

Disease Marketing and Patient Coping: A Research Study

by

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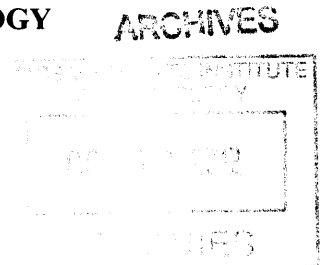
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Dedication

To my parents, Yew Kee and Bien Yan, for their constant love and support no matter which endeavors I choose to undertake

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Submitted to the Harvard-MIT Division of Health Sciences and Technology on August 15, 2012 in Partial Fulfillment for the Degree of Master of Science in Health Sciences and Technology at the Massachusetts Institute of Technology

Abstract

BACKGROUND: There is a high prevalence of disease marketing actions in the United States that are targeted towards patients with chronic illness. However, no study has assessed the direct effects of these marketing actions on patient coping attitudes and behaviors.

OBJECTIVES: This study aims to investigate whether the mere presence of disease marketing impacts patient coping and if so, how do they affect patients' coping attitudes and behaviors.

METHODS: We conducted a controlled experiment using online questionnaires to assess the disease perceptions, coping decisions and disease disclosure behaviors of 108 subjects. The subjects were divided into two groups where the experimental group (N = 55) was shown marketing actions associated with a fictitious disease called Karlsen's Disease while the control group (N = 53) was not shown any marketing actions. The subjects were then asked a series of questions related to health-related coping behaviors and non-health related social behaviors. T-tests and chi-square analyses were used to analyze the behavioral differences between the experimental (high-marketing) and control (no-marketing) groups.

RESULTS: Subjects in the high-marketing group were overall significantly more willing to draft a will than subjects in the no-marketing group ($t(106) = 2.64, p = 0.01$); High-

marketing group subjects were overall significantly more likely to wear a medical ID bracelet than no-marketing group subjects ($\chi^2(1, N = 108) = 3.71, p = 0.05$); Among subjects who were willing to request a menu accommodation at a dinner party, those who were in the high-marketing group were significantly more likely to disclose their disease to the party host ($\chi^2(1, N = 90) = 4.65, p = 0.03$); Subjects in the high-marketing group were also significantly more likely to anticipate greater understanding from the party host towards their menu accommodation request. When controlled for gender, women in the high-marketing group were more likely to join a patient support group ($t(61) = 1.75, p = 0.09$), and less likely to ask family and friends to shave their heads in show of solidarity ($t(18) = -1.97, p = 0.07$) than women in the no-marketing group; Men in the high-marketing group were more likely than men in the no-marketing group to disclose their health condition to the dinner party host ($\chi^2(1, N = 47) = 3.61, p = 0.06$). Finally, among subjects with at least a 4-year college degree, those in the high-marketing group were more willing than those in the no-marketing group to wear a face mask to protect themselves from airborne pathogens in crowded public places ($t(61) = 1.79, p = 0.08$).

CONCLUSIONS: Based on our results, the presence of disease marketing is anticipated to have a general positive impact on patient coping attitudes and behaviors. Chronically ill patients exposed to disease marketing actions are expected to anticipate less stigma from others, have increased willingness to disclose their illness and adopt health seeking behaviors. Disease marketing is also expected to have differential impact on patients based on their gender and level of education. Follow-up studies using real patients with chronic illness should be carried out to confirm the findings from this study.

Thesis Supervisor: Renée Richardson Gosline, PhD

Thesis Supervisor: Richard Rox Anderson, MD

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Chapter 1: Introduction

Disease marketing and branding are frequently used to raise awareness about diseases, increase support for patients or increase sales of a product or service. The most common marketing actions seen in the mass media are disease awareness campaigns and direct-to-consumer (DTC) advertisements carried out by disease advocacy groups and pharmaceutical companies. Organizations such as the American Cancer Society, Susan G. Komen Foundation and pharmaceutical companies such as Pfizer, Inc. spend millions of dollars annually on major marketing and advertising campaigns (Stahl, 2012; Ad Age Insights, 2010). In addition, highly recognizable items and symbols such as the yellow Livestrong bracelet and pink ribbon are also frequently used to brand diseases.

Disease marketing and branding in the mass media play a role in influencing patient and public attitudes by affecting disease perceptions such as disease stigma, disease prevalence and severity. Mosca and colleagues showed that there is a strong view among women in the US that breast cancer and cancer in general are the leading causes of death in women. Moreover, women consider breast cancer as one of their greatest personal health fears (Walsh-Childers et al., 2011). In reality, cardiovascular disease remains as the biggest cause of mortality for women in the US (Mosca et al., 2004). Such perceptions are partially explained by the significant presence of marketing and advertising around cancer and breast cancer (Arnst, 2007).

Research has been done to understand the effects of disease marketing on gaining public support, donations, and reducing public stigma for chronic diseases, but no study has looked at their direct effects on patient coping. My advisors and I hypothesize that disease marketing actions can influence patient attitudes, which in turn determine their coping behaviors and ultimately influence their health outcomes. Therefore, we are convinced that understanding the impact of disease marketing on patient attitudes and coping behavior is a critical component to improving patient health outcome.

In this thesis, we aim to investigate whether the mere presence of disease marketing can

affect the coping attitudes and behaviors of patients with chronic illness. More specifically, we would like to understand how the presence of marketing images affects patients' disease perceptions, coping decisions and disease disclosure behaviors – factors that indicate patients' coping attitudes towards their illnesses. We chose to focus on chronic illnesses for this thesis because chronic conditions such as diabetes, cancer, and cardiovascular disease are a big and growing public health problem in the US. Chronic diseases account for 70% of deaths in the US each year. Among those, cardiovascular disease, cancer and stroke are responsible for more than 50% of the deaths (CDC website, 2010). As the size of aging population continues to grow in the US (Administration of Aging website, 2011), the burden of chronic illness on the US is also expected to grow.

This thesis will be organized in the following manner. In the background section, we will provide an overview of the chronic illness patient journey, followed by a discussion of the factors that affect the patient illness experience. Then, we would provide an overview of disease marketing in the US and the possible ways that disease marketing could impact public and patient perceptions and attitudes on diseases. Having established background knowledge on the patient journey, the state of disease marketing in the US and its relationship with patient disease experience, we would then describe the methods used to evaluate the hypothesis. Following that, we would present the analysis and discussion of our study results. Finally, we will review possible follow-on studies and conclude with a summary of the analysis and implications for disease marketing strategy.

Chapter 2: Background

Introduction

“Three months later, at the follow-up clinic, I was asked lots of questions, and I found myself saying yes more than no. I was then told “you have SLE [systemic lupus erythematosus] and need to see a rheumatologist. Where would you like to be seen?” Shell shocked, I said “My local hospital.” And I was sent on my way. I had never heard of SLE and didn’t know what it was, let alone where I should be treated. My head was spinning, thinking about all the questions I had been asked and what they meant. I went to the local library and looked up lupus in a medical textbook. I read that I was probably going to need kidney dialysis and that the likelihood of survival for five years was low. I had promised my parents that I’d telephone and tell them what had happened, but how was I going to tell them all this?”

- Jane Robinson, 2006

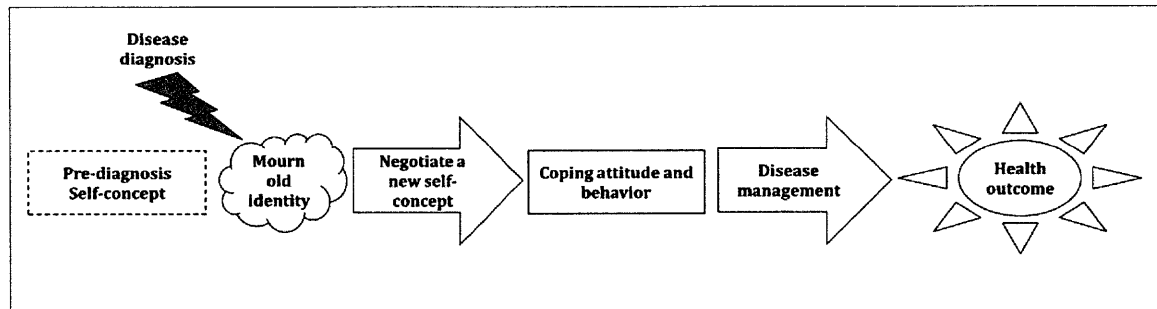
Receiving a disease diagnosis can be a life-altering event for most individuals, signifying a formal transition from health to illness (Mullan, 1985; Boehmke & Dickerson, 2006). For those with chronic conditions, the diagnosis is also the starting point of a life-long patient journey. One where patients are required to adapt and deal with the changes in order to maximize survival and to restore a sense of normalcy to their lives.

The patient journey is highly varied among individuals and is largely determined by several factors, namely, patient’s personal characteristics, disease characteristics, and the environment and community surrounding the patient (Bosworth & Steuer, 2011; Sweeney et al., 2009; Purdy & Leedham, 2009; Robinson, 2006; Brooks, 2006; Baker & Graham, 2004). Within a patient’s environment, disease marketing in the mass media plays a role in influencing patient attitudes and coping behaviors. Common disease marketing actions in the mass media such as disease awareness campaigns and direct-to-consumer (DTC) drug advertisements could exert their effects on patients directly or indirectly through other individuals within the community. To illustrate, disease awareness campaigns can not only directly empower and educate patients regarding their illnesses (Olson 2002, pages 124-144), but they can also educate the community about the disease and reduce social stigma associated with the disease (Rusch et al., 2008), hence indirectly benefiting patients by reducing prejudice and discrimination against them.

The following sections in the background will introduce the patient journey model, outline the factors that influence each patient journey, provide an overview of disease marketing in the mass media and describe the potential ways disease marketing could impact public and patient attitudes and behaviors.

Overview of Patient Journey for Chronic Diseases

Figure 1: Chronic disease patient journey model: Patient path from pre-diagnosis to post-diagnosis outcome



The chronic disease patient journey begins with a definite diagnosis (Figure 1), followed immediately by a period of shock and grief. Feelings of anxiety and fear consume patients as they grapple with their lives suddenly thrown into disarray and are faced with the possibility of disability, disfigurement or death (Boehmke & Dickerson, 2006; Weissman & Worden, 1976; Mullan, 1985; Robinson, 2006). Patients mourn the loss of their former pre-diagnosis healthy selves. Some patients may also undergo a period of denial that could last up to years (Robinson, 2006) before accepting their changed health status.

After the initial phase of grieving, patients begin a process of negotiating a new social identity that incorporates their illness into their personal narratives. During this period, patients start to make sense of their disease and what it means to their day-to-day life and their future plans. Patients need to adapt to a multitude of life changes, ranging from treatment side effects and surgery scars, to disrupted performance in various family, work and social roles (Boehmke & Dickerson, 2006). Moreover, as the disease progresses and

health deteriorates, issues such as poor mobility, pain and fatigue could further limit patients' daily activities and change their future outlook.

Patients' ability to both physically and emotionally adapt to their disease-related challenges influence how well they cope with their illness and their ultimate health outcome. It has been shown that patients who approach their disease with a positive attitude tend to do better compared to those who approach their disease with a fatalistic attitude (Scheier & Carver, 1985; Rustoen & Begnum, 2000). Negative emotional coping is shown to be associated with higher levels of anxiety and depression (Schussler, 1992). Furthermore, Marusic and Goodwin (2006) found that patients who practice maladaptive coping (avoidant and emotional) rather than adaptive coping (rational and detachment) were more likely to have suicide and deliberate self-harm ideations.

Although the stages outlined in the patient journey model are fairly consistent across most chronic diseases, the individual patient experience within each stage could vary tremendously. The variation among patient experiences is largely determined by patients' personal characteristics, disease characteristics and patients' surrounding community and environment.

Factors Influencing Individual Patient Journey Experience in Chronic Illness

1. Patient Personal Characteristics

1.1 Patient's Baseline Self-Concept

Prior to disease diagnosis, every individual has a pre-formed self-concept or self-identity, broadly defined as how one perceives and evaluates oneself (Gecas, 1982). A person's self-concept is made up of the individual's physical, psychological and social attributes.

According to Carl Rogers (1959), self-concept consists of three components:

- i) **Self image** – how one views him or herself. For example, a person could define him or herself based on physical traits such as skin color or height,

social roles such as husband or mother, or personal traits such as cheerful or hardworking. The Twenty Statement Test that assesses self-image found that individuals see themselves mostly through their social roles and personality traits (Kuhn, 1960).

- ii) **Self-worth or self-esteem** – how much value one places on him or herself. An individual could have a positive or a negative view of him or herself. For example, a person with positive self-esteem tends to have greater confidence in his or her own capabilities while a person with negative self-esteem tends to have less confidence in his or her own capabilities.

Four factors that influence self-esteem are how positively or negative others react to a person (more positive reactions from others, greater self-esteem), how one compares to a reference group of individuals (greater improvement over reference group, greater self-esteem), the type of social roles that one assumes (greater prestige associated with social role, greater self-esteem) and the level of identification with social roles and groups that one belongs to (greater identification with social role or group with higher status, greater self-esteem) (Argyle, 1969).

- iii) **Ideal self** – what the person one aspires to become. If there is a mismatch between how one currently sees him or herself and the person's ideal self, the individual is more likely to value him or herself less.

It is not difficult to imagine that a patient's pre-diagnosis self-concept can influence the initial reaction to a diagnosis and disease coping in the later stages of the chronic illness. For example, a patient who has high baseline self-esteem and considers herself tenacious prior to diagnosis is more likely to cope well with the disease. On the other hand, another patient who bases her self-image predominantly on physical appearance is more likely to cope poorly when diagnosed with a physically disfiguring disease. As these examples suggest, each patient's self-concept pre-diagnosis can be wildly different as a result of each individual's unique combination of self-image, self-esteem and ideal self. Each

patient's pre-diagnosis baseline self-concept can inform how the patient deals with the disease, leading to highly variable disease experiences among patients. In general, those who are optimistic and are able to maintain their sense of self in the face of distress tend to cope better than those who are fatalistic and are overwhelmed by challenges (Edgar et al, 1992; Scheier and Carver, 1985; Rustoen and Begnum, 2000).

1.2. Patient's Self-Efficacy

Self-efficacy is another concept that plays an important role in influencing the individual patient journey experience in chronic illness. According to Albert Bandura (1995), self-efficacy is "the belief in one's capabilities to organize and execute the courses of action required to manage prospective situations". In simple terms, self-efficacy is one's belief in his or her own ability to achieve a goal in a given situation.

Similar to self-concept, each individual has a pre-formed level of self-efficacy prior to disease diagnosis. The baseline self-efficacy level is a product of life experiences and socioeconomic factors such as education level, occupation, and wealth. The positive correlation between socioeconomic and self-efficacy levels has been well documented (Boardman and Robert, 2000). According to Bandura (1977), there are four sources of self-efficacy:

- i) **Performance accomplishment** – based on personal mastery experiences, individuals who have repeated successes at a certain task would have higher self-efficacy at the task. Performance accomplishment is a particular important source of self-efficacy
- ii) **Vicarious experience** – individuals may observe others perform certain tasks and then use the observation to inform their own self-efficacy on those tasks. If the model succeeds in those tasks, the observer would have higher self-efficacy on the tasks. Vicarious experience is more effective when a person considers him or herself similar to the model

- iii) **Social persuasion** – individuals could be encouraged or discouraged by others to alter their self-efficacy for a certain task. For example, a person who receives constant encouragement from his peers during a difficult time may believe that he is more able to overcome the adversity as compared to another person who does not receive any encouragements

- iv) **Physiological factors** – unusual stressful moments can cause individuals to feel physiological symptoms of heightened anxiety such as heart palpitations and sweaty palms. Therefore, the level of stress signals felt by individuals may inform them of their level of personal competency. Since the stress signals tend to interfere with good performance, individuals anticipate better performance when they are not tense and overwhelmed with anxiety

The definition and sources of self-efficacy suggest that the notion is closely linked to people's perception of level of personal control. Someone who is confident of his or her ability to control a situation has higher self-efficacy in that situation than another person who does not have the same level of confidence. Bandura (1997) has shown that individuals with differing self-efficacies approach the world in essentially different ways. Individuals with high self-efficacy tend to believe that they are in charge of their lives through their own actions whereas individuals with low self-efficacy tend to believe that their lives are outside of their own control.

Therefore, it is reasonable to expect that patients with higher baseline level of self-efficacy would cope better with their disease as they see their diagnosis as another surmountable challenge. Patients with higher self-efficacy are also more likely to take a proactive stance towards managing their disease, hence leading to a better health outcome. It has been shown that patients who consider their disease to be controllable adopt a more active coping strategy that focuses on dealing with the underlying causes of their diseases (Schussler, 1992).

1.3. Patient's Ability to Renegotiate Identity

Patient journey can also vary based on individuals' ability to integrate their illness into their personal narrative, a storyline that is constructed from a series of events throughout an individual's life. A personal narrative is a critical component of one's personal identity as the narrative provides meaning to a person's everyday interactions. The formation of the narrative is an open-ended, ongoing process that undergoes constant evolution (Mathieson and Stam, 1995). Simply stated, having a personal narrative helps individuals to answer the question, "Who am I?" and to navigate life with a sense of order and direction.

