancer in the under 50 population. Because people under 50 fall outside the recommended screening age and focusing on young people at risk may be a culturally viable frame, organizations did not put the sole burden of personal responsibility on people under 50, but rather they also emphasized the importance of educating providers.

By working mainly within the Dominant Epidemiological Paradigm, colorectal cancer organizations individualize the complex risk factors that can be attributed to differential CRC outcomes based on race and gender (e.g. insurance status, geography, institutional and interpersonal discrimination). More specifically, one important process by which these organizations individualize risks are by way of focusing on screening and awareness and framing race and gender as problems of individual awareness that must be managed by at risk people. By bringing a social constructionist perspective of risk into a study on health social movement frames, we can see how the taken for granted ideas of risk as they related to categories of difference may determine what frames these organizations construct and what frames they don't

construct. While frames are often portrayed as deliberate choices in the social movements literature (P. Brown et al., 2012), we can also study how concepts of what risk is and who is at risk shape the assumptions that these deliberate choices are built upon.

With this approach to the study of risk in mind, studying movement leaders and advocates understandings of risk can help in understanding why certain categories of difference - in the case of this study, age, space, and insurance status-- are mobilized as collective illness identities while others are not. As long as colorectal cancer organizations portray differential CRC outcomes based on race and gender as personal problems, or problems rooted in “misconceptions,” it may remain difficult for these organizations to mobilize race and gender narratives in relation to collective illness identities and construct social movement frames which focus explicitly on structural causes of racial and gender inequalities in CRC.

In the process of constructing frames which are more viable than valid and individualizing risk, especially when it comes to race and gender, colorectal cancer advocacy organizations construct common assumptions of colorectal cancer which may further obscure differential health outcomes based on race and gender. Colorectal cancer is constructed by these organizations as a disease which can largely be addressed through increasing screening rates and awareness. When colorectal cancer advocacy organizations focus on these aspects of the disease without focusing on differential access to screening and treatment, and institutional and interpersonal discrimination, these organizations construct “ways of seeing” (Lupton, 2013) colorectal cancer within the Dominant Epidemiological Paradigm as a disease which can be overcome through increased individual responsibility. This construction of the disease elides the complex structural factors that contribute to the disproportionately high rates of colorectal cancer among African American men.

While in this thesis I argue that colorectal cancer advocacy organizations construct colorectal cancer as a disease that can be overcome through screening and awareness, the findings from this thesis also confirm that disease advocacy organization maybe more “Janus faced”, or may look inward to a specific disease but also look outward to approaches in health activism that move beyond disease approaches to address issues in access and equity that span across multiple disease, than previously described (Epstein, 2016). For example, James, a patient navigator and advocate, expressed a desire within his organization to move past disease specific organizing and to start directly addressing spatial disparities through coalitional work. Could it be that because these organizations are still relatively new that we are seeing them first gain traction in the field of cancer activism as a legitimate movement before they branch out into other priorities? Furthermore, how might colorectal cancer be constructed differently within these growing coalitions? These question merit further empirical investigation.

There are some important limitations to this study that should be noted. First, while I was able to interview leader and advocates from three major colorectal cancer advocacy organizations at the local and national level, my sample of nine participants limits how generalizable the claims of this thesis can be. Also, the interview sample of this study was overwhelmingly white (seven identified as white, one identified as white and Hispanic, and one identified as black). While this majority may represent the demographics of the movement leaders and advocates of these organizations, it is still important to gather more information on racial and ethnic minorities’ perspectives in these organizations. Furthermore, while I focused on three major colorectal cancer organizations, these organizations are a major part of, but should not represent the totality of the colon cancer social movement. Lastly, while I closely analyzed the diagnostic and prognostic frames that movement advocates constructed, I did not have

sufficient data from the interviews to analyze which other organizations and social movements these frames were coming from or were influenced by. Future research could focus on how colon cancer organizations form frames within the larger *field* (Ray, 1999) of cancer activism and health social movements.

