

**Evaluating the Implications of Stigma-Induced Identity Threat for Health and
Health Care**

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Dedication

To Sarah and Moe

Abstract

Introduction: Individuals with a stigmatized social identity may experience identity threat in the form of discrimination, prejudice, stereotype threat or internalized prejudice. Identity threat is a stressor that can contribute to physiological and psychological outcomes. In a health care setting, increased vigilance for identity threat can affect communication and impede individuals' ability to attain high-quality health care.

Methods: This dissertation consists of three manuscripts that examine the implications of stigma and identity threat in the health care domain for three sets of stakeholders: patients, caregivers, and providers. The first manuscript assesses whether perceived discrimination as well as other facets of expected stigma are associated with mental and social health outcomes in a sample of 70 individuals who provide care for veterans with a traumatic brain injury. The second manuscript uses a sample of 1109 men who have been diagnosed with colorectal cancer to assess whether stigma related to cancer and self-blame or the perception that others blame them for the disease are associated with depressive symptoms. The third manuscript explores the theoretical underpinnings of identity threat as it relates to the medical encounter, provides several examples of how identity threat may affect the quality and substance of a medical encounter, and suggests evidence-based strategies to ameliorate the effects of the threat.

Results: In manuscript 1, perceived discrimination and other facets of stigma were associated with strain, depressive symptoms, anxiety symptoms, and social isolation

in multivariable models. In manuscript 2, cancer stigma and self-blame for acquiring cancer were associated with greater depressive symptoms, after adjustment for several known clinical and non-clinical stressors. In manuscript 3, several evidence-based strategies are presented which providers may use to communicate to clients and patients that identity threats are non-normative and individuals with stigmatized identities are safe and welcome.

Conclusions: Having a stigmatized social identity and experiencing behavioral reactions to that identity has potentially numerous negative health and health behavior consequences for patients and caregivers. Health care systems and providers can create clinical environments that communicate safety for all social identities, and may improve care outcomes for several marginalized and stigmatized social groups.

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Chapter 1: Introduction

The consequences of having a stigmatized social identity include discrimination, prejudice, stereotype threat and internalized prejudice. These represent stressors that can result in allostatic overload and subsequent physiological and psychological sequelae, as well as a myriad of coping behaviors and strategies that can put a stigmatized individual at risk for emotional and physiological harm. This dissertation consists of three manuscripts that examine the implications of stigma and identity threat in the healthcare domain for three sets of stakeholders: patients, caregivers, and providers. An overview chapter that explains study methods, survey design, measurement of key variables, and limitations, as well as theoretical foundations in detail precedes each manuscript. The first manuscript, located in chapter 4, is titled "*Perceived stigma, strain, and mental health among family caregivers of veterans with traumatic brain injury*". It, assesses whether perceived discrimination, or the behavioral manifestation of stigma, as well as other facets of expected stigma are associated with several mental and social health outcomes in a sample of individuals who provide care for veterans with a traumatic brain injury. The second manuscript, located in chapter 6, is titled "*Stigma, self-blame, and psychological distress in men with colorectal cancer*". It uses a sample of men who have been diagnosed with colorectal cancer to assess whether stigma related to cancer and self-blame or the perception that others blame them for the disease are associated with depression. The third manuscript, located in chapter 8, is

titled “*Stigma and identity threat in health care: The importance of creating identity-safe environments*”. It explores and discusses the theoretical underpinnings of identity threat as it relates to the medical encounter, provides several examples of how identity threat may affect the quality and substance of a primary care medical encounter, and suggests evidence-based strategies to ameliorate the effects of the threat.

Table 1: Three Paper Format

Title	Objective	Design	Sample
Perceived stigma, strain, and mental health among family caregivers of veterans with traumatic brain injury	To assess the association between caregiver reported experiences of discrimination and stigma and caregiver personal strain and emotional distress	Cross-sectional survey	70 caregivers of veterans who were hospitalized for moderate-to-severe traumatic brain injuries
Stigma, self-blame, and psychological distress among men with colorectal cancer	To assess the associations between stigma related to having cancer, self-blame and perceived blame from others and depressive symptoms	Cross-sectional survey	1109 male veterans diagnosed in 2008 with colorectal cancer
Stigma and identity threat in primary care: The importance of creating identity-safe environments	To apply concepts from stigma, identity threat, and stereotype threat literature to the patient experience in the primary care medical encounter	Critical Review / Research Agenda	None

Chapter 2: Background

2.1 Stigma

Stigma, a Greek word for ‘mark’, has historically been used to denote lower social status and immorality. Erving Goffman (1) adopted the term to describe the ‘marked’ identity of people with traits that are different than what is considered normal or ideal. Stigma dehumanizes and devalues the stigmatized, reducing identity to a single “mark” or flaw. (2) Goffman described three categories of conditions that elicit a stigma response: “tribal identities”, “abominations of the body”, and “blemishes of the character.” Having a trait or social identity that is stigmatized can elicit behavioral responses from other people, thus, models of stigma have grown to include observer and interpersonal consequences of having a marked identity: beliefs about the stigmatized characteristics (stereotypes), attitudes toward the trait (prejudice), and action taken in response to the trait (stigmatization or discrimination). (3)

2.2 Stereotypes

Stereotypes are at the foundation of the stigma process. Stereotypes can be conceptualized as expectancies resulting from observations of other people. (4) The Dual Process Model of perception suggests that there are two modes of processing. One occurs automatically and is highly efficient, and the other is conscious, slow, and requires more cognitive effort, time and energy. (4-6) Unless motivated to apply conscious processes, humans tend to process new information using an unconscious,

rapid and effortless process whereby new information is compared to existing schemas, or cognitive models. (4, 7, 8) An individual is immediately categorized according to social cues like dress, speech, or setting. The schema for that group fills in other information about the individual based on their perceived group membership. (7, 9) A stereotype is a schema accompanied by attributions and expectations about the individual based on their group membership. These attributions provide explanations for why something is as it is; and evidence has shown that individuals interpret behavior differently depending on characteristics of the actors that are unrelated to the behavior. (9-12) With stigmatized characteristics of the body, there is an immediate process to determine “why” something is as it is. For example, when an observer is confronted with an individual with severe scarring, they may have an automatic affective response. The common cognitive process is to try to categorize the individual according to the cause of the scarring. The observer may attribute the scarring to violence, and categorize the individual as dangerous; or the observer may immediately attribute the scarring to an automobile crash and categorize the individual as a victim. The distinction between attributions is important because attributions to behavior or actions that are the “fault” of the individual tend to elicit an anger response, whereas attributions to victimization or “poor luck” tend to elicit a pity response. Attributions lead to beliefs about “deservingness” as well as expectancies or predictions of the individual’s future behavior. For instance, if the observer attributes scarring to violence, the expectancy may be that the individual is likely to act violently again and was disfigured through

his or her own choices. Future confirmations of expectancies are likely because observers tend to seek information that confirms their expectancy and ignore or minimize information that may disconfirm it. (13, 14)

When observed behavior is not in line with expectancies, however, the observer's reaction tends to be more severely positive or negative than when behavior is expected. Expectancy violation theory describes the affective response to new information. When an individual observes behavior of an actor that disconfirms an expectancy that the individual has for that actor's social group, the individual is likely to evaluate the information more extremely positively or negatively, depending on the valence of the behavior. In other words, observing negative behavior that is not expected elicits a stronger negative affective reaction than observing expected negative behavior. (15) This has implications for populations that are stereotypically associated with strength and independence. Military veterans, for example, who are injured or debilitated and require help with activities of daily living may violate the expectations of observers, since a stereotype of servicepeople may be that they are strong and independent. Marketing messages for the Armed Forces reinforce this stereotype in recruiting advertisements: "Not Just Strong, Army Strong". When that stereotype is associated with expectancies of strength, behavior that violates those expectancies, such as being dependent on a caregiver, is likely to be salient to the observer and garner a negative response.

2.3 Stigmatized Characteristics

Stigma occurs because of our need to belong to social groups. Social Identity theory and self-categorization theory (16, 17) explain that we identify with groups in order to establish a social identity, defined by any physical or social characteristic, role, or factor that differentiates a group of people. (18) A person's identity may include his or her race, ethnicity, age group, occupation, place of origin, body shape and size, etc. Social identity provides a source of self-concept and self-esteem, as well as a sense of membership and connection with other people. (16, 19) As a key contributor to self-esteem and self-concept, social identities are valuable and individuals are motivated to protect their identities from anything that would harm self-esteem by devaluing or degrading those identities. (20) Stigma occurs due to the need to maintain or elevate the value of one's own group relative to other social groups. According to sociofunctional models, stigma provides some benefit to the stigmatizer; for example, differentiating and favoring one's own group or denigrating another group may preserve self-esteem and improve the social standing of one's own group. (21) Individuals from powerful groups may use stigma as a tool to maintain the status quo by labeling groups that are different from the powerful majority as deviations from normal, (22) and System Justification Theory suggests that these individuals are motivated to reinforce and justify existing power differences between groups as inherently right. (23, 24) One implication of sociofunctional models of stigmatization for individuals with chronic diseases like cancer is blame for acquiring the disease. Blame is related to stigma in that conditions that can be blamed on the individual (e.g., HIV, drug addiction, lung

cancer) tend to be highly stigmatized. (25) Blame benefits the stigmatizer because focusing on a behavioral cause of the disease increases perceived controllability over disease risk, and also justifies the outcome as a result of poor moral behavior (e.g., smoking, overeating). For example, there are strong public beliefs about the behavioral causes of colorectal cancer, including eating a diet high in animal fats and low in fiber and engaging in receptive anal intercourse. (26) These characteristics are also associated with highly stigmatized characteristics (obesity and homosexuality). Thus, it is possible that stigma in this case may originate from the desire to justify the lower social status of those two groups.

Biological models of stigmatization assert that the benefit of stigma to the stigmatizer may include the effective functioning and survival of the stigmatizer's social group. (27, 28) According to these models, stigmatized conditions are those that are associated with shorter lifespan, reduced mobility and social participation, (29) which may negatively affect the functioning and survival of the community. It follows, then, that individuals with serious illnesses, physical disabilities such as traumatic brain injury, or those whose body or behavioral characteristics are commonly thought to cause disease or shorted life will be viewed negatively.

2.4 Stigma-by-association

Goffman (1) hypothesized that the discredit of stigma could be passed from a person with a stigmatized trait to individuals who associate with that person. Stigma-by-association, also called courtesy stigma or family stigma, occurs when social stigma is applied to people who are close to the person with the stigmatized

trait. (1, 30-33) There are multiple processes that contribute to the phenomenon of stigma-by-association. The first is automatic stereotyping of an associate of a person with a stigmatized condition because the identities of the two are linked. The identities of the person with the stigmatized trait and the associate become linked in an observer's mind. (34) When the observer encounters the associate, the stereotypes about the stigmatized person are activated through this cognitive link, along with the attitudes and behaviors that accompany them. This process is typically an automatic process; however, stigma-by-association can be perpetuated intentionally. Following the dual-process perception process described above, observers evaluate a situation heuristically, and if a stereotype is activated, then that stereotype can be generalized to the associate who does not have the stigmatized condition. The observer may then seek out information that confirms the incorrectly-applied stereotype. For example, if an individual is associated with someone who has a mental illness, an observer may initially unconsciously apply stereotypes about people with mental illness to the associate, and then consciously confirm those stereotypes by seeking out or differentially attending to behavior or information about the associate that is consistent with the stereotype. (35)

A second potential process to occur in associates of the stigmatized individual could be called stigma-by-proximity, whereby the associate experiences avoidance and discrimination because he/she is often in the presence of the stigmatized individual who is actually receiving the discrimination. For example, a

cohabitating caregiver of someone who is stigmatized because of a medical condition may feel stress as a result of other people avoiding the household.

Stigma-by-association has been observed in caregivers of individuals with Alzheimer's disease, (36) people with mental illness, (37-39) HIV or AIDS, (40) and family members of people with eating disorders, (41) cerebral palsy, (42) obesity, (43) schizophrenia, (31, 38, 39, 44, 45) and other mental illnesses. (38, 46, 47) It has been shown to predict stress, social avoidance, and a number of negative physical and mental health outcomes in associates of individuals with stigmatized characteristics. (48)

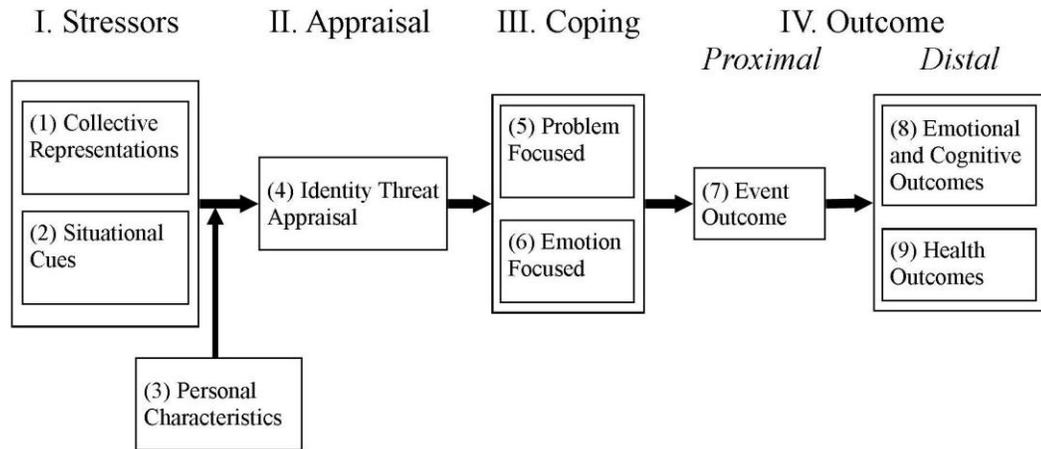
2.5 Effects of Stigma - Stress and Coping

The stress and coping framework is a useful tool to conceptualize the effects of stigma. In the model of transactional stress and coping, (49-52) stressors in the environment create demands on the body or the mind which can cause stress and thereby alter the physical or emotional state of the individual. Stressors are evaluated through two appraisals, a primary appraisal where the individual assesses the stressor and its demand, or the degree to which it will require emotional, physical, or social resources to return the body and mind to their balanced states, and a secondary appraisal, where the individual assesses his or her available resources to cope with the demands of the stressor. Two sets of outcomes emerge from the process: first, if the coping resources and strategy is sufficient to meet the demands of the stressor then the body and mind return to a state of balance, if they are not sufficient, then negative emotional and physical outcomes occur. (52) Second,

coping strategies themselves have positive and negative short term and long term consequences to the health of the individual. (49, 51, 53, 54)

2.6 Effects of Stigma - Stigma-Induced Identity Threat

Stigma-induced Identity Threat is the model that describes how having a stigmatized identity can lead to stress and stress-related health outcomes through the stress and coping process. (2) Due to its relationship with self-esteem and sense of self, social identity is a commitment, or an entity that has high importance to its owner, and thus, is particularly sensitive to threat. (2) Threat is a situation that communicates the possibility of harm. By possessing a stigmatized identity, an individual's exposure to identity-linked stressors is increased. Stigma-induced identity threat can occur as a result of discrimination or other identity-related threatening situations, and lead to a number of psychological, physiological and social outcomes. Stigmatizing situations and the expectation that stigma will occur cause considerable stress. (2, 20, 55) In the model of stigma-induced identity threat, stigma-related identity threat occurs as a result of three factors: collective stereotypes, situational cues, and individual characteristics.

Figure 1: Stigma-Induced Identity Threat (2)**I. Stressors****(1) Collective Representations**

Collective representations are beliefs and stereotypes about a social group. Members of the stigmatized groups who are aware of common representations about their group are also aware that they may be devalued in the eyes of out-group members, and may be victims of discrimination. (56) In social situations, people are highly attuned to the identities that are vulnerable, and can experience heightened awareness of group stereotypes for those identities. (57, 58) Awareness of stereotypes may lead to vigilance, a constant state of readiness and watchfulness for threat, and stereotype threat.

(2) Situational Cues

Situational cues communicate threat in many ways. For example, a situation where an individual is discriminated against or treated poorly is threatening to social

identity if the behavior is perceived to be identity-motivated. Other, more subtle cues include being outnumbered by members of a dominant social group, (59, 60) or being in a situation where a member of the dominant group is in a position of power. (61) Several situational cues have been shown to threaten identity. In one study, a simple suggestion that a college instructor may be sexist reduced the performance of female students in the class, even in the absence of explicitly sexist behavior. (62) In numerous studies, individuals with stigmatized identities who are asked to perform tasks relevant to a stereotype of that identity, (20) in the presence of people in the majority or nonstigmatized social group, (63-65) or after having the stigmatized identity made salient, (65) display evidence of undergoing stereotype threat. For example, African American students and Latino and Latina students administered difficult test questions along with White students were shown to score lower than White students, on average, if they were told that the test measures IQ. However, when they were told that the test was not indicative of intelligence, the disparity in scores was drastically reduced. (66) Women who were asked to indicate their sex before taking the AP calculus exam scored significantly lower than those who indicated their sex after the exam. (67) People with severe mental illness performed significantly worse on a critical thinking task if they disclosed their mental illness before beginning the task. (68)

(3) Personal Characteristics

A number of individual characteristics influence the perception of identity threat. Sensitivity to stigma and heightened vigilance for threat may increase an

individual's perception of a situation as threatening. Evidence shows that individuals who are more aware of stigma and the potential for identity threat are more likely to report discrimination. (56, 69-71) Strong identification with the stigmatized group has also been linked to increased perception of stigma threat (72) as has ambiguity as to whether threat is occurring in a situation (attributional ambiguity). (73, 74) Strong importance placed on the domain that is stereotyped is also associated with increased identity threat. (2) For example, if a stereotype about one's group is lack of athleticism, and the individual values athleticism greatly, he/she is more likely to experience identity threat in that domain. Beliefs and attitudes may alter the threat experience as well. For example, just world beliefs may motivate an individual to see unfair treatment as deserved, and not a result of prejudice. There are also characteristics that buffer the link between stigmatized social identity and stress. A strong sense of in-group favoritism, for example, may sustain self-esteem. (75) Some groups are more likely to exhibit in-group favoritism than others; for example, some racial minorities exhibit high levels of in-group favoritism, whereas people who are obese exhibit very little. (75) Negative feelings towards one's own group identity are referred to as internalized or self-stigma. In self-stigma, the individual who is aware of stereotypes about his/her social group accepts and endorses those stereotypes as well. This phenomenon has been demonstrated in numerous groups, including people with mental illnesses (76, 77) and people who are obese. (78-80) These people may self-discriminate or experience

shame and low self-esteem ('I have this condition, therefore I am worthless'). This process may be especially important for people with visible conditions. (81)

II. Appraisal

(4) Identity Threat Appraisal

Situational cues and stereotypes create threats, or the potential for harm to occur to an individual's identity. Identity threat appraisal is activated to evaluate a threat that is considered harmful and self-relevant.

The primary appraisal is the assessment of the relevance and demands of the situation. If the stressor is perceived to be harmful to physical or emotional balance, then it is considered a stressor of one of three forms: harm/loss, threat, or challenge. (82) Threat is the perception that one is at risk for a negative or possibly harmful event. For example, being stigmatized has the potential to lead to rejection, humiliation, lack of access to resources, or direct attack. There are four primary types of identity threat: categorization threat, identity value threat, distinctiveness threat, and acceptance threat. Categorization threats occur when an individual is forced to represent a social group or take on a social identity. Identity value threats occur when an individual is made to feel like their social group is not valued. Distinctiveness threat occurs when a higher-order stereotype of an individual's social group is applied to an individual. Acceptance threat occurs when an individual is made to feel like they do not belong in the setting. (83) If primary appraisal detects one of these threats to a social identity, then the physiological stress response of allostasis is initiated. Other potential results of primary appraisal are perceived

harm/loss and challenge. (52) Harm/loss is the perception of damage that has already occurred. In this case, the potential for additional harm is not present. (82)

Challenge is the perception of an opportunity for gain, wherein an individual is positioned to meet the demands of the stressor.

