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PEOPLES' EXPERIENCES WITH POUCHES (P.E.W.P.) STUDY: MEDICAL CLINICIAN COMMUNICATION AND THE STIGMATIZATION OF PEOPLE WITH AN OSTOMY

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PEOPLES' EXPERIENCES WITH POUCHES (P.E.W.P.) STUDY:
MEDICAL CLINICIAN COMMUNICATION AND THE STIGMATIZATION OF PEOPLE WITH AN OSTOMY

A DISSERTATION APPROVED FOR THE
DEPARTMENT OF SOCIOLOGY

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Dedicated to my husband, Tony, and our fur babies, Jake, Lily, and Chloe, I could not have done this without each of you. Thank you, Tony, for your unwavering support.

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Chapter 1: A Brief Introduction and Dissertation Overview

Introduction

Few studies have examined the quality of medical clinician communication with ostomy patients after surgery and the resulting patient health outcomes. There is also a paucity of research on ostomy patient stigma, especially as it pertains to the role of medical clinicians in ostomy stigmatization. This dissertation addresses these gaps in the literature on ostomy patients' experiences with medical clinicians and ostomy patient stigma.[1]

An ostomy is a surgically created opening on the abdomen that allows for the discharge of bodily waste into an external or internal pouch (UOAA 2018). Indications for ostomy surgery include, but are not limited to, cancer, inflammatory bowel disease (IBD), diverticulitis, trauma and other reasons, and there are several types of ostomies, such as colostomy, ileostomy, urostomy. An ostomy is categorized as a disability under the Americans with Disabilities Act (ADA) because of the life-changing nature of eliminating bodily fluids differently and having to wear a prosthetic device (i.e., ostomy appliance) (Gleba and Mueller 2019), and is associated with high morbidity and mortality (Sheetz et al. 2014).

Millions of individuals are living with an ostomy appliance in the United States and almost 100,000 receive one each year (WOCN 2017). Ostomy surgery is not new; the first ostomy surgery was recorded in the late-18th century (Cataldo 1999). Ostomy surgical rates in the United States are comparable to or higher than other countries. For instance, estimates for individuals undergoing ostomy surgery in China are similar to the United States (Zhang, Chen, and Zhang 2018), the United Kingdom has an estimated 100,000 people living with an ostomy (Colostomy Association 2016), and Canada approximates 13,000 ostomy surgeries are

[1] Stigma, by definition, is "an attribute that is deeply discrediting" where the stigmatized person is seen as "not quite human" (Goffman 1963:3,5).

performed each year (Recalla et al. 2013).

I use patient-centered care as a framework in understanding medical clinician-patient interactions at the hospital. A patient-centered care medical encounter is considered to be the optimal interaction between patients and medical clinicians because during this exchange, clinicians consider patients' perspectives, values and needs in decision making. Also, health care that is patient-centered produces a meaningful discussion between both parties and results in positive patient health outcomes (Bertakis 2009; Epstein and Street 2011; Street 2013). I also draw from modified labeling theory posited by Link and colleagues (1989), which helps us to understand the stigmatization process as it pertains to the patient, such as culturally derived expectations of devaluation and discrimination based on having a labeled[2] status.

Dissertation Overview

The substantive chapters of this dissertation, chapter 2, 3 and 4, are organized as three separate and complete studies. Each study investigates ostomy patients' experiences with medical clinicians through the communication patients receive. I answer several open questions in the chapters that follow. First, in Chapter 2, I investigate quality of medical clinician communication and whether this communication adequately prepares ostomy patients to care for their new appliance. I also test whether the quality of clinician communication differs based on patient demographic characteristics. Next, Chapter 3 examines whether ostomy patients experience stigmatizing sentiments from medical clinicians. I use a triangulation of data (quantitative and qualitative) to answer this question. Thirdly, in Chapter 4, I test ostomy stigma and medical clinician communication from a quantitative perspective and provide a newly

[2] Labeling is the application of a 'mark' on an individual seen as being deviant. Labeling can result in positive or negative consequences (Rosenfield 1997). Stereotypes, which are learned from childhood, are important to the labeling process (Fletcher and Reynolds 1967; Scheff 1966). I discuss more on labeling in the discussion on modified labeling theory in Chapter 4.

created ostomy-specific stigma scale. Finally, Chapter 5 summarizes and draws conclusions from the findings presented in the previous chapters.

Chapter 2: An Examination of the Quality of Medical Clinician Communication with Ostomy Patients

Chapter 2 Abstract

Background: Health disparities are a persistent problem for many patient populations and a major concern of the healthcare system. Decades of research demonstrates the importance of medical clinician communication in patient health outcomes. Few studies, however, have focused on medical clinician communication with a patient group that often faces discrimination: people with an ostomy. An ostomy is a surgically rerouted bowel and/or bladder, resulting in bodily fluids discharged into a pouch.

Objective: To investigate whether interactions between ostomy patients and medical clinicians adequately prepare ostomy patients to care for their new appliance, and whether the quality of clinician communication differs based on patient demographic characteristics.

Method: Using a nonprobability national sample of 353 ostomy patients, I conducted a retrospective quantitative study. I measured quality of clinician communication from self-reports from ostomy patients, coding open-ended responses using the open-coding method.

Results: The results show that a little more than half (53%) reported receiving adequate communication from clinicians. Log binomial regression models show a statistical relationship between ostomy patients' educational attainment and reporting receiving adequate communication. Notably, patients with a high school degree or fewer years of educational attainment were statistically more likely to reported receiving adequate communication compared to patients with a postgraduate degree.

Conclusion: The results suggest that not only do ostomy patients need better communication from clinicians following their surgery, but also, patients with higher educational attainment may be expecting more from their medical clinicians in the way of information and communication.

Key words: provider-patient communication, ostomy, quality health care

Despite years of scrutinization and examination of 'health' and 'health care' disparities in the United States, disparities still persist (Barr 2019; HealthyPeople.gov 2020; IOM 2001a) and endure across the life course (Brown et al. 2016; Ferraro, Shippee, and Schafer 2009). The prevalence of health disparities in the United States is well documented (Barr 2014; Braveman, Kumanyika, Fielding et al. 2011; Budrys 2017; Katz, Chateau, Enns et al. 2018; Peck and Denney 2012; Smedley, Stith and Nelson 2003). However, there is debate over the definition of health disparities in the literature. According to the U.S. Department of Health and Human Services' *Healthy People* (2020), health disparities are:

> *"... a particular type of health difference that is closely linked with economic, social, and/or environmental disadvantage. Health disparities adversely affect groups of people who have systematically experienced greater social or economic obstacles to health based on their racial or ethnic group; religion; socioeconomic status; gender; age; or mental health; cognitive, sensory, or physical disability; sexual orientation or gender identity; geographic location; or other characteristics historically linked to discrimination or exclusion"*

The National Institutes of Health (NIH) defines health disparities as "differences in the incidence, prevalence, mortality and burden of diseases and other adverse health conditions that exist among specific population groups" (Braveman et al. 2011:S149). The controversy over the various definitions of health disparities refers to whether the definition should refer only to differences in health outcomes for disadvantaged individuals or also imply an injustice is present (Braveman et al. 2011; Braveman 2014a); this controversy is ongoing (Braveman 2017). The absence of a unified definition of 'health disparity' has likely contributed to the lack of progress in ameliorating them. Notably, the definitions offered by *Healthy People* and the NIH do not reference health care services nor differences in treatment or delivery of care (Berkowitz and McCubbin 2005). Scholars have since recognized the need to focus on disparities within the healthcare system, termed 'health care disparities,' which are defined as inequalities that occur

within the health system (ISI Language Solutions 2020) and refers to a number of factors impacting individual health, such as health insurance status, health care accessibility, and health care quality (Artiga, Orgera, and Pham 2020).