However, the diagnosis of an unexpected chronic illness throws a life of sensible order into chaos, even if only momentarily. The life-course of formerly healthy individuals are forcibly interrupted, and in most cases, permanently altered. Individuals have to suddenly undergo new treatment regimens that disrupt their daily routines, deal with disrupted relationships as a result of their illness and even re-evaluate their life priorities. This kind of abrupt change to a person's life-course threatens to invalidate the individual's conception of his or her self-identity. For example, cancer patients have described feelings of lack of fit between their healthy and post-diagnosis selves and that they noticed the discrepancies between their pre- and post-diagnosis lives even early on in the course of their disease (Mathieson and Stam, 1995).

In order for patients to regain their personal identity, a sense of coherence in their lives and begin to come to terms with their illness, they have to reconstruct a new personal narrative that takes their illness into account and reconcile the new narrative with the their life stories prior to illness. This narrative re-evaluation is necessary because the former meanings upon which individuals based their lives on when they were healthy is no longer available to them post-diagnosis (Mathieson and Stam, 1995). The process of re-negotiating a new identity to include their illness allows patients to "give meaning to the disease", providing a vehicle for patients to make sense of not only their illness but also their lives (Mathieson and Stam, 1995).

Patients who are better able to integrate their disease into their personal narratives and realign their pre- and post-diagnosis identities are anticipated to accept their altered health status sooner and better. Rather than being in denial, patients acknowledge that their life-course has changed. Patients' acceptance of their illness allows them to start coping with their new health condition and its impact on their daily lives. Better coping also means that these patients are more likely to have better emotional health and adopt health seeking behaviors, leading to better overall health outcome. Patients who are less able to renegotiate their identity post-diagnosis, in contrast, would have a very different experience. They would more likely have a prolonged period of denial followed by poor coping and ultimately, poor health outcome.

2. Chronic Disease Characteristics

2.1. Disease Severity

The patient journey is highly influenced by disease severity. Chronic conditions that have higher severity are expected to have a greater negative impact on patients' lives. Differences in disease severity could be considered in two ways. The first way is two distinct diseases that pose different threat levels to patient survival or normal functioning. In this context, ALS or Lou Gehrig's disease is a more severe disease than Crohn's disease because ALS has a greater threat to survival and can cause greater physical impairments to the patient than Crohn's. The second way is the same disease with different levels of threat to survival or normal functioning. An example would be stage I cancer versus advanced stage metastatic cancer. Patients with severe disease are more likely to have worse prognosis, to undergo more intensive medical intervention and experience greater physical disabilities, hence they are likely to have a harder time coping with their illness.

2.2. Disease Noticeability

The extent of disease noticeability could impact a person's patient journey by increasing disease salience, causing greater patient stigmatization and greater stress. A disease could be noticeable through visible physical disfigurements such as skin rash, interference in daily activities such as inability to walk due to joint pain from lupus, or other behaviors that suggest the presence of an illness such as medication use. A noticeable disease not only makes patients' affliction obvious to others, but it also makes the disease more salient to the patients themselves. For example, a patient suffering from rheumatoid arthritis is constantly reminded of her condition every time she sees her deformed fingers and experience restricted mobility due to joint stiffness and pain. People around the arthritis patients would be privy to her condition by seeing her deformed fingers. By comparison, chronic hypertension is likely to be less salient to a patient since the condition is not visible to the eye and does not usually cause obvious symptoms. Similarly, others would not know about the patient's hypertension just by observing her.

High disease noticeability can lead to patient stigmatization. A person who has a conspicuous illness is more likely to be socially stigmatized than another person who is able to conceal the illness. Erving Goffman (1963) defines stigma as "an attribute that is deeply discrediting" and can reduce the stigmatized person "from a whole and usual person to a tainted, discounted one". An individual with an illness is viewed to have a shortcoming that makes the person different and inferior compared to other healthy individuals. Stigmatized individuals could experience loss of status, social exclusion, and discrimination (Corrigan and Watson, 2002). Stigma has been suggested to cause chronic stress and increased depression since it puts individuals at an enormous social disadvantage (Link and Phelan, 2006; Quinn and Earnshaw, 2011). Chronic stress not only puts patients directly at risk for developing other stress-related diseases, but it also indirectly leads to worse health outcomes as individuals try to conceal their diseases. For example, patients may delay seeking medical care or forgo seeking care altogether for fear of being labeled with the disease. For those already diagnosed, they may become non-compliant with their treatment (Link and Phelan, 2006).

It is important to note that regardless of disease noticeability, there is a base level of disease-associated stigma that varies significantly across diseases. In general, patients with diseases that are strongly associated with negative stereotypes such as HIV/AIDS and schizophrenia tend to face greater stigma than patients with diseases that lack those negative stereotypes such as cardiovascular disease. However, having a high-stigma disease alone is insufficient to cause patient stigmatization. The disease needs to also be noticeable or known to others in order for patient stigmatization to take place.

Overall, diseases with greater noticeability tend to exert a greater negative impact on patients' social and personal lives due to increased disease salience and increased patient stigmatization. Consequently, patients are likely to have poorer disease coping and have worse emotional and physical health outcomes.

3. Patient Community and Environment

Patient's community and environment also play an important role in shaping the individual's disease experience. Depending on the country and neighborhood where a patient lives, the community could be very different in its culture, beliefs and norms. The prevailing community culture and norms play a big role in shaping the patient disease experience by influencing the patient's attitudes and behaviors towards different diseases.

The two main ways the community can affect a patient's disease experience are through experienced and anticipated stigma. In the next three sections, we will explain the difference between experienced and anticipated stigma and their relationship with the patient disease experience, followed by a section on how social and cultural norms affect patient anticipated stigma and finally, a section on how mass media representations affect patient anticipated stigma.

3.1. Experienced Stigma, Anticipated Stigma and Their Relationship with the Patient Disease Experience

An individual who resides within a community could learn about stigma in two ways, one way is to have personally experienced the effects of stigma such as discrimination and social exclusion, also termed “experienced stigma”. The second way is to have gained the knowledge of negative stereotypes by learning about the beliefs of other members in the community or learn about those stereotypes through the media. In other words, one does not actually have to experience stigma in order to know what is stigmatized in the community. Individuals who have directly experienced stigma or know about the negative stereotypes associated with their identities could learn to anticipate stigma. Anticipated stigma is defined as the expectation of receiving mistreatment if a person’s concealed stigmatized identity is exposed (Quinn and Earnshaw, 2011).

Even though experienced stigma is important, anticipated stigma is believed to be the stronger predictor of behavioral outcomes. The effects of experienced stigma on patient attitudes and behaviors are believed to be mediated through its relationship to anticipated stigma. More specifically, individuals who have experienced discrimination or social distancing due to overt signs of illness are more likely to anticipate stigma in the future. As a result, these individuals conceal their illness to prevent future mistreatments (Quinn and Earnshaw, 2011). For example, a study showed that lupus erythematosus patients who have previously experienced stigma rely on cosmetics and clothing to camouflage their skin rash, swelling, hair loss and other observable physical changes caused by the illness. In addition, some of these patients also isolate themselves in their own homes in order to avoid being seen during periods of disease flare-ups. The same patients reported feeling socially withdrawn and depressed (Hale et al., 2006).

Anticipated stigma is inversely correlated with health seeking behaviors that are associated with disease disclosure (Quinn & Earnshaw, 2011). For example, patients who strongly anticipate stigma are likely to avoid seeking social support, medical care or physical assistance - situations that may require them to reveal their stigmatizing medical

condition. This may consequently lead to poorer mental and physical health outcomes among those patients. A study on the effect of stigma on chronically ill individuals showed that those who anticipated greater stigma from healthcare workers were less likely to seek medical care when they need it (Earnshaw & Quinn, 2012). Anticipated stigma has also been shown to increase the level of reported illness among patients with concealed stigmatizing disease (Quinn & Chaudoir, 2009).

3.2. Influence of Social and Cultural Norms on Anticipated stigma

As we have alluded to in the previous section, the social and cultural norms of the patient's community have a big influence in determining whether a disease is perceived positive or negatively. Any disease that is associated with social deviance in the context of the patient's local or larger community tend to carry greater stigma. For example, HIV/AIDS remains a stigmatizing disease in the US, due to its associations with sexual promiscuity, drug abuse and homosexuality – behaviors that are widely known to be socially unacceptable within the American culture. It not surprising then, that individuals living with HIV/AIDS are often subject to discrimination (Herek et al., 2002). Consequently, whether through experienced stigma or through knowledge about American social norms, HIV/AIDS patients in the US are more likely to anticipate stigma from others.

As social and cultural norms evolve over time, the level of stigma associated with a disease can change. For example, breast cancer was considered a taboo subject in the US up until 1970's when the only treatment option for women were highly disfiguring Halsted radical mastectomies. As the women liberation movement took hold in the US in the 1970's, it spurred a change in attitudes and in treatment approaches towards breast cancer. Knowledge of the disease improved and newer, less-invasive techniques became available, and the stigma associated with breast cancer declined (Olson, 2002, pages 27-124). What was once a closeted disease for women, breast cancer in the present day is an openly discussed disease. Modern day breast cancer patients are empowered to speak up and seek treatment. They also anticipate less stigma than ever before.

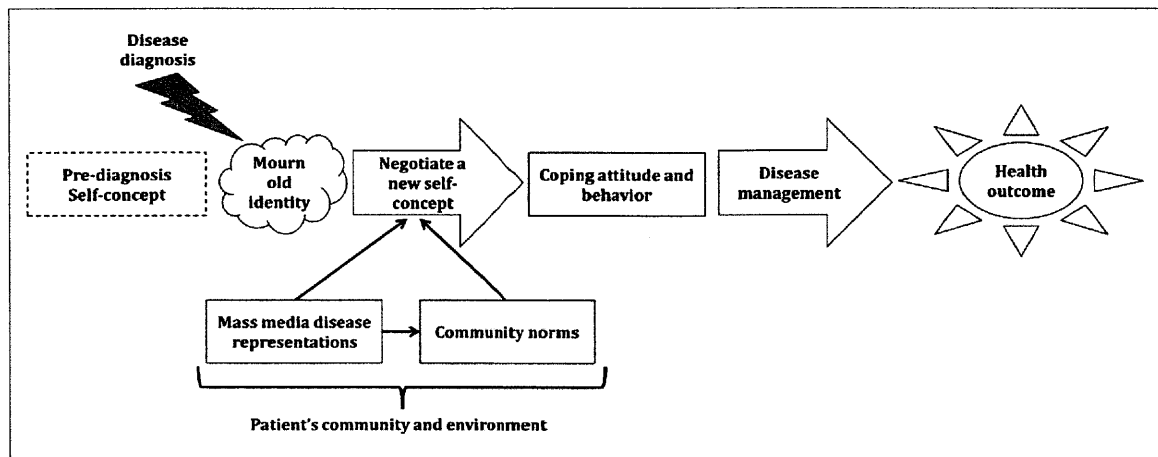
3.3. Influence of mass media representation on anticipated stigma

Mass media also plays a critical role in influencing societal attitudes towards diseases. Disease depictions are frequently seen on television, film, radio, internet, newspapers and magazines in the form of advertisements, entertainment or news. Consistent, biased portrayals of diseases could create or perpetuate certain public impressions regarding those diseases. For example, the popular movie *American Psycho* released in 2000 and the highly publicized Virginia Tech massacre news in 2007 negatively portrays mentally ill patients as dangerous. Although the majority of individuals with mental illness are neither dangerous nor violent (Link et al., 1999; Swanson et al., 1990), the media focus on negative portrayals of mentally ill patients continues to reinforce the public perception that mental illness is associated with violence. As a result, individuals who are living with mental illness and or have a previous history of mental illness highly anticipate stigma and are likely to conceal their health condition.

If the media could reinforce negative disease stereotypes, it could also counter negative disease stereotypes by presenting positive images of patients and information that educates the public on the disease. The breast cancer awareness campaign is a good example for illustrating this point. The explosion of breast cancer awareness advertising in mainstream media beginning in the 1990's played a significant role in accelerating the reduction of breast cancer stigma by generating support, recognition and respect for breast cancer patients (Klawiter, 2004). This increased publicity, along with increasing medical knowledge and changing gender norms in the US (Olson, 2002, pages 124-144) transformed breast cancer from being a high-stigma disease in the 1960's to being a low-stigma disease in the present day.

Overall, each patient's community and environment can have a strong influence on his or her disease journey experience. The key factors that shape the patient's experience are the community norms and culture, as well as disease representations in the mass media (figure 2). In the next section, we will provide a background on disease marketing in the US and how it affects public and patient attitudes.

Figure 2: Influence of Patient’s Community and Environment on Patient Journey



Disease Marketing in the United States

Disease marketing is prevalent in the US mass media. Common marketing actions range from drug advertisements to disease awareness promotional activities such as charity walks and fundraisers. Drug and disease awareness advertisements are frequently seen or heard in media outlets such as television, radio, internet and print media while disease awareness activities such as the American Cancer Society Relay for Life and the Avon Walk for Breast Cancer have involved millions and thousands of participants respectively (Avon Walk for Breast Cancer, 2012; American Cancer Society, 2009).

The disease marketing actions found in the US usually feature diseases in order to achieve one of the following goals: increase public awareness around a certain disease, or promote a specific product or service, such as a drug, medical device or hospital services. Majority of disease marketing and branding campaigns, whether focused on promoting a product or raising disease awareness, tend to generate support for patients. For example, Pfizer’s direct-to-consumer (DTC) advertising for Viagra promoted the drug by focusing on the message that erectile dysfunction is a medical problem that affected even powerful men like former senator and presidential candidate Bob Dole and baseball athlete Rafael Palmiero and that the health condition could be fixed with Pfizer’s drug. Pfizer’s advertising strategy essentially decoupled issues of masculinity related to sexual performance from sexual impotence, allowing erectile dysfunction to be viewed as a

medical issue that does not threaten a man's masculine self-esteem (Conrad & Leiter, 2004). Even though Pfizer's primary goal for its advertising campaign is to increase Viagra sales, the advertising campaign also reduced the stigma associated with erectile dysfunction, allowing men with the issue to come out and seek help. In general, disease marketing in the US could be broken down into three categories, namely advocacy marketing, pharmaceutical DTC marketing and cause-related marketing (CRM).

1. Disease Advocacy Marketing

Disease advocacy marketing is usually run by non-for-profit disease advocacy organizations such as the Leukemia and Lymphoma Society and the American Heart Society. Disease advocacy marketing campaigns frequently focus their marketing messages on raising disease awareness, soliciting financial donations and rallying support for patients. The marketing strategy employed by disease advocacy organizations makes sense given that their primary missions often include disease education for patients, physicians and the general public, fundraising to support disease-related activities such as treatment research, patient welfare advocacy and providing disease-related resources to patients and healthcare providers (Nijsten and Bergstresser, 2010).

2. Pharmaceutical Direct –to-Consumer (DTC) Marketing

Pharmaceutical DTC marketing is commonly carried out to increase physician prescriptions of a marketed drug by increasing patient demand for the medication. DTC advertising is ubiquitous in the mass media. For example, drugs such as Abbott Laboratories' Humira and Eli Lilly's Cymbalta, are heavily advertised in magazines and television. The DTC marketing industry has grown significantly since the Food and Drug Administration (FDA) first relaxed its regulations in 1997 to allow pharmaceutical DTC advertising on television (Donohue et. al, 2007). DTC advertising spending in the US in 2010 was estimated at \$4.2 billion, representing a 620% increase from \$700 million spent in 1996 (Sulik, 2011; Ad Age Insights, 2010). Although DTC marketing's primary aim is to increase drug sales, it indirectly increases disease awareness by referencing the

illnesses that are treated by the marketed drugs. In some cases, DTC marketing also leads to reduction of disease-associated stigma (Conrad & Leiter, 2004).

3. Cause-Related Marketing (CRM)

CRM is a form of marketing that ties a product, service, brand or company with a social cause. Usually, a portion of the sales revenues is donated towards the cause. An example is Yoplait Yogurt's partnership with the Susan G. Komen Breast Cancer Foundation. In the partnership, Yoplait Yogurt's parent company, General Mills, pledged to donate ten cents to the foundation for breast cancer research for every cup of yogurt sold. Yoplait's "Save Lids to Save Lives" campaign with Susan G. Komen Foundation has been tremendously successful in raising Yoplait's brand image and sales while increasing breast cancer awareness. By 2005, the partnership generated over \$12 million for the foundation's research activities (Berglind and Nakata, 2005). CRM marketing is a big industry in the US, IEG reports that total CRM spending by North American companies in 2011 is estimated at \$18.1 billion (IEG, 2012).