Stereotype Threat

Stereotype threat is a specific type of identity threat where the individual's behavioral, physiological, and affective response to threat occurs without discrimination, prejudice or any major or subtle behavior from someone else that would signal devaluation. Stereotype threat occurs in situations where an individual is aware of a stereotype about him or herself and believes that he or she may be at risk of arousing that stereotype in another person's mind or behaving in a way that confirms the stereotype. (20, 58) This causes the individual to become preoccupied with the possibility of identity threat, and can initiate a stress response without evidence that he or she has been the target of threatening behavior. (84) This expectation for and preoccupation with threat can dramatically and negatively affect an individual's ability to concentrate and perform cognitively challenging tasks. (20, 58, 84)

III. Coping

(5) Problem-focused or (6) Emotion-focused Coping

These strategies are employed as a response to stress. (49, 85, 86) Coping strategies are important because they present a potentially modifiable aspect of the

stigma-induced threat process. For example, people who blame discrimination rather than blaming themselves for the threat may avoid feelings of shame and protect their self-esteem. (73, 87-92)

Coping Strategies

In the secondary appraisal of the stress and coping framework, the individual makes two determinations: the efficacy expectation - what coping strategies are available and could be successfully enacted, and the outcome expectation - the potential effectiveness of those strategies at eliminating or reducing stress. (52)

Problem-focused coping strategies are attempts to manage stress by directly affecting the interaction between the individual and the environment that is causing the stress. (52, 86) This can be accomplished by defining the problem and choosing a solution that will reduce the size or impact of the problem directly or indirectly. (93) Emotion-focused coping is aimed at managing the emotions that arise as a result of the stressor. (52) These strategies include avoidance, minimization, disengagement, repression, forgiveness, and many other cognitive and behavioral tools. For example, emotion-focused reappraisal strategies include changing the meaning of the problem through reframing or empirical investigation of the validity of thoughts aroused by stress. (52) Some emotion-focused coping strategies aim to increase the level of emotional response. These strategies, e.g., self-blame, catastrophizing, self-punishment, are sometimes used to become acutely aware of the stressor in order to initiate another emotion or problem-focused coping response. For example, people with severe illnesses may engage in self-blame for causing the

disease in order to feel like they have greater control over their recovery and eventual prevention of recurrence. (82, 94)

Coping Resources

There are a number of factors that help determine what coping strategies are available to be used in a given situation. (52) Personal resources like health, self-concept, positive self-esteem, mastery, material resources, and problem-solving skills increase the number and effectiveness of available coping strategies. For example, someone with greater material resources may have greater access to counseling, and someone with greater mastery in a certain situation may be better equipped to engage in a problem-focused coping strategy. A lack of resources may constrain the ability to use certain strategies to cope with stigma. Someone with poor social skills is less likely to have the social network available to help provide emotional or tangible support. Other factors can constrain the use of certain coping strategies, for example, one's desire to avoid a stigmatizing label may prevent him from using anti-depressive medications to reduce negative emotions. (95, 96)

Maladaptive Coping

A vast literature on stress has shown that there are coping responses to stress that can be particularly harmful. (2, 81, 85, 97-101) Coping strategies that are adaptive in that they meet the immediate demands of stress can be maladaptive in terms of their effect on health or other domains. Several maladaptive behaviors have been linked to identity threat among stigmatized populations. (102-104) Examples of maladaptive coping strategies include excessive and dangerous use of drugs or

alcohol, (105, 106) binge eating or food deprivation, (54, 107) smoking, (108, 109) avoidance of situations that may be challenging, withdrawal from social networks and social isolation, lying, procrastinating, and avoiding situations where stigma is expected to be a problem. (70, 110-115) Modified Labeling theory asserts that individuals with a social identity that is stigmatized will withdraw and isolate themselves in order to avoid being labeled by other people. (116) In the health care domain, this may contribute to lower follow-up rates and the greater likelihood of missing medical appointments among members of minority groups (117) and people who are obese or overweight who fear being weighed, (118) and delaying or failing to obtain needed medical care and preventive health care services. (113, 119-122) Recent research has shown that people who are stigmatized are less likely to seek mental and physical health care (112, 113) or participate in physical activity. (110, 114, 115) If the stigma is salient in most situations and it is difficult for the stigmatized person to find social interactions where stigma is not expected, then the stigmatized person may withdraw from all social situations. (116, 123-127)

Disengagement and Disidentification

Disengagement is a coping strategy whereby an individual who experiences threat withdraws from a situation as a defense mechanism. Individuals who experience identity threat in a certain domain regularly may disidentify, or redefine their group's identity in ways that distinguish it from the majority group, often in oppositional ways. These individuals detach their self-esteem from the domain, and cease expending energy in behaviors associated with it. This phenomenon,

disidentification, may help explain the tendency of some people to view health promotion behaviors (e.g., exercising and healthy eating) as characteristic of specific groups, (128) and has been cited as the reason women are underrepresented in fields like engineering. (63, 129) It also may help explain correlations between experiences of body weight stigma and reduced physical activity, (115) since individuals are more likely to engage in behaviors that are seen as central to their self-concept. (57, 58)

IV. Outcomes

(7) Event Outcomes

There are a number of potential consequences to the stress process. Adaptation, or ability to change and grow in response to changes in the environment, is the ultimate goal of the stress process. (130) The need to adapt to stressors in the environment sets off a series of physiological changes that affect many body systems and functions. These changes, called allostasis, prepare the body to meet the demands of stress, but also provide a mechanism for stress to cause negative health effects. (130-132)

Homeostasis

Homeostasis is the tightly regulated balance maintained by various systems in the body. Feedback systems respond to imbalances in order to keep homeostatic systems like body temperature, blood glucose, and blood pressure within a narrow healthy range. (130) If a homeostatic system is not able to maintain that balance, then disease occurs. (133) Hans Selye (134) proposed that dysregulation of

homeostasis could be caused by stress, which evokes a process he called the General Adaptation Syndrome, characterized by stimulation of the hypothalamic-pituitary-adrenal axis, leading to release of cortisol enabling the body to respond to the imbalance. (130)

Allostasis

Research on General Adaptation Syndrome led to the concept of allostasis, which describes how several interconnected systems of the body react to stressors as part of a centralized system. (130, 135, 136) Whereas homeostatic systems of the body are required to stay within a certain range of operability, allostatic processes are free to adapt and respond to stress. (137) As such, allostasis allows humans to survive in extreme conditions that would otherwise tax homeostatic systems to the point of collapse. Allostasis can orchestrate changes in the body in anticipation of an event and continuously monitor the balance between external stressors and internal resources. This has ramifications for the stress caused by stigma. The brain of an individual who expects stigma to occur is beginning the allostasis process in order to deal with the threat. (130)

Allostatic Response

The allostatic response to stress is complex, with numerous feedback loops, involving the brain as well as other systems in the body which produce and transport the chemical signals to the homeostatic systems of the body. These chemicals work in both central allostasis (brain) as well as peripheral allostasis (other organ systems) to adapt the body in response to stress. (130)

Central allostasis is a set of responses to stress that occur in the structures of the brain that make up the limbic system: primarily the amygdala, hippocampus, basal ganglia, and medial prefrontal cortex. (130, 135, 136, 138) Each of these brain structures plays an important role in emotion as well as remembering and being vigilant for stressful events. The amygdala and basal ganglia are important for consolidating memories of threatening stimuli in order to avoid future threats. (138) The medial prefrontal cortex is important for higher-level processing and coping with identity threat and the hippocampus is vital for contextual memory of events that caused an emotional response. (130, 135, 136, 138) The hippocampus and amygdala are also responsible for activating the peripheral allostatic response, i.e., the sympathetic nervous system and the hippocampal-pituitary-adrenal (HPA) axis. Activation of these symptoms results in the release of the primary chemicals of allostatic response: catecholamines [noradrenaline (norepinephrine), adrenaline (epinephrine)], and cortisol (glucocorticoid). (130, 139, 140)

Adrenaline and noradrenaline, produced by the adrenal glands and the locus ceruleus, are key components of the fight or flight response to stress. (130) Their release results in increased glucose availability as well as vasoconstriction and accelerated heart rate to increase blood and oxygen flow to the skeletal muscles. (139) They also increase the production of pro-inflammatory cytokines, and are active in transporting immune cells to targets throughout the body. (139) In the brain, they enhance the ability of the hippocampus and amygdala to store and consolidate memories of threat. Cortisol is a steroid that is produced in the adrenal

glands and has a number of effects throughout the body. One function is to activate liver enzymes to convert protein and lipids into carbohydrates, resulting in a rush of available energy for confronting a stressor. In the brain, it enhances the ability of the hippocampus to store fear-related memories.

(8) Emotional and Cognitive Outcomes

Integrated Process Model

A number of cognitive performance deficits resulting from identity threat have been observed, including deficits in information processing, (20, 141, 142) memory, (143, 144) learning, (63) rational decision-making, (145) and fluency of verbal and nonverbal communication. According to the Integrated Process model of stereotype threat, the effects of stereotype threat are mediated by a combination of three distinct elements: the effect of stress on short-term cognitive functioning, active monitoring of performance in interactions, and suppression of negative thoughts and emotions. (144) Acute stress affects cognitive function, as described previously. Cognitive capacity is further taxed by continuous monitoring of one's own performance and appearance in the interaction, as well as heightened vigilance for threat cues, a process that requires effort. (146) Finally, effortful emotional coping strategies like thought suppression (147) and emotion regulation which are used to manage the stress of the situation can occupy further the cognitive capacity of the stigmatized individual, greatly reducing the working memory available for engaging in the interaction or performing whatever task has initiated the stereotype response.

(10) Health Outcomes

Allostatic load

Although allostasis allows the body to adjust to the immediate demands of stress, chronic, long-term or repeat exposure to allostasis has damaging effects on many systems of the body. The accumulation of the effects of allostasis is called allostatic load. (131, 132, 137, 139) In the brain, chronic exposure to cortisol and catecholamines results in over-development and hyper-responsiveness of the amygdala, and atrophy of the dendrites of the hippocampus and medial prefrontal cortex, which may lead to excessive fearful memory production and impair cognitive functioning. (141) Human imaging and animal studies have found that these changes to the structure of the brain are prevalent among individuals with post-traumatic stress disorder and severe depression and anxiety. (138, 148, 149) Furthermore, the medial prefrontal cortex is the site where glucocorticoids initiate the shutdown of the HPA axis response, (150) a process that may be slowed by atrophy, resulting in extended exposure to stress hormones following a stressful incident.

In the cardiovascular system, allostatic load increases the concentration of glycosolated hemoglobin and the ratio of LDL to HDL cholesterol, contributing to atherosclerosis. (140, 151) Chronic blood pressure elevation resulting from repeated stress has damaging effects on the kidneys and the epithelial walls of the arteries. (151-154) Identity threat has a cardiovascular response that is distinct from the response to identity-relevant situations that trigger challenge. When an individual

with a stigmatized identity experiences an identity threat, increased cardiac output occurs with no change in arterial volume, causing increased blood pressure. (124, 153, 155-158) In contrast, challenge is characterized by increased cardiac output along with adrenaline-induced arterial dilation, which results in little change in blood pressure. (124) Chronically elevated cortisol results in sustained elevated blood glucose and insulin resistance, contributing to risk for onset of type II diabetes and metabolic syndrome as well as exacerbation of type I diabetes. (132, 159) Through cytokine production, endocrine imbalance, and alterations in appetite signals, allostatic load can contribute to obesity and can alter body fat distribution, increasing abdominal adiposity. (132)

Other effects of allostatic load include exacerbation of asthma symptoms through constriction of airways; ulceration of the esophagus, stomach, and other areas of the gastrointestinal tract, as well as elevated risk for ulcerative colitis and inflammatory bowel syndrome; increased susceptibility to viral infections (132); and increased risk of autoimmune and inflammatory disorders like rheumatoid arthritis and Grave's Disorder. (130, 140, 151, 154, 160, 161)

Anxiety

Anxiety is a commonly reported outcome of the physiological effects of allostasis. Stigmatized health-related identity and perceived identity threat have been shown to be associated with anxiety among individuals with epilepsy, (162) individuals with Hepatitis C (163, 164); individuals with inflammatory bowel disease

(165); individuals with rectal cancer (166); individuals with HIV (167) and qualitatively among women with fibromyalgia and chronic fatigue syndrome. (168) Allostatic load also increases risk of emotional arousal, intrusive thoughts, (169) and anger, (170) which are predictive of anxiety and depression. (171-173)

Depression

There is ample evidence that acute (174) and chronic exposure to stress contributes to depression. (175, 176) Evidence from several experiments also support a causal link between identity threat and stress processes. (59, 129, 177) It follows that experiences of identity threat would be associated with depression. In one study, parents of children with mental retardation, autism, or developmental delays were administered measures of perceived stigmatization and depressive symptoms at two timepoints. Perceived stigma predicted subsequent depression at follow-up, independent of baseline depression. However, depression at baseline did not predict stigma at follow-up, lending support to the hypothesis that the relationship between identity threat and depression is causal. (178) Another longitudinal study found that among people with mental illnesses, expectations of stigma at baseline predicted severity of depression 18 months later. (179) Evidence for the association has been found in cross-sectional studies of several stigmatized groups, including groups with stigmatized health conditions like HIV/AIDS (180-182); obesity (183-185); Hepatitis C (163, 164, 186); inflammatory bowel disease (165); and rectal cancer. (166)

Self esteem

There is ample evidence that stigma and threatened stigmatized identity causes lowered self-esteem. (187-190) Longitudinal studies of individuals with stigmatized identities have shown that stigma precedes reduced self-esteem in people with mental illnesses. (189, 191) Cross-sectional associations between stigma and lower self-esteem has been found in several populations, including people with mental illness, (192) children of lesbian mothers, (193) gay men, (194) adolescents with epilepsy, (195) individuals with HIV/AIDS, (196) and individuals with cancer. (196)

Chapter 3: Overview of Paper 1 - Caregivers of Individuals with Traumatic

Brain Injury

3.1 Introduction

Nearly 38,000 service members have been wounded in action in the wars in Iraq (Operation Iraqi Freedom, OIF) and Afghanistan (Operation Enduring Freedom, OEF). (197) Many of these injuries occur as the result of blasts, causing traumatic brain injury (TBI). The RAND Corporation reported in 2008 that 19.5% of the 1.64 million deployed US servicemembers reporting having experienced at least a mild TBI. (198) In the US, there are a total of 1.4 million diagnoses of TBI each year. (199) Individuals with TBI may have many neurological effects of the injury, which can have long-term behavioral and cognitive effects (200, 201); many will require intensive rehabilitation and life-long informal care by unpaid family members. (202, 203) Research in many patient populations has shown that active caregivers improve health outcomes of chronically ill individuals; however, they can incur a relatively high degree of strain that can result in negative outcomes for the caregiver and the care recipient. (47, 204-208)

The overall strain on the caregiver is dependent on a number of factors, including number of care tasks provided, and the relationship to care recipient. (209-211) Little is known about the effects of stigma on the caregiver. Veterans with TBI and their caregivers may experience social stigma due to the care recipient's visible (e.g., scarring, amputation) and invisible (e.g. neurobehavioral symptoms) injury and

treatment effects, (212) but the degree to which stigma contributes to stress among individuals with TBI and their caregivers is not known. In other populations, caregiver stigma-by-association and care recipient stigmatization have been shown to increase caregiver strain and affect both the health of caregiver and the outcomes for the care recipient. (39, 41, 42, 213) However, clear information for patients, families, and providers on the best approaches for coping with stigma is lacking.

3.2 Informal Caregiving

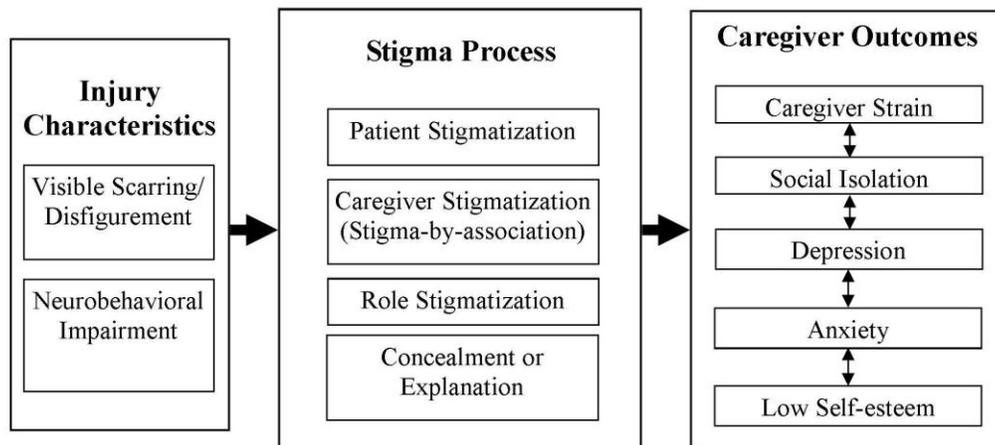
Health care providers working in the VA Rehabilitation Centers report that the involvement of family in the rehabilitation and caregiving process is significant. Family members like spouses, parents, siblings and children play a vital role in their injured loved one's rehabilitation and are likely to continue to play a role in long-term care and rehabilitation after discharge. (214) Caregiving responsibilities are likely to include assisting with activities of daily living, administering and monitoring medication, providing transportation, participating in treatment plans and medical decisions, coordinating services and benefits from the Department of Defense and the VA, as well as advocating for the care recipient in acquiring benefits and social and community services. (214)

3.3 Framework for Understanding the Effects of Caregiver Perceived Stigma

The study design and analysis is based on the conceptual model shown in Figure 2, which draws upon a stress and coping framework (52) and model of stigma-induced identity threat in which caregivers and care recipients respond to stigma-induced stress by engaging in specific coping behaviors. (2) In this model,

caregiver stigma-by-association and care recipient stigmatization is influenced by characteristics of the injury that make it more salient in a public setting: visibility and neurobehavioral impairment. Caregiver stigmatization-by-association leads to negative outcomes, including strain (subjective burden), social isolation, depression, anxiety, and low self-esteem. This research will focus on the independent association between stigma process variables and caregiver stress outcomes, independent of caregiver demographic characteristics and other stressors that may contribute to psychopathology.

Figure 2: Conceptual Model for Assessing Effects of Stigma on Caregiver Outcomes



3.4 Why Might Individuals with TBI be Stigmatized?

Though perceived stigma has not been measured in people with TBI, it is expected to be high for a number of reasons. First, many individual with moderate-to-severe TBI have long-lasting cognitive and/or behavioral effects, such as inappropriate social interaction, impulsivity, and control of anger. (200, 201)

Research involving people with invisible but otherwise perceivable stigmas, such as severe mental illness, has demonstrated that the fear and disgust aroused by these conditions represent a considerable source of stress. (215) It is likely that some of the behavioral or cognitive injury effects among individuals with TBI closely resembles symptoms of severe mental illness. Moreover, there is evidence that the general public and health care professionals tend to underestimate the seriousness of TBI and the persistence of some cognitive and behavioral effects, leading to unrealistic expectations for individuals who have experienced TBI. (216) Hence, limitations resulting from the TBI (e.g., difficulty performing family or work responsibilities) may be attributed to a lack of effort, leading to heightened stigmatization. (215, 217, 218) In addition to these stigmas, the individual with TBI may experience devaluation related to stereotypes about violent behavior among returning service people that have been highlighted in popular media or related to stereotypes about weakness associated with impaired functioning.

In addition, many people admitted to Rehabilitation Centers have injuries like burns and wounds or treatment effects like craniectomies that are visible and difficult to conceal. Visible stigmas are among the most meaningful and debilitating because

the stigma becomes an essential part of the self-identity of an individual as well as the characteristic that defines them in public perception. (219) Qualitative research has shown that the experience of being stared at or intentionally not looked at is very common and stressful to people with facial deformities. (123, 220) Empirical research has demonstrated the presence and severity of stigmatization in response to a number of visible stigmas. One study found that, when interacting with a person with a physical disability compared to a non-disabled person, people tend to end interactions sooner and create more physical space between themselves and the person with the disability. (221) In another study, researchers digitally altered photographs of ten persons with posttraumatic or congenital facial abnormalities to remove the stigmatized condition. Adult volunteers rated persons with abnormal facial characteristics significantly less honest, employable, trustworthy, optimistic, effective, capable, intelligent, popular, and attractive. (220) A number of studies have identified behavioral and physiological indicators of anxiety among individuals who are interacting with a person who has a physical disability or disfigurement. People may smile less frequently and stare more, (222) and are more likely to self-report feeling tense (221) when interacting with a person with a disability. Interactions with individuals with physical deformity have also been shown to cause a cardiovascular response consistent with increased stress. (223) Other research has shown that people will avoid social interactions with a person with a disability if it is socially acceptable to do so. (125, 221, 224) Research using the complexity-extremity theory (225) has suggested that people tend to have less nuanced

evaluations of people they do not identify with as common-group members. So, an injured veteran who is in the company of non-veterans may be evaluated with less complexity, resulting in a perceived identity that is based on easily-available information like the injury or its effects. After discharge, the veteran's companions are less likely to have military service in common, and the veteran may be more likely to be aware of the less-nuanced evaluations of their companions.

Besides being stigmatized due to what Goffman refers to as an "abomination of the body," individuals in this population may experience stigma related to "blemishes of the character" too. Villains, for instance, are frequently denoted by facial scars or deformity in both movies and literature. (123) Facial and other deformity can lead to perceptions of dangerousness and arouse fear or uncertainty, which can lead others to avoid the stigmatized person.