The current article focuses on the quality of health care. Quality health care is one of three main goals of the United States' healthcare system (Budrys 2016). Quality of health care refers to "the degree to which health care services for individuals and populations increase the likelihood of desired health outcomes and are consistent with current professional knowledge" (Agency for Healthcare Research and Quality 2018). Other elements of health care quality include effectiveness, efficiency, equity, patient-centeredness, safety, and timeliness (Agency for Healthcare Research and Quality 2018). Lower quality health care has been cited as a reason why health disparities exist, and this finding holds true even when accounting for health care access (Smedley et al. 2003).

In the current study, I investigate the quality of health care by examining medical clinician[3] communication with a patient group that is under-studied and often marginalized: people with an ostomy. An ostomy is a surgically diverted diseased bowel and/or bladder, which is rerouted to the abdomen for the discharge of bodily waste, and a pouch is placed on the abdomen for bodily waste collection (UOAA 2018). Approximately one million individuals in the United States live with an ostomy, and nearly 100,000 receive an ostomy each year (WOCN 2017). Indications for ostomy surgery are cancer, inflammatory bowel disease (IBD, e.g., Crohn's/colitis), diverticulitis, trauma and other reasons (UOAA 2018).

Ostomy surgery is a life-changing operation. Everyday life, as the patient knew prior to surgery, is gone. Replacing the old way of everyday living is a constant, daily, 24 hours a day,

[3] I use the term 'clinician' as an umbrella term for medical professionals, such as physicians, nurses, ostomy-trained nurses, physician assistants, etc. I will specify which medical professional I am referring to, where applicable.

seven days a week, anxiety-ridden, self-care routine unlike most other medical conditions. Patients have described it as 'difficult' to accept their new way of life and they worry over disclosing the ostomy to others (Anne Kjaergaard Danielsen et al. 2013). Several qualitative studies have examined ostomy patients' experiences in their everyday lives (Claessens et al. 2015; A. K. Danielsen, Burcharth, and Rosenberg 2013; Diebold 2016), but literature on ostomy patients' health outcomes from a quantitative perspective is lacking, particularly regarding interactions with medical clinicians after ostomy surgery. For instance, qualitative studies have described what living with an ostomy is like for patients (Claessens et al. 2015; Anne Kjaergaard Danielsen et al. 2013; Diebold 2016), and how living with an ostomy negatively affects quality of life (Erwin-Toth 1999; Grant et al. 2011; Popek et al. 2010), and results in feelings of anxiety (Richbourg, Thorpe, and Rapp 2007), and shame (Colman 2014; Diebold 2016). One quantitative study examined ostomy patients' quality of life based on contact with an ostomy care nurse (Aronovitch, Sharp, and Harduar-Morano 2010), and another quantitative study analyzed perceptions of quality of care for an ostomy outpatient clinic in Sweden (Persson et al. 2005). In the Sweden ostomy patient study, Persson and colleagues (2005) found that the majority of respondents were dissatisfied with the quality of ostomy care they received. Recent studies support this finding in general/non-ostomy specific healthcare settings (Abadel and Hattab 2014; Batbaatar et al. 2016).

Overall, research on ostomy patients' health outcomes tends to focus on patients' knowledge, skills or adjustment relating to the type of ostomy care instruction they received at the hospital, such as educational materials on how to clean and care for their ostomy, video tutorial, verbal instruction, or a combination (Colwell and Gray 2007; Crawford et al. 2012; Haugen, Bliss, and Savik 2006; WOCN 2017). No known studies have examined ostomy

patients' experiences at the hospital with medical clinicians from a sociological perspective. The current study addresses this gap in our understanding of ostomy patient experiences, and addresses questions not yet answered, such as whether ostomy patients receive quality medical clinician communication in order for patients to feel prepared to care for their ostomy once at home, and whether there are differences in the quality of communication by ostomy patients' demographic characteristics. I examine the quality of medical clinician communication through the lens of patient-centered care (PCC), which is medical care that respects patients' "preferences, needs, and values" (IOM 2001a:3). I discuss how PCC is in direct contrast to conceptualization of the medical encounter given by Talcott Parsons' (1902-1979), an American sociologist and a major figure in medical sociology. I also provide a detailed background on the medical encounter and the various types of interactions and social roles that medical clinicians and patients exhibit during medical encounters.

THE MEDICAL ENCOUNTER

The medical clinician-patient encounter is an important component of patient health outcomes. A medical encounter is a brief interaction between a medical professional and a patient seeking care in an effort to treat patient ailments. In the past, the medical encounter transpired as home visits from the local physician (Starr 1982), while today, the medical visit is generally conducted in-person at a brick-and-mortar location or using online telemedicine technologies. Even though digital health technologies are becoming used more now than in the past (Lupton 2014), particularly during the current global health pandemic (Koonin et al. 2020), the in-person medical encounter at a brick-and-mortar location is currently still the main mode of delivering healthcare services (Dillard 2020; St. Luke's Health 2020).

The medical encounter encompasses 14 different elements, from preparing the room environment, assessing the patient, to closing the interview (Goold and Lipkin Jr. 1999); these 14 elements are generally achieved within an average of 17-minutes (Shaw et al. 2014). During this brief exchange between medical clinician and patient, a couple of complex processes occur, such as (a) negotiations of *control and influence* in the medical encounter between clinician and patient, and (b) *expectations* of each other's performance in the encounter. Each of these processes help to explain the interaction between clinician and patient.

Control and Influence in the Medical Encounter

Negotiations of control and influence in the medical encounter are best depicted in Roter and Hall's (2006) doctor[4]-patient relationship typology (Figure 2.1). This typology demonstrates four different interaction types between doctor and patient and the level of influence and control each exhibit in the medical encounter. The four types of interactions are: (a) paternalistic, (b) consumerist, (c) mutuality, and (d) default. Talcott Parsons (1951) was a strong proponent of the of the paternalistic encounter type, which is discussed first.

[Figure 2.1 here]

Paternalistic. The paternalistic encounter type demonstrates high-physician control and influence and low-patient control and influence, which means that doctors direct the medical visit and patients are passive participants. This encounter type represents Parsons' (1951) influential conceptualization of the doctor-patient relationship. In order to understand how Parsons conceptualized the doctor-patient relationship, we must first understand his worldview

[4] Parsons wrote in the 1950s and used the term 'doctor' to refer to physicians, which is now an outdated term (Markel 2011; Weiss 2019). Terminology has changed over time due to the nature of health care delivery today—unlike in the past, there are now many other medical providers that see and assess patients, such as physician's assistants and nurse practitioners (Light and Levine 1988; Vinson 2016). I will use the term 'doctor' when referring to Parsons' work and Roter and Hall's typology.

and how it influenced his position on the doctor-patient interaction. Parsons was born in 1902[5] in the United States, and was a structural functionalist, which was a dominant theoretical approach between the 1930s and 1970s in the U.S. (Appelrouth and Edles 2016). Functionalist's view society as "systems within systems;" which is a system of interrelated parts working together toward a common goal or "for the good of the system" (Appelrouth and Edles 2016:347). Similar to how a human body functions with different organs working together for the overall function of the body, a society is functional when all of its "parts" (e.g., economy, family, government, healthcare, etc.) work together. When one part of the system is dysfunctional, the whole system is dysfunctional. As each entity of a society performs an expected role (i.e., "sets of obligations" (Appelrouth and Edles 2016:352)), the whole system remains functional. For example, a parent's role in society is to care for children, or a professor's role in society is to educate pupils. Thus, in the medical encounter, the function or role of doctors was to be the authoritarian in the encounter, directing the visit, and the function or role of patients was to listen to "what the doctor orders" and follow directives, without questioning the authority figure. I discuss this role differential below.