The explosion of CRM since the first CRM campaign between Marriott Corporation and March of Dimes in 1967 (Chong, 2010) has also resulted in several highly recognized disease brands and symbols due to widespread co-branding. For example, Product RED, a brand founded by the U2 musician, Bono, and the former mayor of the city of Santa Barbara, Robert Shriver, became ubiquitous and highly synonymous with AIDS awareness after extensive co-branding with popular retail brands such as GAP, Nike, Starbucks and Dell (MSNBC news website, 2007; The Global Fund to Fight AIDS, Tuberculosis and Malaria website, 2012). Similarly, the pink ribbon and pink color became highly recognizable symbols for breast cancer awareness after Susan G. Komen Foundation extensively partnered with corporations to co-brand items with the foundation's pink ribbon logo. As a result of these partnerships, the pink ribbon logo and its breast cancer association became highly ubiquitous in the public and are seen on a diverse selection of items, ranging from New Balance shoes to Kitchen Aid mixers (Singer, 2011).

Disease Marketing Impact on Public Perception and Attitudes Toward Diseases and Patients

Disease publicity plays an important role in influencing public perceptions about diseases (Young, et al., 2008; McMenamin et al., 2005) and patients. Significant marketing around a disease could heighten public disease awareness and shape people's perception of the disease's prevalence and severity. For example, breast cancer has received significant media attention since the early 1980's and became one of the most frequently reported cancers in the media (Braun, 2003; Marino and Gerlach, 1999). Surveys on perceptions of breast cancer showed that many women believe that breast cancer is the leading cause of death among women in the US (Mosca et al., 2004) Unsurprisingly, American women fear breast cancer the most, even though heart disease remains the biggest killer of women in the US (Wider, 2005). In addition to raising disease awareness, disease marketing could impact public opinions on a disease by increasing public knowledge about the disease, increasing patient – non-patient interactions, and projecting certain patient images.

Disease marketing could be used to educate the public and reduce misconceptions and stigma associated with a disease. For example, disease advocacy advertisements that include disease statistics can inform the public about the actual prevalence and severity of a disease. These advertisements may also educate the public on disease causes, risk factors and where to seek care. Increased general knowledge about a disease may remove disease misconceptions and reduce social stigma surrounding the disease. A 2009 survey conducted by Kaiser Family Foundation showed a positive correlation between misconceptions related to HIV transmission and stigmatizing attitudes. In the same study, findings point towards signs that HIV/AIDS may carry less stigma in the US today than in the past. For instance, 44% of the survey respondents say that they would feel comfortable having a co-worker with HIV/AIDS, up from 32% in a similar survey conducted in 1997. The reduction in HIV/AIDS stigma in the US may be related to increased knowledge about the disease. Herek and colleagues (1997) indicated that

HIV/AIDS education in the US has been somewhat effective in communicating how HIV is transmitted. In the study, virtually all subjects knew that HIV could be transmitted by needle-sharing and unprotected sexual intercourse with infected individuals. The proportion of study subjects who believed that HIV could be spread through the casual contact of kissing on the cheek also slightly decreased from 17% in 1991 to 13% in 1997, an indication that certain myths around HIV transmission were slowly being cleared up.

Disease marketing could also increase patient – non-patient interactions, potentially removing negative stereotypes associated with a disease and improving public attitudes towards the disease. For example, disease marketing events such as charity walks and dinners often bring together patients and non-patient supporters. During these events, non-patients have the opportunity to personally interact with patients, allowing non-patients to increase their knowledge about the disease, reduce their anxiety regarding contact with patients and develop greater empathy for patients (Pettigrew & Tropp, 2008). Moreover, studies have shown that lack of contact between patients with stigmatizing disease such as HIV/AIDS are associated with increased prejudice, stereotyping and discrimination (Genberg et al., 2007; Hamra et al., 2005; Zelaya et al., 2008).

In addition to facilitating direct intergroup contact between patients and the public, disease marketing also provides opportunity for indirect contact between the two groups of individuals through media campaigns. One example is the “In Our Own Voice” campaign launched by National Alliance of Mental Illness in 2008, whereby individuals living with mental illness share their personal stories to audience members. Early assessment of the program suggests that it reduces prejudice among community members more than public education alone (Rusch, et al., 2008). Another example is the media campaign is carried out by the Avon Foundation for Women to promote its “Walk for Breast Cancer” event that takes place annually in nine different cities in the US (Avon Walk for Breast Cancer website, 2012). The Avon Walk for Breast Cancer advertisements are commonly seen in women magazines and they frequently feature images of breast cancer survivors. Media campaigns are believed to reduce stigma the

same way as person-to-person contact does, which is through increased knowledge, empathy and decreased anxiety in the presence of patients (Pettigrew & Tropp, 2008).

While the presence of disease marketing alone may impact public perceptions about different diseases, the images and narratives projected by those marketing actions also play an important role in shaping public perceptions about diseases and patients. For example, print advertisements for depression drugs, such as Eli Lilly's Cymbalta and AstraZeneca's Seroquel, frequently feature the image of a "victim" (figure 3) – an individual who looks helpless, haggard, and defeated by his or her illness. Cancer print advertisements, on the other hand, frequently feature images with themes of survivorhood and victory against illness. Such images are seen in advertisements carried out by the Stand Up To Cancer Organization and the Avon Foundation for Women (figure 4). For the advertisers, those images may be effective in generating public sympathy and empathy for patients, which could translate to increased public support and donations. However, those images and narratives are frequently biased and oversimplified, creating stigmatizing disease stereotypes and unrealistic expectations regarding patient behaviors. In the case of depression, someone with little knowledge about the disease may be led to expect that individuals suffering from depression have low self-efficacy and weak character after consistently being exposed to the "victim" images in the media. In the case of cancer, the same person may be led to expect that individuals living with cancer have high self-efficacy, are optimistic and are capable of fighting the disease. Therefore, when a cancer patient does not adopt a positive and can-do attitude towards battling the disease, the patient could be faced with social stigma because his or her attitude does not fit with the images projected in the media (Ehrenreich, 2001).

Figure 3: Sample Depression Print Advertising

Figure 4: Sample Cancer Print Advertising

Overall, disease marketing plays a significant role in shaping the public perception of a disease by educating the public, facilitating intergroup interactions between patients and the public, and projecting certain patient images and narratives in the media. Those

perceptions, could affect the level of stigma associated with a disease and could in turn lead to discrimination and prejudice against patients with that disease.

Disease Marketing Impact on Patient Perception and Attitudes Towards Their Diseases and Themselves

Disease marketing can also have a direct impact on patient perceptions about their disease and themselves. Marketing actions around a disease could have both positive and negative effects on patient perception and attitudes. Positive effects of disease marketing on patient perceptions include reduced anticipated and experienced stigma, increased patient empowerment, increased perception of support. Two potential negative effects of disease marketing on patient are increased patient self-stigma when projected patient images in the media do not fit with the actual patient and increased perception of disease severity.

A major positive effect that disease marketing has on patients is that it could lead to reduced experienced and anticipated stigma by patients. A reduction in stigma can benefit patient in numerous ways but the two main ways that will be discussed here are improved patient psychological wellbeing and increased disease disclosure behavior. Increased publicity around a disease can reduce social stigma associated with the disease, patients therefore experience less discrimination when others know about their health condition. For those who have concealed diseases, they can anticipate less stigma and more supportive reactions if their condition is revealed to others. Less discrimination and less fear of disease disclosure lead to reduced stress and anxiety among patients (Quinn and Earnshaw, 2011).

Moreover, disease marketing that counters negative stereotypes associated with a disease may help reduce internalized stigma among patients, further improving their psychological wellbeing. Improved psychological wellbeing could in turn, lead to better disease coping and ultimately, better health outcome for patients. As patients experience and anticipate less stigma, they become more likely to disclose their illness. Patients'

greater openness to disease disclosure would promote better psychological health since non-disclosure behavior is believed to be a barrier for patients in seeking social support (Quinn and Earnshaw, 2011). Patients who are less afraid to disclose their health condition due to reduced stigma may also be more likely to seek medical care and have better healthcare utilization (Quinn and Earnshaw, 2011). Therefore, increased disclosure behavior not only promotes better psychological wellbeing among patients, but also better physical health outcome.

Patient empowerment is another positive effect that disease marketing can directly have on patients. The best example of this is in the area of breast cancer, a disease that is highly marketed and advertised in the US. In the first three weeks of February 2012 alone, Susan G. Komen Foundation ran almost 10,000 radio and television advertisements while Avon Foundation for Women aired about 6,000 commercials on its breast cancer awareness and research walks (Sullivan, 2012). Moreover, during the National Breast Cancer Awareness Month that takes place in October each year, many other corporations and charitable organizations join in the breast cancer awareness campaign and run their own breast cancer-related advertisements and marketing efforts (Levere, 1996). The significant publicity around breast cancer awareness has led to reduced stigma, increased patient knowledge and ultimately, patient empowerment (Olson, 2002, pages 124-144). The modern day marketing-driven breast cancer movement has resulted in the acceptance of second opinions, spread of support groups and other resources for patients, as well as advances in less invasive surgeries. As a result of the increased support and knowledge, breast cancer patients in the present day have the capacity to actively engage in their own care as opposed to being passive patients in a paternalistic care model (Olson, 2002, pages 171-220). Patients who proactively engage in their own care may have a better sense of control over the disease, which in turn increases their sense of self-efficacy. Increased self-efficacy could then improve patients' attitude towards the disease and motivate them to adopt health seeking behaviors, ultimately improving their health outcome.

The third positive effect that disease marketing can have on patients is the increased perception of support from others. The attention created by marketing actions on a particular disease can generate the perception that the disease is important, and that the general community cares about the disease. The increased sense of support from others can lead patients to anticipate more empathy from others. Simply stated, patients will come to expect others to be more empathetic and understanding of their situation if their health condition is revealed. This perceived sense of support, combined with reduced stigma, could further reinforce pro-health behaviors among patients. For example, they are more likely to seek help or reveal their medical condition when needed as they have less fear of experiencing prejudice and greater anticipation of a supportive response. Therefore, increased perception of support from others could reinforce other health-promoting behaviors that result from disease marketing i.e. increased patient empowerment and increased disease disclosure, resulting in better health outcome for the patient.

While high levels of marketing around a disease bring many benefits to patients, it can also have some negative consequences for patients. One main negative effect that can result from disease marketing is the increased potential for self-stigma when the images projected in disease marketing do not fit with the image of an actual patient. Patient experience can vary tremendously from person to person based on patient background, experience and disease characteristics. However, mass media projections of patient images are often one-dimensional and oversimplified, hence they fail to fully represent the broad spectrum of disease and patient presentations that exist in the real world. As a result, the patient images and narratives that are featured in the media can sometimes be unrealistic for many patients.

This can be illustrated by the use of Lance Armstrong as a role model in the Livestrong campaign against cancer. Lance Armstrong, an American road racing cyclist who won the Tour de France seven consecutive times after surviving metastasized stage three testicular cancer (Majendie, 2005), is also well known for his public battle with cancer. Armstrong offers a story that is counter-stereotypical to most cancer patients, one where

he was not only able to overcome a life-threatening illness, but also win arguably the most grueling sporting event in the world, multiple times, no less. An excerpt of Armstrong's story from the Livestrong website (2012) describes his reaction to his cancer diagnosis, "Then a combination of physical conditioning, a strong support system and competitive spirit took over. He declared himself not a cancer victim but a cancer survivor. He took an active role in educating himself about his disease and the treatment. Armed with knowledge and confidence in medicine, he underwent aggressive treatment and beat the disease." Armstrong's ability to defiantly and aggressively take charge of his illness, along with his Tour de France wins as a cancer survivor has been a source of inspiration for many patients (Triplett, 2004). Armstrong's story has been tremendously successful in generating public support for the cancer cause, having raised \$61.5 million through his foundation between 1996 and 2005 (Ruibal, 2005).

While Armstrong is considered by many to be an aspirational figure, he is hardly representative of the average cancer patient. Therefore, using him as a cancer survivor role model may set unrealistic expectations for the average cancer patient. Armstrong's role in the Livestrong campaign sends the message that for someone to become an exemplary survivor, the person must be strong and determined, take rational actions, engage in battle, have faith in medicines and win. Moreover, individuals are encouraged to render their illness invisible (Sulik, 2011 pages 82-89), concealing signs of weakness or distress. As the Livestrong campaign is one of the more dominant anti-cancer campaigns in the mass media, his approach of dealing with cancer could be accepted by many, patient and non-patient alike, as the standard approach to the disease. Patients who are unable to live up to those standards, then, may feel that they have not fought adequately against their illness, and may self-blame for any negative outcomes from their illness, even when it is not justified. This situation causes those patients to experience self-stigma, leading to reduced self-esteem and self-efficacy (Corrigan & Watson, 2002), which in turn affect patients' ability to cope with their illness and ultimately negatively impacting their overall health outcome.

Another potential negative effect from disease marketing for patients is the increased perception of disease severity. For example, several studies have shown that the great amount of media attention around breast cancer has led women to believe that their risk of dying from breast cancer is much higher than it actually is (Smith et al., 1996; Black, Nease & Tosteson, 1995; Blakeslee, 1992). As a result, breast cancer patients may overestimate their risk of dying from the disease and experience increased fear and anxiety, leading to potentially poorer disease coping.

In summary, disease marketing in the US could have both positive and negative effects on patients either directly or indirectly through patients' surrounding community. Many of these effects are mediated through anticipated or experienced stigma and could have far-reaching consequences on patients' coping behavior and ultimately, their health outcome.

Chapter 3: Thesis Objectives and Methodology

Thesis Objectives

Disease marketing is highly prevalent in the US mass media and is commonly used to promote disease awareness, increase support for certain populations and promote sales of medical products and services. Disease advocacy activities such as charity walks, DTC pharmaceutical drug advertisements and hospital advertisements are among the most ubiquitous forms of disease marketing.

While many studies have shown that high disease publicity in the mass media can influence public perceptions regarding chronic diseases and certain patient populations (Williamson et al., 2011; Gottlieb, 2001; McMEnamin et al., 2005), no study has examined the direct effect of disease marketing actions on the coping attitudes and behaviors of patients living with chronic illnesses. We hypothesize that the presence of disease marketing can affect patient coping attitudes and behaviors and that those effects are mediated by the level of stigma anticipated by patients. Therefore, the goal of this thesis is to investigate whether the mere presence of disease marketing can affect patients' perceptions of their chronic disease and their coping and disease disclosure behaviors. Furthermore, if such an effect is present, we would like to explore how patients' coping attitudes and behaviors are affected by the presence of disease marketing. Our study is approved by the MIT Committee on the Use of Humans as Experimental Subjects (protocol #1202004896).

In order to answer our research questions, we conducted an experiment consisting of two online questionnaires. In both questionnaires we presented a vignette that describes a fictional chronic disease called Karlsen's Disease (KD) and asked research subjects to imagine themselves as having been diagnosed with the disease. We then presented the subjects with a series of scenarios in which they are asked to make decisions on coping behavior. From their indicated behaviors, we could infer their underlying attitudes towards their disease. Both online questionnaires in the experiment were identical except for the images shown to the subjects. In the experimental questionnaire, subjects were

shown KD-related marketing images and were told that marketing activities were carried out to promote KD awareness. In the control questionnaire, subjects were not shown any marketing images and there was no mention of any KD-related marketing activities. The difference in subject responses between the two questionnaires could be attributed to the presence or absence of disease marketing activities. We then used Stata statistical software to analyze the difference in responses between the subjects in the high-marketing group and subjects in the no-marketing group.

Online Questionnaires

The online questionnaires in our experiment specifically measure subjects' perceptions about disease, disclosure and coping behaviors when they are placed in the position of a patient who is suffering from chronic Karlsen's Disease. More specifically, subjects are asked to estimate disease prevalence, decide how they would behave and whether they would reveal their condition in different provided scenarios. The questionnaires contained a combination of multiple-choice, sliding scale and Likert scale questions that assessed both health-related behaviors and non-health related social behaviors. In order to encourage subjects to fully imagine themselves as the described KD patient, we used a gender-neutral name, "Drew", in the questionnaires. We also referred to Drew as "he/his" or "she/her" based on the subjects' indicated gender. The questionnaires were designed using Qualtrics online survey software.

The KD description is designed to simulate early stage cancer, a life-threatening disease with uncertain prognosis. Moreover, we chose to simulate cancer because it is among the most highly marketed diseases in the US. The 92% 5-year survival rate (please see the next section) that we presented for KD in the questionnaires is based on the published overall 5-year relative survival rate for melanoma patients (National Cancer Institute SEER website, 2011). We employed a fictitious disease as the stimuli in our questionnaire so that we could control for the differences in disease knowledge or level of exposure to disease marketing among our subjects. By using a made up disease, we can be confident that any significant differences in response between the high-marketing and

no-marketing groups result from the level of exposure to marketing activities in the experiment and not due to differences in disease knowledge or disease experience among subjects. To ensure that we do not cause any unnecessary psychological harm to our subjects, we included a full disclosure statement at the end of the questionnaires clarifying that Karlsen's Disease is a fictitious disease.