3.5 Why Might Caregivers of Individuals with TBI be Stigmatized?

The majority of the caregivers of individuals with TBI are spouses or parents of the care recipient. The sudden and dramatic shift in role from spouse or parent of an adult to caregiver is likely to be accompanied by a great stigma burden for a number of reasons. First, their loved one is likely to have long-term cognitive and behavioral effects of TBI and possibly post traumatic stress disorder. A heavy stigma-by-association burden has been shown in caregivers and family members of people with mental illness, (3, 37-39, 44, 45, 213, 226) Alzheimer's disease, (36, 37, 227) and autism, (228) which all have symptoms that can resemble neurobehavioral symptoms in individuals with TBI. Stigma burden among these groups is closely

correlated with severity and visibility of the person's behavioral disease symptoms, (229) or cognitive impairment. (36) Second, previous studies have shown that younger age of the caregiver and being the spouse of the person with the condition are strong predictors of stigma-by-association. (213) In one study of family caregivers of individuals with mental illness, spouse caregivers reported twice as much social avoidance from friends as parent caregivers. (230) Due to the visibility of injuries, stigma-by-association (31) is expected to be a primary source of stigma for caregivers because of avoidance of social contact by former acquaintances. A secondary source is stigmatization due to the role of caregiver. Caregiving is not necessarily a highly valued social role. Reduction in social roles has been shown to predict stress among caregivers. (231) It removes an individual from providing material benefit to society, and concentrates his/her efforts on a single recipient. It has been demonstrated that caregivers who report that they have lost part of their identity (role engulfment) have lower self-esteem and mastery, and worse mental health. (232) In this population, caregiving was often not a choice, and caregivers may feel their identity especially devalued and threatened from individuals from previously occupied social groups (e.g., former coworkers).

3.6 Caregiver Stress

Most caregivers are likely to be family members of the care recipients and will be motivated to protect them from harm. Stigmatization of the care recipient, then, is likely to lead to stress among caregivers. Research among parents of children with special health care needs identified the desire to protect the care

recipient from discrimination and unfair treatment as a cause of stress and anxiety. (33, 42) Besides the stress of caregiving and the potential stress of identity threat, many caregivers face a reduction in coping resources. Financial resources may be depleted for caregivers and their families, and social networks may also be reduced, (232) leading to less support, greater isolation and loneliness. (233-238)

3.7 Caregiver Outcomes

Providing care to someone with TBI may be burdensome and result in high levels of stress, depression, anxiety, and lack of time for social activities. Furthermore, the experience of stigma across a wide range of conditions has been shown to increase social isolation, (123-126) and symptoms of depression and anxiety. (239-241) Perceptions of stigma-by-association has been shown to increase the subjective strain of caregiving, (33, 39, 42, 213) strain relationships, (38, 46) and increase avoidance of social situations among caregivers of individuals with TBI (48) and other stigmatized conditions. (40, 230, 242, 243) Perceptions of care recipient stigmatization have also been shown to increase caregiver subjective ratings of strain. (33, 38, 42) Avoidance of stigmatizing social situations and social withdrawal by the caregiver can be an attempt to cope with stigma-by-association, an attempt to protect the care recipient from experiencing stigma within interpersonal interactions, or a combination of both. Social withdrawal may lead to less tangible and emotional support for the caregiver, (242) and a subsequent increase in caregiver strain.

3.8 Methods

3.8.1 Study Population

The target population for this study is caregivers of veterans who experienced a traumatic brain injury and were treated and discharged from one of four VA Rehabilitation Centers located in Minneapolis, MN; Richmond, VA; Palo Alto, CA; and Tampa, FL, between 2001 and 2008. These facilities provide rehabilitation services for US veterans with traumatic brain injury, many of whom have other injuries as well. Individuals present to the VA Rehabilitation Centers with penetrating and non-penetrating head injuries, at different levels of consciousness, and with amputations, skin and soft tissue wounds, multiple fractures, burns, visual and hearing loss, pain, and post-traumatic stress disorder, among other injuries. (214)

The caregiver was defined as the person who currently provides help with any daily activities for the injured veteran. Eligible caregivers for this study were those who provided care for a veteran who was <50 years old, and had a diagnosis of TBI. This study was a pilot for a large survey of caregivers of injured veterans who served during the Operation Enduring Freedom/ Operation Iraqi Freedom (OEF/OIF) era, from 2001 to 2008. Caregivers of individuals injured during OEF/OIFF will be studied as a group in subsequent analyses. For this pilot study, eligible veterans were also discharged from a VA Rehabilitation Center between 2001 and 2008, but were not classified as OEF/OIF because they were discharged from the military prior to the start of OEF/OIF. These veterans were older than OEF/OIF veterans, (average age is 31 for OEF/OIF veterans and 41 for this sample), more likely to have served during peacetime or during Operation Desert Strike/Desert Storm, and thus, may be

more likely to have injuries that occurred in a non-combat situation (e.g., a vehicle crash or fall), after their military service ended. For this reason they may be more comparable to a civilian population, and the results may be more generalizable to individuals with TBI in the general public.

3.8.2 Identifying Study Sample

Identifying the study sample was done in two steps. First, all eligible individuals were identified through VA administrative records and their next-of-kin information was extracted from Veterans Health Information Systems and Technology Architecture (VISTA) records. Second, the identified next-of-kin were sent a letter asking them if they consider themselves the primary caregiver (“someone who is available to the patient for care and support if they ever needed it”), and if not, if they could identify someone who is. One primary caregiver was surveyed per injured veteran. It is likely that multiple people participate in providing care, but only the primary caregiver for each individual was identified and surveyed. This is a common procedure and limitation of caregiving research.

In cases where the next-of-kin contact information was not valid, we used an online database service (Lexis Nexis) to locate the most recent address or phone number. Non-responders with available telephone numbers were called and encouraged to complete the survey.

3.8.3 Sample Size

One hundred thirty nine individuals with TBI were identified who met inclusion criteria. We were able to identify 123 caregivers using next-of-kin records

or subsequent nominations, 70 of whom (57%) returned surveys. Additionally, 15 (12%) returned refusals, and 38 (31%) did not return surveys. Data were not available on the caregivers who did not respond, but a comparison of the veteran care recipients of individuals who responded and those who did not showed that there were no significant differences in the average age of care recipients (responders: mean=41, S.D.=7, non-responders: mean=42, S.D.=7; $p_{t\text{-test}}=.51$) or the proportion of care recipients who were non-White (responders: 16%, non-responders: 14%; $p_{\text{chi-square}}=.90$), female (responders: 7%, non-responders 10%; $p_{\text{chi-square}}=.53$), or married (responders 37%, non-responders 34%; $p_{\text{chi-square}}=.64$).

3.8.4 Study Design

The study was carried out in conjunction with a large observational study of caregivers of individuals with serious injuries. It included a cross-sectional *mailed survey* of primary family caregivers, as well as abstraction of veteran demographic information from VA records.

3.8.5 Mailed Survey Data Collection

A self-administered mailed survey was chosen for the following reasons: (1) self-administered formats are a cost-effective and reliable medium for quickly collecting data from a large number of people; (2) phone and face-to-face interviews may not be feasible in this population of caregivers given the geographic dispersion and time constraints due to caregiving responsibilities. A self-administered survey provides respondents with the flexibility to respond when they choose. (3) Technologies like caller ID and increased cell phone usage have reduced response

rates for phone surveys (244); and (4) a self-administered survey avoids differential bias caused by an interviewer.

The two most effective ways to reduce non-response for mailed surveys are multiple contacts and inclusion of an incentive in the mailing (rather than promise one following survey completion). (245) Incentives have also been found to decrease item non-response. (246) Survey procedures outlined in Dillman's Tailored Design Method (TDM), (245) were used to maximize the response rate. The initial mailing included a \$20 cash incentive, a letter explaining the study's purpose, the survey, detailed instructions for completing the survey, and a postage-paid return envelope. Participants who do not respond to the mailed survey were sent a second mailing including a cover letter, second survey, and postage-paid return envelope. Reminder postcards were sent approximately 3-5 days after each mailing. After the second mailing and postcard, the survey was sent by Federal Express, a method that has yielded very good responses in hard-to-reach populations in other surveys. Instructions for opting out of the survey were included in the cover letters for all mailings.

3.8.6 Questionnaire Development

The survey was developed by a multidisciplinary team, which included the author (SP). The questionnaire was consistent with previous research (245) which suggests that item non-response can be minimized by keeping the survey layout, question wording, and response categories simple (e.g., written at the 6th grade or lower reading level, no more than 3-5 response categories for any question) and clear

(e.g., visually uncluttered, no complicated skip patterns). The questionnaire underwent several rounds of cognitive interviews with key informants, an essential step in developing high quality survey instruments. (246) The cognitive interview approach (in which a study interviewer reviews the instrument in detail with a respondent) examines the cognitive processes that respondents use to answer survey questions in order to uncover both explicit and implicit problems in survey questions. These processes include the respondent's comprehension of the question, the retrieval from memory of relevant information in order to answer the question, and the process for making a decision on how to answer the question. The cognitive interview was used to uncover ambiguous and misleading questions, as well as the level of complexity and thought that goes into understanding and answering questions. An advisory board, consisting of family members of individuals with TBI took part in the cognitive interview phase.

3.8.7 Measures of Stigma

In order to measure various aspects and sources of identity threat, multiple measures were used. See Table 2 for items and psychometric properties for all scale measures of primary dependent and independent variables.

The perceived behavioral manifestation of stigma in others was measured using five items from the Williams Day-to-day Discrimination Measure, (247, 248) which were chosen based on face validity for this population. The measure was used once in reference to the care recipient (e.g., "He/She feels that...") and once in reference to the caregiver (e.g., "I feel that..."). Response options for all independent variable

items were “never”, “rarely”, “sometimes”, “often”, and “nearly always”. In factor analysis, caregiver discrimination items loaded to one factor; Cronbach’s alpha was .89 and item-scale correlations ranged from .62 to .81. Care recipient discrimination items also loaded to one factor; Cronbach’s alpha was .90 and item-scale correlations ranged from .66 to .82. When placed into a single factor analysis, constrained to extract two factors, the scales loaded cleanly to separate factors, with the exception of one item, which loaded weakly to both scales. This is not surprising, given the small sample size, and scale variables were computed as designed to maintain the integrity of the scales.

Discrimination was chosen as a construct because it is the most easily recognized behavioral manifestation of stigma and prejudice. The day-to-day discrimination measure was chosen over measures of lifetime instances of major discrimination to help isolate discrimination that is due to caregiving for an individual with TBI, an acquired and recent state, relative to many of the other identities that may engender major discrimination, like minority race. We do not ask respondents to identify the reason they felt they were discriminated against, a task that is difficult to do, as people attribute unfair treatment to many different causes; rather, we adjust in analysis for other stigmatized identities.

Because many caregivers forfeit other life roles in order to devote the time needed to help their care recipient, we measured caregiver role stigma, or felt stigma associated with the role of caregiver. This construct was measured by two items that were created for this study: “I feel there is a stigma that goes with caregiving”, and “I

feel that most people think less of a person who provides care for someone else”. These items were based on the wording of stigma items used previously, (39) but no published or validated measure of this construct is available. In factor analyses, these items consistently loaded to a unique factor. The two-item factor explained 88% of the variance and had a Cronbach’s alpha of .84.

Caregiver need to cover/explain was expected to be a coping response to stigma, as caregivers may try to dispel observers’ judgments by explaining that the behavioral effects were acquired in military service, or avoid stigma by avoiding those who may stigmatize. These two seemingly different coping responses loaded to the same underlying factor in principle components analysis, so they were combined to form a single scale. The two items were: “I feel I have to cover up my care recipient’s injuries”, which was included in the Experiences of Caregiving Inventory (39) and “I feel the need to explain to others how my care recipient got the injuries,” which was written by the authors. The scale variable represents a need to influence others’ perceptions of the care recipient. The factor explained 77% of the variance; Cronbach’s alpha was .69 and the item correlation was .54.

3.8.8 Primary Dependent Variables

Caregiver Strain was assessed using the short form of the Zarit Burden inventory, (249) which has been used extensively throughout caregiving research to assess the burden of caregiving. Two factors were identified: personal strain (eight indicator items, Cronbach’s alpha=.89, item-scale correlations were .52-.75); and

role strain (two indicator items, Cronbach's $\alpha=.75$, correlation $=.60$), or conflict between caregiving and other responsibilities.

Low Self-esteem is an outcome of stigma and identity threat, and was hypothesized to be reduced by experiences of discrimination as well as perceived caregiving role stigma. This construct was measured using the 10-item Rosenberg Self-esteem Scale. (250) A single mean-score variable was created that had a Cronbach's α of .90 and item-total correlations of .36-.80.

Depression and Anxiety were measured with the PROMIS depression and anxiety short form scales. (251-255) The National Institutes of Health PROMIS initiative developed, validated, and standardized item banks to measure patient-reported outcomes relevant across common medical conditions for use as a "common currency" across research projects. (256-258) Item banks were calibrated using item-response theory on a sample of 21,133. Short forms from each bank were developed and compared with other well-validated and widely accepted measures. All short forms demonstrated good reliability and moderate to strong correlations with widely-used measures. These scales measure frequencies of symptoms reflecting negative affect (depression scale) and autonomic arousal and threat (anxiety scale) over the past seven days. The depression scale consisted of eight items and the anxiety scale consisted of seven items; both with strong psychometric properties. Depression had a Cronbach's α of .92, with item-scale correlations between .57-.87; anxiety had a Cronbach's α of .93, with item-scale correlations of .61-.84).

Social Isolation is expected to be a result of experiencing stigma, since avoidance of social situations is a means to cope with repeated identity threat. This construct was measured using three items from the UCLA Social Loneliness Scale. (259) The selected items had the highest factor loadings to the dominant factor in two large population studies. The measure had good internal consistency (Cronbach's $\alpha=.95$) and item-scale correlations were .87-.90.

3.8.9 Analysis

We fit multivariate linear regression models predicting each dependent variable: personal strain, role strain, self esteem, depression, anxiety, and social isolation. Covariates included demographic factors that may also lead to discrimination and poor treatment and other predictors and moderators of stress in caregiving, including measures of the amount of caregiving performed and a measure of caregiver social support.

3.8.10 Potential Sources of Bias

Due to its cross-sectional design, this study is vulnerable to bias from known and unknown confounders. We have partially addressed this possibility in analysis by adjusting for several potential confounders including social support and relationship of the caregiver to care recipient. Likewise, we adjusted for several sociodemographic factors that are known to predict perceived discrimination and may be associated with elevated strain or distress. The potential for selection bias is high, since potential participants were recruited with a wide net (all caregivers of all identified individuals with TBI were contacted) and participants self-selection to

participate may be based on a number of unknown factors. For example, caregivers who respond may be more or less likely to be strained than the actual population of caregivers. Caregivers who experience a great deal of strain and may not respond to a survey study that competes for time with caregiving tasks; or those with a high degree of emotional distress may be less inclined to participate as well. However, those same caregivers may be more likely to respond, since the survey is more likely to speak to their experiences, and they may appreciate an outlet to explain their experiences to people who want to know. Caregivers who experience little strain or perform few care tasks may be more likely to view the survey as not pertaining to them. During recruitment, several strategies were used to reduce the risk of self-selection bias. First, incentives were mailed in the first mailing with the questionnaire, a strategy that creates a sense of social responsibility to reply, and may reduce the risk of opting-out by caregivers who perform fewer care tasks. Second, questionnaire instructions and the accompanying letter explicitly stated that all caregivers who performed most of care tasks for the injured veteran were important to the study, regardless of how many care tasks were actually performed. Third, non-responders to several mailings were contacted via telephone and encouraged to respond. Recall bias may affect questionnaire responses because respondents are reporting throughout the survey on experiences that occurred in the past (e.g., care tasks, instances of discrimination), and misclassification bias is a possibility when respondents interpret questionnaire items, however these risks are

minimized by the use of validated measures with strong psychometric properties in most cases.

Another potential limitation is the generalizability of the study, as it is not known how veterans who are admitted to TBI Rehabilitation Centers may differ from those who are not. It is possible that this group benefitted from having advocates who helped secure admittance into these facilities, which may indicate greater financial or social supportive resources for these veterans. Finally, temporality is an issue in all cross-sectional research. Longitudinal studies which have shown that stigma precedes distress help support the causal model we propose.

Table 2: Items for Primary Independent and Dependent Measures and Scale Properties

Construct	Cronbach's Alpha	Item	Item-Scale Correlation	Factor Loading
Caregiver Discrimination	.89	You have been treated with less courtesy than other people.	.80	.88
		You have been treated with less respect than other people.	.79	.87
		You have been received poorer service than other people at restaurants or stores.	.72	.83
		People have acted as if they are afraid of you.	.62	.75
		People have acted as if they're better than you are.	.77	.86
Care Recipient Discrimination	.90	He/She has been treated with less courtesy than other people.	.82	.90
		He/She has been treated with less respect than other people.	.81	.90
		He/She has been received poorer service than other people at restaurants or stores.	.74	.84
		People have acted as if they are afraid of him/her.	.66	.78

		People have acted as if they're better than he/she is.	.81	.88
Caregiver Role Stigma	.84	I feel there is a stigma that goes with caregiving.	.75	.92
		I feel that most people think less of a person who provides care.	.75	.88
Need to Cover/Explain	.69	I feel I have to cover up my care recipient's injuries.	.54	.75
		I feel the need to explain to others how my care recipient got the injuries.	.54	.92
Social Isolation	.95	How often did you feel you lacked companionship?	.90	.96
		How often did you feel left out?	.89	.95
		How often did you feel isolated from others?	.87	.94
Depression	.92	I felt worthless.	.63	.72
		I felt that I had nothing to look forward to.	.72	.79
		I felt helpless.	.73	.80
		I felt sad.	.72	.79

		I felt like a failure.	.57	.67
		I felt depressed.	.78	.83
		I felt unhappy.	.83	.87
		I felt hopeless.	.87	.91
Anxiety	.93	I felt fearful.	.61	.69
		I felt anxious.	.75	.82
		I felt worried.	.73	.80
		I found it hard to focus on anything other than my anxiety.	.84	.89
		I felt nervous.	.79	.86
		I felt uneasy.	.87	.92
		I felt tense.	.82	.88
Low Self Esteem	.90	I feel that I'm a person of worth, at least on an equal plane with others. (Reversed)	.79	.86
		I feel that I have a number of good qualities. (Reversed)	.70	.78

		All in all, I am inclined to feel that I am a failure.	.53	.60
		I am able to do things as well as most other people. (Reversed)	.73	.80
		I feel I do not have much to be proud of.	.36	.41
		I take a positive attitude toward myself. (Reversed)	.77	.84
		On the whole, I am satisfied with myself. (Reversed)	.70	.77
		I wish I could have more respect for myself.	.65	.73
		I certainly feel useless at times.	.74	.79
		At times I think I am no good at all.	.80	.85
Personal Strain	.89	I feel angry when I am around my care recipient.	.65	.75
		I feel that my care recipient affects my relationship with family members or friends in a negative way.	.72	.80
		I feel strained when I am around my care recipient.	.68	.77
		My health has suffered because of my involvement with my care recipient.	.71	.79

		I don't have as much privacy as I would like because of my care recipient.	.62	.70
		My social life has suffered because I am caring for my care recipient.	.66	.74
		I have lost control of my life since my care recipient's injury.	.75	.83
		I feel uncertain about what to do about my care recipient.	.51	.63
Role Strain	.75	Because of the time I spend with my care recipient I don't have enough time for myself.	.59	.89
		I feel stressed between caring for my care recipient and trying to meet other responsibilities for my family or work.	.59	.89

Chapter 4: Perceived Stigma, Strain, and Mental Health in Family Caregivers of Veterans with Traumatic Brain Injury

4.1 Abstract

Objectives: We examined if perceived stigma is associated with strain, social isolation, and poor mental health in a sample of family caregivers.

Methods: Seventy family caregivers of veterans with traumatic brain injury (TBI) completed a mailed survey that assessed perceptions of discrimination related to their caregiver role and perceptions of stigma associated with their care recipient's injuries. Outcomes, including caregiver strain, social isolation, depression, and anxiety were also assessed. We examined the associations between the outcomes and discrimination and stigma with multivariate linear regression.

Results: Both the perceptions of caregiver discrimination and the stigma associated with injuries were significantly associated with caregiver strain, social isolation, depression and anxiety, after controlling for demographic and socioeconomic characteristics.

Conclusions: Discrimination and stigma experienced by family caregivers of individuals with TBI is an important stressor that may lead to poor caregiver health outcomes. In order to promote both caregiver and care recipient health, we suggest that mental health support services consider this important stressor.

4.2 Introduction

Family caregivers of people with severe mental illnesses, HIV/AIDS, and other stigmatized conditions have been shown to experience “stigma-by-association”. (31, 36-47) Stigma refers to the marked identity of people with traits that are different from what is considered normal or ideal. Stigmatized individuals are affected by the beliefs and attitudes (prejudice) of others, as well as the behavior (enacted stigma or discrimination) of others, in response to the stigmatized trait or condition.(3) Perceived stigma is both the experience of discrimination or poor treatment because of a devalued trait and the expectation or fear that those behaviors will be encountered. “Felt stigma” refers to the knowledge that one’s trait may be stigmatized and “enacted stigma” refers the behavioral response of others to the stigmatized condition (e.g., poor treatment, discrimination). (260) “Stigma-by-association” occurs when enacted stigma is directed to an associate (e.g., family member, coworker) of the person with the stigmatized trait and occurs because of their association.