To Parsons (1951), as a functionalist, illness was considered dysfunctional for society to run smoothly, and patients were considered "deviant" due to sick individuals not being able to be fully functional and contributing members of society (Lupton 1997). Deviance is defined as "non-normative beliefs, behaviors, and identities" in a society (Worthen 2016:4). In response to this phenomenon, Parsons argued that doctors and patients have institutionalized roles to perform

[5] At the time of Parsons writing, doctors held a unique power position in society with high authority (Starr 1982). Parsons maintained that doctors held "high levels of technical competence" (Parsons 1951:434), and had a "superiority to his fellows" (p. 435). Because of doctor's skills, knowledge, and unique status position, doctors were afforded high levels of prestige in society (Starr 1982). A recent study showed that medical doctors' prestige differs based on where their medical training took place (Jenkins 2020); U.S. trained medical doctors were afforded more prestige, more resources, and more opportunities than their counterparts who were trained outside of the U.S.

in order to maintain a functional social system. He coined this scenario the "sick role." While critics of the sick role discuss several flaws with the concept (Heidarnia and Heidarnia 2016; Levine and Kozloff 1978; Wolinsky 1988), Parsons outlined four expected and institutionalized roles that doctors and patients should adopt. The first expectation is that the sick individuals should not be held responsible for being ill. They are exempt from performing their social roles, but this "exemption requires legitimacy…and the doctor often serves as a court of appeal as well as a direct legitimatizing agent" (Parsons 1951:436). That is, doctors are the sole provider of legitimizing a patient's illness. Doctors are considered a "gatekeeper" for patients to enter into the sick role and exit out of the sick role. The second expectation is that the sick individual should not be expected to get well on their own or "by an act of decision or will" (Parsons 1951:437). Sick individuals are recognized as not being responsible for their conditions and need to be cared for through therapeutic means (i.e., a medical doctor). This aspect is important in the acceptance of patients seeking help in order to get well again and return to society. The third expectation is that sick individuals must recognize that illness is undesirable, and they are obligated to want to get well again. Although, to Parsons, most illnesses were "psychosomatic" (i.e., caused by a mental factor), which motivates individuals to avoid fulfilling their social roles, in general (Lupton 1997:567). The sick individual may enjoy the temporary exemption from social responsibilities, and they may put themselves into harms way because of the desire to avoid fulfilling social roles and responsibilities. Parsons maintained that the motivation to avoid responsibilities was likely due to "unconscious wishes," driving individuals to unnecessarily exposing themselves to an illness or injury (Lupton 1997:567). Thus, there is a balance of motivations here between enjoying the exemption from social responsibilities and getting well again (Parsons 1951). The last expectation that Parsons outlined explains that sick individuals

must seek "technically competent help," (i.e., a medical doctor) and they must cooperate with the doctor's directives (i.e., adherence). They must do this so that they get well again and return to society in order to fulfill their societal social responsibilities (Parsons 1951:437). Parsons argued that doctors were to act as social control agents for society, restoring sick individuals back to a healthy state and returning them back to society in order to be productive members of society. Doctors were able to exercise this authority because their authority was embedded in their long-standing professional status and prestige in society (Conrad 2007; Freidson 1970; Starr 1982). We see this authority in practice when universities require a sick student to provide a "doctor's note" in order to officially excuse a class absence.

The roles and expectations outlined in the sick role concept depict Parsons' conceptualization of the power differences between doctor and patient. Parsons viewed the relationship as asymmetrical and paternalistic in nature (Williams 2005). The authoritarian doctor holds a high degree of power, control and influence in the encounter, and the patient as subordinate in the relationship, holding a low degree of power, control and influence (Parsons 1951; Roter and Hall 2006).

A key element to paternalistic medical interactions is that patients do not have the necessary or relevant medical knowledge to treat themselves and patients are situationally dependent on clinicians' medical expertise. This element, however, is changing in more recent years with the advent of direct-to-consumer pharmaceutical advertising (Ventola 2011), increased access to and use of online health information (Hale et al. 2014; Seçkin 2020) and digital health technologies (Lupton 2014), and increases in patient health literacy (Miller 2016; Sorensen et al. 2012). The increased use of digital health and access to online health information allows patients to not only develop knowledge relevant to their ailment, but also "maintain health

and counter illness" (Fox, Ward, and O'Rourke 2005:1299; Shaw and Baker 2004). As a result of changes in patients' medical knowledge, paternalistic medical encounters are becoming less prominent than in decades past (Bertakis et al. 2009; McCormack et al. 2011; Street et al. 2007). Paternalistic encounters are also a clear departure from other types of doctor-patient interactions, such as the consumerist encounter type.

Consumerist. The second doctor-patient encounter type that Roter and Hall proposed is the consumerist interaction. The patient as a consumer in healthcare originated from the development of consumerism in the 1960s (Reeder 1972), when a number of consumer activist groups emerged to advocate for general consumer safety, among other issues (Stole 2015). Consumerism was theorized by Thorstein Veblen in the late 1800s (Trigg 2001) in his influential work on conspicuous consumption, which holds that individuals' patterns of consumption are influenced by consumption patterns of individuals with higher socioeconomic statuses. As Veblen's theory pertains to medicine, studies show conspicuous consumption occurs in healthcare, such as 'cosmetic surgery tourism' (Masi de Casanova 2007:1) when patients travel to another country for cosmetic surgery at a lower cost. We see conspicuous consumption in healthcare through the doctor-patient typology consumerist, modeled by Roter and Hall (2006).

A consumerist doctor-patient encounter reflects similar consumeristic interactions to, for instance, shopping around to buy a car or house maintenance services. Similar to these interactions, the exchange between doctor and patient features a "marketplace transaction" (Roter and Hall 2006:27) where doctors sell preventative and noncurative services, such as annual examinations, and patients can shop around for their medical provider. In this encounter type, there is high-patient control and influence, with patients directing the medical visit, and low-clinician control and influence, with clinicians acting more of a technical consultant and

accommodating patients' requests. Generally, higher-educated patients and younger patients are most likely to adopt the consumerist approach in the medical encounter (Roter and Hall 2006:32).

Notably, during the consumer movements, a shift occurred in medicine from a purely curative focus of health care to a preventative focus (Roter and Hall 2006). This shift prompted patients to become more of a consumer of healthcare services than merely passive participants (Roter and Hall 2006). Healthcare consumerism became even more prominent as many patients began taking an active role in the care they received (Tomes 2006). This phenomenon continues to shift (Lynch 2018; Shim 2010; Vinson 2016), especially with patients wanting more access and transparency from medical providers (Gallegos 2018), as digital health technologies grow in importance and shape the relationship (Jenkins and Hernandez 2020; Lupton 2016), and as patient-centered care becomes increasingly important in health care (Aboumater 2013; IOM 2001a).