1. Karlsen's Disease Description and Questions

1.1. Karlsen's disease description:

"This survey is brought to you by American Karlsen's Disease Society (AKDS): AKDS is a US-based organization that advocates for Karlsen's Disease. Karlsen's Disease is a potentially life-threatening disease with no cure and unclear prognosis. But if diagnosed early, there are available treatments to manage the disease.

Research has shown that:

- *Patients under treatment have an average 70% chance of entering remission and an average 5-year survival rate of 92%*
- *Patients **NOT** under treatment have an average 16% chance of spontaneous remission and an average 5-year survival rate of 81%"*

1.2. Marketing prompt in high-marketing questionnaire

"AKDS organizes fundraising events, including annual charity walks and auctions. The goal of the organization is to raise awareness about Karlsen's Disease as well as to raise money. As part of its fundraising efforts, AKDS also sells T-shirts and pins that feature the AKDS logo. All the money raised by AKDS is given out as research grants."

Figure 5: KD-Related Images in High Marketing Questionnaire



1.3. Scenarios and questions in questionnaires:

Note: For full questionnaire, please refer to Appendix

Patient scenario:

“Today we will talk about a scenario that involves a person named Drew who lives in your area. 2 years ago Drew was diagnosed with Karlsen’s Disease. Drew has been able to live with the disease, as a treat program has kept the disease under control and allowed Drew to continue about his/her daily life.”

Questions and other scenarios:

- i. Please estimate the percentage of US population diagnosed with Karlsen’s Disease (Answer options: 0-100% on a sliding scale)*
- ii. Hair loss is one of the common side effects of the drugs that Karlsen's Disease patients take. Drew's doctor has determined that the current drug is the best treatment currently available for Karlsen's Disease. Therefore,*

changing treatment is not an option. Moreover, Drew is advised to continue with the course of therapy, as stopping the treatment may lead to rapid progression of the disease. If you were in Drew's shoes what would you decide to do about your hair loss? (Answer options: multiple choice)

iii. *Given your Karlsen's-related hair loss, please give the extent to which you agree or disagree with the following statement:*

- *If I had complete hair loss, I would ask my family and/or friends to shave their heads out of solidarity (Answer options: Likert scale)*

iv. *Drew's treatment for Karlsen's Disease involves multiple weekly visits to the doctor's office that can be disruptive to a work schedule. Moreover, the medications cause side effects that can cause discomfort and require extra rest. If you were in this situation, would you rather reveal your condition to your boss and take several sick days **OR** would you rather keep your condition a secret and take several vacation days? (Answer options: multiple choice)*

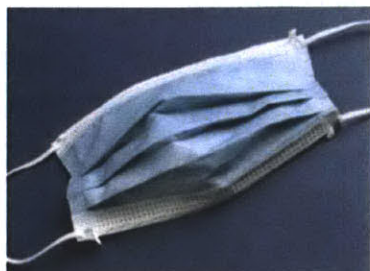
v. *If you were in Drew's situation, please indicate the extent you agree with the following statements:*

- *I will start drafting a will (Answer options: Likert scale)*
- *I will join a patient support group (Answer options: Likert scale)*

vi. *You are advised by your doctor to wear a medical alert ID at all times. One option is to wear a medical alert ID **bracelet**. The bracelet is worn on your wrist and is very obvious to other people. Another option is to wear a medical alert ID **necklace**. The necklace is worn around the neck and could be hidden under a shirt. The bracelet is much more likely to be discovered than the necklace in an emergency. Which medical alert ID would you wear? (Answer options: multiple choice)*

- vii. *You learn that sodium/salt aggravates your symptoms. Your doctor has put you on a sodium/salt-restricted diet to control the swelling side-effect that you occasionally experience from your Karlsen's Disease medication. Every time you consume any foods that is not low in sodium, your legs and face swell up a day later. The swelling causes discomfort and is generally bad for the disease progression, but it is otherwise not immediately life-threatening. Imagine you are invited to a dinner party by your neighbor who you've know for a few months. You feel that you are in fine shape to attend, but the dinner will surely involve foods that have a higher sodium content than is advised by your doctor. Please choose the option below that best describes how you would handle this situation, given the sodium-restricted diet. (Answer options: multiple choice)*
- viii. *What reaction do you anticipate if you were to ask the dinner party host for a menu accommodation? Please indicate how understanding you expect the dinner party host to be. (Answer options: Likert scale)*
- ix. *Once again, please imagine that you are in Drew's situation and you are living with Karlsen's Disease. People with Karlsen's Disease are especially susceptible to bacteria and viruses in their environments. Doctors often recommend that patients wear surgical masks (like the one seen below) in places like airplanes and subways to protect themselves during periods when the illness is most active.*

Figure 6: Surgical mask exhibit in questionnaires



If you are in Drew's position, and assuming that you do not generally travel on airplane or subways with people you know, how likely are you to wear the mask during these occasions?

- *How likely are you to wear a mask when traveling on airplane or subway?(Answer options: Likert scale)*

Subject Recruitment

We recruited 108 subjects via Amazon Mechanical Turk (AMT) website, an internet crowd sourcing web service that coordinates the supply and demand of tasks that require human intelligence to complete (Paolacci et al., 2010). AMT allows individuals to get paid in exchange for completing tasks that are posted on the website. The reason we used AMT as our source of subjects is because the web service allows us to recruit a large number of diverse subjects from throughout the US in a time-efficient and cost-effective manner. Moreover, subjects recruited from AMT have been shown to be comparable to subjects recruited from traditional sources (Paolacci et al., 2010).

In order to obtain a subject pool that is representative of the general US adult population, we pre-screened potential subjects for individuals who meet the following criteria: 21 years of age or older, born and currently reside in the US, have at minimum completed high school and do not work in the healthcare industry. We excluded individuals with healthcare occupations because they are likely to have above average knowledge about diseases and are potentially less susceptible to disease marketing effects. Once subjects passed the pre-screening test, they are randomly assigned to either the high-marketing or no-marketing questionnaire. The subjects are kept anonymous by not collecting any personally identifiable information from them.

Limitations of Methodology

While the vignette technique in our experiment allowed us to control for variables and ask focused research questions, it is not without its limitations. One key limitation is that our subjects are not real patients and may not have experienced the daily challenges associated living with early stage cancer, the disease that KD aims to mimic. However,

we believe that using non-patients as our subjects does not invalidate our research findings for two reasons.

First, we believe that with the high prevalence of chronic diseases in the US, many people either live with some form of chronic illness or know someone else who has a chronic illness. Therefore, they are likely to have some direct or indirect experience with chronic illnesses. Second, we have structured our vignette to describe a patient who has been diagnosed with a chronic disease for only two years. We believe this is a relatively early point in the patient journey, a time where the patient is likely still in the process of renegotiating his or her new identity to transition from being a “healthy person” to a “patient”. We believe that at this point, patients may still have limited knowledge about the disease and the disease’s social status. Therefore, we believe that using subjects who are not real patients helps simulate this disease unfamiliarity.

Another limitation with our research method is that we are unable to capture the complete reality and complexities of living with chronic disease by using a written vignette to stimulate subject responses. Our vignette only provides limited information regarding Karlsen’s Disease and a basic description about “Drew” – the protagonist in the vignette. While it is our intention to limit the information that we provide so that subjects could fill in the gaps with their own experiences, the abstract nature of the stimuli may be difficult for subjects to fully imagine themselves as “Drew”. However, it is important to note that the goal of this research is to not to provide a full answer to the question of how disease marketing affects patient coping attitudes and behavior, but rather, to provide some preliminary findings such that follow-up studies could be carried out in the future to fully answer the question.

Chapter 4: Results

Subject Demographics

The study had a total of 108 subjects with 55 subjects in the high-marketing questionnaire and 53 subjects in the no-marketing questionnaire. The subjects' ages ranged from 21 years old to greater than 55 years old with the majority being younger than 55 years old. Subjects aged 26-35 make up the largest subject segment with 37.9% of the total subject pool. On the whole, the age distribution across the high-marketing and no-marketing groups is fairly comparable. In terms of gender, there were overall more women in our subject pool than men. Women constituted 56.5% of the total subjects and 56.3% of the high-marketing subjects and 56.6% of the low-marketing subjects.

When the subject pool is broken down by education, 96.3% of them have a Masters degree or less and 95.3% have at least some college education. Individuals with a 4-year college degree constitute the bulk of the subjects, making up 42.6% of all subjects. We also recorded subjects' residential location and have grouped them into geographical regions in the US. Subjects are widely dispersed throughout the US, but subjects from the Midwest make up the largest group at 41.7% of total subjects. Individuals from the Northeast and the West Coast only make up 15.7% of the total subject population. Finally, we also assessed the health status of our subjects and 46.3% of the overall subject population are in "excellent health with no known health issues". However, a fairly significant proportion of the subjects, 42.6% of them, said that they have either "good health with minor health issues" or "manageable chronic health issues". Table 1 provides a summary of the subject demographics.

Table 1: Summary of Subject Demographics

Age	High Marketing Questionnaire	No Marketing Questionnaire	Total
21-25	9	12	21
26-35	20	21	41
36-45	14	9	23
46-55	9	8	17
>55	3	3	6
Gender			
Male	24	23	47
Female	31	30	61
Highest Level of Completed Education			
High school	3	2	5
Some college	12	18	30
2-year college degree	7	5	12
4-year college degree	27	19	46
Masters degree	4	7	11
Doctoral degree	2	1	3
Professional degree (JD)	0	1	1
Region of Residence^{1*}			
Northeast	3	6	9
Midwest	21	24	45
West Coast	1	7	8
South Atlantic	12	10	22
East South Central	16	6	22
West South Central	2	0	2
Subject Health Status			
In excellent health with no known health issues	29	21	50
In good health but have previously experienced serious health issues	2	5	7
In good health with minor health issues	13	17	30
Have manageable chronic health issues	9	7	16
Have difficult to manage chronic health issues	2	3	5
In poor health with serious health issues	0	0	0

¹ US region breakdown obtained from US Census Bureau website (2007)

* Reported Northeast states include Connecticut, New Hampshire and New Jersey
 Reported Midwest states include Illinois, Indiana, Michigan, Minnesota, Nebraska and North Dakota
 Reported West Coast states include Alaska, Arizona, California, Colorado, Hawaii and Montana
 Reported South Atlantic states include Delaware, Florida, Georgia, Maryland
 Reported East South Central states include Alabama and Mississippi
 Reported West South Central states include Arkansas and Louisiana

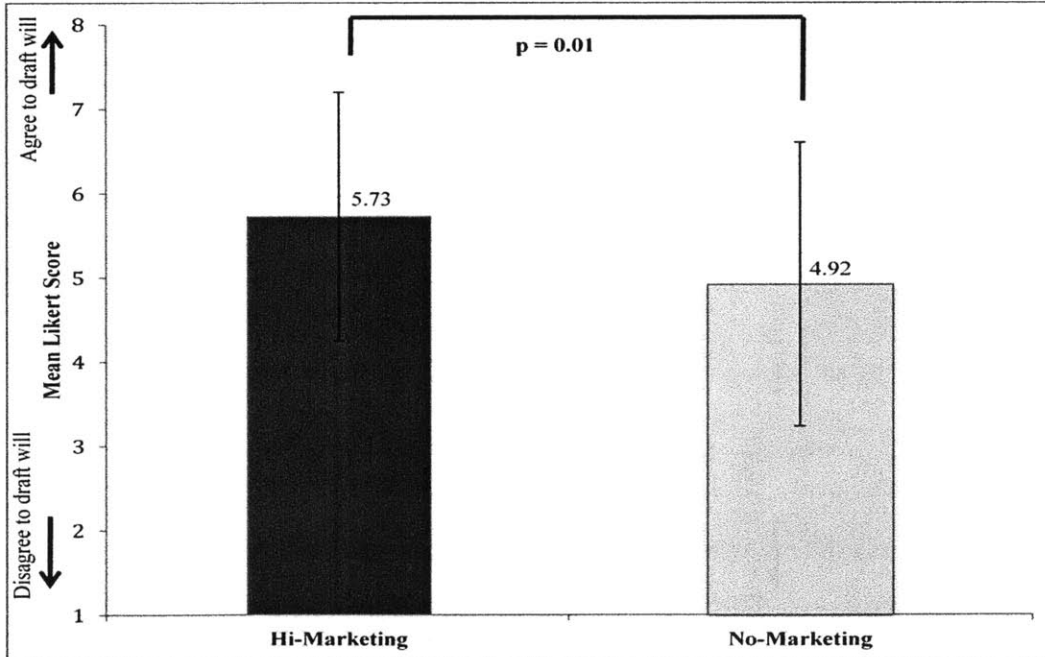
Summary of Findings

1. Marketing Presence Overall Impacts Subject Behavior

In our study, we found four significant overall differences in patient behavior between subjects who were exposed to marketing actions and subjects who were not exposed to marketing actions.

The first key finding from the experiment is that subjects in the high-marketing group were significantly more willing to draft a will than subjects in the no-marketing group, $t(106) = 2.64, p = 0.01$ (figure 7). Individuals in the high-marketing group had an average score of 5.73 on the Likert scale while individuals in the no-marketing group had an average score of 4.92 (on a seven point scale where one is “strongly disagree” to drafting a will while seven is “strongly agree” to drafting a will).

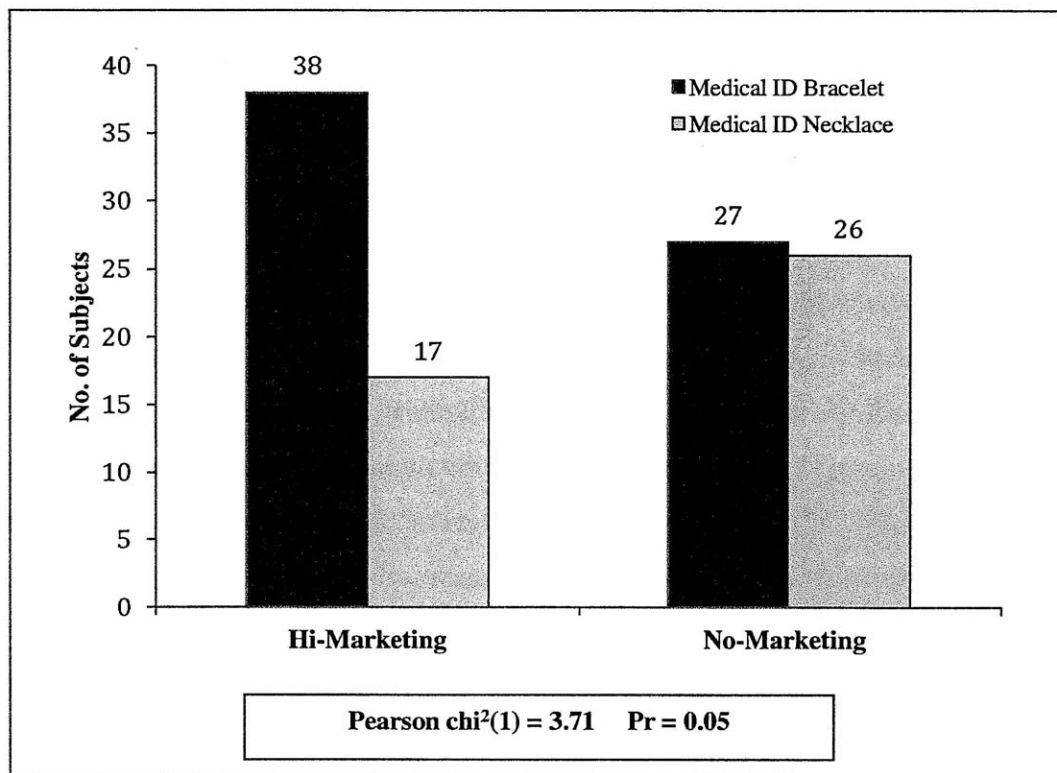
Figure 7: Mean Likert Scores on Willingness to Draft a Will



Note: Error bars denote standard deviation

The second key finding in this study is that there was a significant correlation between the presence of marketing and subjects' choice of wearing a medical alert ID bracelet or a medical alert ID necklace, $\chi^2(1, N = 108) = 3.71, p = 0.05$ (figure 8). The medical alert ID bracelet was described in the questionnaire to be very obvious but also more likely to be discovered in an emergency. On the other hand, the medical alert ID necklace was described to be easily hidden but less likely to be discovered during an emergency. More subjects in the high-marketing group preferred to wear a medical alert ID bracelet to a medical alert ID necklace. Subjects in the no-marketing group, on the other hand, were just as likely to wear a medical alert ID bracelet or a medical alert ID necklace.