Visible and invisible injuries may be stigmatized. Increasingly, young military service members have been exposed to severe war-related injuries that are often polytraumatic, affecting more than one body region or system. In this era of modern warfare where explosions are a common mechanism of injury, Traumatic Brain Injury (TBI) is particularly common. (214, 261) TBI can have long-lasting effects not only on the service member, but also on his or her family members, particularly if the service member requires assistance with daily living. Furthermore,

TBI, which may not be accompanied by physical scarring or obvious debilitation, can have noticeable (but not apparently explainable) effects like difficulty communicating or regulating emotions. People who encounter veterans with these injury effects may act or react in ways that are discriminatory or depict discomfort or disgust. Caregivers, in turn, may observe these situations when they are with the affected individual or they may expect the person they provide care for (“care recipient”) to be stigmatized, possibly causing considerable stress. With the exception of a small number of studies, (39, 41, 42, 213, 262) little is known about the relationship between stigma and caregiver strain.

In prior caregiving studies, strain, often conceptualized as personal burden, predicts a number of emotional and physiological health outcomes, (263-265) including all-cause mortality. (266) Stigma, whether felt or experienced in the form of enacted stigma, constitutes a threat to the perceiver’s self-image and well-being, (2) and may thus be a considerable source of strain. Using a stress and coping model, there are multiple pathways whereby stigma experiences and perceptions can affect a caregiver. First, when stigma-related threat is considered harmful to an individual’s self-concept and self-esteem, the appraisal of threat reaction has been shown to cause a cascade of physiological reactions, (2, 49, 52) leading to anxiety and other mental health outcomes, (169-172, 188, 190, 240) as well as other disease outcomes. (110, 151-154, 156, 161, 267) Second, caregivers may engage in coping strategies that can be harmful themselves (e.g., drug or alcohol use, binge eating). Third, to avoid threat, caregivers may withdraw, resulting in social isolation, (40, 48,

123-127, 230, 242, 243) which may reduce tangible and emotional support, (242) and increase caregiver strain. Fourth, a caregiver may experience attributional ambiguity about the reason for the felt or enacted stigma, and may be uncertain whether the stigma is directed at the care recipient or him/herself, which may require different coping responses aimed at protecting oneself (in the case of stigma-by-association) or protecting both oneself and the care recipient. With the prevalence of TBI in the veteran population high and rising, it is important to determine factors associated with strain and ill health among their family caregivers. The goal of this study was to describe the relationship between emotional health and enacted and felt stigma among caregivers of veterans with TBI.

4.3 Methods

4.3.1 Sample

The sample consisted of 123 identifiable informal caregivers of former inpatients of one of four Veterans Affairs (VA) physical rehabilitation units, located in Minneapolis, MN; Richmond, VA; Palo Alto, CA; and Tampa, FL. These facilities provide rehabilitation services for US veterans with traumatic brain injury, many of whom have other injuries as well. Eligible individuals were discharged between 2001 and 2008. For each individual with TBI, one caregiver was identified by the next-of-kin records; if a caregiver was not immediately identified, then subsequent nominations by next-of-kin were requested. The caregiver was defined as the person who currently provides help with any daily activities for the injured veteran. Eligible caregivers for this study were those who provided care for a

veteran who was <50 years old, and had a diagnosis of TBI. For this study, caregivers of veterans who were injured in Operation Enduring Freedom and Operation Iraqi Freedom (OEF/OIF) were excluded. Of the 139 eligible individuals with TBI, we were able to identify 123 caregivers using next-of-kin records or subsequent nominations, 70 of whom (57%) returned surveys. Additionally, 15 (12%) returned refusals, and 38 (31%) did not return surveys.

4.3.2 Materials

All potential participants were mailed a self-administered survey in February 2009. Care recipients were not contacted; the caregiver provided all survey data, and demographic information was abstracted from VA medical records. The questionnaire included scales that measured a wide range of caregiver experiences. All scale variables were created by calculating a mean of indicator variables, as determined by principle components analysis. All indicator variables were recorded on a five-point scale, unless otherwise indicated. This study was approved by the IRB's of the Minneapolis Veterans Affairs Medical Center and the University of Minnesota

4.3.3 Primary Independent Variables

Enacted stigma was measured using the Williams Day-to-day Discrimination Measure, (247) which presents the participant with examples of common discriminatory situations and has been shown to predict depression and generalized anxiety in stigmatized populations. (103, 247) Due to space constraints in the survey, five of the original 10 items were selected based on item face validity for this

population. The measure was used once in reference to the care recipient (e.g., “He/She feels that...”) and once in reference to the caregiver (e.g., “I feel that...”). Response options for all independent variable items were “never”, “rarely”, “sometimes”, “often”, and “nearly always”. In factor analysis, caregiver discrimination items loaded to one factor; Cronbach’s alpha was .89 and item-scale correlations ranged from .62 to .81. Care recipient discrimination items also loaded to one factor; Cronbach’s alpha was .90 and item-scale correlations ranged from .66 to .82

Because many caregivers forfeit other life roles in order to devote the time needed to help their care recipient, we measured caregiver role stigma, or felt stigma associated with the role of caregiver. This construct was measured by two items that were created for this study: “I feel there is a stigma that goes with caregiving”, and “I feel that most people think less of a person who provides care for someone else”. These items were based on the wording of stigma items used previously. (39) In factor analyses, these items consistently loaded to a unique factor. The two-item factor explained 88% of the variance and had a Cronbach’s alpha of .84.

Caregiver need to cover/explain was measured using two items: “I feel I have to cover up my care recipient’s injuries”, which was included in the Experiences of Caregiving Inventory (39) and “I feel the need to explain to others how my care recipient got the injuries,” which was written by the authors. The scale variable represents a need to influence others’ perceptions of the care recipient. The factor

explained 77% of the variance; Cronbach's alpha was .69 and the item correlation was .54.

4.3.4 Primary Dependent Variables

Caregiver Strain was assessed using the short form of the Zarit Burden Inventory, (249) which has been used extensively throughout caregiving research (209, 263-265, 268-286) to assess the burden of caregiving. Two factors were identified: personal strain (eight indicators, Cronbach's alpha=.89, item-scale correlations were .52-.75); and role strain (two indicators, Cronbach's alpha=.75, correlation=.60), or conflict between caregiving and other responsibilities.

Self-esteem was measured using the 10-item Rosenberg Self-esteem Scale. (250) A single mean-score variable was created that had a Cronbach's alpha of .90 and item-total correlations of .36-.80.

Depression and Anxiety were measured with the PROMIS depression and anxiety short form scales. (251, 252) These scales measure frequencies of symptoms reflecting negative affect (depression scale) and autonomic arousal and threat (anxiety scale) over the past seven days. The depression scale consisted of eight items and the anxiety scale consisted of seven items; both with strong psychometric properties. Depression had a Cronbach's alpha of .92, with item-scale correlations between .57-.87; anxiety had a Cronbach's alpha of .93, with item-scale correlations of .61-.84).

Social Isolation was measured using three items from the UCLA Social Loneliness Scale. The selected items had the highest factor loadings to the dominant

factor in two large population studies. (259) The measure had good internal consistency (Cronbach's $\alpha=.95$) and item-scale correlations were .87-.90.

4.3.5 Covariates

Caregiver demographic and personal characteristics included continuous age, sex, race (white/non-white), two dichotomous variables indicating parental or spousal relationship to care recipient compared to all others, poverty, and education. To create a dichotomous poverty variable, we used a single item that measured income divided by the number of household members supported by that income and compared it to Department of Health and Human Services standards for poverty. (287) Highest educational attainment was a dichotomous variable representing whether or not the caregiver graduated from college. Obesity was also used as a covariate, because it is a highly stigmatized characteristic that may be a cause of perceived discrimination and poor treatment. Obesity ($BMI \geq 30$ versus < 30) was calculated using self-reported current height (feet, inches) and weight (pounds). Most veteran demographic information, including continuous age, sex, and race (white/non-white), was taken from VA medical records. Education attained by the individual with TBI was measured via caregiver report.

Self reported level of caregiving was measured in the questionnaire and transformed into three continuous variables for analysis. *Months spent caregiving* is the difference between the questionnaire completion date and the date the caregivers reported they started doing things to help their care recipients due to their injuries. *Average hours/week spent caregiving* is a combination of items that measured hours

spent caregiving on a typical weekend day, hours spent caregiving on a typical weekday, and number of days/week spent providing care. *The number of caregiving tasks performed* was a continuous variable reflecting a count of the number of activities of daily living, instrumental activities of daily living, and medical tasks that the caregivers reported performing for the care recipient in the past two weeks. Activities of daily living consisted of seven tasks including eating, getting in and out of bed, getting dressed, bathing, and toileting. Instrumental activities of daily living consisted of twelve tasks including managing money, making telephone calls, doing housework beyond what the care recipient would normally do, providing transportation, and helping navigate benefits, medical, and insurance systems. Medical care tasks consisted of nine tasks including changing bandages, administering medicine, managing side effects of treatment, pain, or seizures, and helping with prosthesis or a medical device.

Caregiver social support was measured by the six items, including items from the Medical Outcomes Study social support survey instrument that measure emotional/informational support, affectionate support and tangible support. (288-292) Items were recorded on a five-point scale and measured whether someone was available in the past seven days to “listen when you need to talk”, “give good advice about a problem”, “show you love and affection”, “help with daily chores”, “provide emotional support”, and “trust and confide in”. In factor analysis, these items loaded to one common factor with a Cronbach’s alpha of .94 and item-scale correlations of .64-.89. A continuous mean score variable was created.

4.3.6 Analysis

Item response frequencies were calculated and proportions of individuals responding “sometimes”, “often”, or “nearly always” were reported. We then fit linear regression models predicting each dependent variable: strain, self esteem, depression, anxiety, and social isolation. First, simple linear regression models were used to measure bivariate associations. Then, covariates were added to the model in two steps. In the first step, demographic factors that may also lead to discrimination and poor treatment were added to the models. By doing this, these demographic factors are statistically controlled for, essentially mimicking a homogeneous sample in terms of adjusted demographic factors. In models where caregiver discrimination-by-association was the primary independent variable, these factors were: caregiver nonwhite race, age, poverty, having graduated from college, and obesity. For models where caregiving role stigma or need to cover/explain were the primary independent variables, demographic factors were adjusted for during this stage as well. Although the items measuring these independent variables were specific as to the reason for the behavior or attitude (caregiving or care recipient’s condition), demographic covariates were included to control for differences in experience across demographic category. In the case of caregiver perceptions of discrimination against the care recipient, care recipient demographic factors were adjusted for, since these are the characteristics that the caregiver may attribute discrimination or poor treatment to. These covariates were: care recipient non-White race, lack of college degree, continuous age, and sex.

In the second step, we adjusted for potential confounders and other predictors and moderators of stress in caregiving. These factors include the three measures of exposure to caregiving: months spent caregiving, average hours/week spent caregiving, and number of caregiving tasks performed. We also adjusted for caregiver/care recipient relationship in this step using two dichotomous variables indicating parent/child or spousal relationship, as well as caregiver social support.

We used pairwise deletion for missing data. We examined model diagnostic charts (normal quantile graphs, residual graphs, residual by fitted value graphs) to detect severe violations to the normality and homoscedasticity assumptions of multivariate linear regression, and found no gross violations. We examined Cook's distances and variance inflation factors and found no evidence of influential outliers or collinearity in each fully adjusted model.

4.4 Results

As shown in Table 3, most caregivers were female (90%), were married or living with a partner (67%), and were most frequently the parent (39%) or the spouse/partner (31%) of the care recipient. Seventy-four percent of caregivers were white and 34% had earned a college degree. After taking household size into account, 19% had incomes that were below the poverty line. The average age of caregivers was 53 years ($SD=13$). The majority of care recipients were male (93%), and were not married or living with a partner (63%). Seventy four percent of care recipients were white. Fifty-eight percent attended at least some college and their average age was 41 years ($SD=6$).

Frequencies of endorsement of each item in the independent measures are presented in Table 4. Items that indicated discrimination of the care recipient were endorsed most frequently; between 25% and 47% of respondents answered at least “sometimes” on each of the individual items that make up that scale. Items that indicated caregiver discrimination were endorsed by between 17–32% of participants; the two items that indicated caregiving stigma were endorsed by 12–29% of participants; and the items that indicated a need to influence outside perception of the care recipient were endorsed by 14–50% of caregivers.

As shown in Tables 5 and 6, nearly all bivariate associations were significant and positive. All associations adjusted for demographic characteristics (caregiver or care recipient) were positive; and the vast majority were significant at $\alpha=.95$. In the fully adjusted model (Table 5), caregiver discrimination-by-association was significantly associated with personal strain (standardized $B=.54$), social isolation ($B=.40$), depression ($B=.39$), and anxiety ($B=.37$). Perceived caregiving stigma was significantly associated with personal strain ($B=.40$), social isolation ($B=.29$), depression ($B=.40$), anxiety ($B=.34$), and self esteem ($B=.40$). Felt need to cover the condition or explain to others how the condition came about was significantly associated with depression ($B=.41$), and anxiety ($B=.33$). Caregiver perception of discrimination toward care recipient (Table 6) was significantly associated with caregiver personal strain ($B=.30$), social isolation ($B=.24$), and anxiety ($B=.32$).

4.5 Discussion

Among caregivers of people with TBI, perceived discrimination-by-association and stigma associated with caregiving were associated with caregiver personal strain, depression, anxiety, and social isolation. Stigma associated with caregiving was also associated with caregiver self-esteem. Concealment or explanation of the care recipient's condition was associated with anxiety and depression. In addition, caregiver perceived discrimination against the care recipient was positively associated with caregiver personal strain, anxiety, and social isolation.

The relationship between caregiver perceptions of discrimination toward themselves and negative outcomes suggest that stigma-by-association is a significant stressor in this population, since other demographic factors that a caregiver might attribute poor treatment to (e.g., non-white race, poverty, obesity) were statistically adjusted for in the models. This is a novel finding in this population, but is consistent with research that shows that families of people with other stigmatized conditions experience a great deal of stress from stigma-by-association. (39, 41, 42, 213, 262) Associations involving caregiver perceptions of discrimination toward their care recipients represents a different stress response. In these instances, the caregiver may be experiencing stress due to the need to protect their care recipient from harm. This is consistent with previous research by Green (42, 262) that found that parent caregivers of children with disabilities felt a great deal of stress related to fear that their care recipients would experience discrimination and unfair treatment. Associations with need to conceal injuries or explain how they occurred suggest that the emotional and social outcomes in these models are a result of the care recipient's

injuries. The perceived need to conceal/explain their care recipient's condition was not associated with social isolation, which is logical because caregivers who take these actions do so because they likely are in social situations with their care recipient. Future research should explore mediation pathways of concealment and other coping mechanisms.

This is one of the first investigations about whether the caregiving role creates a sense of felt stigma among caregivers. The findings support that hypothesis, especially the association of caregiving with lower self-esteem. As the only stigma-related predictor of self-esteem, this finding suggests that the role of caregiver itself may be linked to identity confusion and possible reduction in self-worth. Future studies may be warranted to examine whether pre-caregiving work and social roles alter this association.

Caregiving personal strain, which has been shown to predict numerous caregiver outcomes, (263, 264, 293) as well as quality of care performance and care recipient outcomes (47) was associated with each source of felt or enacted stigma after adjustment for other known predictors of strain, including time spent caregiving and social support. This finding is striking, and suggests that the health of the care recipient, as well as the caregiver, could be affected by intervening in the processes by which caregivers experience and cope with stigma. Also important is the association between stigma and social isolation, as social re-integration is an important component of the recovery and rehabilitation of individuals with TBI,

(294) as well as an important component of veteran and military family health following military discharge. (295)

These data are cross-sectional and the associations would be more convincing if found in longitudinal data. While it is certainly possible that depression or anxiety could precede or contribute to perceived stigma or experiences of discrimination, it is less likely that personal strain or social isolation would precede stigma. A small number of longitudinal studies have also found that stigma predicts change in distress over time, (179, 240, 296) including one that showed that the longitudinal association was unidirectional (distress was not associated with future perceived stigma). (178) An additional limitation of the study design is that the measures of perceived discrimination did not ask the caregiver to identify the reason for the poor treatment. These items were worded in this way because individuals do not always know why they are being treated poorly, and asking a caregiver to attribute the behavior to a trait or characteristic is a difficult task. Therefore, items ask the caregiver to identify the behavior only, and we rely on statistical adjustment to balance the sample in terms of commonly stigmatized characteristics, including race, sex, obesity, and age. Strengths of this study include the use of a variety of measures of stigma and related concepts, covariates that are thought to cause stress or moderate the effect of stress on health outcomes, and behavioral attitudinal outcomes of stress. The validity of the findings are also bolstered by the consistent lack of association with role strain, which is likely to be highly correlated with personal strain and depressed affect, but was predictably not associated with any type of felt

or enacted stigma. Also, the associations we found were strong and consistent in multivariate analysis despite having a relatively small sample. Future study of these and related data should explore the mediators and moderators of these stress and coping pathways, as well as the association of specific care recipient injury characteristics and stigma. These data suggest that a better understanding of the stigma processes that accompany caregiving for someone with visible injuries and/or behavioral effects of injuries will provide insight into possible future interventions to improve the health of caregivers and their care recipients.

Table 3: Characteristics of 70 Caregivers and Care Recipients of Injured Military Personnel from Four U.S. Veterans' Affairs Rehabilitation Centers, 2009

	Caregiver Demographic Characteristics N=70	Care Recipient Characteristics N=70
	% (n)	% (n)
Female Sex	90% (63)	7% (5)
Age	Mean=53 (S.D.= 13)	Mean=41 (S.D.= 7)
<30	3% (2)	3% (2)
30-39	16% (11)	37% (26)
40-49	19% (13)	57% (40)
50-59	26% (18)	3% (2)
60-69	23% (16)	(0)
70-79	11% (8)	(0)
Unknown	3% (2)	(0)
Marital Status		
Married/Living with Partner	67% (47)	37% (26)
Single/Divorced/ Separated/Widowed	32% (22)	63% (44)

Unknown	1% (1)	(0)
Relationship to CR		
Spouse/Partner	31% (22)	
Boy/Girlfriend	4% (3)	
Parent	39% (27)	
Child	4% (3)	
Other Relative/Friend	7% (5)	
Other/Unknown	14% (10)	
Race		
Nonwhite	23% (16)	16% (11)
White	74% (52)	46% (32)
Unknown	3% (2)	39% (27)
Education		
Some High School	7% (5)	(0)
High School Grad	23% (16)	40% (28)
Some College	34% (24)	37% (26)
College Degree	34% (24)	19% (13)
Unknown	1% (1)	4% (3)
Living in Poverty*	16% (11)	NA
Unknown Income	10% (7)	

*According to Health and Human Services standards for income per household size

**Table 4: Frequency of Endorsement of Stigma and Discrimination Items,
Caregivers of Injured Military Personnel from Four U.S. Veterans' Affairs
Rehabilitation Center, 2009**

Percent (N) responding "Sometimes, Often, or Nearly Always"

Caregiver Discrimination ^a	% (N)
You have been treated with less courtesy than other people.	31.7% (21)
You have been treated with less respect than other people.	25.8% (17)
You have received poorer service than other people at restaurants or stores.	16.9% (11)
People have acted as if they are afraid of you.	20.0% (13)
People have acted as if they are better than you are.	29.3% (19)
Caregiving Stigma ^b	
I feel there is a stigma that goes with caregiving.	28.7% (19)
I feel that most people think less of a person who provides care for someone else.	12.1% (8)
Conceal/Explain ^b	
I feel I have to cover up my care recipient's injuries.	13.9% (9)
I feel the need to explain to others how my care recipient got the injuries.	50.1% (33)
Care Recipient Discrimination ^c	
He/she has been treated with less courtesy than other people.	45.4% (30)
He/she has been treated with less respect than other people.	47.0% (31)
He/she has received poorer service than other people at	24.6% (16)

restaurants or stores.	
People have acted as if they are afraid of him/her.	47.0% (31)
People have acted as if they are better than him/her.	46.0% (29)

^aQuestion was “In your day to day life, how often have any of the following things happened to you?”

^bQuestion was “How often do you feel the following things happen?”

^cQuestion was “In his/her day-to-day life, how often have any of the following things happened to your care recipient?”