Mutuality or Patient-Centered. The third typology that Roter and Hall proposed is the mutuality medical encounter type (also known as patient-centered, or collaborative), which is considered to be the optimal doctor-patient exchange because both parties are committed to working together using their respective strengths and resources (Goold and Lipkin Jr. 1999; Roter and Hall 2006). There is a meaningful interaction between doctor and patient where both parties' perspectives are being heard and appreciated (Roter and Hall 2006). For example, during a medical visit, a doctor may ask the patient what he/she/they think about the treatment options that the doctor offered. The patient may counter with something like, "yeah, or what about…" and then pros and cons are discussed in an open exchange. This example of a collaborative and reciprocal exchange not only allows for both participants to have their voices heard, but also, this

encounter type becomes overall more productive for both participants. In this exchange type, it is then required for both patients and doctors to hold similar control and influence, which is a deviation from traditional, paternalistic encounter types.

Patient-centered care (PCC) was formally recommended in 2001 by the Institute of Medicine (IOM)[6]. PCC considers "patients' needs, perspectives, and individual experiences; provision of opportunities to patients to participate in their care; and enhancement of the patient-clinician relationship" (Epstein and Street 2007:1). The attention on PCC came into sharp focus following a series of concerns in the late-1990s regarding patient safety describing an alarming number of patient deaths due to preventable medical errors (Donaldson 2008; IOM 2001b). After a series of congressional hearings, a subsequent report was released, *Crossing the Quality Chasm*, which focused on improving health-care quality (IOM 2001a). *Chasm* outlined six aims with one aim specifically emphasizing that health care should be patient-centered. After these reports were released, hospitals throughout the United States implemented new patient safety and care measures (Leape and Berwick 2005) and considerable efforts have been made to provide PCC throughout the nation since that time (Donaldson 2008).

While PCC has been conceptualized and labeled in various ways, such as mutuality, collaborative or participatory, the general consensus is that PCC consists of communication between clinician and patient aimed to include the patient's perspectives and involve the patient in decision making (Street 2013). PCC has since been widely recognized as an important component in considering patients' desires, values and preferences when making treatment decisions (Bertakis, Franks, and Epstein 2009; IOM 2013). When PCC is directly measured, researchers generally use a validated scale from the Agency for Healthcare Research and Quality

[6] IOM has been renamed to Health and Medicine Division (HMD), a division of the National Academies of Sciences, Engineering, and Medicine (the National Academies).

(2018), which is part of the U.S. Department of Health & Human Services. The specific questions on this validated and widely used 6-item scale, ranging from 0-100, are: (a) your [insert nurse or physician] explained things in a way that was easy to understand, (b) your [insert nurse or physician] listened carefully to you, (c) your [insert nurse or physician] treated you with courtesy and respect, (d) your [insert nurse or physician] seemed to know important information about your medical history, (e) your [insert nurse or physician] showed respect for what you had to say, (f) your [insert nurse or physician] spent enough time with you. The benefits of PCC have been examined in various medical contexts, such as during primary care and specialists' office visits, as well as during hospital stays, which is the context I focus on in the current study. While I do not measure PCC directly in the current study, I use PCC has a reference for what medical interactions should encompass.

Default. The last encounter type of Roter and Hall's (2006) typology is the default interaction between doctor and patient. The term 'default' is misleading because this encounter type rarely occurs. The default encounter refers to low-patient control and influence and low-physician control and influence. During this type of exchange, both parties have defaulted and acquiesced their control in the encounter and neither party is taking an active role in the interaction. Their expectations of each other are at odds or there is a dysfunctional standstill between them. The patient may feel frustrated, angry or untrusting, and will leave the care of that medical provider because of the patient's frustration or unmet expectations.

Expectations in the Medical Encounter

Each participant in the medical encounter brings with them expectations of the others' performance. The status characteristics theoretical (SCT) framework helps to explain this process. SCT is a component of the expectation-states framework, which shows the importance

of how a status-organizing process of prestige and power emerges during interactions (Berger, Cohen, and Zelditch 1972). Expectations are an important aspect of social interactions because each individual has performance expectations of the other, which influences how they relate to one another. Performance expectations arise from previously held beliefs about the status characteristics that people possess, such as certain proficiencies or a physical characteristic. Expectations based on external status differences arise from prior beliefs about the different status characteristics that people hold (Berger, Rosenholtz, and Zelditch 1980).

There are two types of status characteristics: specific and diffuse. *Specific* status characteristics encompass proficiencies, abilities and achievements that are relevant to the interaction (Berger et al. 1972), such as a patient's ability to communicate with their clinician during a medical visit. On the other hand, *diffuse* status characteristics refer to individuals' characteristics, such as race, gender or age (Burke 2006). Diffuse is a status characteristic "from which one infers general assumptions" about the person (Berger et al. 1972:242). There is a higher expectation assumed of individuals with higher-status characteristics, and a lower expectation assumed of individuals with lower-status characteristics.

The level of participation within an interaction is dependent on a person's status characteristic (Berger et al. 1972). For example, non-whites tend to act differently with other non-whites than when they are in the company of whites; similarly, women act differently with other women compared to when women and men interact (Berger et al. 1972). Individuals of the same status characteristic produce an "equal exchange" (Berger et al. 1972:488) because their status characteristics would cancel each other. For example, a white woman interacting with another white woman would produce an exchange that is equal, following SCT.

According to SCT, suggestions from an individual with a higher-status are more likely to be viewed as favorable compared to suggestions from someone with a lower-status (Burke 2006). SCT applies to strangers, acquaintances, and more intimate relationships (Berger et al. 1972), but also it applies to clinicians and patients (Peck and Conner 2011). Applying SCT to the clinician-patient interaction, both participants bring expectations of the other, which shapes their interaction. During the status-organizing process, it becomes evident that clinicians hold high status and influence and patients hold less status and influence because, as Parsons argued, patients are "not the best judge of their own needs" (Parsons 1951; Starr 1982:5). As such, both clinicians and patients perform their roles within the medical encounter in accordance with their level of status.

There are practical implications of this theory for patient outcomes. For example, Cooper et al. (2003) found that encounters with a same race physician and patient (i.e., race-concordant, e.g., white physician with a white patient) lasted longer than race-discordant encounters (e.g., white physician with a non-white patient). Shorter medical visits are associated with fewer preventative measures being taken, and patients feeling less ease in discussing ailments (Roter and Hall 2006). Additionally, Peck and Conner (2011) found that when race and gender status differences were present in a medical interaction, the encounter resulted in a physician-centered exchange (e.g., paternalistic). Finally, Miller and Peck (2019) found that when race status differences were present in medical interactions (e.g., white physician with a non-white patient), patients of color were more likely to experience physician communication in the form of microaggressions, which are communications that are subtle, verbal or non-verbal insults directed toward racial minorities, and other marginalized groups (Nadal 2013; Pierce et al. 1977; Sue 2010).

THE ROLE OF CLINICIAN COMMUNICATION IN HEALTH DISPARITIES

Decades of research suggests that medical clinician communication has tangible consequences for patients, both positive and negative. Clinician communication is associated with patients' feelings of control in the encounter (Epstein et al. 2005), patient satisfaction (Batbaatar et al. 2016; Ha, Anat, and Longnecker 2010; Peck and Denney 2012), patients' understanding of medical information (Epstein and Street 2007; Schinkel et al. 2016), patient trust (Aragon et al. 2007) and adherence to treatment directives (Young et al. 2017). Deficient medical clinician-patient interactions can lead to negative patient health outcomes, such as microaggressions (Miller and Peck 2019; Sue 2010), misdiagnoses (Singh et al. 2007; Zolnierek and Dimatteo 2009), and impact treatment adherence rates (Street 2013).