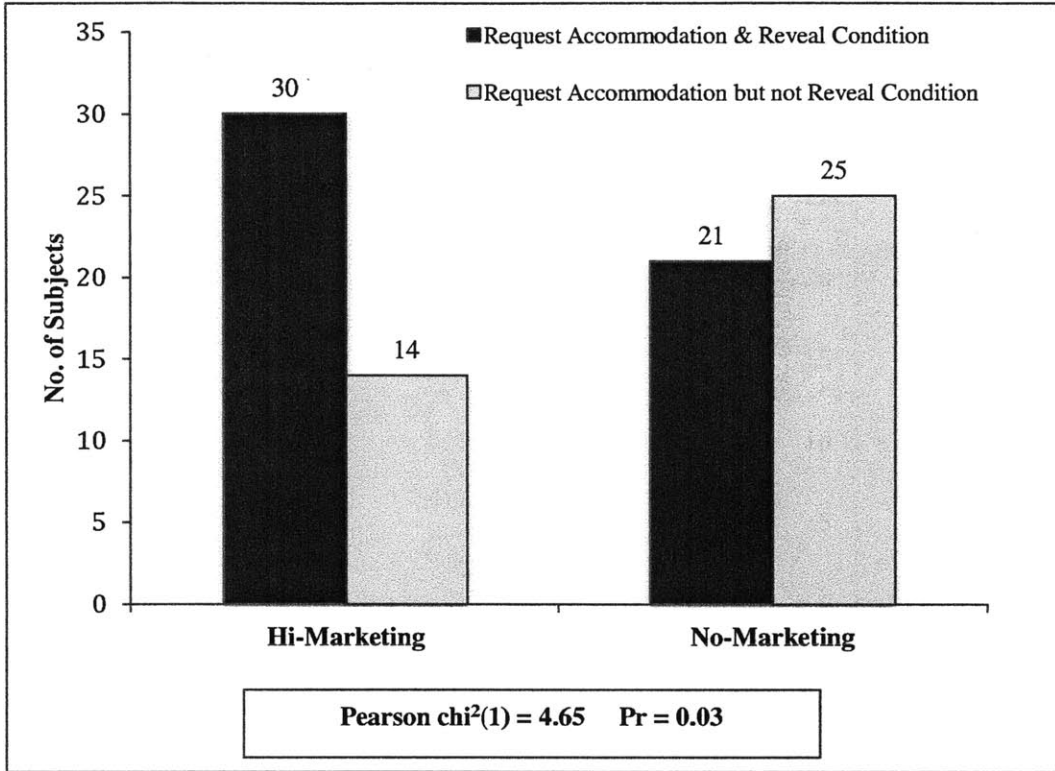
Figure 8: Choice of Medical ID Bracelet vs. Medical ID Necklace Among Subjects



When we asked the subjects whether they would request a dinner party host to accommodate their dietary sodium restrictions into the party menu and whether they would disclose their condition to the host, we found that overall there was no significant correlation between marketing presence and disease disclosure among subjects. However, among those who chose to request a menu accommodation, we found that subjects in the

high-marketing group were significantly more likely to reveal their medical condition than subjects in the no-marketing group $\chi^2(1, N = 90) = 4.65, p = 0.03$ (figure 9).

Figure 9: Disease Disclosure Among Subjects Who Request for Menu Accommodation

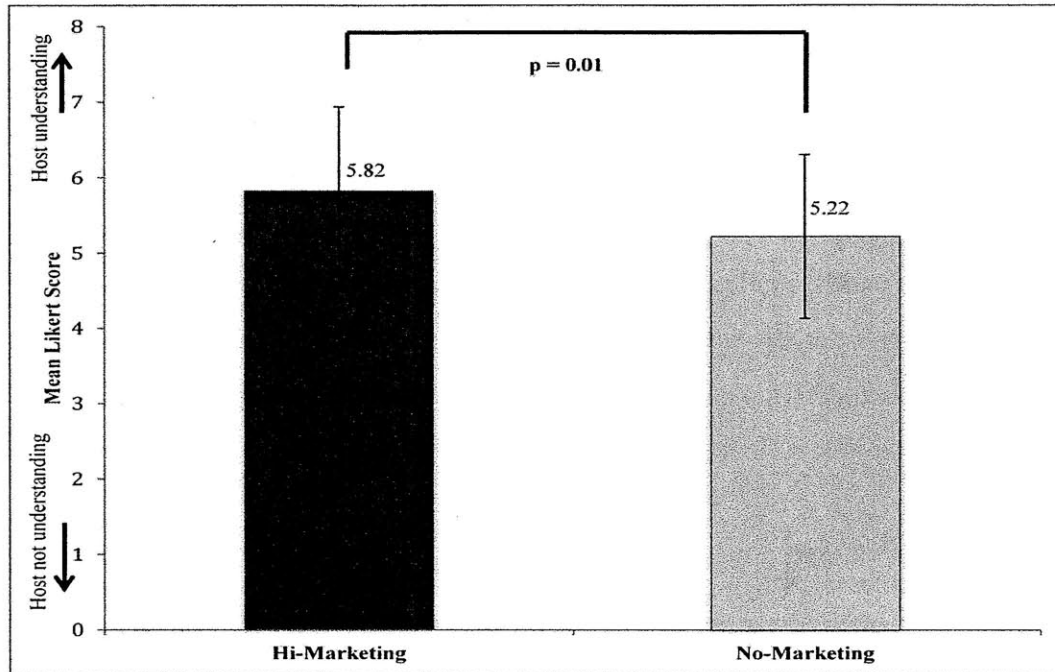


In addition, we posed a follow-up question to subjects who said they would request the menu accommodation, asking how understanding they think the dinner host would feel about their request.

We found that subjects in the high-marketing group were significantly more likely to believe that the host is “very understanding” compared to subjects in the no-marketing group. When we performed an initial analysis of the responses from all subjects who chose to request a menu accommodation, we found that there was no significant difference between the high and no-marketing groups, $t(90) = 1.61, p = 0.11$. However, when we excluded four subjects who were outliers (they were the only ones who selected “2” and “3” on a possible Likert scale of one to seven, where one is “not understanding” and seven is “very understanding”) from our analysis, there was a significant difference between the high-marketing and no-marketing groups, $t(86) = 2.56, p = 0.01$, (figure 10).

The mean Likert score for the high-marketing group excluding the four outlying responses was 5.82 while the mean Likert score for the no-marketing group was 5.22.

Figure 10: Mean Likert Scores on Anticipated Understanding from Dinner Host to Subjects' Menu Accommodation Request



Note: Error bars denote standard deviation

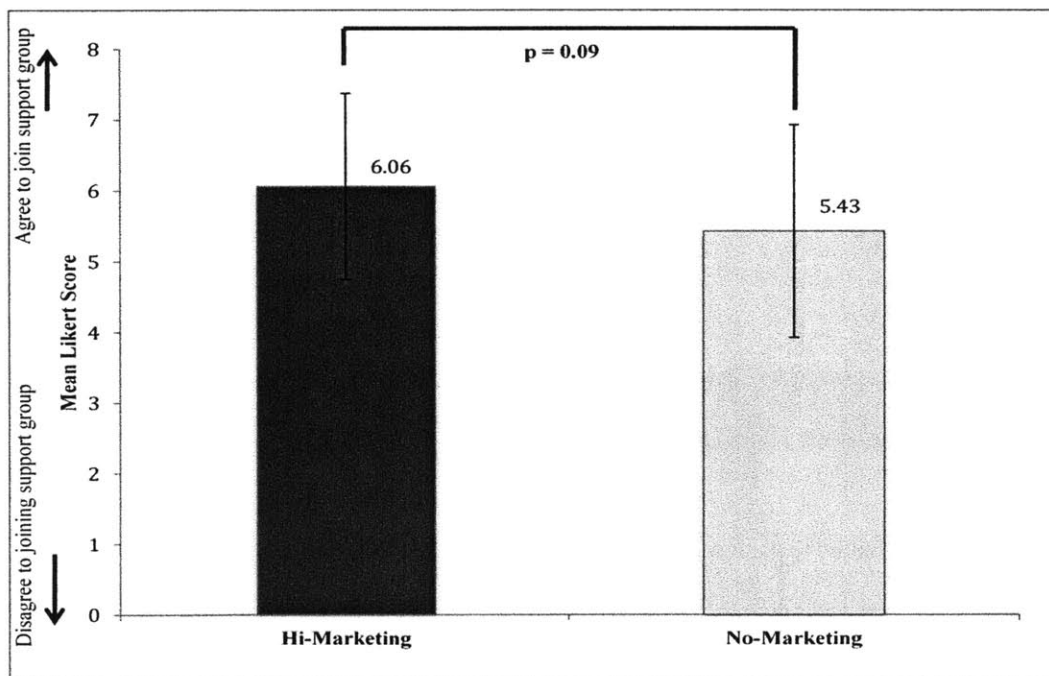
Finally, we found that there is no significant difference in subjects' perception of Karlsen's Disease prevalence between subjects in the high-marketing and no-marketing groups.

2. Marketing Presence Affects Subjects Differently Based on Their Gender and Education Level

In addition to overall differences found between the high-marketing and no-marketing groups, we found that subject responses varied for several questions in the questionnaires based on their gender and level of education.

While we found no overall significant difference between the high-marketing and no-marketing groups on their willingness to join a patient support group, we found marginally significant differences among women in the two groups. Women in the high-marketing group were more willing than women in the no-marketing group to join a patient support group $t(61) = 1.75, p = 0.09$, (figure 11). The average Likert score for women in the in the high-marketing group was 6.06 while the average Likert score for women in the no-marketing group was 5.43 (on a seven point scale where one is “strongly disagree” and seven is “strongly agree”). We conducted a similar analysis for men but we did not find a significant difference between men in the high-marketing and no-marketing groups.

Figure 11: Mean Likert Scores on Willingness to Join a Patient Support Group Among Women Subjects

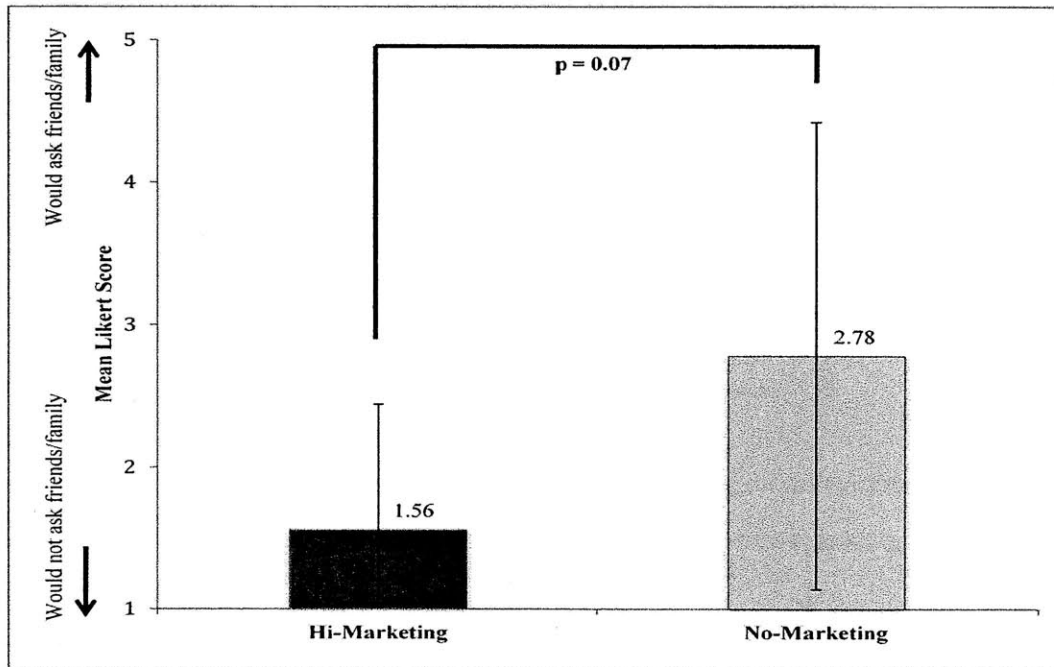


Note: Error bars denote standard deviation

Moreover, we found that among women who decided to not to wear wigs to cover their medication-induced hair loss, subjects in the high-marketing group were less willing to ask their family and friends to shave their heads in an act of solidarity. The difference between women in the high-marketing group and no-marketing groups was marginally

significant, $t(18) = -1.97, p = 0.07$ (figure 12). The mean Likert score for women in the high-marketing group was 1.56 and the mean Likert score women in the no-marketing group was 2.78 (on a seven point scale where one is “strongly disagree” to asking friends and family to shave heads and seven is “strongly agree” to asking friends and family to shave heads). When we controlled for male gender, we found that there was no significant difference between men in high-marketing and no-marketing groups in asking family and friends to shave their heads as a show of support.

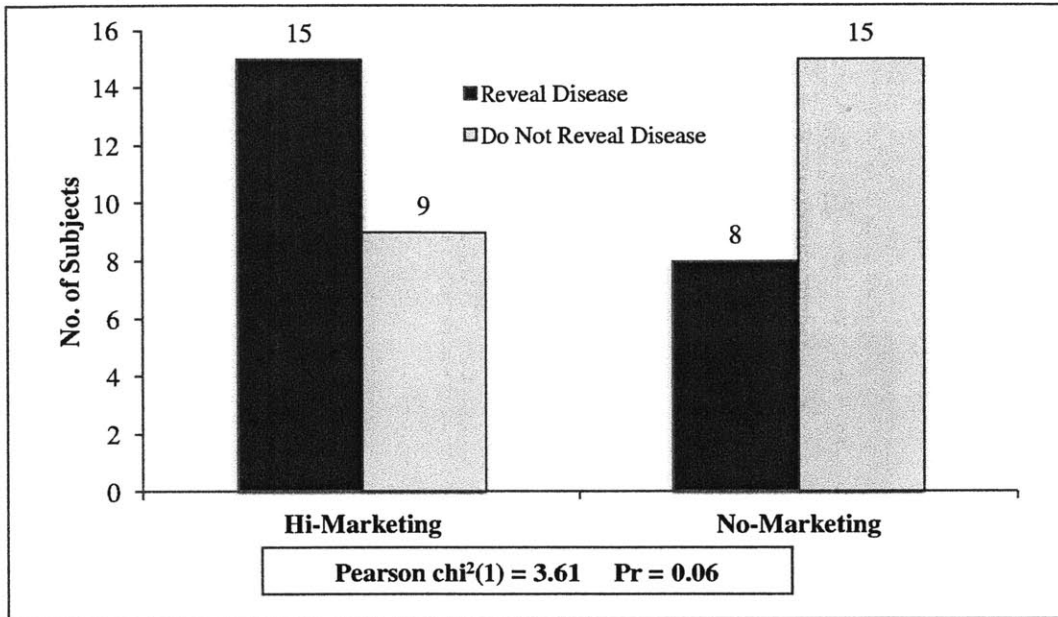
Figure 12: Mean Likert Scores on Willingness to Ask Family and Friends to Shave Heads Among Women Subjects



Note: Error bars denote standard deviation

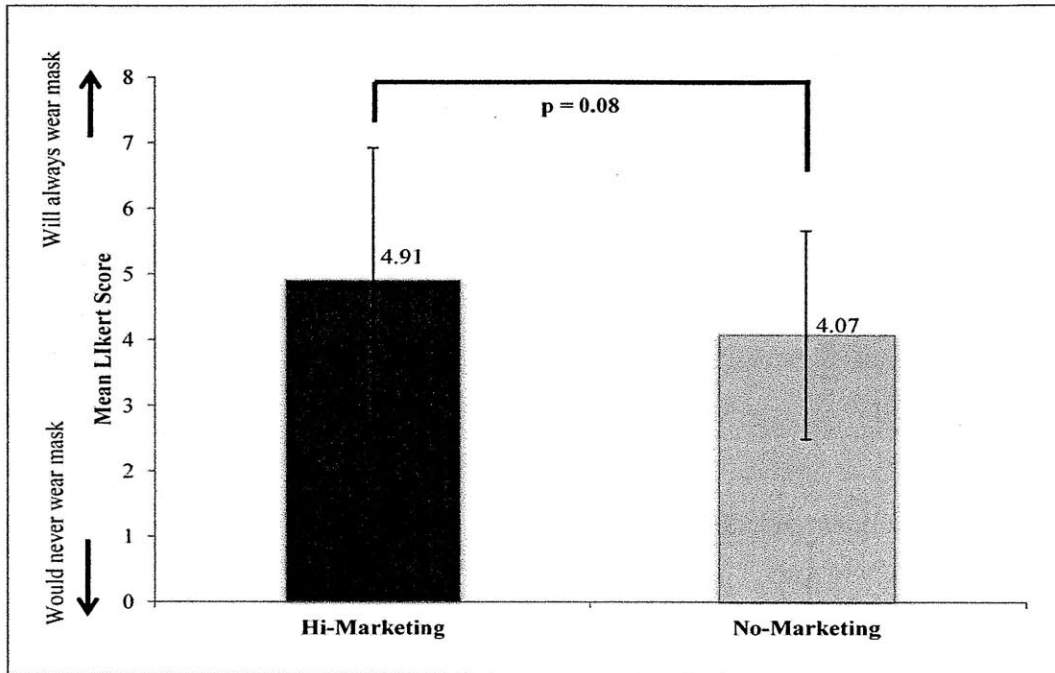
We found a marginally significant correlation between marketing action and disease disclosure behavior when we controlled for male gender. Men in the high-marketing group were more likely to reveal their health condition to the dinner party host than men in the no-marketing group, $\chi^2(1, N = 47) = 3.61, p = 0.06$ (figure 13). However, we did not find a significant correlation between marketing action and disease disclosure when we analyzed responses from all subjects or when we controlled for female gender.