Table 5: Standardized Regression Coefficients from Bivariate and Multivariate Linear Regression Models with Caregiver Felt and Enacted Stigma, Caregivers of Injured Military Personnel from Four U.S. Veterans' Affairs Rehabilitation Centers, 2009

Dependent Variable	Independent Variable	Unadjusted	Adjusted 1	Adjusted 2
Caregiver Personal Strain	Caregiver Discrimination	.61***	.69***	.54***
	Caregiving Stigma	.48***	.53***	.40*
	Conceal/Explain	.42**	.48**	.25
Caregiver Role Strain	Caregiver Discrimination	.27*	.32*	.19
	Caregiving Stigma	.25*	.30*	.11
	Conceal/Explain	.38**	.43**	.25
Caregiver Social Isolation	Caregiver Discrimination	.69***	.70***	.40***
	Caregiving Stigma	.57***	.57***	.29**
	Conceal/Explain	.45***	.50***	.14
Caregiver Depression	Caregiver Discrimination	.53***	.52***	.39*
	Caregiving Stigma	.50***	.51***	.40**
	Conceal/Explain	.46***	.55***	.41**
Caregiver Anxiety	Caregiver Discrimination	.52***	.51***	.37*
	Caregiving Stigma	.51***	.49***	.34*
	Conceal/Explain	.49***	.50***	.33*
Caregiver Self-	Caregiver Discrimination	.36**	.41**	.28
	Caregiving Stigma	.36**	.38**	.40*

Esteem	Conceal/Explain	.20	.25	.12
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Statistical significance of t-test: * $p < .05$, ** $p < .01$, *** $p < .001$

Adjusted Model 1 Covariates

Caregiver characteristics: white race, female sex, education \geq college degree, living in poverty, age, obese BMI

Adjusted Model 2 Covariates

Caregiver characteristics: white race, female sex, education \geq college degree, living in poverty, age, obese BMI

Possible confounders: months of caregiving, number of caregiving tasks, hours of care provided/week, social support, spousal or parental relationship to care recipient

Table 6: Standardized Regression Coefficients from Bivariate and Multivariate Linear Regression Models with Caregivers' Perceived Stigmatization of Care Recipients from Four U.S. Veterans' Affairs Rehabilitation Centers, 2009

Dependent Variable	Independent Variable	Unadjusted	Adjusted 1	Adjusted 2
Caregiver Personal Strain	Care Recipient Discrimination	.45***	.41***	.30*
Caregiver Role Strain	Care Recipient Discrimination	.22	.16	.04
Caregiver Social Isolation	Care Recipient Discrimination	.46***	.46***	.24*
Caregiver Depression	Care Recipient Discrimination	.29*	.28*	.16
Caregiver Anxiety	Care Recipient Discrimination	.37**	.39**	.32*
Caregiver Self-Esteem	Care Recipient Discrimination	.27*	.28*	.18

Statistical significance of t-test: * $p < .05$, ** $p < .01$, *** $p < .001$

Adjusted Model 1 Covariates

Care recipient characteristics: white race, sex, education \geq college degree, age

Adjusted Model 2 Covariates

Care recipient characteristics: white race, sex, education \geq college degree, age

Possible confounders: months of caregiving, number of caregiving tasks, hours of care provided/week, social support, relationship to caregiver

Chapter 5: Overview of Paper 2 - Individuals with Colorectal Cancer

5.1 Introduction

In 2007, the age-adjusted 17-year prevalence of colorectal cancer in the US was .26%, which represents 1,112,493 cases. (297) The one-year incidence of new cases of colorectal cancer has been estimated to exceed 80,000 cases. (298) The prevalence of depression among people diagnosed with colorectal cancer is far greater than that seen in the general public with population estimates commonly reported to be around 30%. (299, 300) The point prevalence of depression in the general US population is approximately 10%. (301) A number of explanations for the high prevalence have been proposed, and various risk factors have been identified that increase the likelihood that someone with colorectal cancer will become depressed. Psychological distress and depression, besides being disease states that greatly reduce a person's quality of life, have also been shown to predict non-adherence to treatment, may shorten life, (302) and can affect the body's ability to recover from some treatments. (303) Thus, it is important to develop a fuller understanding of which risk factors lead many people with colorectal cancer to develop depressive symptoms, while others do not. A number of clinical factors have been shown to contribute to risk of depression, possibly through stress processes. Known risk factors for depression among individuals with cancer include several clinical characteristics and effects of the disease that may cause stress, emotional distress, and psychopathology. These stressors include reduced physical functioning, (304) fatigue, (305) pain, (306-308) and advanced disease progression.

(309, 310) Other stressors that have been linked to depression among individuals with cancer are comorbidities, (304) fear of death and disability, fewer or loss of social contacts, (304) and loss of independence.

5.2 Why might individuals with colorectal cancer be stigmatized?

Cohen and Lazarus (311) list five demands frequently confronted by people with severe illnesses: 1) reduce harmful environmental conditions to enhance prospects of recovery, 2) adjust to new negative realities, 3) maintain positive self-image, 4) maintain emotional balance, and 5) continue satisfying relationships. Stigma and internalized or perceived external blame are stressors that, for a person with colorectal cancer, can create demands to 2) *adjust to new negative realities*, like a devalued and stigmatized social identity; 3) *maintain positive self-image* in the face of discrimination and unfair treatment, and 4) *maintain emotional balance* throughout these threatening experiences. A cancer diagnosis is likely to become an important part of an individual's identity, affecting many facets of life, as well as the perceptions of others. The identity is associated with disability, weakness, and death, so it is not likely to be highly valued in the eyes of others and is likely to affect the behavior toward the individual with cancer. Associates may react with fear, pity, or discomfort tainting social interactions with awkwardness; or may avoid the individual with cancer altogether, avoiding emotions that are conjured by thoughts of cancer and its ramifications or the reality that they too are at risk for the disease. Furthermore, colorectal cancer may result in the use of a colostomy (bypassing part of the colon and anus) or ileostomy (bypassing entire colon), which

can include a noticeable stoma (opening in the skin where semisolid waste exits into an ostomy pouch), and may lead to situations where other people react in ways that demonstrate disgust.

Stigma may also cause stress as the individual adjusts to new realities and meaning. An individual with colorectal cancer may have to reduce participation in roles that are valued components of his or her identity. For example, advanced disease or side-effects of treatment may prevent the individual from working, and he or she may perceive stigma related to the loss of that valued role. Likewise, if the person with cancer requires help with activities of daily living, he or she could experience stigma related to the “care recipient” role. Incontinence and colostomy or ileostomy are substantial changes to the body and affect body functions that are taboo to many people and may alter self-image, and represent a new stressful reality.

5.3 Methods

5.3.1 Study Population

The target population for this study is men who were diagnosed with colorectal cancer in any VA facility and have survived their initial treatment. The VA Cancer Registry was used to ascertain 2511 living individuals who were treated at any Veterans Affairs medical facility nationwide and received a diagnosis of invasive colon or rectal cancer during 2008. Of those individuals, 421 were excluded because they were identified in the registry as having stage 0 cancers or because VA medical records indicated that they died before the questionnaire was

mailed. The remaining 2090 people were mailed a questionnaire, information about the study, and a \$10 incentive in the fall of 2009.

5.3.2 Identifying Study Sample

The Department of Veterans Affairs (VA) cancer registry was used to identify all individuals diagnosed with colorectal cancer in 2008. Since 1995, the Cancer Registry is comprised of uniformly reported information on all individuals who are diagnosed with and/or receive their first course of treatment for invasive cancer at any VA Medical Center. Data integrity standards were established by the American College of Surgeons' Commission on Cancer Facility Oncology Registry Data Standards (FORDS) data collection guide. (312) Data captured include medical history, cancer treatments, outcomes, and demographic characteristics.

5.3.3 Sample

Of the 2090 individuals mailed questionnaires, 303 were ruled ineligible because they indicated that their diagnosis occurred before 2008, they received the majority of their care outside the VA, or were reported deceased by a family member or caregiver. Of the remaining 1787 surveys that were sent to eligible individuals, 64% (1147) were completed and returned, 476 could not be reached, and 164 declined to participate. Due to the small number of female respondents in the VA, 36 women were excluded from analysis, resulting in 1109 completed surveys for analysis.

To assess non-response bias, we compared individuals who returned questionnaires (regardless of eligibility) to those who did not return questionnaires

(total n=2090) on factors available in the Cancer Registry. Responders included a significantly greater proportion of White individuals (77% vs. 69%; $p_{\text{chi-square}} < .001$), and married individuals (53% vs. 40%; $p_{\text{chi-square}} < .001$). There was not a significant difference between responders and non-responders in average cancer stage ($p_{\text{t-test}} = .06$) or age at diagnosis ($p_{\text{t-test}} = .46$).

5.3.4 Mailed Survey Data Collection

A self-administered mailed survey was chosen for the following reasons: (1) self-administered formats are a cost-effective and reliable medium for quickly collecting data from a large number of people; (2) phone and face-to-face interviews may not be feasible in this population of caregivers given the geographic dispersion and time constraints due to caregiving. A self-administered survey provides respondents with the flexibility to respond when they choose. (3) Technologies like caller ID and increased cell phone usage has resulted in greater response rates for mailed surveys compared to phone surveys (244); and (4) a self-administered survey avoids bias caused by an interviewer.

The two most effective ways to reduce non-response for mailed surveys are making multiple contacts and including an incentive in the mailing (rather than promise one following survey completion). (245) Incentives have also been found to decrease item non-response. (246) Survey procedures outlined in Dillman's Tailored Design Method (TDM), (245) were used to maximize the response rate. The initial mailing included a \$10 cash incentive, a letter explaining the study's purpose, the survey, detailed instructions for completing the survey, and a postage-paid return

envelope. Participants who do not respond to the mailed survey were sent a second mailing including a cover letter, second survey, and postage-paid return envelope.

5.3.5 Questionnaire Development

The questionnaire was developed by a team of National Cancer Institute, VA, Department of Defense and University of Minnesota scientists, including the author (SP), to assess a variety of domains of patient-centered quality of care. Choice of constructs and measures (Table 7) was guided by National Comprehensive Cancer Network guidelines, the empirical evidence on interpersonal aspects of care that affect quality and outcomes, prior studies such as those conducted by the Cancer Care Outcomes Research and Surveillance Consortium and the work of the NCI-funded Outcomes Measurement Working Group and the National Quality Forum.

5.3.6 Measures of Stigma

All cancer stigma and blame items were measured on a four-point scale of “Not At All True”, “A Little True”, “Somewhat True”, and “Completely True”. Cancer stigma was measured using four items developed for this study based on a review of relevant literature. “I feel that some people avoid me because I have colorectal cancer” and “I feel that some people feel awkward and tense around me because I have colorectal cancer” were based on items from the Social Rejection subscale of Fife & Wright’s (196) Experiences of Rejection and Stigma measure that were more frequently endorsed by individuals with cancer and had strong face validity; and variations of “I feel there is a stigma that goes with having my condition”, and “I feel most people think less of a person who has colorectal cancer”

were used in previous research by the author (SP). In principal components analysis, a single factor accounted for 73% of the variance in the four items, so a mean score with Cronbach's alpha of .87 and item-total correlations of .70 to .76 was computed.

We chose these items to measure stigma because they captured aspects of stigma thought to be relevant for individuals with colorectal cancer. Fife and Wright's measure is one of the only measures that has been used in individuals with cancer. Due to questionnaire space limitations and our desire to reduce respondent burden in a questionnaire that included measures of many facets of cancer care and health, we chose the two items that we thought best captured the expected behavioral response of others to individuals with cancer: awkwardness and avoidance. These items were also more frequently endorsed by individuals with cancer in the original study, relative to other scale items. The adapted items were chosen because they capture a more general feeling of stigma and perceived lack of value to others.

The individual's perception that others blame him for the illness (other-blame) was measured by one item: "I feel other people think I am to blame for my illness". Item distribution was skewed toward less perceived blame, so the ordered categorical variable was transformed into a dichotomous variable to compare those who reported perceiving any blame to those who reported perceiving no blame.. Self-blame was measured by a single item, "I feel I am to blame for my illness". This variable was also dichotomized so that any response other than "Not at all true" was coded as having some self-blame. Both of these items were based on items from

the internalized shame subscale of Fife & Wright's measure.(196) Self-blame and other-blame were moderately correlated at $r=.29$, but factor analysis confirmed they were distinct constructs as was cancer stigma. The self-blame item is not fully a measure of behavioral or characterological self-blame, but rather an affirmative response to the item is likely to reflect both concepts.

5.3.7 Primary Dependent Variables

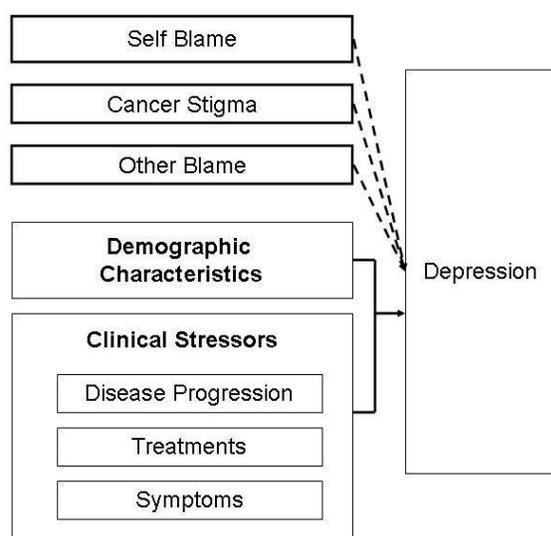
Psychological distress was measured using the short form of the NCI PROMIS Depression Scale, (251, 252) which measures frequency of depressive symptoms over the most recent 6 months. The scale consisted of eight statements: "I felt...worthless", "that I had nothing to look forward to", "helpless", "sad", "like a failure", "depressed", "unhappy", and "hopeless". Respondents indicated agreement with the statements on a 1 "Never" to 5 "Always" scale. The PROMIS measure was chosen due to its excellent validity and reliability, described earlier. (253-258) The Depression scale loaded to one factor in principal components analysis. A mean score was calculated amongst participants who responded to five or more of the items, and converted to t-scores. The resulting scale had a Cronbach's alpha of .95 and item-scale correlations of .82 to .86. One drawback to this measure is that there are no published cutpoints to define a clinical depression case. The scale is thus used as a continuous measure of depressive symptoms.

5.3.8 Analysis

Bivariate and multivariate linear regression was used and beta coefficients interpreted to assess the association between cancer stigma, self-blame, and other-

blame and depression score before and after adjustment for other known clinical stressors that may contribute to depression risk and potential demographic predictors of variation in depressive symptoms (see figure 3). Linear regression was chosen because there is no published or accepted cutpoint for the dependent measure that defines a depression case. We chose to model the outcome continuously to assess variation in depressive symptoms severity (regardless of clinical “caseness”) as a function of stigma and blame.

Figure 3: Framework for Assessing the Independent Effects of Cancer Stigma, Self-blame and Blame from Others on Depression.



5.3.9 Potential Sources of Bias

Due to its cross-sectional design, this study is vulnerable to bias from known and unknown confounders. We have partially addressed this possibility in analysis

by adjusting for several potential confounders including sociodemographic factors and other predictors of depressive symptoms in individuals with chronic diseases. The potential for selection bias is high in survey research. There was no difference in age at diagnosis or cancer stage between responders and non-responders, however, responders were significantly more likely to be White and married than non-responders. This may affect the generalizability of the results. Follow-up analysis showed that neither White race nor marital status were significantly associated with depressive symptoms in simple linear regression models. It cannot be determined whether non-response is associated with key independent variables or the outcome, but individuals who responded may be less likely to experience depressive symptoms than the population they represent. During recruitment, strategies to reduce the risk of self-selection bias were used. First, incentives were mailed in the first mailing with the questionnaire, a strategy that creates a sense of social responsibility to reply, and may reduce the risk of opting-out by caregivers who perform fewer care tasks. Second, non-responders to several mailings were contacted via telephone and encouraged to respond. Recall bias may affect questionnaire responses because respondents are reporting throughout the survey on experiences and feelings that occurred in the past. Social desirability bias may be an issue, because many of the concepts being measured are very personal, and in some cases may be embarrassing. This effect may be especially pertinent to a sample of male veterans, who may be less comfortable disclosing personal information than other populations. However

likely these types of information bias are to occur; there is little evidence that they would occur differentially by the primary dependent or independent variables.

Table 7: Items for Primary Independent and Dependent Measures and Scale Properties

Construct	Cronbach's Alpha	Item	Item-Scale Correlation	Factor Loading
Cancer Stigma	.87	Some people avoid me because I have CRC	.76	.86
		Some people feel awkward/tense around me because I have CRC	.75	.86
		There is a stigma that goes with having my condition	.71	.80
		Most people think less of a person who has CRC	.70	.80
Self-blame		I think I am to blame for my illness		
Other-blame		Other people think I am to blame for my illness		
Depression	.96	I felt worthless	.85	.89
		I felt that I had nothing to look forward to	.86	.90
		I felt helpless	.86	.89
		I felt sad	.85	.88

		I felt like a failure	.83	.87
		I felt depressed	.85	.89
		I felt unhappy	.87	.90
		I felt hopeless	.89	.92

Chapter 6: Stigma, Self-blame, and Depressive Symptoms in Men with Colorectal Cancer

6.1 Abstract

Objective: We measured the prevalence of stigma, self-blame, and perceived blame from others for their illness among men with colorectal cancer and examined whether these factors were associated with depressive symptoms, independent of other known predictors of psychological distress.

Methods: Self-administered questionnaires were returned in the fall of 2009 by 1109 eligible male US veterans who were diagnosed with colorectal cancer at any VA facility in 2008. Questionnaires assessed stigma, feelings of blame, and depressive symptoms as well as other facets of health, cancer characteristics, and quality and type of medical care. We report the prevalence of cancer stigma, self-blame, and perceived blame from others. We used multivariate linear regression to assess the association between these factors and a measure of depressive symptoms. Covariates included several measures of overall health, cancer progression, physical functioning, symptom severity, and sociodemographic factors.

Results: Thirty one percent of respondents endorsed at least one item in a measure of cancer stigma and 25% reported feeling that they were at least “a little” to blame for their illness. All three independent variables were associated with depressive

symptoms in bivariate models; cancer stigma and self-blame were significantly associated with depressive symptoms in the multivariate model.

Conclusions: Cancer stigma and self-blame are problems for a significant minority of men with colorectal cancer and are independent predictors of depressive symptoms. They may represent an important source of stress in men with colorectal cancer

6.2 Introduction

The potential for cancer patients to experience the stress of stigma, self blame, and blame from others is widely acknowledged. (313-317) Stigma is a stressor involving having a social identity that is marginalized and devalued. It can lead to internalized feelings of lower value, shame, and expectations for discrimination. These, it turn, have been shown to contribute to symptoms of depression and overall poor mental health. (166, 179, 181, 182, 185, 318) Despite this, there has been relatively little study of the prevalence and impact of perceived stigma and blame among cancer patients. Most studies to date involve small samples and qualitative methodology (26, 319-327) with unknown generalizability. The handful of quantitative studies largely focus on lung and breast cancer patients (316, 317, 328-330). Stigma associated with lung cancer may be unique in the way it is confounded with the documented stigma associated with smoking (331, 332) and research on perceived stigma among breast cancer patients may not generalize to men. As a result, little is known about the prevalence and the mental health impact of stigma, self blame, and being blamed by others for one's illness among men with

colorectal cancer. This represents a significant gap in our understanding of the factors that contribute to the high rates of depression in people diagnosed with colorectal cancer (CRC), which is far greater than that seen in the general public with population estimates frequently higher than 30%, (299, 300) compared to 10% in the general US population.

Individuals with colorectal cancer may experience high levels of stigma and blame for several reasons. Any cancer diagnosis affects many facets of life and the perceptions of others, and is likely to become an important part of an individual's identity. The "cancer patient" identity is associated with disability and death, so it is likely to be devalued by others and affect their behavior toward the individual with cancer. Associates may react with fear, disgust, or pity, tainting social interactions and resulting in avoidance of the individual with cancer, and prompting some to avoid disclosure of diagnosis. (333) CRC may result in the use of a colostomy or ileostomy, which can be noticeable, and may lead to situations where other people react in ways that demonstrate disgust. (319) Incontinence and stoma use affect body functions that are taboo to many people and may alter self-image. Men may also experience colonoscopy or examinations of the rectum as threatening to masculine identity. (334-336)

People may react with disapproval towards individuals with conditions with strong and generally accepted behavioral causes, like lung cancer or sexually transmitted infections. When individuals internalize feelings of blame, it can lead to guilt and shame. Individuals with CRC may feel external or internalized blame for

their disease because of beliefs that eating a high-fat or low-fiber diet, using tobacco products or alcohol, or engaging in receptive anal sexual intercourse contribute to disease etiology. (26) Others may experience self-blame because of having postponed cancer screening. Characterological self-blame, or the belief that one deserves CRC because of negative feelings about one's character, may also be a source of stress. Behavioral self-blame may be considered a strategy for coping with the risk of relapse because it increases a sense of control. However, here it is conceptualized as a type of negative thought that can lead to guilt about acquiring the disease, and contribute to stress outcomes. (82) This perspective is supported by longitudinal studies that have found that both types of blame are associated with psychological distress later in disease progression support this perspective. (337-339)

The goal of this study was to address this gap in our understanding of stigma and blame in men with colorectal cancer by assessing 1) the prevalence of perceived cancer stigma, self-blame and perception of blame from others for their illness among 1109 men with CRC receiving care at any VA facility, and 2) examine the associations between depressive symptoms and cancer stigma, self-blame, and the perception of blame from other s, independent of other known predictors of depression including numerous clinical stressors and demographic characteristics that may be associated with depression.

6.3 Methods

6.3.1 Participants

We used the Veterans Affairs (VA) Cancer Registry to ascertain 2511 living patients who were treated at any VA medical facility nationwide and received a diagnosis of invasive colon or rectal cancer in 2008. Of those individuals, 421 were excluded because they were identified in the registry as having stage 0 cancers or because VA medical records indicated that they died before the questionnaire was mailed. The remaining 2090 individuals were mailed a questionnaire, information about the study, and a \$10 incentive in the fall of 2009. Of the 2090 individuals who were mailed questionnaires, 303 were ruled ineligible because they indicated that their diagnosis occurred before 2008, they received the majority of their care outside the VA, or were reported deceased by a family member or caregiver. Of the 1787 surveys that were sent to eligible individuals, 64% (1147) were completed and returned, 476 people could not be reached, and 164 declined to participate. Thirty-six women were excluded from analysis, resulting in 1109 completed surveys for analysis. This study was approved by the IRB's of the Minneapolis Veterans Affairs Medical Center and the University of Minnesota.