Studies show that clinicians communicate with patients differently based on patients' demographic characteristics, such as race/ethnicity, gender, age and socioeconomic status. This difference in communication contributes to health disparities (Artiga et al. 2020; Barr 2019; Cooper et al. 2012).

Race/Ethnicity Health Disparities

People of color have historically been treated differently than whites in many aspects of social life. Differential treatment has occurred on college campuses, the criminal justice system, and even at a local Starbucks when two black men were arrested for simply having a meeting. These examples are not new. Racism has a long history in the United States and still persists (Bobo 2017; Hall and Fields 2015; Inkeep 2021; Phelan and Link 2015; Smedley and Smedley 2012). The differential treatment of people of color is deeply embedded in American culture. While overt racism is less common today, racism continues to exist in less explicit forms. This less explicit form of racism, called implicit bias or color-blind racism (Bonilla-Silva 2014), is an

unconscious attitude or stereotype that impacts our decisions, actions, and understandings (Staats 2014), occurs in everyday life and also within the healthcare system (Cooper et al. 2012; Penner et al. 2016; Sacks 2019; Smedley and Smedley 2012; Smedley, Stith, and Nelson 2003).

A large body of evidence demonstrates that racial and ethnic minorities are treated differently in the healthcare system, specifically the medical encounter, which contributes to racial health disparities (Cooper et al. 2012; Peck and Denney 2012; Roter and Hall 2006; Street, Gordon and Haidet 2007). For example, black patients are often given less medical attention (Barkan 2017), poorer communication from medical clinicians and shorter medical visits (Cooper et al. 2012; Roter and Hall 2006), as well as fewer recommendations for medically advisable treatments and procedures for a range of illnesses compared to white patients (House 2015; Smedley et al. 2003). Fewer recommendations for medically advisable treatments hold true even when diagnoses, insurance coverage, and access are the same as whites (House 2015).

Cooper et al. (2012) argue that the differential treatment of black and other patients of color is likely because of implicit bias. Bias may reflect conscious or unconscious biases (Cooper et al. 2012). Implicit biases may be exhibited in clinicians' nonverbal communication to racial and ethnic minority patients compared to white patients, such as excessive blinking (indicating anxiety), minimal eye contact (indicating aversion), closed-off postures (indicating avoidance) (Smedley et al. 2003:162). Furthermore, data show that clinicians hold a number of stereotypes about black patients which impacts patient health (Cooper et al. 2012; Ford et al. 2019; Marcelin et al. 2019; Sacks 2019). For example, studies have shown that clinicians perceive that black patients will not adhere to clinicians' assessments (Cooper et al. 2012; Lutfey and Ketcham 2005), or clinicians make assumptions about black patients' intelligence, education levels, and drug and alcohol use (Smedley et al. 2003). One study showed clinicians' communication style

differed with patients that clinicians perceived as better communicators and were more contentious with black patients whom they perceived as worse communicators (Street et al. 2007).

Gender Health Disparities

Gender health disparities are often a result of socioeconomic conditions that lead to negative health outcomes (National Research Council 2014) and are perpetuated by sexism (Barkan 2017). Health disparities by gender are seen in women experiencing differences in obtaining healthcare services compared to men (Peck and Denney 2012), differences in health outcomes (National Healthcare Quality Report 2010), morbidity rate differences (World Health Organization 2016), and income differences (e.g., gender pay gap) which impacts women's health. Violence against women is also another predictor of women's health (Barkan 2017; Crenshaw 1991; National Academies of Sciences 2017). Other significant inequities that contribute to gender health disparities must be understood from an intersectionality perspective because gender disparities often stem from the accumulation of socioeconomic disadvantage. The accumulation of socioeconomic disadvantage is especially evident for African American women, which was tested using the "weathering hypothesis" (Geronimus 1992; Geronimus et al. 2006). The weathering hypothesis posits that "[b]lacks experience early health deterioration as a consequence of the cumulative impact of repeated experience with social or economic adversity and political marginalization" (Geronimus et al. 2006:826). The cumulative health impact of inequalities is grounded theoretically using the cumulative inequality (CI) theory. Central to CI is how the accumulation of risks and opportunities across the life course contribute to an individual's life chances (Burge and Street 2010; Ferraro et al. 2009). The CI theory "privileges

gender differences in the accumulation of inequality by noting the distinct processes for men and women that lead to inequality" (Ferraro et al. 2009:416).

In addition to the above factors contributing to gender health disparities, the interaction between patients and medical clinicians also plays a role. Studies show that women are differentially treated in the medical encounter by clinicians compared to men (Bertakis et al. 2009; Grace 1995; Roter and Hall 2006; Sacks 2019). For instance, clinicians are more likely to ignore women's medical ailments or negate their pain experience compared to men (Grace 1995; Roter and Hall 2006); women patients report men clinicians are "condescending and dismissive of their health concerns" (Barkan 2017:140). Interestingly, studies show that women clinicians are more patient-centered with patients than men clinicians (Bertakis 2009; Roter and Hall 2015).

Furthermore, women patients are generally provided with more medical information from clinicians than men, due to women asking more questions during the medical visit, but the terminology used is generally less technical with women compared to men, which some scholars argue is because of sexism (Roter and Hall 2006). Finally, a recent study found that black middle-class women experience race and gender discrimination in healthcare settings due to biases and stereotyping, such as being perceived as "angry, loud, promiscuous" (Sacks 2019:3). The women in this study (Sacks 2019) described that they find themselves with their guards up in anticipation of discrimination as they enter into a medical encounter.

Age-related Health Disparities

Research on age-related health disparities show that disparities persist across the life course and this research has recorded several notable findings (Burge and Street 2010; Ferraro et al. 2009; Gorman and Read 2006; NIA 2021; Settersten and Angel 2011). For example, early life

financial concerns have impacted levels of disability, and the prevalence of comorbidities across the life course (Settersten and Angel 2011). Economic disadvantages contribute to worse health for women in later life, considering that women live longer than men (Gorman and Read 2006; National Center for Health Statistics 2017; Settersten and Angel 2011). These disadvantages follow women across the life course and continue as women make life decisions, such as whether or not they should enter into an assisted living facility (ALF) and which facility they can afford. The type of ALF is associated with an individual's well-being (Street and Burge 2012), and impacts social relationships (Burge and Street 2010). Examining the cumulative effect of disparities across the life course is essential to understanding how economic, behavioral, and social factors impact health later in the life (Braveman 2014b).

The National Institute of Aging (NIA 2021) *Strategic Directions* report for 2020-2025 outline several goals to address age-related disparities, such as biological or disease-specific problems, economic related issues, behavioral and social issues, all of which contribute to age-related health disparities, which they define as "differences in any health-related factor – disease burden, diagnosis, response to treatment, quality of life, health behaviors and access to care." One aspect of the goals outlined in this report include researching age-related issues in health care quality and biases, which encompasses the way that medical clinicians interact with the aging population, contributing to health disparities.

Studies focused specifically on age-related disparities in the medical encounter are lacking in more recent years, and the studies that have examined this topic have produced contradictory findings. For instance, Roter and Hall (2006) described studies that found physicians being reluctant treating older patients, and communication styles differed between older and younger patients, such as an easy-going exchange between physicians and younger

patients, and interactions with older patients are described as physicians using "baby talk" and being less responsive to older patients' mention of psychosocial issues compared to younger patients (Roter and Hall 2006:59). In contrast, Peck (2011) found that older patients were more likely to experience patient-centered communication from physicians. These contradictory findings are likely due to sample differences; the physicians who took part in Peck's (2011) study were trained in gerontology medicine. Roter and Hall conclude that the difference in treatment in the medical encounter between younger and older patients stem from ageism, and stereotyping, and contribute to age-related health disparities.