Figure 13: Disease Disclosure Among Men



We also found that subjects' education level plays a role in modulating their response to some of our questions. When we asked subjects whether they would be willing to wear surgical masks to protect themselves from potential airborne pathogens when traveling in airplanes or subways, we initially found no overall significant differences between subjects in the high-marketing and the no-marketing groups. However, when we restricted our analysis to include only subjects who have completed at least a 4-year college degree, we found that there is a marginally significant difference between subjects in the high-marketing group and subjects in the no-marketing group, $t(61) = 1.79$, $p = 0.08$ (figure 14). College-educated subjects in the high-marketing group were more willing to wear a mask in airplanes and subways than their counterparts in the no-marketing group. The average Likert score for subjects in the high-marketing group was 4.91 while the average Likert score for subjects in the no-marketing group was 4.07 (on a seven point scale where one is "I would never wear the mask" and seven is "I will always wear the mask").

Figure 14: Mean Likert Scores on Willingness to Wear a Mask Among Subjects with At Least 4-Year College Degree



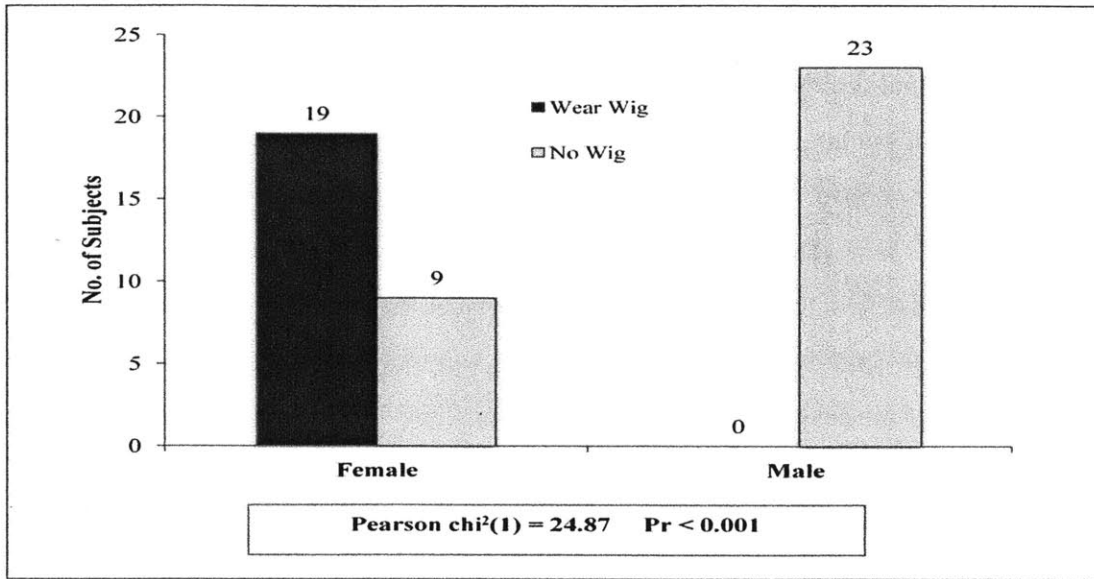
Note: Error bars denote standard deviation

3. Baseline Behavior Differences Between Gender

In addition to analyzing the effects of marketing presence on subject behavior, we also wanted to investigate whether there are any pre-existing baseline behavior differences in between men and women subjects. In order to do this, we evaluated the responses from subjects in the no-marketing group to determine whether there were any gender-based behavior differences even without exposure to marketing.

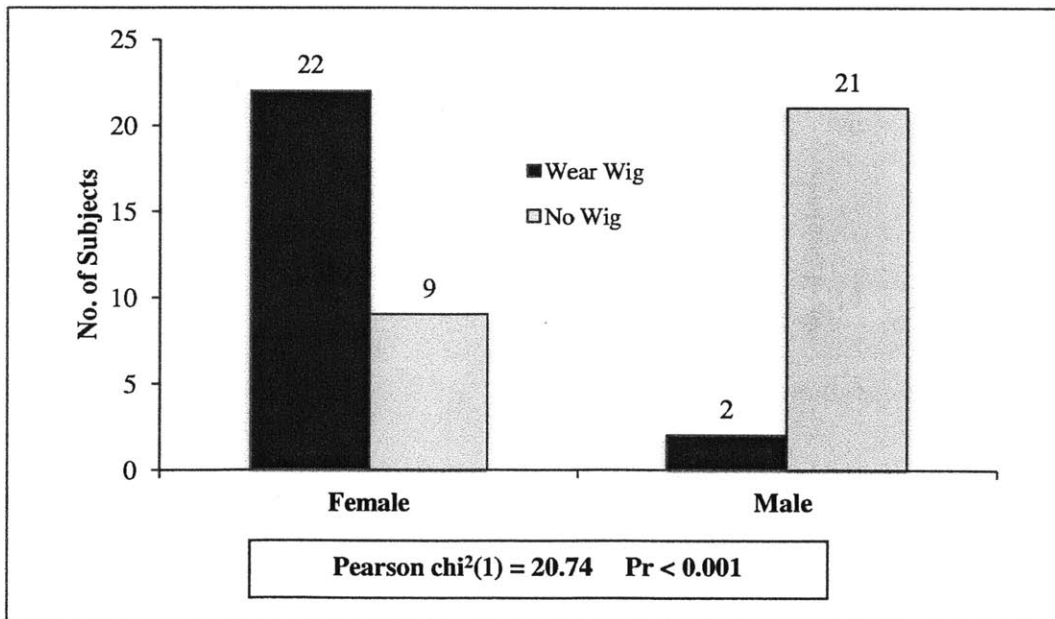
First, we found that there was a very strong correlation between gender and the decision to wear a wig. Within the no-marketing group, women overwhelmingly preferred to wear a wig to cover up their medication-induced hair loss while men overwhelmingly preferred not to wear a wig to cover up their hair loss, $\chi^2(1, N = 51) = 24.87, p < 0.001$ (figure 15).

Figure 15: Baseline Gender Preferences on Wig-Wearing Among Subjects



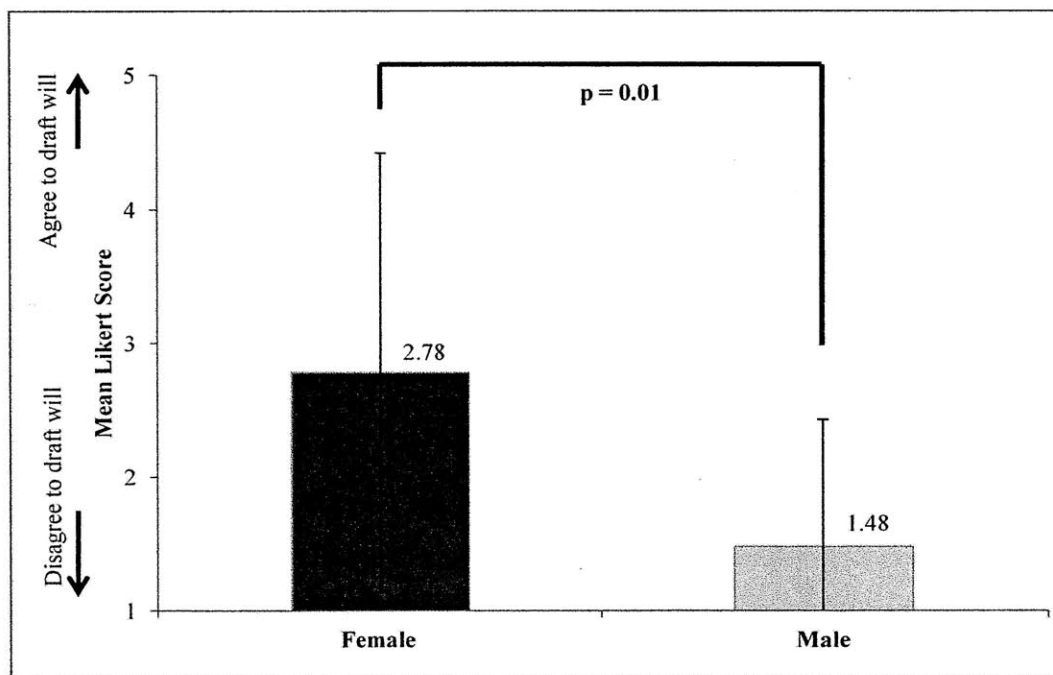
This pre-existing difference in preference was so strong that subjects did not change their preferences even with exposure to marketing actions, i.e. women remained significantly more likely to wear a wig while men remained significantly less likely to wear a wig, $\chi^2(1, N = 54) = 20.74, p < 0.001$ (figure 16).

Figure 16: Baseline Gender Preferences on Wig-Wearing Among Subjects in High-Marketing Group



Secondly, we discovered that there was a baseline difference between men and women in their likelihood to ask family members to shave their head as a gesture of support. Women in the no-marketing group were significantly more likely than men within the same group to ask their family to shave their heads, $t(32) = -2.82, p = 0.01$ (figure 17). The average Likert score for women in the no-marketing group was 2.78 while the Likert score for men was 1.48 (on a seven point scale where one is “strongly disagree” to requesting family and friends to shave head and seven is “strongly agree” to requesting family and friends to shaving head). When subjects were exposed to marketing actions, female subjects become less likely to ask their friends and families to shave their head (women average Likert score 1.56, men average Likert score 1.43 – data not shown), erasing the gender-based difference seen in the no-marketing group.

Figure 17: Baseline Gender Differences in Subjects’ Mean Likert Scores on Willingness to Request Family and Friends to Shave Head

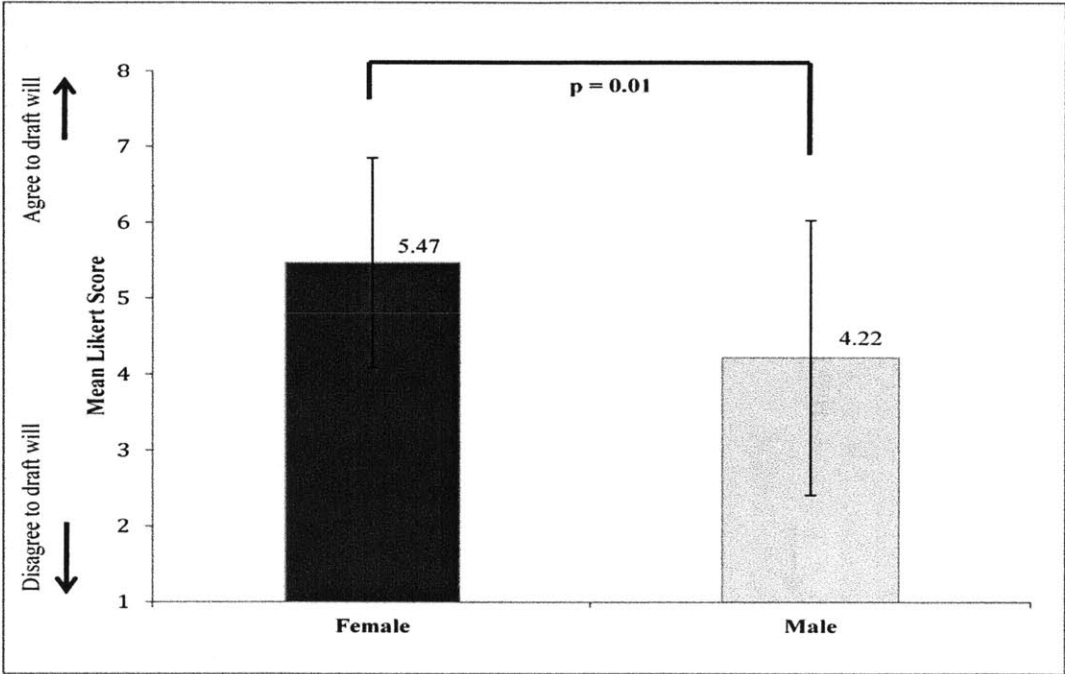


Note: Error bars denote standard deviation

In addition, we also found that there were baseline gender differences when it comes to subjects’ willingness to draft a will. Women in the no-marketing group were significantly more willing to draft a will than men in the same group, $t(53) = -2.85, p = 0.01$, (figure

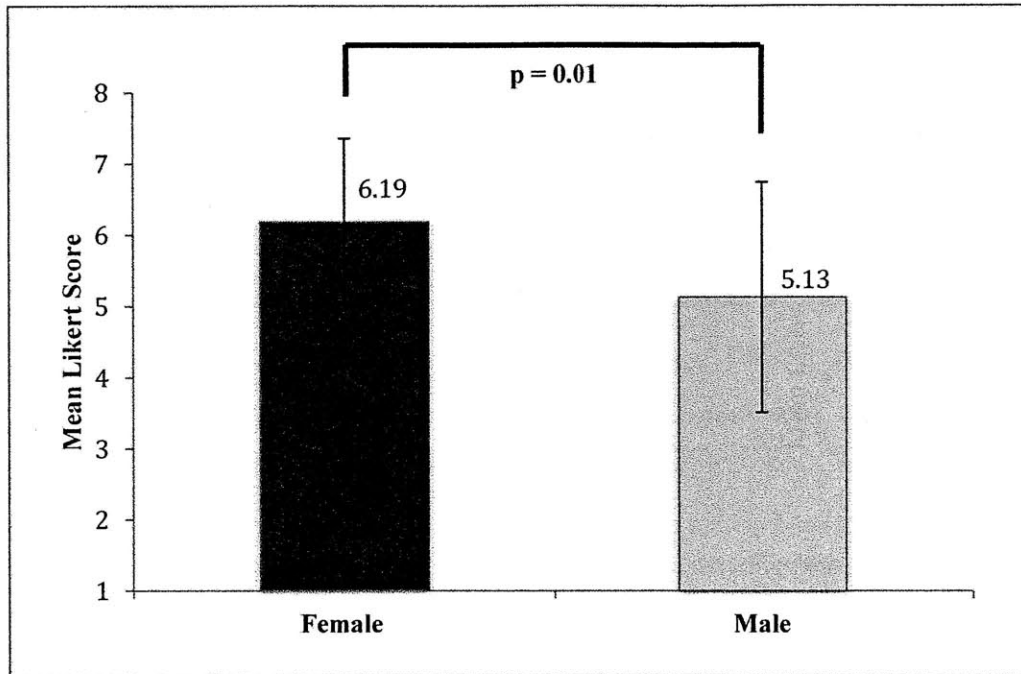
18). The mean Likert score for women in the no-marketing group was 5.47 while the mean score for men was 4.22 (on a seven point scale where one is “strongly disagree” to drafting a will and seven is “strongly agree” to drafting a will). Moreover, this gender-based preference persisted even in the high-marketing group i.e. women remained significantly more willing than men to draft a will $t(55) = -2.84, p = 0.01$, (figure 19). The mean Likert score for women in the no-marketing group was 6.19 while the mean score for men in the same group was 5.13.

Figure 18: Baseline Gender Differences in Subjects’ Mean Likert Scores on Willingness to Draft a Will



Note: Error bars denote standard deviation

Figure 19: Gender Differences in High-Marketing Group Subjects' Mean Likert Scores on Willingness to Draft a Will



Note: Error bars denote standard deviation

Chapter 5: Discussion

The Presence of Marketing Actions Increases Subject Perceptions of Disease Severity, Reduces Disease-Associated Stigma and Increases Disease Disclosure

The results from our experiment suggest that the presence of marketing actions affects subjects' perceptions of disease severity. This conclusion is based on the finding that subjects were more willing to draft a will after having been exposed to marketing actions. People frequently associate will writing with impending death (Singletary, 2012), therefore, subjects in the high-marketing group were more willing than subjects in the no-marketing group to draft a will because they believed that they were more likely to die from Karlsen's Disease than their no-marketing counterparts. In other words, study subjects believed that their disease was more severe after being exposed to disease marketing actions. This finding is consistent with other studies that have reported that increased marketing around a disease lead people to perceive the disease to be more severe (Smith et al., 1996; Black, Nease & Tosteson, 1995; Blakeslee, 1992).

The results from our study also suggest that disease marketing can encourage patients to adopt health seeking behaviors by reducing the stigma associated with disease disclosure. Subjects who were shown marketing actions were more inclined to wear an obvious, but potentially more life-saving medical ID bracelet, whereas subjects who were not exposed to marketing actions more inclined to wear an easily hidden, but potentially less life-saving medical ID necklace. The more obvious medical ID bracelet confers greater stigma to the wearer since it reveals the wearer's health condition. Therefore, high-marketing subjects' willingness to wear the medical ID bracelet despite the increased risk of disease disclosure suggests that disease marketing reduces the stigma anticipated by patients. Consequently, patients are less concerned about concealing their disease and are more likely to adopt behaviors that promote their health but may also make their health condition known to others. This finding is consistent with studies that have found that anticipated stigma is inversely related to patient health seeking behaviors that are associated with disease disclosure (Quinn & Earnshaw, 2011; Earnshaw & Quinn, 2012).