6.3.2 Materials

The questionnaire had a 7th grade reading level and was developed by a team of National Cancer Institute, VA, Department of Defense and University of Minnesota scientists to assess a variety of domains of patient-centered quality of care. Choice of constructs and measures was guided by National Comprehensive Cancer Network guidelines, (340) empirical evidence about aspects of care that affect quality and outcomes from prior studies, (341) the NCI-funded Outcomes

Measurement Working Group (342) and the National Quality Forum. (343) The questionnaire included several validated scales as well as some that were adapted for this study. Scale variables were created using principal components analysis with varimax rotation to identify underlying latent factors.

6.3.3 Independent Variable Measures

Three independent variables were created: cancer stigma, self-blame, and blame from others. All cancer stigma and blame items were measured on a four-point scale of “Not At All True”, “A Little True”, “Somewhat True”, and “Completely True”. Self-blame and other-blame were moderately correlated at $r=.29$, but factor analysis confirmed they were distinct constructs as was cancer stigma.

The cancer stigma scale consisted of four items adapted for this study. Two items, “I feel that some people avoid me because I have CRC” and “I feel that some people feel awkward and tense around me because I have CRC” were adapted from the social rejection subscale of the Experiences of Rejection and Stigma Measure (196) that were more frequently endorsed by individuals with cancer and had strong face validity. Two items, “I feel there is a stigma that goes with having my condition”, and “I feel most people think less of a person who has CRC” were used in previous stigma research. (344) In principal components analysis, a single factor accounted for 73% of the variance in the four items, so a mean score with Cronbach’s alpha of .87 and item-total correlations of .70 to .76 was computed.

Self-blame and the perception of blame from others (other-blame) were each measured by one item: “I feel other people think I am to blame for my illness,” and “I feel I am to blame for my illness. Two dichotomous variables were created that categorized respondents into “no blame” vs. “any blame,” so any response other than “Not at all true” was coded as having some self or other-blame. Both of these items were based on items from the internalized shame subscale of the Experiences of Rejection and Stigma Measure. (196)

6.3.4 Dependent Variable Measures

Depressive symptoms were measured using the short form of the NCI PROMIS Depression Scale, (251, 252) which measures frequency of depressive symptoms over the most recent 6 months. The National Institutes of Health PROMIS initiative developed, validated, and standardized item banks to measure patient-reported outcomes relevant across common medical conditions for use as a "common currency" across research projects. (253-255) Item banks were calibrated using item-response theory on a sample of 21,133. Short forms from each bank were developed and compared with other well-validated and widely accepted measures. All short forms demonstrated good reliability and moderate to strong correlations with widely-used measures. (256-258) The scale consisted of eight statements: “I felt...worthless”, “that I had nothing to look forward to”, “helpless”, “sad”, “like a failure”, “depressed”, “unhappy”, and “hopeless”. Respondents indicated agreement with the statements on a 1 “Never” to 5 “Always” scale. The Depression scale loaded to one factor in principal components analysis. A mean score was calculated

for participants who responded to five or more of the items, and converted to t-scores based on population averages published by PROMIS. (345) The resulting scale had a Cronbach's alpha of .95 and item-scale correlations of .82 to .86.

6.3.5 Demographic Covariates

We asked respondents to report their age, race, ethnicity, marital status, and education. We supplemented incomplete questionnaire data with demographic information in the VA Cancer Registry, where available. Respondents could choose multiple race and ethnicity categories; dichotomous variables indicating whether the respondent identified as Black, White, or Hispanic/Latino were created. For highest level of education attained, a dichotomous variable was created indicating high school degree or less vs. more than a high school degree. Participants were categorized as married versus not married. Age was modeled continuously.

6.3.6 Clinical Stressors

We measured 10 clinical stressors by questionnaire or VA Cancer Registry audit.

- Pain Impact was measured with the NCI PROMIS Pain Impact short form. (252) Six items, including “How much did pain interfere with your day to day activities?” and “How much did pain interfere with your enjoyment of life?” were measured on a 1 “Not at all” to 5 “Very much” scale. A mean score was calculated and converted to PROMIS population-based t-scores. Scale items loaded to one factor in principal components analysis with Cronbach's alpha of .98 and item-scale correlation of .88-.94.

- Fatigue was measured using six items from the NCI PROMIS Fatigue short form, (252) including “How often did you feel tired?” and “How often did you experience extreme exhaustion?” Responses were recorded on a 1 “Never” to 5 “Always” scale and mean score was calculated. Scale items loaded to one factor with Cronbach’s alpha of .92 and item-scale correlations of .70-.82.
- Four-level cancer stage at diagnosis was abstracted from the VA Cancer Registry.
- The Charlson Comorbidity Index (CCI), (346) was calculated using ICD-9 codes from VA medical records. The CCI is calculated by assigning a value between 0 and 6 for each comorbid condition from a list of diseases ranked by risk of mortality. The sum of these values was calculated.
- Whether the respondent had a colostomy or ileostomy was ascertained in the questionnaire by a single item that included a short description of an ostomy.
- Bowel problems were measured using items selected from the defecation subscale of the EORTC CRC Quality of Life Questionnaire, (347) along with two items measuring problems with diarrhea and constipation taken from the EORTC Quality of Life Questionnaire. (348) Participants indicated experiencing problems on a scale of 1 “Not at all” to 4 “Quite a bit”. Mean scores were calculated and transformed to a 100-point scale.
- Eight items used by the Cancer Care Outcomes Research and Surveillance Consortium (341) to measure frequency of common symptoms: shortness of

breath, trouble sleeping, appetite, nausea, vomiting, sore mouth, trouble swallowing, and extremity pain or numbness, were combined to form a symptom index. Participants indicated experiencing problems on a scale of 1 “Not at all” to 4 “Quite a bit”. Mean scores were calculated and transformed to a 100-point scale.

- Self-reported health was measured with a single-item subjective indicator of overall health. Responses were combined into a dichotomous variable representing poor, fair, or good health versus very good or excellent health.
- Self-reported receipt of surgery, chemotherapy, or radiation therapy within three months prior to questionnaire completion was recorded via questionnaire items and combined into a dichotomous variable for any treatment in the past three months.

6.3.7 Statistical Analysis

Item response frequencies for all items and scales were calculated. Beta coefficients of bivariate and multivariate linear regression were interpreted to assess the association between cancer stigma, self-blame, other-blame and depression score before and after adjustment for other known clinical stressors and demographic predictors of depressive symptoms. We chose to adjust for all measured clinical stressors in order to provide a rigorous test for the independent associations between stigma, blame, and depressive symptoms. In order to address missing questionnaire response data, analyses were performed in multiple imputed datasets. Five complete datasets were created in SPSS v18.0 using Markov-Chain Monte Carlo estimation.

Multivariate linear regression was performed in each imputed dataset, and the pooled results were reported. Values of imputed dichotomous variables were rounded to the nearest valid whole number response so that the results could be interpreted. This procedure, while common, may introduce bias, so we performed identical multivariate regressions in the unimputed complete-case data and compared the results. The complete-case analysis did not reveal substantially different model results or beta coefficients for any variable, so the results of the multiple imputations analyses are reported.

6.3.8 Sample Characteristics

Sample characteristics are presented in Table 8. Seventy-nine percent of respondents were White, 13% were Black, and 3% indicated they were another race; 6% indicated they were Hispanic or Latino. The average age of respondents was 68 years (S.D. =10), 52% (579) were married, and 52% indicated they had a high school diploma or less education.

Based on best available staging information, 36% of the sample had stage 1 or localized cancer, 26% had stage 2 cancers, 21% had stage 3 cancers, and 17% had stage 4 or distally metastasized cancers. Sixty-five percent had 0 mortality-relevant comorbid diseases, and the average Charlson Comorbidity Index was .74 (S.D. =1.2); one third (347) of the respondents indicated that they were in poor or fair health, 60% indicated their health was good or very good, and 8% indicated that their health was excellent. Compared to published US population averages, the average PROMIS Pain Impact T-score was 51. On the PROMIS Fatigue scale, 44% of

respondents indicated that they experienced at least one of the fatigue problems “often” or “always”. The average Defecation Index score was 27.8 (S.D. =19.6), with 31% of respondents who did not have a stoma indicated that they experienced at least one problem with defecation “Quite a bit.” Symptom index score was 24.1 (19.0), with 44% of respondents reported experiencing at least one symptom “Quite a bit”. Nineteen percent of participants indicated that they currently had a stoma. Thirteen percent of participants reported receiving surgery, chemotherapy, or radiation within the last three months.

6.4 Results

Table 9 presents the prevalence of cancer stigma, self-blame and perceived blame from others. Cancer stigma score mean was 1.3 (S.D. =.51) with 31% (334) endorsing at least one item, 19% endorsing at least 2 items, and 12% endorsing at least 3 items as being “a little true”, “somewhat true”, or “completely true”. Ten percent (107) of respondents indicated that it was at least “a little true” that other people blamed them for their illness, and 25% (266) reported that they felt it was at least “a little true” that they were themselves to blame for their illness.

Table 10 presents the relationship between stigma, self blame, and perceived blame from others and depression, independent of several demographic characteristics and clinical factors that have been shown to predict psychological distress. The average PROMIS depression t-score was 50.3 (S.D =10.9), or approximately the same as the average score in the general U.S. population. In simple linear regression analysis, cancer stigma, self-blame and blame from others

were all associated with greater depressive symptoms in the pooled multiple imputation analysis (cancer stigma: unstandardized beta=6.38, $p<.001$; self-blame: $b=6.43$, $p<.001$; other-blame: $b=6.73$, $p<.001$). When modeled simultaneously, only stigma and self-blame remained significant predictors of worse depressive symptoms (cancer stigma: $b=5.40$, $p<.001$; self-blame: $b=4.08$, $p<.001$; other-blame: $b=.05$, $p>.05$).

After adding to the model clinical stressors (recency of diagnosis, pain, fatigue, comorbidity score, overall health, stage at diagnosis, recent treatment, symptom index score, defecation problems score, and stoma) and sociodemographic factors (race, age, education, marital status), greater perceived stigma remained a significant independent predictor of depressive symptoms ($b=1.92$, $p<.01$). Likewise, self-blame was significantly associated with depressive symptoms ($b=2.67$, $p<.001$). The perception that other people blame the individual with CRC for the disease remained nonsignificant ($b=-.51$, $p>.05$).

6.5 Discussion

Our findings suggest that stigma, self-blame, and blame from others are experienced by a significant minority of men with CRC, a group that is not usually associated with experiences of stigma, and not usually thought to experience as much self-blame as, say, individuals with lung cancer. One-third of the respondents reported some stigma related to CRC, and one in four reported that they felt some self-blame for their cancer.

Our findings indicate that those who experience stigma or self-blame related to CRC may have more frequent symptoms of depression. This association persisted after controlling for clinical characteristics of the disease and demographic characteristics that may be associated with depression. Our findings also suggest that there is no association between the perception of blame from others and depressive symptoms, independent of felt stigma and self-blame. Perceived external blame may not be as potent a stressor as cancer stigma or self-blame. More likely, external blame and cancer stigma are conceptually similar, as perceived blame may be interpreted as disgust or another response to stigmatized social identity.

The association between cancer stigma and depression is consistent with previous research that has found associations between depressive symptoms and elements of stigma (166, 349-351), or self-blame (337, 338, 352) in individuals with cancer. This study adds to the evidence that stigma and self-blame are important stressors for individuals with cancer, and may partially explain why some individuals with CRC develop depressive symptoms and others do not. Furthermore, these findings suggest that improved ability to predict variation in perceived stigma and self-blame may inform interventions to reduce symptoms of depression for individuals who report these feelings.

Stigma and self-blame reduction interventions might reduce provider focus on behavioral causes of CRC and emphasize genetic predisposition or the lack of knowledge about necessary and component causes. Health care organizations can also take steps to create environments where individuals with CRC feel safe

discussing identity issues or embarrassing symptoms. For example, health care providers could tell patients that it is common to have symptoms and problems with bowel function, stoma care, sexual function, and can provide referrals for counseling to discuss stigma, loss of ability to perform valued roles, or other issues of identity. Mental health care providers can be aware that identity issues and self-blame may be component causes of distress, and teach coping methods for adjusting to the new negative identity of “cancer patient” and exercises to help maintain positive body image despite loss of function. Additionally, health care providers should be aware that messages about the ability of “positive thinking” or other behaviors to improve the chance of cure and survival may have the unintended effect of causing guilt and self-blame if the patient does not maintain the behavior.

The prevalence of clinical depression was difficult to assess in our sample because there are not published clinical cutpoints for the PROMIS Depression scale, and the mean score in our sample was approximately equal to the mean score in the general population, suggesting that depression may not be as prevalent in our sample as in previous studies. However, individuals with life-threatening disease tend to rate quality-of-life more positively in self-administered questionnaires than in-person interviews, due to a shift in individuals’ expectations and standards for themselves. (353) This may also be attributed to the exclusion of women from our sample, as some research shows women are at higher risk for depression than men (304, 354) US military veterans may experience depressive symptoms at a different rate than other men. According to the VA National Center for Veterans Analysis and

Statistics, there were 19,059,530 living male US veterans 40 years of age or older in 2008, (355) which is approximately 29% of all US males age 40 years or older. (356) Individuals who seek care at VA Medical Centers may also be unique among veterans. VA patients, on average, have fewer years of education and lower incomes than veterans who receive care elsewhere. (357) Since lack of financial resources may be a considerable source of stress, one might expect depression to be more prevalent in this population compared to other populations of individuals with CRC. These findings may be affected by social desirability bias caused by the stigma associated with depression, and we do not know whether male veterans who under-report perceived stigma and self-blame would be more likely to under-report depression symptoms. The possibility of differential bias is a limitation of the study's cross-sectional design. Another limitation of the design is that the observed effects may be a result of confounding bias, or perhaps occur in the other direction bidirectionally. However, longitudinal research has shown that perceived stigma predicts subsequent depression, (179, 240, 296) and one study found the association to be unidirectional. (178) For individuals who may perceive stigma and blame as a result of psychological distress, it is likely that the relationship between the factors is cyclical, or that perceived stigma, self-blame and depressive symptoms are closely related..

Despite the study limitations, our findings suggest possible implications for reducing symptoms of depression in men with CRC. These results were found in a large sample of men and add to the sparse evidence that stigma and self-blame may

lead to depression in men with CRC. They suggest that the significant minority of men with CRC who report feeling stigmatized or blaming themselves may benefit from counseling or other intervention to address and cope with these negative feelings. Future research should examine predictors of variation in stigma and self-blame, as well as coping mechanisms and other attitude and personality factors that mediate the effect of stress on depression, to help identify areas for intervention.

Table 8: Characteristics of 1109 Male Veterans Diagnosed with Colorectal Cancer in 2008

Factor	% (n) or Mean (SD) N=1109
Age	68 (10)
≤50	3% (29)
51-60	16% (172)
61-70	43% (457)
71-80	26% (275)
81+	13% (143)
Race / Ethnicity	
Black	13% (145)
Hispanic	6% (62)
White	79% (878)
Education	
≤ High School diploma	52% (557)
> High School Diploma	48% (519)
Married	52% (579)
Clinical Factors	
Depression t-score	50.3 (10.9)
Stage at Diagnosis	
1	36% (390)

2	26% (278)
3	21% (226)
4	17% (185)
Charlson Comorbidity Index	.74 (1.2)
Overall Health	
Excellent	8% (83)
Very Good	26% (279)
Good	34% (367)
Fair	24% (263)
Poor	8% (84)
Pain Impact t-score	51.0 (10.6)
Fatigue	2.5 (.9)
At least 1 problem “Often” or “Always”	44% (469)
Defecation Index	27.6 (19.6)
At least 1 problem “Quite a bit”	31% (309)
Stoma	19% (187)
Symptom Index	24.1 (18.8)
At least 1 problem “Quite a bit”	44% (469)
Treatment within 3 months	13% (141)

Table 9: Prevalence of Stigma and Blame in 1109 Male Veterans Diagnosed with Colorectal Cancer in 2008

	% (N) responding “a little true”, “Somewhat true” or “Completely true” N=1109
Stigma	
I feel that some people avoid me because I have colorectal cancer.	10% (109)
I feel that some people feel awkward and tense around me because I have colorectal cancer.	19% (204)
I feel there is a stigma that goes with having my condition.	25% (249)
I feel that most people think less of a person who has colorectal cancer.	13% (141)
1 or more items endorsed	31% (334)*
2 or more items endorsed	19% (198)*
3 or more items endorsed	12% (122)*
Blame	
I feel I am to blame for my illness	25% (266)
I feel other people think I am to blame for my illness	10% (107)

*The denominator is the number of respondents who completed all four items

%’s represent valid percent among respondents; no imputation

Table 10: Results of Bivariate and Multivariate Linear Regression Models Predicting PROMIS Depression Score: 1109 Male Veterans Diagnosed with Colorectal Cancer in 2008

Independent Variable	Bivariate Association	Multivariate Model 1	Multivariate Model 2
Cancer Stigma	6.38*	5.40*	1.92*
Any Self-blame	6.43*	4.08*	2.67*
Any Other-blame	6.73*	.05#	-.51#

* $p < .01$

#Not Significant

- All Results are averages from five datasets with imputed missing data

Multivariate Model 1: Three independent variables modeled simultaneously

Multivariate Model 2: Three independent variables adjusted for demographic and clinical covariates: age, race/ethnicity, marital status, education, cancer stage at diagnosis, overall health, comorbidity, pain impact, fatigue, problems with defecation, index of common symptoms, having a stoma, and receipt of surgery, chemotherapy, or radiation treatment within past 3 months.

Chapter 7: Overview of Paper 3 - Identity Threat in Health Care

7.1 Statement of Problem

Identity threat has been shown to dramatically affect performance and increase anxiety in a number of settings, though the phenomenon is understudied in the healthcare encounter. Many physicians are unaware of the effects of threatened stigmatized identity, and how they may create threatening situations while providing patient care. The primary care encounter is a situation where identity-based threats may occur more frequently than other interactions. This may occur for a number of reasons: First, stigmatized social identities (e.g., sexual history, smoking status, disease status) which are concealable in public domains are exposed in the course of medical examination or history-taking. Second, the medical encounter is one where highly stigmatized identities (e.g., body size, minority ethnicity) are likely to be very salient, because there is 1) a built-in power difference between the roles of physician and the patient; 2) likely to be race, class, sex, age, and other important demographic differences between the physician and patient; 3) patients expect that stigmatized characteristics such as body size and smoking status will be directly threatened and openly devalued; and 4) doctors and other health care providers, like the general public, have been shown to hold implicit and explicit negative expectations and biases toward many stigmatized social groups, including racial minorities, (358-360) women, (361) and obese people, (362-364) that unconsciously affect their behavior when providing care, generating subtle identity threats. (365) Indeed, studies have

found a disturbingly high prevalence of experiences of discrimination in health care among members of stigmatized social groups (54, 366); and there is extensive documentation that stigmatized patients believe healthcare providers see them as less worthy of good care and unintelligent, due to their social identity. (362, 367-372) These beliefs may be particularly damaging based on evidence that expectations for threat are enough to trigger a threat response. (20, 62)

Four primary types of identity threat have been described by Branscombe et al (83): categorization threat, identity value threat, distinctiveness threat, and acceptance threat. Categorization threats occur when a patient is forced to represent a social group or take on a social identity. Obese patients may experience this threat, since the monitoring of weight, a highly stigmatized characteristic, is part of nearly every medical encounter. The categorization threat implications of a new diagnosis could be particularly stressful, as patients must begin to understand the identity contingencies of the new identity. Identity value threats occur when a patient is made to feel like their social group is not valued. This type of threat may occur frequently with social groups like smokers or obese patients, which are clinically relevant identities and openly devalued in a medical setting. Stigmatized social categories like lower-income patients may also feel devalued in a medical setting, if they are turned away or forced to take steps to demonstrate ability to pay. Distinctiveness threat occurs when a higher-order stereotype of an individual's social group is applied to an individual. As discussed previously, physicians have

unconscious negative expectations of patients with stigmatized social identities like race, socioeconomic class, or sex. (11, 360) Under time pressure, physicians rely on these stereotypes for information and may make assumptions about a young person's sexual activity, or an obese person's fast food consumption. Acceptance threat occurs when a patient is made to feel like they do not belong in the setting. This threat may be signaled by a lack of racial diversity among an institution's staff, which has been shown to create identity threat among members of some groups. (60, 64, 373) Waiting room reading materials or artwork may also fail to represent minority groups, suggesting that members of minority groups do not belong.