Socioeconomic Status Health Disparities

Socioeconomic status (SES) plays an important role in health disparities for marginalized and disadvantaged populations. SES is generally measured by an individual's educational attainment, income, and/or occupational prestige (Barr 2019). SES is linked to many barriers that negatively impact health (House 2015; Link and Phelan 2010) and has been described as a "fundamental cause of disease" (Link and Phelan 1995). People with lower-SES have "poorer life-course trajectories" (House 2015:66), have higher mortality and morbidity rates (World Health Organization 2016), and experience high rates of psychosocial and behavioral risk factors, and overall declined health because of their lower-SES position (House 2015). In the ostomy patient population, lower-SES is also associated with fewer reversals of ostomies (Zafar et al. 2016).

Although there are few recent studies investigating SES and health disparities as it pertains to the medical encounter, studies demonstrating disparities in clinician communication do exist. For example, lower-SES patients tend to receive lower quality information from physicians, and are more likely to experience physician-centered (i.e., paternalistic) encounters

compared to higher-SES patients (Peck and Denney 2012; Roter and Hall 2006). Interestingly, other studies have found that patients with lower income generally rate clinicians' communication as high (i.e., more favorable), and those with lower education tend to have high trust in their clinician (Coats et al. 2018). Furthermore, a 2013 study in Canada examined discrimination as it pertained to perceived patient SES when patients called for medical appointments (Olah, Gaisano, and Hwang 2013). They found that patients with a perceived lower-SES were less likely to be offered a medical appointment than higher-SES individuals.

While there is some evidence of health care disparities in the medical encounter as they pertain to SES, scholars argue that examining SES health disparities independently is insufficient (Brown et al. 2016; Wilson et al. 2019). They argue that in order to understand health disparities, more broadly, studies need to use an intersectional perspective. Intersectionality considers how multiple identities intersect and produce social inequities (Crenshaw 1991; Monrouxe 2015). For example, poor black younger women are shown to have higher morbidity, obesity, and even "relatively early death" (House 2015:84) compared to most other populations. Studying these variables separately would obscure important factors contributing to health inequities.

Thus far I have discussed what the medical encounter encompasses, how clinician-patient communication relates to patient health outcomes in general patient populations, and the role of clinician communication in health disparities by patient demographic characteristics. Now I turn to ostomy patients' experiences with health disparities and the research questions being examined.

RESEARCH QUESTIONS

Ostomy-related health disparity studies have shown differences in health outcomes for racial minority patient groups after ostomy surgery, such as longer hospital stays and higher

complication rates (Sharp et al. 2020), higher risk for readmission to the hospital (Chu et al. 2015; Gunnells et al. 2016), longer wait times for ostomy reversal surgery (Gunnells et al. 2018), and lower rates of ostomy reversal (Zafar et al. 2016). Other ostomy-specific health disparity research has focused on difficulties with paying (Coons et al. 2007), and access to ostomy supplies in low-middle-income countries (Muzira et al. 2018).

No known studies have examined ostomy-related health disparities as it pertains to the medical encounter, specifically clinician communication. Thus, I investigate the following open research questions: (1) Do ostomy patients receive quality communication from medical clinicians while at the hospital? (2) Does the quality of communication from medical clinicians differ by ostomy patients' demographic characteristics?

METHODS AND DATA

Sample and data collection

I use original data that I collected in the summer and fall of 2017 from ostomy patients. Using a non-probability method, I recruited participants from ostomy support groups throughout the United States who were affiliated with the United Ostomy Associations of America (UOAA). I sent emails to the managers of 60 ostomy support groups affiliated with the UOAA. Additionally, participants were recruited through Facebook, Twitter, and Reddit, and I posted the questionnaire link on UOAA's discussion board. Hard copy questionnaires were mailed as requested. 94% filled out the questionnaire online and 6% via hardcopy.

Respondents were eligible to participate if they had an ostomy, were aged 18 or older, and could read and write English well enough to complete the questionnaire. Respondents signed online informed consent forms prior to accessing the questionnaire. The questionnaire was self-administered and comprised of closed-ended and open-ended questions. The questionnaire was

pre-tested by a University faculty member with an ostomy and advanced doctoral students trained in methodology. The study and methods were approved by the University of Oklahoma, Approval #8040 on 05/04/2017. A total of 359 patients are included in the study. Of the 359 respondents, there are 353 patients included in the current analyses; the six excluded respondents had missing data on one or more of the variables used in the analyses, and analyses of the excluded respondents show that they were similar to that of the overall patient characteristics in the sample.

Variables

Dependent Variables. To measure the quality of clinician communication (RQ1), I examined responses to the following open-ended question, *"Was there anything that the medical staff could have done to make you feel better prepared to take care of your ostomy at home?"* I used open-coding to create general categories that reflected explicit responses. By definition, open-coding is the initial classification of concepts where "data are broken down into discrete parts, closely examined, and compared for similarities and differences." (Rubin and Babbie 2011:625). Important to this process is to create conceptual codes that are drawn from empirical indicators (Grbich 2013:83).

Two researchers with advanced methodology training and experience coding open-ended responses reviewed each response separately. Upon reviewing responses separately, each researcher coded the responses into specified categories using a coding sheet with definitions for each category that reflected clinician communication. Intercoder reliability was computed, in order to analyze whether each coder arrived at a comparable result (Singleton and Straits 2010). The resulting *k* score, which indicates the level of agreement to which each coder arrived at a

comparable result, ranged from 0.46 to 0.99 agreement, which indicates moderate to high agreement. All disagreements were reconciled to achieve 100% agreement.

The final coding scheme consisted of 14 categories (discussed in detail below). One category reflected adequate clinician communication, and 13 categories reflected inadequate communication. If a respondent left no response to this survey question, I coded the nonresponse as an adequate encounter (n=130, 36%) since the respondent did not specify experiencing an inadequacy in his/her/their care. Thus, adequate or high-quality clinician communication reflects a satisfactory or sufficient clinician-patient interaction. Examples of respondents describing adequate communication include: "I received excellent instruction both times…the nurses were professional, kind, and very helpful. I can't say enough good things about them." or "No [there was not anything that the medical staff could have done to make me feel better prepared to take care of my ostomy at home]. Everything was explained while I was still in hospital on a daily basis..."