Furthermore, our study results suggest that disease marketing can increase patients' willingness to seek help from others, especially when needed to manage their health condition. We believe that this effect is also mediated by reduction in anticipated stigma. More subjects in the high-marketing group than in the no-marketing group selected to request menu accommodations at a dinner party to meet their low-sodium diet needs. Subjects were told that consuming foods that are not low in sodium, while not immediately life threatening, poses a health risk to them.

We directly assessed the level of anticipated stigma by asking subjects who chose to request menu accommodations to indicate how understanding they believe their dinner host would be towards their request. We found that subjects in the high-marketing group perceived the dinner party host to be more understanding than subjects in the no-marketing group. This finding shows that disease marketing can influence patients to anticipate less stigma and more empathy from others.

The presence of disease marketing did not seem to generate the perception of increased disease prevalence among our study subjects. One possible explanation for this finding is that the disease marketing images and descriptions we have used in this study were not provocative enough to generate the perception of increased prevalence. Another possible explanation for this observation is that subjects may have automatically assumed that Karlsen's Disease is a rare disease since they have not heard of this disease prior to our study.

Overall, disease marketing is associated with increased disease disclosure and improved health seeking behavior, indicating that marketing actions can lead to positive coping attitudes among patients with chronic illnesses. A positive attitude towards one's illness can in turn lead to better health management and overall improved health outcome. However, our study also shows that disease marketing is not without its risks. Presence of disease marketing could lead patients to perceive greater disease severity, and may lead patients to experience increased anxiety and psychological stress.

Gender and Education Level Play an Important Role in Modulating the Effects of Disease Marketing on Subjects

While we found that disease marketing uniformly affected the behavior of all subjects in certain scenarios provided in our study, we also found that there were scenarios where disease marketing affected subjects differently based on their gender and level of education. This is not surprising given that people's social behavior and personalities are strongly influenced by their gender (Eagly & Wood, 1999; Eagly, 1995) and the roles associated with their gender (Eagly & Steffen, 1984; Eagly, 1987). For example, studies have shown that boys are raised by parents to conform to societal notions of masculinity such as being agentic (Block, 1973; Hartley, 1959a & 1959b). Girls, on the other hand, are frequently pressured by parents to conform to communal norms within the society (Block, 1973). Since societal norms of masculine and feminine behaviors are ingrained in most people and inform much of their social behavior, it is no surprise that gender-related notions extend to health behaviors. For example, Springer and Mouzon (2011) found that men with strong masculinity beliefs are half as likely than men with moderate masculinity beliefs to receive preventive care.

In addition, the positive association between education and health outcomes has been well documented (Adler & Ostrove, 1999; Adler & Newman, 2002). Education not only serves as marker for better socioeconomic status, but it has also been suggested to independently promote health in several ways. Firstly, education attainment has been posited to teach people "learned effectiveness", enabling people to better merge seemingly unrelated behaviors into a unified healthy lifestyle. Secondly, education may also increase the sense of personal control, causing individuals to seek and act on information that improves health. Finally, individuals growing up in a well-educated household may inherit their healthy lifestyle from their parents (Mirowsky & Ross, 1998).

Our study findings suggest that women on the whole are more likely to seek social support than men when faced with chronic illness. We found that women were more

likely than men to join a support group even in the absence of disease marketing (data not shown). Exposure to disease marketing actions further strengthens this behavior. Women subjects were more willing to join a support group after being exposed to marketing actions associated with Karlsen's Disease. Men in the study, however, remained unwilling to join a patient support group after having seen disease marketing actions. We believe that there are two reasons for this difference in response among male and female subjects.

The first reason is that men and women have a tendency to deal differently with problems, whether consciously or subconsciously, as a result of their expected gender roles. Femininity is commonly associated with vulnerability and emotional expression while masculinity is commonly associated with strength, stoicism and emotional control (Courtenay, 2000; McQueen & Henwood, 2002; Warren 1983). For example, women often are taught since young to "talk about their troubles" (Block, 1973) while men often are trained since young to be self-reliant (Barry, et al. 1971). Therefore, the notion of joining a patient support group, which is often associated with seeking emotional and social support, is more acceptable to a woman than a man with strong masculine beliefs. We believe that this explains why women subjects in our study were more willing than men to join a support group with or without exposure to disease marketing actions.

We posit that the second reason for the observed gender-based difference in subject responses is related to the marketing actions we used. We believe that the marketing actions that we used were not compelling enough to convince our male subjects to join a patient support group. Since there is arguably a higher psychological barrier for men to join a support group, our use of basic T-shirt and billboard images along with brief mentions of disease advocacy activities were not sufficient to change the men's preconceived notions about support groups.

Our study results also suggest that women are more likely than men to feel more empowered after exposure to disease marketing and have less need for explicit show of support from others. Women subjects in the high-marketing group were less willing than

women in the no-marketing group to ask their family and friends to shave their heads to show solidarity. While we initially anticipated the opposite result i.e. women becoming more willing to ask others to shave their heads after exposure to marketing actions, we deem that our results do not mean that women become less empowered after seeing marketing actions. Rather, we believe that our results indicate that women subjects felt more empowered by the marketing images and as a result, they felt less need for others to show their support by the explicit act of head shaving.

While the increased sense of empowerment among women subjects in the high-marketing group seems contradictory to their concurrent increased willingness to join a patient support group, it is not necessarily so. It is important to note that while some individuals join patient support groups to obtain emotional support, others join in order to seek more information about their disease (Krizek, et al., 1999). In other words, women's increased willingness to join a patient support group may also be a sign of empowerment, represented by their pro-active attitude towards disease self-education.

It is also possible that women subjects who were exposed to marketing actions perceived the disease to be well known and important, therefore they were less compelled to seek additional attention from others. Women subjects who were not exposed to marketing actions, on the other hand, may feel a greater need to raise awareness about their disease and have others make public gestures of support to validate their disease.

We must point out that for the question assessing subjects' willingness to ask family and friends to shave their heads, the differences found between the women in high-marketing and no-marketing groups were based on a small sample size (N = 18). The small sample size is due the fact that we restricted the question to subjects who chose not to cover their treatment-induced hair loss and that majority of our women subjects opted to cover their hair loss with wigs. Therefore, only a minority of women subjects were followed-up with the question assessing their willingness to ask their family and friends to shave their heads as a gesture of support.

It is not surprising that women overwhelmingly prefer to cover their hair loss. Other studies have found that women who experience hair loss due to illness or treatment side effect experience negative psychosocial effects including anxious preoccupation, helplessness and feelings of diminished attractiveness. These women usually try to conceal their hair loss by either wearing a wig or altering their hairstyle (Cash, et al., 1993; Rosman, 2004). Women's hair imparts special cultural and personal meanings related to gender identity, sexuality and attractiveness (Cash et al., 1993) therefore, visible hair loss causes women to lose part of their identity and to experience lower self-esteem. In addition, since female baldness is rarely seen in public compared to male baldness, women with hair loss face additional stigma as they tend to be seen as having "something wrong".

Men subjects, on the other hand, remained highly unwilling to ask family and friends to shave their heads as a gesture of solidarity despite being exposed to marketing actions. 70% of the men in the no-marketing group and 81% of men in the high-marketing group "strongly disagreed" to asking family and friends to shave their head (difference not significant). We hypothesize that the main reason for this observation is that male baldness is commonly seen and regarded as "normal" within the society (Cash et al., 1993). Therefore, the men in our study likely did not feel a need to obtain support from others if they experience hair loss and decide to shave their heads. Men experiencing hair loss as a result of cancer treatment were found to cope better than women who experienced the same side effect. Unlike women, the men accepted their hair loss as a normal and necessary part of their treatment (Rosman, 2004). Men who experience baldness due to androgenetic alopecia (male pattern baldness) were also found to cope better than their female counterparts. These men were able to actively cope with their distress and most were able to retain their own sense of personality (Cash, et al. 1993).

Our study results so far have indicated that men overall seemed less likely than women to adopt health seeking behaviors when faced with a life-threatening chronic disease. Furthermore, the marketing actions that have generated an improvement in health seeking behaviors among women subjects in our study seemed to have been somewhat ineffective

on men subjects. However, we believe that it is still possible to use disease marketing actions to induce positive coping behavior and increase health seeking behaviors among men. We found that men who were exposed to marketing actions were significantly more likely to disclose their disease to their neighbor. This finding offers hope that disease marketing can overcome gender notions of masculinity that prevents men from divulging their problems and seeking help from others – behaviors that are counter to positive disease coping and health outcome.

Our study results also suggest that education levels can modulate the effects of disease marketing. We found that individuals who have at least completed a 4-year college degree were more likely than those without a 4-year college degree to be influenced by marketing actions to wear a surgical mask to protect themselves from airborne infections. While there was a trend suggesting that subjects in the high-marketing group were overall more likely to wear a mask than those in the no-marketing group (not statistically significant), the difference between the high-marketing and no-marketing group subjects was most pronounced when we restricted the analysis to subjects with 4-year college degrees or more.

One possible explanation for this phenomenon is that subjects with higher education levels are more likely to be compliant with doctor's orders and more pro-active with self-care. This tendency, combined with the increased perception of disease severity resulting from exposure to disease marketing, could increase the subjects' willingness to wear a mask for self-protection. Our study data indicates that even among subjects not exposed to marketing actions, there is a trend showing that subjects with at least a 2-year college degree were more willing than subjects with no college degree to wear a mask (data not shown). This finding offers some evidence that higher education is associated with increased self-care behavior. A study by Rockwell and Riegel (2001) found that higher education and symptom severity are the only two significant predictors of self-care among patients suffering from heart failure. Similarly, Katz (1998) found that rheumatoid arthritis patients who have thirteen or more years of education are significantly more likely to engage in specific self-care activities.

The Level of Disruption Caused by Chronic Disease Precipitates Disease Disclosures by Subjects

Our study suggests that patients' disease disclosure behavior can vary based on the level and frequency of disruption caused by their disease in their interactions with people. We found that study subjects not exposed to marketing actions overwhelmingly selected to disclose their disease to their employer while the same group of subjects overwhelmingly selected to conceal their disease from their neighbor. We believe that the discrepancy in disclosure decision is related to the level of disruption caused by their disease. In the situation involving the employer, we described a scenario that is highly disruptive to subjects' work schedule. The subjects were required to make multiple weekly visits the doctor's office and take additional time off to rest from their treatment side effects. We believe subjects preferred to disclose their health condition to their employer in this scenario because they needed a valid justification for their frequent absence from work. Studies have found that when employees require the use of medication or medical equipment at work or are frequently absent from work due to their illness, they are more likely to disclose their disease to their employers in order to provide an explanation for their behavior (Munir et al., 2005; Clark et al., 1991).

It is also possible that subjects felt more protected against discrimination when disclosing their condition to their employer. Since all of the subjects in this study are US citizens and current US residents, they may have anticipated protection from federal laws against job-related discrimination. Most employers in the US with 15 employees or more are covered by US Equal Employment Opportunity laws that prohibit employers from discriminating against job applicants or employees based on their disability, ethnic/national origin, color, race, age, religion and sex (EEOC website, 2012). Moreover, US employees are also protected by the Americans with Disabilities Act (ADA), a law that prohibits employers from discriminating against qualified individuals with disabilities. Similar to the US Equal Employment Opportunity law, the ADA applies to employers with 15 employees or more (ADA website, 2008).

In contrast to subjects' high willingness to disclose their disease to their boss, subjects overwhelmingly preferred to conceal their disease from their neighbor in the absence of disease marketing actions. We believe that most subjects preferred not to reveal their illness to their neighbor in the dinner party scenario because they think their illness would not be disruptive to their interaction with their neighbor. Moreover, the dinner party was implied to be a one-time and non-recurring event. It may also be possible that unlike in the workplace, subjects feel that there are no safeguards that exist in a casual social setting to protect them from being discriminated against.

The finding that subjects were more willing to disclose their health condition to their boss than their neighbors is consistent with the results found in a study by Modi and colleagues (2010). In their study assessing disease disclosure among adults with cystic fibrosis, 51% of the 865 subjects said they would disclose their illness to "all" or "most of" their bosses/supervisors while only 25% of subjects said that they would disclose their illness to "all" or "most of" their neighbors.

Future Research

This study has offered some preliminary insights on the impact of disease marketing on patient coping attitudes and behavior. However, further research is necessary in order to fully understand the underlying mechanism of how disease marketing actions modulate patient coping. To this goal, we propose several areas for future research.

First, the findings in this study should be validated by interviewing patients with chronic illness. While we are convinced that most of our study subjects have a sense of what it is like to live with a chronic illness, either through personal experience or interactions with other chronically ill patients, we believe that many of them have not experienced first-hand, the daily challenges of living with a serious chronic illness. Therefore, interviews with real patients are essential to confirm the results from this study. Moreover, direct patient interviews would provide a richer context to our findings as they allow for deeper probing and specific follow-up questions that our online experiment did not permit.

Secondly, we propose that a study should be carried out to evaluate the narratives commonly used in disease marketing campaigns that are ubiquitous in the US mass media. This study only evaluated the mere presence of disease marketing using images and messages that are neutral and do not evoke strong emotions among subjects. Our goal for this study is to assess whether the presence of marketing actions alone would affect patient coping attitudes and behaviors. Therefore, another study that assesses the impact of common disease marketing narratives such the “survivorhood” model used in cancer and the “victimhood” model used in mental illness is necessary to shed more light on the relationship between disease marketing and patient coping.

Finally, we propose further study on the differential impact of disease marketing on patients based on their gender. Our study has shown that patients react differently to disease marketing actions based on their gender, whereby women were more easily influenced by marketing actions to adopt health seeking behaviors than men. While we hypothesize that the behavioral differences is rooted in traditional gender norms, additional studies need to be carried out to confirm our hypothesis and identify the circumstances where gender plays a role in modulating the effects of disease marketing on patients.

Chapter 6: Conclusions

Our research indicates that mere presence of disease marketing could affect the coping behavior and attitudes of individuals living with chronic illness in a largely positive manner. Based on our results, we anticipate that exposure to disease marketing actions could cause patients to anticipate less stigma from other people. As a result, patients become more willing to disclose their illness and adopt health seeking behaviors that are associated with disease disclosure. Furthermore, our study results suggest that disease marketing actions could have differential impact on patients based on their gender and education level. Female subjects and subjects with higher education seemed more likely to be influenced by disease marketing actions to adopt health seeking behaviors.

However, disease marketing is not without its risks, as it could increase perceived disease severity among patients. Subjects exposed to marketing actions in our study seemed to perceive greater disease severity than those not exposed to marketing actions. Finally, our study findings have resulted in several key implications for disease marketing strategy for marketing actions that are targeted towards patients with chronic illness. We will discuss the implications in the following section.

Implications for Disease Marketing Strategy

1. Disease Marketing Actions Should be Targeted Towards High-Stigma Chronic Diseases that have Low Public Profile

Based on our study findings, we highly recommend that disease marketers should target their marketing efforts at high-stigma chronic diseases that are not publicly well-known. We believe that disease marketing would have maximum positive impact on patients with low-profile, high-stigma chronic diseases because disease marketing actions such as disease advertising and charity walks are effective at reducing patients' anticipated stigma. When patients experience and expect less stigma from others, they become more likely to disclose their health condition and become more likely to adopt health seeking

behaviors such as increased willingness to ask for accommodations or support from others. Examples of low profile, high-stigma diseases that could benefit from marketing actions include Crohn's Disease, Ulcerative Colitis, Inflammatory Bowel Syndrome, Hepatitis C and psoriasis.

2. Patients' Gender Should be Taken into Account in Disease Marketing Actions

We also recommend that disease marketers tailor their disease marketing messages, images and designs to be gender-appropriate when targeting patients. Given that men and women largely cope with health conditions differently based on their gender roles, disease marketing should take patients' genders into account in order to maximize their effectiveness. For example, an advertisement that promotes patient support group for a disease that affects predominantly male patients should consider calling the group "patient information gathering" instead of "patient support group". For diseases that affect both genders, marketers should consider using multiple marketing messages and designs to target male and female patients separately.

3. Disease Marketers Should Collaborate with Health Care Professionals to Mitigate Potential Negative Effects of Marketing

While disease marketing has many benefits for patients, it could also lead patients to perceive greater disease severity and experience unnecessary anxiety and stress. While it is possible that a slight increase in perception of disease severity may generate a sense of urgency for some patients to adopt pro-health behaviors, studies have shown that highly marketed diseases could instill disproportionate fear among individuals (Smith et al., 1996; Black, Nease & Tosteson, 1995; Blakeslee, 1992). Therefore, we recommend that disease marketers should always work closely with health care professionals to ensure that accurate information is presented to patients in the marketing materials. Such collaboration will help maximize the benefits of disease marketing and minimize any potential negative effects that could result from those marketing actions.