7.2 Methods

For the third paper, we examined evidence on identity and stereotype threat from the fields of social psychology, educational psychology, and sociology for relevance to medical care encounters. We used PubMed, PsychInfo, and Sociological Abstracts to identify literature published between 1979 and 2010 relevant to identity threat and stereotype threat, as well as stigma, prejudice, and discrimination. Keywords included "social identity" "threat" "stereotyped attitudes", "self concept", "stigma", "prejudice", and "discrimination", by themselves, and in combination with "primary health care", "health services accessibility", "physicians", "physician-patient relations", "delivery of health care", and "obesity". This paper is not an exhaustive review of the literature, but rather a critical analytic review of evidence for relevance to patients' experiences of medical care. In this paper, we apply existing empirical evidence from different disciplinary perspectives

to propose a theoretical framework illustrating the hypothesized impact of medical care encounters on patient experiences of identity threat and, in turn, the impact of identity threat on quality and outcomes of medical care for individuals with stigmatized social identities. We apply this evidence to suggest a research agenda to testing various intervention strategies for creating clinical environments that may communicate identity safety for individuals with a wide range of social identities and reduce the deleterious effects of identity threat in the medical encounter.

Chapter 8: Stigma and Identity Threat in Health care: The Importance of Creating Identity-safe Environments

8.1 Abstract

Individuals with a stigmatized social identity may experience identity-relevant threats in interactions with physicians and other health care providers. These threats may be caused by overt prejudice or subtle indications in the provider's behavior or the clinical environment that the patient's social identity is not valued. Threats can also occur due to the patient's expectation or fear that he or she will be stigmatized or viewed stereotypically. Any of these forms of identity threat can cause stress as well as vigilance for cues of discrimination, which, in turn, can reduce cognitive functioning, elevate state anxiety, and may interrupt the ability to communicate efficiently. These effects are likely to have implications for adherence, satisfaction, and health care utilization. Research in the fields of educational and social psychology has identified promising strategies that have been shown to reduce the frequency and effects of identity threat, which could be applied in healthcare settings. This paper discusses the implications of identity threat for the health care encounter, and advances a research agenda for developing and testing strategies to reduce its occurrence.

8.2 Introduction

Despite attempts to deliver health care equitably, communication barriers between physicians and individuals who feel stigmatized may impede the goal of providing high quality care to all patients. Health care inequities have been widely documented for a number of social groups and several causes for these disparities have been proposed. Much attention has been paid to the effects of race discrimination on disparities (103) and the social and health care utilization ramifications of having highly stigmatized medical conditions like HIV/AIDS (374) and mental illness. (375) However, there has been less examination of how and why stigma, identity threat and stereotype threat reduce quality of care across a wide range of social identities. Physicians' may undermine their own efforts to provide consistent and high-quality care if patients' social identities are devalued and insecure. In this paper, we define and review the evidence on stigma and identity threat in light of their significance for patient behavior and outcomes, and discuss strategies physicians can use to reduce the deleterious effects of stigma and identity threat for patients.

8.3 Stigma, Social Identity and Self Esteem

A stigmatized person has an attribute, behavior, or reputation that is socially discredited and conveys a devalued social identity within a particular context. Social identities are the categories, roles and social groups that define each person and give a sense of self. (19, 21) An individual's social identities may include his or her race or ethnicity, gender, occupation, disability, place of origin or schooling, sexual

orientation, physical characteristics, etc. Each social identity has accompanying values and emotional significance for the individual, and is also a source of self-concept and self-esteem. (376) Identities can be externally imposed and people are generally aware of being assigned a social identity whether or not they accept it. People can either distance themselves or internalize societally imposed social identities. For example, a middle-aged obese female physician may only endorse or embrace the physician social identity for herself, but she is likely to be aware that others are ascribing the social identities associated with undervalued categories (middle-aged women, obese people). This individual may or may not draw self-esteem from her stigmatized identities; however, her self esteem is likely to be affected by the stigmatizing behaviors and attitudes of others. Since self esteem is both positively and negatively linked to social identities, individuals are generally motivated to protect the social groups that they identify with from anything that may devalue or degrade them.

8.4 Identity Saliency

Social psychology theory and research provide insight into what happens when social identities are threatened. While people do not continuously monitor each social identity, certain identities emerge as dominant in particular social situations and form a frame of reference for who they are and what they value in that setting. (376) In one setting, an individual may choose to think of herself in terms of an identity from which she draws confidence, such as her professional identity. Other identities become salient through less conscious processes. Because people are

motivated to protect the social identities that are most relevant to self-esteem, people tend to see themselves in terms of the identity that is most at risk for threat in a given situation, i.e., the identity most likely to be stigmatized. (20) For example, an individual with a visible skin condition may be more conscious of his condition when visiting a beach than in other situations, and he may be more vigilant for threat in that setting.

8.5 Threat in a Healthcare Encounter

Some social situations are more threatening to social identity than others. The medical care interaction is one where the potential for threats to identity to occur is high for several reasons. First, stigmatized social identities associated with behaviors (e.g., sexual activity, smoking, alcohol use) that are concealable in public domains, are exposed in the course of medical examination or history-taking. Second, the medical encounter is one where highly stigmatized identities (e.g., body size, minority ethnicity) are likely to be very salient because there are 1) built-in power differences between physician and patient; 2) likely to be important demographic differences (e.g., race, class, sex, age) between the physician and patient; 3) patient expectations that stigmatized characteristics such as body size and smoking status will be directly threatened and openly devalued; and 4) health care providers, like the general public, have been shown to hold implicit and explicit negative expectations and biases toward many stigmatized social groups. Providers have been found to have negative biases towards racial minorities, (358-360) women, (361) and obese people, (362, 364, 377) that unconsciously affect their

behavior when providing care, generating subtle identity threats. (378) Studies have found a high prevalence of discrimination in health care experienced by members of stigmatized social groups (54, 366); and patients' experiences of identity threat outside of the encounter may affect expectations for and satisfaction with medical care. (379, 380) There is extensive documentation that patients with stigmatized identities believe healthcare providers see them as less worthy of good care and unintelligent, due to their social identity. (107, 362, 367, 369-371)

The diagnosis and categorization of patients into a new disease category (e.g., "AIDS patient" or "cancer patient") may be another source of identity threat. The stress-and-coping literature (311) names at least two identity-relevant demands that people with severe illnesses confront: adjusting to new negative realities of the disease and maintaining positive self-image. If the disease or its associated behavior is stigmatized, the perceived harm of a new diagnosis may be accompanied by identity threat. For example, a diagnosis of a sexually transmitted infection, such as HIV or Hepatitis C, may elicit patient worries about being negatively perceived or discriminated against. (163, 381) Patients with a new or existing stigmatized disease may be vigilant for signs of disapproval of behavior from their healthcare providers. A disease label can be particularly stigmatizing; e.g., people avoid certain stigmatizing labels like "mentally ill" to avoid incorporating the label into their identity. (22) Also, a new diagnosis or discussion of a condition that is relevant to an existing stigmatized identity may cause threat. For example, a discussion of metabolic syndrome or type 2 diabetes for an obese patient may be stressful as the

patient copes with the possibility that a devalued identity played a role in contributing to a serious disease.

8.5.1 Stereotype Threat

Identity threat can influence the medical encounter without an actual threatening occurrence, due to a phenomenon called stereotype threat. Stereotype threat is a specific type of identity threat, where the patient's behavioral, physiological, and affective responses to threat occur due to the patient's expectation that a threat will occur. (382) This expectation causes preoccupation with, and vigilance for, threat that can dramatically and negatively affect an individual's performance. (20, 84) For example, in one study that took place in an educational setting, a simple suggestion that the instructor could be sexist reduced the performance of female students in the class, even in the absence of explicit sexist behavior. (62) It follows that patients who are primed to expect negative attitudes based on their experiences with doctors or community-held beliefs about health care providers and systems may walk into the medical encounter with a high level of vigilance for cues of threat.

8.6 Consequences of Identity Threat for the Patient

8.6.1 Physiological Effects

Identity threat in the medical encounter may have a number of direct and indirect negative consequences that undermine health promotion and caregiving. Identity threat causes psychological and physiological stress, (59, 124, 129) which influences short-term and long-term health outcomes including cardiovascular disease, immune disorders, inflammatory diseases, depression, and anxiety. (131,

156, 157, 159, 160, 383) A distinct cardiovascular response to identity threat has been identified, where individuals who have stigmatized identities experience increased blood pressure in response to identity threat (124, 153, 155, 158) while those with non-stigmatized identities experience little change in blood pressure. (124, 158) Other short-term stress markers have also been observed as a result of identity threat, including elevated cortisol. (384) Physiological response to threat may cause a reduction in self-efficacy since patients who experience anxiety and stress may attribute it to their own lack of ability or intelligence in the healthcare domain. (385) Stress from identity threat may also lead to unhealthy coping strategies like smoking, binge or disordered eating, and drug and alcohol use. Indeed, many of these behaviors have been linked to identity threatening experiences among stigmatized populations such as experiences of prejudice or discrimination. (102-104, 386, 387)

8.6.2 Adherence

The quality of patient-provider communication is associated with treatment adherence, (388-391) so detrimental effects of stigmatization on communication in the medical encounter may result in lower adherence. Social identities and internalized self-identity may also play a role in adherence. Patients who grapple with a new negative illness identity may reject treatments in an attempt to preserve pre-diagnosis identities. (392) For example, an obese patient recently diagnosed with type 2 diabetes may find it difficult to accept that his behavior may have increased his risk. Therefore, he may assume his pre-diagnosis identity, where his

size may have been part of his identity, but not as central a component as to potentially harm his life. Blood sugar checks and altered diet, which are inconsistent with that pre-diagnosis identity, may be put aside.

8.6.3 Avoidance

Avoidance is one process by which individuals may cope with identity threat. People avoid situations where they feel they do not belong or are not welcome. (110, 113) This may contribute to lower follow-up rates, missed medical appointments (117, 393) and delaying needed or preventive medical care among members of stigmatized groups. (113, 119-121) One possible result of such avoidance is that people with stigmatized identities may present, on average, with more advanced and harder to manage disease, resulting in a more negative health care experience and worse outcomes.

8.6.4 Disidentification

Another form of coping may be through disidentification. Patients who experience identity threat may redefine their group's identity in ways that distinguish it from the majority group, often in oppositional ways. Patients may detach their self-esteem from the domain, and cease expending energy in behaviors associated with it. Disidentification may help explain the tendency of racial/ethnic minorities to view health promotion behaviors (e.g., exercising and healthy eating) as "White" and unhealthy behaviors (e.g., eating fast food and red meat) as characteristic of their racial/ethnic group. (128) It also may help explain correlations between experiences of body weight stigma and lower physical activity among obese women. (115)

Individuals are more likely to engage in behaviors that are seen as central to their self-concept. (57, 58) Thus, a patient may determine that behaviors like treatment adherence and managing diet are not central to her sense of self-worth, and thus are not important to her.

8.7 Consequences for the Medical Encounter

8.7.1 Disengagement

Disengagement occurs as a defense mechanism against information that is threatening to the patient's identity. During disengagement, a patient withdraws from the interaction, and reduces or ceases communication. Numerous studies have shown that individuals can respond to threat by shifting attention away from the source of the threat, and that those with stigmatized identities may be more likely to cope in this way. (394, 395) The patient who is disengaged is likely to discount feedback about performance in a particular area or view that feedback as irrelevant or unimportant. So, for instance, a diabetic patient who has disengaged in response to threat might reject feedback about elevated HbA1c levels, or a smoker might dismiss information about the negative effects of smoking.

8.7.2 Satisfaction

Patient satisfaction with the quality of healthcare suffers when patients feel their identities have been threatened. In one qualitative study of 41 patients who were dissatisfied with their healthcare, nearly every patient pointed to feelings of identity threat as a key motivator behind their low satisfaction ratings. (396) Specifically, 40 of the patients reported feeling dehumanized, objectified,

stereotyped, disempowered, or devalued by their interactions with health care providers. It may be the case that part of the reason why patients who share a social identity with their physicians report greater satisfaction with care (397-399) is that those patients are less likely to experience identity threat compared with patients who do not share a social identity with their physicians.

8.7.3 Trust

Patient trust of health care providers has been shown to predict use of recommended treatments and preventive measures, as well as patient satisfaction. (400, 401) A patient who is vigilant for threat or feels devalued by their physician is not likely to trust that physician. (402) In one study, members of various race/ethnicity groups scored lower on a measure of trust toward an individual if that individual identified him/herself as a member of a different race group. (403) This effect, moreover, was mediated by anticipated prejudice, demonstrating how *expectations of threat* (i.e., stereotype threat) can reduce trust even in the absence of an actual threat.

8.7.4 Performance Effects: Cognitive Resources and Working Memory

Evidence suggests that performance deficits in the medical encounter related to identity or stereotype threat are mediated by a situational loss of working memory. This memory loss has three main contributors: 1) a physiological stress response that causes cognitive deficits, 2) increased vigilance for additional cues of threat, and 3) effort to suppress negative thoughts and anxiety. (144) These three processes occur as a result of stereotype and identity threats and combine to cause a number of

performance deficits in the medical encounter including difficulty recalling and thus describing symptoms and later recall of instructions.

8.7.5 Attention and Information Processing

Identity threat can affect the quality of the medical encounter by interfering with the patient's ability to devote cognitive resources to the interaction. (141) For example, if a provider is teaching a self-care skill, a patient experiencing and/or being vigilant for identity threat may have reduced cognitive capacity, lowering his ability to learn and recall the new information. (143) Through these processes, experiences of identity threat might contribute to non-adherence among minority social groups (119, 404) and lead to disparities in health outcomes that are highly contingent on effective patient self-management. (405, 406)

Similarly, based on research evidence that threat impedes the ability to perform well on math tests and other complex thinking tasks, (20, 142) as well as research that shows a detrimental effect of stress and anxiety on cognitive functioning, (407, 408) identity and stereotype threat may impede patients' ability to make judgments and decisions that are concordant with their goals and values.

8.7.6 Communication

Identity threat may impair the patient's verbal and nonverbal communication skills, (409, 410) reducing fluency, self-disclosure, and response to the provider's questions. This might be one factor underlying poorer quality of clinical encounters (e.g., lower levels of positive affect, patient participation, and shared decision-making; less time spent by providers in relationship-building behaviors) for Black

compared with White patients. (398, 411-413) Poorer and less participatory communication is associated with lower rates of patient adherence, utilization, self-management, and symptom recovery. (414-416) The effect of poor communication may be cyclical, as impaired verbal and nonverbal communication may reinforce physicians' stereotypes about patients' intelligence, affecting their behavior in ways that further threaten the patient. (11) Additionally, impaired communication may signal to physicians that they have done something wrong or offended in some way, increasing their anxiety and further affecting the quality of communication. (417)

8.8 Strategies to Reduce Threat in the Medical Encounter

Identity threat and stereotype threat intervention research has largely been limited to educational settings. This and other research in nonclinical settings points to identified several promising avenues for reducing threat that should be tested in health care settings.

8.8.1 Elicit Values and Strengths

A way to reduce identity threat is to give patients the opportunity to focus on and affirm their individual- and group-valued characteristics and strengths. For example, in one study, Black students who were randomly assigned to write an essay about what values were important to them performed better, over the course of the semester, than those who did not. (418) It is particularly important that providers give patients from stigmatized groups the opportunity to demonstrate their competence and intelligence. For instance, in discussing a health problem that will require significant behavioral change, the physician might ask the patient about a

time in his life in which he has dealt with a significant challenge, and encourage him to discuss the qualities within himself that helped him overcome it. This emphasizes that the provider cares about and values the patient's unique perspective and hence may help diminish the patient's fear of being viewed stereotypically.

8.8.2 Normalize and Provide External Attributions for Anxieties

It is possible to reduce the effects of stereotype threat by helping individuals attribute anxiety and task difficulty to external circumstances rather than lack of ability. (419, 420) For instance, providers might check in with patients who seem anxious and distracted, reassure them that such feelings are normative, and offer practical coping techniques (e.g., take a friend or family member with her, come into the exam room with a few questions, etc). Similarly, for patients who have difficulties changing a behavior, providers might explain that changing behavior is difficult for many people, help identify barriers, and work together to come up with a plan to overcome them.

8.8.3 Reduce Salience of Stigmatized Identities

It may be possible to make potentially stigmatized identities less salient in the clinical setting. One strategy might be to increase time between asking about potentially threatened identities and the medical encounter. One study showed that performance of high school women on a challenging calculus exam significantly improved by moving the question measuring sex to the end of the exam. (65) In another study, people who disclosed a mental illness prior to completing a complex task performed poorly compared to people with mental illnesses who did not

disclose. (68) In a clinical setting, asking patients to provide medical history, if it is essential information, far in advance of the appointment may reduce the immediacy of threat related to revealing stigmatized social identities, and make those identities less salient to patients once they arrive in the clinic. Another strategy may be asking patients to indicate whether they are interested in being weighed, discussing weight, or discussing smoking cessation prior to the visit, and agreeing to adhere to patients' wishes regarding discussion of these topics. Alternatively, discussion of smoking and weight could take place at the very end of the encounter, delaying the threat until after most of the important clinical communication has taken place. Stereotype threat can be averted if the provider indicates that she has high standards for the patient and communicates that she is confident that the patient has the ability to meet those standards and be successful (e.g., at behavior change, at achieving health-related goals). This style of feedback is associated with increased acceptance of the feedback and motivation to improve (421) and may enhance patient adherence to treatment protocols.

8.8.4 Identity Safe Physical Environment

While it is impossible to eliminate all sources of identity threat from the medical care environment, steps can be taken to create an environment where all patients feel that their social identities are safe and valued. A health care institution can provide numerous cues that identity threats are not normative and diversity is valued. Pro-diversity mission statements and policies signal that the institution prioritizes making all patients feel welcome. In one series of studies, Black

professionals were presented with corporate materials in which the company's philosophy about diversity (a color-blind approach versus an approach that touted the benefits of diversity) and minority representation (low versus high) were systematically varied. (64) Identity threat was most activated in settings in which there was a low minority representation and when the company advocated a color blind philosophy. Interestingly, explicit information that the company valued diversity offset the stereotype threat associated with low minority representation. Other visual cues that diverse social groups belong in the setting include artwork, or images of role models with diverse social identities.

The presence of physicians and other clinical staff who represent minority or other stigmatized social groups is a powerful indicator of acceptance. Efforts may be made to increase the diversity of staff and providers across multiple areas of social identity, including socioeconomic class, age, sex, race, disability and body size. The demonstrated acceptance into the health care environment of staff members with stigmatized social identities may go a long way toward creating a feeling of belonging and safety for patients who share that identity. Furthermore, patients who share common group identities with their physicians have been shown to communicate better with the provider, and be more satisfied with their care. (398)

Another way to avoid situations that threaten the identities of some patients is to strive for medical instruments and office furniture that is useable by all patients. When patients are forced to use "special" implements because of their stigmatized social category, the experience focuses attention on the patient's differentness, and

may cause considerable threat. By using medical and office equipment that is usable to the greatest number of people, those patients avoid feeling that their identity is different from what is expected. For example, making sure that all examination tables, waiting room seats, and medical instruments (e.g., blood pressure cuffs) are usable for the entire patient population, regardless of size, may avoid sources of threat for people who are larger.

8.8.5 Identity Safe Interpersonal Environments

As discussed previously, physicians have unconscious negative expectations of patients with stigmatized social identities. (358, 360) Under time pressure, physicians rely on these stereotypes for information and may make assumptions about a young person's sexual activity, or an obese person's fast food consumption. Thus, one way to improve the identity safety of a health care environment is to provide physicians and clinical staff with the resources and skills to minimize their risk of applying unconscious negative attitudes and stereotypes. A number of factors reduce the likelihood that providers will be prone to unconscious bias. 1) Physician empathy or ability to understand a patient's experience may reduce the strength of unconscious negative expectations of the patient. Exercises in perspective-taking and writing from the vantage of a stigmatized patient have been shown to increase empathy and reduce bias among physicians. (422) These exercises could be used as part of continuing education or cultural awareness training. 2) Creating a sense of partnership between the patient and provider may foster a shared identity as members of the same team, help develop a psychological bond, and ease vigilance

for identity threats in patients. Partnership building has been shown to reduce unconscious negative attitudes in interracial interactions and improve patient satisfaction with care. (423, 424) 3) Individuals who attempt to repress negative stereotypes about a group can experience stereotype rebound, where those stereotypes and attitudes re-emerge as more salient. (425) There may be strategies that reduce the application of rebounded stereotypes, including motivation to be non-prejudiced and having practice with stereotype control. (426) Providers who are aware of the possibility that they may experience unconscious attitudes, and focus their attention on the patient as an individual, may reduce the influence of those attitudes on their behavior. Thus, tools like the Implicit Association Test, (427) a web-based measure of unconscious bias, may be useful in building awareness among physicians and reducing identity threatening behavior. 4) Positive emotions can reduce physicians' tendency to rely on stereotypes and increase their focus on the patient as an individual. (428, 429) Thus, promotion of emotion regulation techniques such as meditation and positive reappraisal may reduce activation of group stereotypes. 5) Physicians who make decisions under time pressure may be more likely to rely on group stereotypes to fill in missing individual information. (430, 431) Thus, to the extent it is feasible, increasing the amount of time that a physician spends with each patient, especially time spent building a relationship, may reduce reliance on stereotypes that threaten the patient's social identity.