The remaining 13 categories reflected inadequate or low-quality medical clinician communication. I coded responses as inadequate if respondents wrote a statement about some type of deficiency in the care received. The 13 inadequate or low-quality communication categories were: (1) *attitude,* the clinician said something that hurt the patient's feelings, or they acted in a way that dissatisfied the patient, such as the clinician acted arrogant. An example of this is: "The two nurses with me said 'such a shame, she's so young to have a bag'. Those words are burned into my mind forever! It hurt me badly." Another example of this is: "The ostomy nurse I had was HORRID. She was not helpful and very degrading to me. I left the hospital with no knowledge of my ileostomy nor the appliances."; (2) *see ostomy nurse*, the patient expressed wanting to see an ostomy-trained nurse sooner than they did in the hospital or have an

opportunity to have a follow-up appointment with an ostomy nurse. An example of this is: “Had me meet with the ostomy nurse much sooner than I did.” And another example is: “An ostomy qualified nurse would have helped. My learning was mostly trial and error.”; (3) *lacked knowledge*, patients felt that nurses were not educated enough about ostomy care or were inadequate in their ostomy-care knowledge. An example of this is: “Floor nurses should be better educated/empowered to care for ostomies.”; (4) *products*, patients were not informed of the different type of ostomy appliance products that are available in the marketplace. An example of this is: “Could have shared more information on all the different types of bags and how to help find the right bag for you!”; (5) *pre-operative information*, patients did not receive pre-operative information about their surgery or they wanted more preparation before surgery of what to expect after surgery. An example of this is: “Let me know how hard it would be and let me know refusing surgery was an option.” Another example of this is: “I think I should be taught how to care for an ostomy prior to actually receiving an ostomy.”; (6) *fix complications or issues*, patients expressed wanting to have been told how to fix specifics issues with the ostomy that arose once at home. An example of this is: “It would have been nice to have more information on peristomal skin issues, as well as possible complications. I ended up with a prolapsed ileostomy that needed surgical repair three times, but did not know what it was the first time. It was incredibly frightening.”; (7) *supervise bag change*, patients expressed wanting to have been supervised and instructed on how to change the ostomy appliance before heading home or they wanted more practice changing it with an ostomy nurse. An example of this is: “Have me do it myself [change the pouch] once before leaving the hospital -- even if that meant having me stay a little longer.”; (8) *wrong information*, patients stated that they were told the wrong information from their medical clinician at the hospital. An example of this is: “…The medical staff was

rushed, had little positive to say, put emphasis on the horrendous binder of everything I 'cannot ever' eat or do. (Which I have found out is a load of crap)."; (9) *missing information*, patients were not told all of the information that they wanted or needed regarding caring for the ostomy. An example of this is: "Introduction of more products, talk about binding foods/small portions, warnings on tight clothes/pressure ulcers, instructions on what to carry with me at all times, etc...I've learned most of what I know from online videos and chat rooms."; (10) *support resources*, patients expressed wanting to be told about ostomy support groups that are available or web links to supportive information about the ostomy or to meet with a person who had an ostomy. An example of this is: "Provided info on local or online support groups or websites I could have gone to for guidance and support from other ostomates."; (11) *socioemotional exchange*, patients stated that they did not receive socioemotional support from their medical clinician at the hospital. An example of this is: "I wish the emotional aspects would have been addressed." And another example: "No support, compassion or anything. No one explained how it was going to ruin your intimacy."; (12) *questions*, patients wanted a contact to call if they had any questions once at home. An example of this is: "Having a help line that you can call with questions."; and finally, (13) *hurried*, patients felt that the nurse was hurried, or the patient did not receive overall basic care with regard to their ostomy (feeling as if they were dismissed). An example of this is: "Not been in such a hurry. Sit down and spend time with the patient answering questions in a relaxed and friendly way." And another example, "The ostomy Nurse came in briefly to change my appliance and give me a quick run down on what to do. Never went into details about what happens if there is leakage, precautions to take such as lifting restrictions etc.."

I coded responses and examine clinician-patient communication in two ways for RQ1. The first way is a dichotomous variable that indicates if clinician communication was reported as *adequate or inadequate*. This variable allows me to understand the presence or absence of quality clinician communication during ostomy patients' hospital experiences. However, because I wanted to examine the data more closely to explore inadequate communication; once every response was coded into categories, I found that respondents may have stated that they experienced multiple inadequacies in their care from medical clinicians. As a result, the second variable I examine for RQ1 is a summed indicator of clinician communication. Specifically, I summed the number of categories representing a deficiency in care that each respondent identified in the open-ended responses. As such, individual's responses could be coded using multiple categories. The resulting count variable ranged from 0 (zero) categories of expressed inadequacies to a total of six (6) categories of expressed inadequacies as stated by respondents. Inadequate or low-quality communication from clinicians, then, is represented by one (1) through six (6) categories of inadequacies in their medical interaction (i.e., one category, two categories, three categories and so on, up to six total categories of inadequacies). High-quality communication, or adequate communication, then, is represented by zero (0) expressed inadequacies. Thus, the variable is a count of the categories or types of inadequacies listed by the respondent, not the actual number of inadequacies; A respondent could have listed two deficiencies in medical clinician communication in the same category; thus, multiple deficiencies within the same code are not examined.

For the current article, considering that there is a scarcity of published studies for which to garner understanding on ostomy patients' experiences with medical clinicians, I am interested in examining adequate clinician communication (RQ1) using both the dichotomous variable and

the count variable in order to lay a foundation for understanding what occurs between medical clinicians and ostomy patients after surgery. I use the dichotomous dependent variable to test research question two (RQ2), which investigates the relationship between clinician communication and patient demographic characteristics.

Independent Variables. The independent variables of interest for the *second research question* (RQ2) includes self-reported patient race, gender, educational attainment, and age. Race was coded as white or nonwhite. Gender was coded as man or woman. Educational categories included (1) high school graduate or some high school, (2) Associate degree/trade certificate/some college, (3) Bachelor's degree was completed. Included in this category are some college or some postgraduate work, and (4) postgraduate degree, which entails master's degree, non-medical doctorate and medical doctorate degrees. Age was a continuous variable, which ranged from age 18 to 89 years.

Control Variable. When analyzing RQ2, I control for the number of years since the patient had ostomy surgery in the multivariate model. This variable ranges from one (1) year since surgery, from the time respondents filled out the study survey (2018), to 65 years since ostomy surgery, at the time respondents filled out the study survey (2018).

Analyses

I start by presenting descriptive statistics of the study sample and descriptive statistics for the dependent variables— the dichotomous and the count variable for number of reported inadequacies of care for research question one (RQ1). For RQ2, I present unadjusted bivariate analyses and adjusted multivariate analyses. The dependent variable used in the analyses is dichotomous. As such, I present analyses from log binomial regression models showing the relative risk of an event (e.g., ostomy patients receiving adequate communication from medical

clinicians) on ostomy patient demographic characteristics, and I control for the number of years since surgery. Risk ratios equal to 1 indicate that an event is equally likely to occur in the two groups being studied. Risk ratios greater than 1 indicate that an event is more likely to occur in the first group, and a risk ratio less than 1 indicates that the event is less likely to occur in the first group.

Although it is common to use logistic regression models estimating odds ratios when modeling a binary outcome, odds ratios are hard to interpret and may "produce a biased estimate" (McNutt et al. 2003:941). Risk ratios offer an interpretable and unbiased estimate for the relative probability of an event occurring (Cummings 2009), compared to using odds ratios (McNutt et al. 2003). All analyses were conducted using STATA 15.

RESULTS

Characteristics of the Study Sample

Table 2.1 shows frequencies and percentages of the variables describing the patient sample. There are three hundred and fifty-three (353) ostomy patients included in this study. The sample is largely women (80%) and white (88%), with the majority (83%) having some college or more. More than half (59%) are aged 51 or older, with a mean age of 53 years old. Mean years since ostomy surgery is eight. Ten percent (10%) of the sample had their ostomy surgery outside of the United States; the majority of this subsample had surgery in Canada or the United Kingdom. Forty-two percent (42%) of the sample had to receive an ostomy because of inflammatory bowel disease (IBD), 31% had cancer and 32% had other reasons for ostomy surgery, such as trauma, diverticulitis, and others.