Appendix

Karlsen's Disease Online Questionnaire:

Q1.1 This is an 10-15 minute survey about medical decisions. Your responses will be very helpful to research that might help medical charities. Only if you complete it will you receive compensation of \$0.80. Your participation in this study is completely voluntary and you are free to choose whether to be in it or not. If you choose to be in this study, you may subsequently withdraw from it at any time. All responses will be kept anonymous and absolutely confidential. This study is sponsored by MIT. If you feel you have been treated unfairly, or you have questions regarding your rights as a research subject, you may contact the Chairman of the Committee on the Use of Humans as Experimental Subjects, M.I.T., Room E25-143B, 77 Massachusetts Ave, Cambridge, MA 02139, phone 1-617-253 6787. By proceeding with the study and clicking the button below, you are acknowledging that you have been apprised of your rights, and are giving consent to participating in this study.

Q2.1 Please insert your Amazon MTurk Worker ID below: Where to find your Worker ID Click on "Your Account" at Amazon MTurk, your Worker ID is located the top right in orange.

Q3.1 Before you take the survey, we'd like to know a bit about you. Please indicate your gender:

- Male
- Female

Q3.2 Please indicate your age range:

- 21-25 years old
- 26-35 years old
- 36-45 years old
- 46-55 years old
- >55 years old

Q3.3 What is the highest level of education you have completed?

- High School / GED
- Some College
- 2-year College Degree
- 4-year College Degree
- Masters Degree
- Doctoral Degree
- Professional Degree (JD)

Q3.4 Were you born in the United States?

- Yes
- No

Q4.1 This survey is brought to you by American Karlsen's Disease Society (AKDS). AKDS is a US-based organization that advocates for Karlsen's Disease. Karlsen's Disease is a potentially life-threatening disease with no cure and unclear prognosis. But if diagnosed early, there are available treatments to manage the disease. Research has shown that:

- Patients under treatment have an average 70% chance of entering remission and an average 5-year survival rate of 92%
- Patients NOT under treatment have an average 16% chance of spontaneous remission and an average 5-year survival rate of 81%

Q4.2 Have you been diagnosed with Karlsen's Disease?

- Yes
- No

Q4.3 AKDS organizes fundraising events, including annual charity walks and auctions. The goal of the organization is to raise awareness about Karlsen's disease as well as to raise money. As part of its fundraising efforts, AKDS also sells T-shirts and pins that feature the AKDS logo. All the money raised by AKDS is given out as research grants.

Image in high-marketing questionnaire:

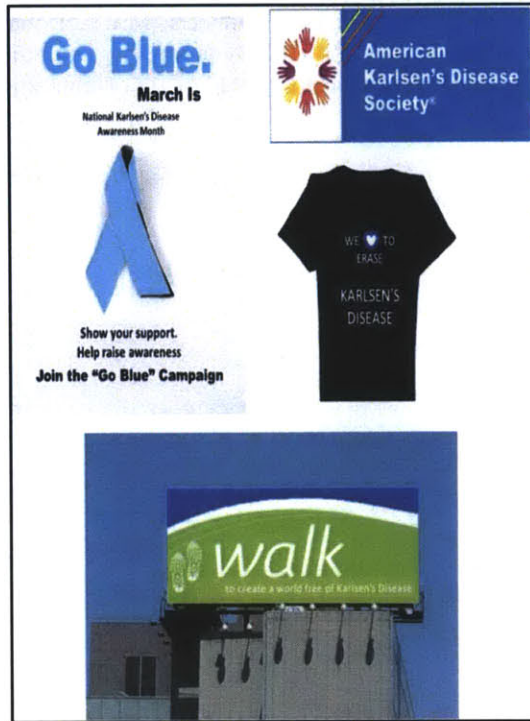
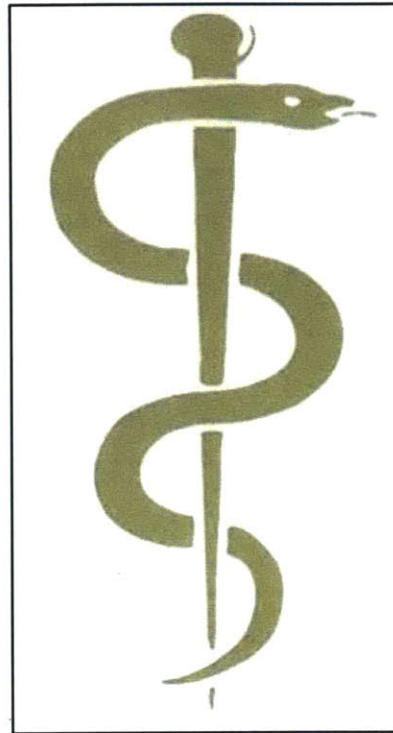


Image in no-marketing questionnaire:



Q4.4 (**High-marketing**) Based on the shown marketing materials, which color do you think is being used as the main Karlsen's Disease color?

- Blue
- Orange
- Green

Q4.4 (**No-marketing**) What color is the symbol above?

- Blue
- Orange
- Green

Q4.5 Please estimate the percentage of US population diagnosed with Karlsen's Disease:
Subject rate on a 0-100% sliding scale

Q4.6 Now, you will be presented with a scenario that relates to Karlsen's Disease, and then asked for your opinion. There are no correct or incorrect responses. Please do your best to really imagine the scenario that we will provide.

Q5.1/5.2 Today we will talk about a scenario that involves a person named Drew who lives in your area. 2 years ago Drew was diagnosed with Karlsen's Disease. Drew has been able to live with the disease, as a treatment program has kept the disease under control and allowed Drew to continue about his/her daily life.

Q5.3 Beginning a month ago, Drew has started to observe noticeable hair loss. In fact, several patches on the scalp are showing visible signs of hair thinning.

Q5.4 Hair loss is one of the common side effects of the drugs that Karlsen's Disease patients take. Drew's doctor has determined that the current drug is the best treatment currently available for Karlsen's Disease. Therefore, changing treatment is not an option. Moreover, Drew is advised to continue with the course of therapy, as stopping the treatment may lead to rapid progression of the disease.

Q6.1 If you were in Drew's shoes what would you decide to do about your hair loss?

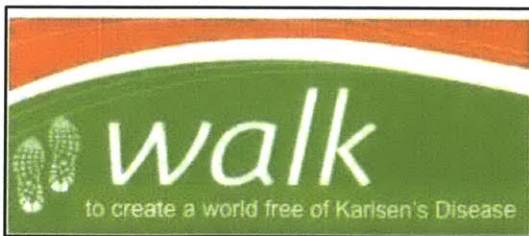
- Keep taking the medication that is causing the hair loss and wear a wig
- Stop taking the medication that is causing the hair loss
- Keep taking the medication that is causing the hair loss, let hair gradually fall out and not wear a wig
- Keep taking the medication that is causing the hair loss, shave head and not wear a wig

*** The following question is displayed if subject selects "Keep taking the medication that is causing the hair loss, let hair gradually fall out and not wear a wig" or "Keep taking the medication that is causing the hair loss, shave head and not wear a wig" in Q6.1**

Q6.2 Given your Karlsen's-related hair loss, please give the extent to which you agree or disagree with the following statement:

	1 (Strongly Disagree)	2	3	4 (Neither Agree Nor Disagree)	5	6	7 (Strongly Agree)
If I had complete hair loss, I would ask my family and/or friends to shave their heads out of solidarity.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

Q6.3 (High-marketing) Please click below to continue



Q6.3 (No-marketing) You're doing great! Please click below to continue

Q6.4 Drew's treatment for Karlsen's Disease involves multiple weekly visits to the doctor's office that can be disruptive to a work schedule. Moreover, the medications cause side effects that can cause discomfort and require extra rest. If you were in this situation, would you rather reveal your condition to your boss and take several sick days OR would you rather keep your condition a secret and take several vacation days?

- I would rather take sick days and not reveal my condition
- I would rather take sick days and reveal my condition
- I would rather take vacation days and not reveal my condition

Q6.5 If you were in Drew's situation, please indicate the extent you agree with the following statements:

	1 (Strongly Disagree)	2	3	4 (Neither agree nor disagree)	5	6	7 (Strongly Agree)
I will start drafting a will	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
I will join a patient support group	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

Q6.6 (High-marketing) Please click below to continue



Q6.6 (No-marketing) You're making great progress. Please click below to continue

Q6.7 You are advised by your doctor to wear a medical alert ID at all times. One option is to wear a medical alert ID bracelet. The bracelet is worn on your wrist and is very obvious to other people. Another option is to wear a medical alert ID necklace. The necklace is worn around the neck and could be hidden under a shirt. The bracelet is much more likely to be discovered than the necklace in an emergency. Which medical alert ID would you wear?

- I would wear the medical alert ID bracelet
- I would wear the medical alert ID necklace

Q6.8 You learn that sodium/salt aggravates your symptoms. Your doctor has put you on a sodium/salt-restricted diet to control the swelling side-effect that you occasionally experience from your Karlsen's Disease medication. Every time you consume any foods that is not low in sodium, your legs and face swell up a day later. The swelling causes discomfort and is generally bad for the disease progression, but it is otherwise not immediately life-threatening.

Q6.9 Imagine you are invited to a dinner party by your neighbor who you've know for a few months. You feel that you are in fine shape to attend, but the dinner will surely involve foods that have a higher sodium content than is advised by your doctor. Please choose the option below that best describes how you would handle this situation, given the sodium-restricted diet.

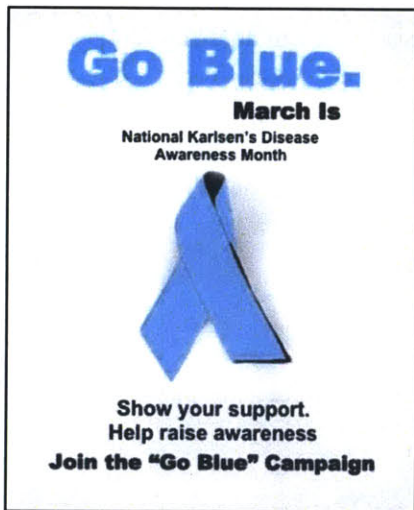
- I would request a menu accommodation and reveal my condition
- I would request a menu accommodation but not reveal my condition
- I would not request a menu accommodation and eat the same food everyone is served, not revealing my condition

* The following question is displayed if subject selects “I would request a menu accommodation and reveal my condition” or “I would request a menu accommodation but not reveal my condition” in Q6.9

Q6.10 What reaction do you anticipate if you were to ask the dinner party host for a menu accommodation? Please indicate how understanding you expect the dinner party host to be.

	1 (Not understanding)	2	3	4 (Moderately Understanding)	5	6	7 (Very understanding)
How understanding will the host be about your special condition?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

Q6.11 (High-marketing) Please click below to continue



Q6.11 (No-marketing) Fantastic job! Please click below to continue

Q6.12 Once again, please imagine that you are in Drew's situation and you are living with Karlsen's Disease. People with Karlsen's Disease are especially susceptible to bacteria and viruses in their environments. Doctors often recommend that patients wear surgical masks (like the one seen below) in places like airplanes and subways to protect themselves during periods when the illness is most active.



Q6.13 If you are in Drew's position, and assuming that you do not generally travel on airplane or subways with people you know, how likely are you to wear the mask during these occasions?

	1 (I would never wear the mask)	2	3	4	5	6	7 (I will always wear the mask)
How likely are you to wear a mask when traveling on airplane or subway?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

Subject Donation Experience and Involvement with Disease-Related Charitable Organizations

Q7.1 Have you ever donated money to a disease-related charitable organization?

- Yes
- No

Q7.2 Please indicate the number of organizations you have donated money to

- 1 organization
- 2 organizations
- 3 organizations
- 4 organizations
- 5 or more organizations

*** Questions 7.3-7.12 are displayed if subject selects "Yes" in Q7.1, subjects can name up to 4 organizations**

Q7.3 Please specify the name of the disease or organization.

Name of disease / organization _____

Q7.4 What was the reason that led you to donate to the organization. Please choose all that apply.

	Name of Disease / Organization
Because you have a family member or friend who was diagnosed with the condition	<input type="checkbox"/>
Because someone you know or the organization solicited your donation	<input type="checkbox"/>
Because you have previously or currently been diagnosed with the condition	<input type="checkbox"/>
Because you think it is important to support efforts to fight against the condition	<input type="checkbox"/>
Other (please specify) _____	<input type="checkbox"/>

Q7.13 Have you ever participated in activities organized by a disease-related charitable organization?

- Yes (1)
- No (2)

*** Questions 7. 14 - 7.29 are displayed if subject selects "Yes" in Q7.13, subjects can name up to 4 organizations**

7.14 How many different disease-related charitable organizations have you been involved with?

- 1 organization
- 2 organizations
- 3 organizations
- 4 organizations
- 5 or more organizations

Q7.15 Please specify the name of the disease or organization

Name of disease / organization _____

Q7.16 What type of activity(ies) or event(s) did you participate in? Please select all that apply.

	Name of Disease / Organization
Walk	<input type="checkbox"/>
Fund-raising dinner or event	<input type="checkbox"/>
Other (please specify) _____	<input type="checkbox"/>

Q7.17 What was the reason that led you to participate in the activity(ies) or event(s)? Please select all that apply.

	Name of Disease / Organization
Because you have a family member or friend who was diagnosed with the condition	<input type="checkbox"/>
Because someone you know or the organization solicited your donation	<input type="checkbox"/>
Because you have previously or currently been diagnosed with the condition	<input type="checkbox"/>
Because you think it is important to support efforts to fight against the condition	<input type="checkbox"/>
Other (please specify) _____	<input type="checkbox"/>

Q8.1 Which occupational category best describes your current employment?

- Management: professional or related occupations
- Management: business or financial operations occupations
- Management occupations, except farmers and farm managers
- Farmers and farm managers
- Business and financial operations
- Business operations specialists
- Financial specialists
- Computer or mathematical
- Architects, surveyors, cartographers, or engineers
- Education, training, or library
- Arts, design, entertainment, sports, or media
- Health diagnosing or treating practitioners & technical occupations
- Health technologists or technicians
- Health care support
- Fire fighting, prevention or law enforcement workers, (including supervisors)

- Other protective service workers (including supervisors)
- Food preparation or serving-related
- Building, grounds cleaning or maintenance
- Personal care or service
- Sales or related occupations
- Office or administrative support
- Farming, fishing, or forestry
- Supervisors, construction or extraction
- Construction trades workers
- Extraction workers
- Installation, maintenance, or repair occupations
- Production
- Supervisors, transportation or material moving
- Aircraft or traffic control
- Motor vehicle operators
- Rail, water or other transportation
- Material moving

Q8.2 In which state do you currently reside?

Subject choose from a drop down menu of 52 states or “I do not reside in the United States”

Q8.3 Please select the statement that best describes your current general state of health:

- I am in excellent health with no known health issues
- I am in good health but have previously experienced serious health issues
- I am in good health with minor health issues
- I have manageable chronic health issues
- I have difficult to manage chronic health issues
- I am in poor health with serious health issues

Q8.4 Do you know anyone who has any of the following medical conditions? Please select all that apply.

- Breast cancer
- Brain cancer
- Multiple sclerosis
- Lupus
- Chronic depression
- Post-partum depression
- Attention Deficit Hyperactivity Disorder (ADD)
- Lung cancer
- HIV/AIDS
- Tourette syndrome
- Schizophrenia
- Mitochondrial disease
- Epilepsy
- Colon cancer
- Karlsen's Disease
- I don't know anyone who has any of the diseases listed above

* The following questions if displayed if subject selects “breast cancer”, “lupus” or “colon cancer” in Q8.4

Q8.5 Would you be interested in getting contacted by the research team for additional follow-up research related to this survey? If so, please enter your email address below:

Email address: _____

Q8.6 Please rate your knowledge on the following medical conditions

	I am very knowledgeable about the disease	I have slightly more than average knowledge about the disease	I have average knowledge about the disease	I have slightly less than average knowledge about the disease	I do not know anything about the disease
Breast cancer	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Brain cancer	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Multiple sclerosis	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Lupus	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Chronic depression	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Post-partum depression	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Attention Deficit Hyperactivity Disorder (ADD)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Lung cancer	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
HIV/AIDS	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Tourette syndrome	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Schizophrenia	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Mitochondrial disease	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Epilepsy	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Colon cancer	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Karlsen's Disease	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

Q8.7 How many health-related surveys similar to this one have you completed within the past 30 days? Please enter "0" if none. _____

Q9.1 Thank you for taking this survey. Your validation code for MTurk is (MTurk Code). You must enter this code in the completion code box in the Amazon MTurk page to get paid.

We would like to disclose that Karlsen's Disease is a fictitious disease. The disease was created for this survey to simulate a variety of medical conditions. Matching descriptions to any specific medical condition is purely coincidental.

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