8.9 Conclusion

Health care providers and the physical and interpersonal health care environment may have the ability to signal that patients with stigmatized social identities are not welcome and not valued. These signals can directly harm patients' health and reduce the effectiveness and quality of their health care. However, there is a need for further research that explores the situations in health care that create identity and stereotype threat for patients, demonstrates the effects of these threats, and tests the efficacy of strategies to promote identity safety for patients with stigmatized social identities. This research would build upon theories of identity and stereotype threat to include individuals with understudied stigmatized social identities that may be at high risk for threat in a health care setting, and may improve the health care experience for these individuals. By striving to create an identity-safe environment where threats are not the norm and patients feel welcome and valued, providers may be able to provide better care for their patients and improve patient outcomes and satisfaction.

Chapter 9: Conclusions

This dissertation explored the effects of stigma and stigma-induced identity threat for three stakeholders in the healthcare system: caregivers, patients, and providers. Among caregivers of veterans with traumatic brain injury, perceived discrimination-by-association, perceived discrimination towards the veteran, stigma of the caregiving role, and felt need to conceal the veteran's injury or explain how it occurred were generally associated with greater stress from caregiving (caregiver personal strain), health outcomes of stress processes (depression, anxiety), a maladaptive coping mechanism (social isolation), and an intrapsychic outcome of repeatedly threatened social identity (self-esteem). Among individuals with colorectal cancer, the stigma of having colorectal cancer and self-blame for acquiring the disease were associated with greater depression, independent of several risk factors for depression. For health care providers, we outlined the sources of identity threat in the health care interaction, the mechanisms whereby these threats alter patient behavior, and the outcomes that might impede the physician's ability to provide high quality care. Finally, we identify several potential evidence-based strategies for reducing the occurrence and effects of identity threat in health care.

9.1 Caregivers

For caregivers, these findings support and advance research that has shown that stigma, conceptualized as perceived discrimination, is a problem among associates of individuals with the stigmatized identity (1, 30-33) that can lead to

stress and negative health outcomes. (432) In prior research, caregiver strain predicted recovery and other outcomes for the care recipient, so caregiver stigma may contribute to poorer outcomes among people who receive informal care. Associations between stigma and emotional distress can be explained by the model of stress and coping, which asserts that stress and stress-related outcomes like depression and anxiety result when the demands of a stressor are greater than the available coping resources. (52) One potential coping strategy, social isolation, can lead to social loneliness, a risk factor for psychological distress. (235, 433) Isolation among caregivers may be self-imposed, as individuals withdraw as a problem-focused coping strategy to reduce the stress of providing care for someone with a stigmatized condition in public, which for this population may include managing the care recipient's behavior, explaining or concealing visible scars or being stared at, whispered about, etc. Reduced self-esteem is an outcome of identity threat, and several studies have shown that stigma reduces the self esteem of the stigmatized. (187-190) This is most poignant in the model showing that lower self esteem is associated with feelings that the caregiver role is stigmatized or devalued.

9.2 Patients

Among patients, the impact of stigmatized identity is addressed in two papers. First, stigma related to having colorectal cancer was associated with greater depression symptoms among men. This association persisted after adjustment for several clinical and demographic factors that may increase risk of depression. This finding is consistent with literature that shows associations between stigma and

emotional distress among individuals with other chronic diseases, (167, 184, 194) including some cancers. (329, 350, 351, 434) .Several qualitative and conceptual papers have discussed various facets of stigma or related concepts among individuals with colorectal cancer, including self-image, (323) reduction and preservation of valued social roles and identities, (320-323) embarrassment over fecal incontinence and stoma, (319) and disclosure of disease. (333) However, the majority of extant empirical studies of stigma and its association with distress among cancer patients have used samples of individuals with lung or breast cancer and have small sample sizes, (316, 317, 328-330) This study is the first to measure the prevalence of stigma and its association with depressive symptoms in a national sample of men with colorectal cancer.

The potential effects of having a stigmatized social identity in terms of stereotype threat and identity threat are addressed in the third paper. The phenomenon of stereotype threat, and the identity threat perspective of stigmatized identity is well studied in education and social psychological literature, but very little has been done to advance these ideas and consider the ramifications of identity threat in the domain of health care. This paper addresses potential effects of stigma in a clinical encounter, including reduced communication ability, anxiety, and coping mechanisms like disidentification as well as patient adherence and health outcomes.

The contribution of blame to depressive symptoms was also assessed among men with colorectal cancer, and self-blame was significantly associated with greater depression symptoms. This finding is consistent with literature showing that self-

blame predicts emotional distress among individuals with lung cancer (329, 351) and individuals with breast cancer. (337-339) However, there are no previously published studies linking self-blame to depression among individuals with colorectal cancer, a disease whose acquisition has a smaller behavioral component than lung cancer. However, research (26) does suggest that some people believe there to be a link between colorectal cancer incidence and behaviors like eating a high fat or low fiber diet, as well as engaging in receptive anal intercourse. Furthermore, it is possible that individuals who have used tobacco or have delayed attaining a screening colonoscopy may blame themselves for acquiring the disease. Diseases with a behavioral cause are more likely to be stigmatized (29, 435), and the perception that other people blame the individual with colorectal cancer for the disease was not associated with depression in either model that also included stigma as a predictor, possibly because perceived blame does not explain additional variation in depressive symptoms beyond perceived stigma.

9.3 Physicians and Clinics

Paper three adapts social psychology and education literature about identity threat and stereotype threat to the medical encounter. Based on the review of the relevant identity threat literature, the medical encounter is one where identity threat is likely to occur because there is a difference in power between physician and patient, and each actor, especially the patient, is motivated and activated to seek certain goals in the interaction. Physicians, however motivated to treat all patients equally and fairly, have been shown to hold unconscious biases that may affect their

behavior toward stigmatized patients in subtle ways. These subtle threats interrupt the care process and impede the physician's ability to provide high-quality care to their patients. A number of recommendations for physicians that may reduce threat are presented, including eliciting the patient's strengths and providing an external reason for the patient's anxiety. The clinical setting can create identity threat as well, as the literature review helped identify several factors that may affect the identity safety of the environment, including the presence of clinical staff and physicians who represent a wide range of cultural identities, the presence of a mission statement or philosophy that includes acceptance of all people, and waiting room furniture and medical instruments that are universally useable.

9.4 Limitations

There are several limitations to the methodologies used in these papers. Specifically, the cross-sectional design of both empirical studies draws into question the causal explanation to the models presented. Directionality is not certain in any of the models, however, each model is grounded in sound theories of stigma and prior empirical work. Also, each model's hypothesized directionality is supported by the use of dependent variables that are unlikely to precede independent variables, for example, social isolation is unlikely to precede perceived discrimination, if a causal relationship is assumed. The use of two VA populations may also reduce or diminish the generalizability of the studies' conclusions. However, there are several strengths of the dissertation as well, including the ability to explore stigma across several domains of the patient care process, and the inclusion of several related

concepts like self-blame and stigma-by-association. In total, the findings presented here suggest that stigma affects health and healthcare at multiple points and for multiple actors.

9.5 Implications

These papers have several implications for the medical care process. The shift to an informal home care model for many chronic conditions including cancer places an added burden of stigma and discrimination on the shoulders of family caregivers, which can contribute to stress and possibly lead to adverse outcomes for the caregivers and the people for whom they provide care. Physicians should be aware of the potential for this stressor among families of individuals with chronic conditions, especially individuals with visible or behavioral effects of their condition. Interventions that aim to support families as well as patients in home care situations and provide strategies and resources to cope with the stress of stigma may be effective at reducing the emotional burden of caregiving.

Clinical setting and physicians contribute to patient anxiety and patient outcomes through subtle threats to valued social identities, especially those identities that are explicitly devalued in clinical settings, like obesity and smoking status. Patients may experience stress in the clinical interaction due to stereotype threat, or the fear of confirming a group stereotype, as well as vigilance for other identity-related threats. The paper makes several recommendations that may help interrupt the identity threat process and create a setting that communicates identity safety: normalizing and providing external attributions for anxiety, eliciting values and

drawing attention to strengths, de-emphasizing stigmatized identities, creating an interpersonal clinic environment that signals that people with stigmatized identities are safe and welcome by hiring diverse staff and training them to be aware of unconscious biases, taking steps to reduce the impact of bias, and adjusting the physical environment through the use of universally-useable furniture and medical instruments, culturally varied artwork and welcoming messages. Creating clinical environments that are safe for all groups and identities may help reduce disparities in care outcomes for several marginalized and stigmatized social groups.

Patients with conditions that are not traditionally associated with high levels of stigma may experience stigma nonetheless, as many diseases have perceived behavioral components, and the “ill” or “diseased” identity itself is not valued and may elicit discriminatory behavior from observers. This stigma may contribute to the stress that individuals with chronic illnesses experience as well as subsequent depressive symptoms. Mental health care providers who are helping people with severe chronic diseases cope with the new negative realities of their conditions should consider the possibility of stigma for these individuals and the stress and mental health implications of that stress.

Generally, one implication of these analyses for health services and public health research is the advancement of evidence for the deleterious effects of stigma into populations not typically associated with social stigma. The application of social identity theory to the study of the health effects of stigma expands the notion of stigma to include any individual who has a social identity that is devalued in a

situation. Furthermore, social identity theory and the theory of stigma-induced identity threat allows for the consideration of previously understudied sources of threat throughout the health care system and outcomes that are not typically measured in health services research. For epidemiologists and public health researchers in general, these papers suggest that stigma and related concepts should be taken into consideration when designing studies or interventions to elucidate or ameliorate emotional distress or other outcomes of stress, as well as interventions to reduce the effects of provider bias, group disparities in incidence of preventable diseases, and disparities in access to and quality of care.

The studies presented here suggest several future directions for research in these datasets and other populations. Among caregivers of veterans with traumatic brain injury, further inquiry into the causes and outcomes of perceived stigma, especially behavioral coping strategies is warranted. A future analysis with a larger sample size should explore whether patient behaviors or injury characteristics contribute to perceptions of stigma and caregiver as well as care recipient outcomes. Among individuals with colorectal cancer, future analyses will assess whether individuals whose identities are associated with specific behaviors that are thought to contribute to the disease (obese, smoker) are more likely to experience self-blame and stigma and whether treatments like colostomies that may be noticeable increase feelings of stigma. Longitudinal investigations of stigma and stigma by association could be used to assess how the accumulation of stress from stigma affects caregivers' and patients' outcomes and behaviors over time.

The conceptualization of identity threat in primary care suggests several possible remediation techniques that may form future intervention studies for the patient and the provider. For example, strategies to increase the identity safety of the clinical environment could be experimentally tested in providers, and strategies to encourage focusing on and affirming valued social identities, or reframing the causes of anxiety as external could be tested in individuals with stigmatized social identities to evaluate change in trust, satisfaction, adherence, and other quality measures. Also, as there is no measure of identity safety in the clinical environment, a future study may be designed to develop this measure.

The effect of having a stigmatized social identity and experiencing behavioral reactions to that identity has potentially numerous negative health and health behavior outcomes. The full scope of this problem in terms of populations effected and effects seen has not received sufficient attention. This dissertation has evaluated the effects of stigma in several groups of actors in the health care system: patients, caregiver, and providers. These papers have demonstrated that stigmatized identity may lead to emotional distress, lower self-esteem, avoidance of care, social isolation and other negative health and quality of life outcomes.

Chapter 10: Bibliography

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Appendix A: Glossary

Caregiving: Activities associated with providing care related to injury or illness and performed by informal, unpaid family caregivers. Care ranges from intensive day-to-day care to simple supportive tasks, such as helping to organize services.

Colostomy: A surgically created opening in the skin where body waste exits the body from part of the colon, bypassing some part of the colon and the anus.

Discrimination: A behavior that represents unequal or unfair treatment toward an individual because of his/her group membership

Dual-process Model: Any model that describes a function that occur through two pathways, often a conscious and an unconscious one. Here it describes the two pathways of evaluating new information, an efficient method that relies on readily available stored stereotypes and a second slower evaluation process that requires energy.

Identity Threat: Perception of the possibility that physical or emotional harm may occur due to one's social identity or group membership

Ileostomy: A surgically created opening in the skin where body waste passes directly from the ileum, or end of the small intestine, bypassing the colon and anus completely.

Ostomy: Surgically-created opening in the skin through which waste exits the body

Prejudice: A belief about or attitude toward a group based on group stereotypes

Social Identity: One of the roles or group memberships that defines how an individual is perceived and sees him or herself.

Stereotype: An easily accessible and common belief about a social group

Stereotype Threat: A feeling or fear that one might confirm a group stereotype or be seen in a stereotypical way

Stigma: A social response of disapproval, fear, or disgust to a person with a characteristic of the body or character that is devalued and considered abnormal or shameful.

Stoma: The end of the ileum or large intestine that is attached to the skin and protrudes from an ostomy

Threat: Perception of the possibility that physical or emotional harm may occur

Appendix B: Study Measures

Paper 1:

Caregiver Discrimination

In your day to day life, how often have any of the following things happened to you?

- You have been treated with less courtesy than other people.
- You have been treated with less respect than other people.
- You have been received poorer service than other people at restaurants or stores.
- People have acted as if they are afraid of you.
- People have acted as if they're better than you are.

Care Recipient Discrimination

- He/She has been treated with less courtesy than other people.
- He/She has been treated with less respect than other people.
- He/She has been received poorer service than other people at restaurants or stores.
- People have acted as if they are afraid of him/her.
- People have acted as if they're better than he/she is.

Caregiving Stigma

How often do you feel the following things happen?

- I feel there is a stigma that goes with caregiving.
- I feel that most people think less of a person who provides care.

Need to Cover/Explain

How often do you feel the following things happen?

- I feel I have to cover up my care recipient's injuries.
- I feel the need to explain to others how my care recipient got the injuries.

Social Isolation

In the past 7 days...

- How often did you feel you lacked companionship?
- How often did you feel left out?
- How often did you feel isolated from others?

Depression

In the past 7 days...

- I felt worthless.

- I felt that I had nothing to look forward to.
- I felt helpless.
- I felt sad.
- I felt like a failure.
- I felt depressed.
- I felt unhappy.
- I felt hopeless.

Anxiety

In the past 7 days...

- I felt fearful.
- I felt anxious.
- I felt worried.
- I found it hard to focus on anything other than my anxiety.
- I felt nervous.
- I felt uneasy.
- I felt tense.

Low Self-esteem

- I feel that I'm a person of worth, at least on an equal plane with others. (Reversed)
- I feel that I have a number of good qualities. (Reversed)
- All in all, I am inclined to feel that I am a failure.
- I am able to do things as well as most other people. (Reversed)
- I feel I do not have much to be proud of.
- I take a positive attitude toward myself. (Reversed)
- On the whole, I am satisfied with myself. (Reversed)
- I wish I could have more respect for myself.
- I certainly feel useless at times.
- At times I think I am no good at all.

Personal Strain

How often do you feel the following?

- I feel angry when I am around my care recipient.
- I feel that my care recipient affects my relationship with family members or friends in a negative way.
- I feel strained when I am around my care recipient.
- My health has suffered because of my involvement with my care recipient.
- I don't have as much privacy as I would like because of my care recipient.
- My social life has suffered because I am caring for my care recipient.
- I have lost control of my life since my care recipient's injury.

- I feel uncertain about what to do about my care recipient.

Role Strain

How often do you feel the following?

- Because of the time I spend with my care recipient I don't have enough time for myself.
- I feel stressed between caring for my care recipient and trying to meet other responsibilities for my family or work.

Social Support

In the past 7 days...

- Was there someone available to whom you can count on to listen to you when you need to talk?
- Was there someone available to you to give you good advice about a problem?
- Was there someone available to you who shows you love and affection?
- Was there someone available to help with daily chores?
- Could you count on anyone to provide you with emotional support (talking over problems or helping you make decisions)?
- Did you have as much contact as you would like with someone you feel close to, someone in whom you can trust and confide in?

Amount of Caregiving

Months

- What was the month and year that you first started doing things to help your care recipient due to his or her injury? Please give us your best estimate.

Hours per week

- In a typical week, on how many days do you provide care or help your care recipient as a result of his or her injuries?
- On a typical 24-hour weekday (Monday through Friday), about how many hours do you provide care for your care recipient as a result of his or her injuries?
- On a typical 24-hour weekend day (Saturday and Sunday), about how many hours do you provide care for your care recipient as a result of his or her injuries?

Tasks

In the past 2 weeks, have you helped you care recipient...?

- Eat?
- Get in or out of bed?

- Get dressed?
- Bathe?
- Get on or off the toilet?
- Clean him or her self after s/he used the toilet?
- With a bedpan?

In the past 2 weeks, have you done any of the following for your care recipient?

- Managed your care recipient's money (paid bills, managed cash)?
- Made telephone calls for your care recipient?
- Done housework you wouldn't normally do (if your care recipient had not been injured)?
- Washed laundry you wouldn't normally wash
- Shopped for your care recipient's groceries?
- Driven your care recipient to a doctor's office, clinic, or hospital?
- Helped your care recipient with therapy (occupational, speech, or physical therapy)?
- Made medical appointments for your care recipient?
- Helped your care recipient with legal issues?
- Navigated the medical system for your care recipient?
- Navigated the VA or Department of Defense benefits system for your care recipient?
- Navigated the health insurance system for your care recipient?
- Administered medication?
- Changed your care recipient's bandages or dressings?
- Helped with you care recipient's prosthetic device?
- Managed any side effects or symptoms?
- Managed you care recipient's pain?
- Helped with assistive devices, such as palm pilots or other vision, hearing, language, or memory aids?
- Helped with mobility devices, such as a wheel chair, cane, or other mobility aids?
- Changed your care recipient's external catheter?
- Managed seizures?

Demographic and Social Characteristics

- Which category represents your combined total household income during the last 12 months? This includes money from jobs, net income from businesses, farm or rent, pensions, dividends, interest, social security payments, disability and any other money income received by everybody in your household.
- How many people are supported on this income?

- What year were you born?
- Are you male or female?
- Are you of Latino/Hispanic origin?
- Which of the following (races) best describes you?
- What is the highest level of school you have completed
- What is your relationship to the person you are helping (your care recipient)?
- About how tall are you without shoes?
- About how much do you weigh without shoes?

Paper 2:

Cancer Stigma

- I feel that some people avoid me because I have colorectal cancer.
- I feel that some people feel awkward and tense around me because I have colorectal cancer.
- I feel there is a stigma that goes with having my condition.
- I feel that most people think less of a person who has colorectal cancer.

Self-blame

- I feel I am to blame for my illness.

Other Blame

- I feel other people think I am to blame for my illness..

Depressive symptoms

In the last 6 months...

- I felt worthless
- I felt that I had nothing to look forward to
- I felt helpless
- I felt sad
- I felt like a failure
- I felt depressed
- I felt unhappy
- I felt hopeless
- I felt worthless
- I felt that I had nothing to look forward to

Pain Impact

In the last 6 months...

- How much did pain interfere with your enjoyment of life?
- How much did pain interfere with your ability to concentrate?
- How much did pain interfere with your day to day activities?
- How much did pain interfere with your enjoyment of recreational activities?
- How much did pain interfere with doing your tasks away from home (e.g., getting groceries, running errands)?
- How much did pain keep you from socializing with others?

Fatigue

In the last 6 months...

- How often did you feel tired?
- How often did you experience extreme exhaustion?
- How often did you run out of energy?
- How often did your fatigue limit you at work (include household chores)?
- How often were you too tired to think clearly?
- How often were you too tired to take a bath or shower?

Bowel Problems***In the last 6 months...***

- Did you have frequent bowel movements?
- Have you had any unintentional release of stools?
- Have you had blood with your stools?
- Have you had difficulty in moving your bowels?
- Have you been constipated?
- Have you had diarrhea?

Symptom Index***In the last 6 months...***

- Were you short of breath?
- Have you had trouble sleeping?
- Have you lacked appetite?
- Have you felt nauseated?
- Have you vomited?
- Have you had a sore mouth or tongue?
- Have you had trouble swallowing?
- Have you had pain, tingling or numbness in your hands or feet?

Other Health Indicators

- Do you currently have a colostomy or ileostomy? An ostomy is when your bowel connects directly to the surface of your belly and you wear a bag or an appliance to collect the waste. Sometimes this is called a stoma.
- In general, would you say your health is: [excellent, very good, good, fair, poor]
- When did a doctor first tell you that you had colorectal cancer? If you don't know the exact date, just estimate the month and year.
- What was the date of your last surgery for colorectal cancer? If you can recall the exact date, please fill that in. Otherwise, just estimate the month and year.
- What was the date of your last chemotherapy treatment for colorectal cancer? If you can recall the exact date, please fill that in. Otherwise, just

estimate the month and year.

- What was the date of your last radiation therapy treatment for colorectal cancer? If you can recall the exact date, please fill that in. Otherwise, just estimate the month and year.

Demographic and Social Characteristics

- How old are you today?
- Are you male or female?
- Are you currently married, living with someone, separated, divorced, widowed, or never married?
- What is the highest grade or level of school that you have completed?
- Are you of Hispanic or Latino origin or descent?
- What is your race? Please mark all that apply.