### **Conclusion**

By analyzing colorectal cancer advocacy organizations' diagnostic and prognostic frames related to race, gender, and risk, I have argued that frames of screening and awareness predominate over frames related to unequal access and treatment within these organizations. Colorectal cancer organizations' focus on screening and awareness and on behavioral rather than structural risk factors related to racial and gender health differences can be explained by the idea that a frame does not need to be valid in order for it to be viable (Kolker, 2004). Within the Dominant Epidemiological Paradigm, which privileges behavioral risk factors stripped from their complex structural contexts (P. Brown et al., 2012), focusing on screening and awareness is more viable than a more structural consideration of discrimination and unequal access across axes of race and gender. When colorectal cancer organizations discuss racial and gender differences as problems of "misconceptions" which racialized and gendered people (in this case, African Americans and men) must manage, these organizations' prognostic and diagnostic frames of screening and awareness are held together by these taken for granted ideas of behavioral risk. Consequently, these organizations do not construct frames related to structural factors of unequal access that explicitly consider racial and gender health differences. By not constructing those frames, colorectal cancer advocacy organizations reproduce 'constructions of colorectal cancer as a problem of individual awareness which then reproduce the disproportionately high rates of CRC among African American men.



This thesis adds to the health social movements literature by bringing together the sociological literatures on health social movements and risk. By bringing together these two bodies of literature to study a hitherto seldom examined social movement, I've shown that a social constructionist perspective of risk can demonstrate how ideas of risk shape what populations are privileged over others as being in need of attention and why health social movements craft certain frames and not others. In the case of the disproportionately high rates of CRC among African American men, colorectal cancer organizations reproduce racial and gender differences in CRC by constructing behavioral risk factors which elide the structural risk factors which contribute to the disproportionately high rates of CRC among this population.

Moreover, by utilizing a social constructionist perspective of risk (Lupton, 2013) to analyze the relational constructions of race, gender, and risk, studies of health social movements can analyze what are the cultural and political drivers that determine why certain categories of difference become politicized as collective illness identities (P. Brown et al., 2012) while others do not. In this type of analysis, we might ask: how might taken for granted ideas of race, gender, and risk shape the processes of defining certain health inequalities as social problems, but other health inequalities as personal problems which can supposedly be overcome through awareness alone?

## Appendix A

### Interview Guide

#### **Demographic Questions (record responses on paper and do not tape record):**

1. How old are you?
2. In terms of race and/or ethnicity, how would you identify?
3. In terms of gender, how would you identify?
4. Can you tell me about your history with [ORGANIZATION NAME]?
  - How long have you been working with them and what is your position in the organization?
5. Would you like your name and position in the organization to remain confidential?

(IF NO: What identifiers would you like to be publicly attached to the information you share today)?

#### **Interview Questions (Tape record with permission from interviewee. Otherwise, record responses by hand)**

##### **Defining the Problem and Raising Awareness**

1. How would you describe your organization (in terms of major goals, funders, and coalitions?)
2. What were the priorities of the organization when you first joined?
3. Are those priorities the same now, or, are they different? (*Probe for: policy objectives, coalitions, methods of spreading awareness and fundraising*)

*FOLLOW UP QUESTION: If different: How have these priorities change over time?*

*Why have they changed over time? Which priorities have remained at the top of list and why?*

4. Do you recall how those priorities have been chosen? (*Probe for: funding, comparisons with other organizations, scientific evidence*)
5. What types of evidence is gathered when priorities are set (Probe for: personal narratives and testimonies, scientific research, stories of successes and failures from other organization, political knowledge)
6. How does your organization communicate the importance of these priorities to others? To policymakers? To clinicians? To survivors and people at risk? To activists?

7. In the process of setting these priorities, were there other priorities being considered as well?
8. What types of language or slogans does the organizations use to raise awareness? (*Probe for: why is this language used? What audiences and issues do you think it speaks to? Why the blue star? Why the color blue?*)
9. In terms of priorities, language, and overall organization, are there are any other organizations – colon cancer based or that focus on another issue --- that your organization has modeled itself after? (*Probe for: Any organizations that the organization has tried to not model itself after?*)
10. Has the language or slogans used to raise awareness changed over time?

Follow Up Question: How so and why?

### **Leading Causes and Target Populations**

11. What does your organization define as some of the leading causes of colorectal cancer?

Follow Up Questions/Probes: How does the organization feel about the genetic factors of the disease? Lifestyle factors? Environmental? Political?

12. Are there any types of disagreements within the organization about these causes? (*Probes: genetics v. environment; lifestyle v. environment, race, age, gender*)
13. Does your organization prioritize any target populations? (*Probes: men, women, low SES, African Americans*)

### **Political Opportunities and Political Culture**

14. How would you describe the current culture around health issues, and specifically cancer, in the U.S.?
15. What do you feel is the most important thing that people should know about the work going on at your organization?
16. Is there important information to share about your organization that we did not cover?
17. Do you have any questions for me?

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