[Table 2.1 here]

Quality of Clinician Communication

Research question one (RQ1) asks whether ostomy patients receive quality clinician communication while at the hospital. Table 2.2 presents descriptive statistics of the quality of clinician communication; specifically, the percentage of adequate and inadequate communication, and the number of reported inadequacies in clinician communication. I found that a little over half of the sample (53%) reported receiving adequate communication (or zero inadequacies) from their medical clinician at the hospital. A little less than half (47%) of the sample reported receiving inadequate clinician communication at the hospital. The number of reported inadequacies ranged from 0 to 6, with a mean just under 1 (.92) and a median of 0.

[Table 2.2 here]

Inadequacies in Clinician Communication

Table 2.3 presents descriptive statistics for the reported inadequacies in clinician communication—the 13 categories of inadequacies. Twenty-percent (20%) of ostomy patients reported experiencing missing information in their ostomy care, and the same percentage (20%) reported wanting information prior to surgery that they did not receive (pre-operative information). The third highest category (12%) was ostomy appliance product choices were not discussed during patients' hospital experiences, and 9% of the sample reported not receiving information on how to fix potential complications or issues that arise with the ostomy appliance.

[Table 2.3 here]

Quality of Clinician Communication and Patient Characteristics

Research question two (RQ2) examines the quality of clinician communication on ostomy patients' demographic characteristics using the dichotomous variable, adequate communication compared to inadequate. As such, Table 2.4 presents both bivariate and multivariate relationships using risk ratios or relative risk (RR) of ostomy patients receiving

adequate medical clinician communication at the hospital. In Model 1, I found that high-school education achieved significance in the bivariate model ($P < .05$). Specifically, the risk ratio was 1.5; thus, patients with a high-school education or fewer years of schooling were more likely to report adequate medical clinician communication compared to patients with a post-graduate degree. This direction of this relationship remained the same in the multivariate model (Model 5) and achieved marginal significance ($P < .10$). The control variable, number of years since surgery, achieved statistical significance at $P < .05$. Patients reported higher quality clinician communication the further back in years the patient had ostomy surgery. Finally, patient race, gender, and age did not achieve significance, which is consistent with the bivariate relationships shown.

[Table 2.4 here]

DISCUSSION AND CONCLUSION

The current study quantitatively investigated the quality of clinician communication with ostomy patients after surgery, which may contribute to ostomy patients' health disparities. Results show that a little over half of the sample rated medical clinician communication as adequate. Inadequate clinician communication was reported by slightly less than half of the patients. Thus, only 53% of ostomy patients reported receiving adequate clinician communication, which is quite low in comparison to other patient samples showing that patients are satisfied with their medical care at high rates. For example, 98% of breast reconstruction patients were satisfied with the interaction with their surgeon (Macadam et al. 2010), and 83% of a general patient population reported moderate satisfaction with their medical care (Krot and Rudawska 2017).

The highest percentage of categories that patients reported as inadequate include not receiving pre-operative information about what to expect after surgery, patients reported experiencing information that was missing in their care, such as not receiving information about diet regimens, or the possibility of physical issues, such as ulcers, and patients reported not being told about ostomy appliance products available to them. The categories of inadequacies in the communication received from medical clinicians is a departure from what patient-centered care should encompass, which includes medical clinicians treating patients with respect, spending enough time with patients, and listening to patients' needs and preferences.

The log-binomial regression models testing the relationship between adequate clinician communication and patients' characteristics show that high school education is significantly related to reported adequate communication in the bivariate model, and marginally significant in the multivariate model. Ostomy patients with a high school degree or fewer years of educational attainment were significantly more likely to report receiving adequate communication compared to ostomy patients with a post-graduate degree. I was not surprised by the results. Studies in the general patient population have found that lower-SES patients rate clinicians' communication as high and have higher trust in their clinician (Coats et al. 2018). The inverse effect of education may be related to levels of patient health literacy. Health literacy is the degree of an individual's ability to "process, and understand the basic health information and services they need to make appropriate health decisions" (Shim 2010:6). Health literacy has been shown to be related to educational attainment and age (Sorensen et al. 2012). Perhaps ostomy patients in the study with lower educational attainment reported receiving adequate clinician communication because of their limited health literacy, suggesting that a limited understanding of health information from medical clinicians may lead patients to assess their care as sufficient. A second, alternative

interpretation of the educational attainment finding may be related to patients' expectations. Studies have documented patients' increased expectations in the care they receive (Lateef 2011), and a growing demand for quality health care (AHRQ 2018). Perhaps patients in the sample with higher education are expecting more from their clinicians.

The findings must be interpreted with limitations in mind. The sample was largely white and female and drawn largely from ostomy support groups. Perhaps white women ostomy patients are more likely to participate in ostomy support groups than other patient populations. A larger sampling of men and non-white ostomy patients would shed some light on differences in hospital experiences. Also, the sample is a nonprobability sample. As such, it is difficult to discern whether the findings can extend to other ostomy patients' experiences with their medical clinicians. I also used a retrospective study design, which may introduce recall bias (remembering a "former state as better or worse than it actually was" (Blome and Augustin 2015:112). Though, emotionally significant events are more likely to be recalled with accuracy compared to more mundane events (Kensinger 2011).

Finally, I measured quality clinician communication using a dichotomous adequate versus inadequate communication variable and included nonresponses to the question, "was there anything else the medical staff could have done to make you feel better prepared to care for your ostomy at home?" in the adequate portion of the variable. By including nonresponses this way, I assumed that the ostomy patient perceived adequate communication from their medical clinician. However, I recognize the possibility of other reasons why patients may not leave a comment, such as feeling incapable of expressing their thoughts, or less willing to answer the question, or being in a hurry to finish the survey. To address this potential limitation, I ran analyses on the patients who did not leave a comment to this question versus those who did. I found no

significant differences in the patient demographic characteristics between those who commented or did not comment. I also analyzed the models using only patients who left a comment about an adequate or inadequate experience and the results did not change substantively; the significant effect for educational attainment was still present for the high school educated or less.

In conclusion, this study demonstrates that medical clinician communication can improve for ostomy patients. Future research needs to assess what is driving patients' perceptions of quality communication, such as the method of instruction received (if any), whether the instruction type helped or hindered patients' abilities to care for their new ostomy, or the hospital where ostomy patients had surgery. A recent study described how resource-deficient medical training environments related to poorer medical training and less supervision for medical doctors who trained outside of the United States compared to medical doctors who trained within the United States (Jenkins 2020). Future research must also investigate ostomy patients' of color experiences with medical clinicians at the hospital. This is a critical open area, and considering the expansive literature demonstrating racial health disparities, this must be a priority for medical sociologists. Finally, future research must examine consequences of clinician communication for ostomy patients, such as ostomy patients' feelings of stigmatization based on their interactions with medical clinicians. By definition, stigma is an "attribute that is deeply discrediting" (Goffman 1963:3), where a person linked with a discrediting attribute may experience rejection, isolation, or discrimination (Link et al. 1997). This is the topic that I turn to next in the dissertation: ostomy patients' experiencing stigmatizing sentiments from medical clinicians.

Tables and Figure for Chapter 2

Table 2.1. Patient Characteristics in the Sample (n = 353)

	N	*%*
Gender		
Female	282	80
Male	71	20
Race		
White	311	88
Non-White	42	12
Education		
Completed H.S. or less	59	17
Completed Associate's	138	39
Completed Bachelor's	97	28
Completed Postgraduate	59	16
Age *(mean= 53 years)*		
18 – 25 years	12	3.4
26 – 35 years	46	13.0
36 – 50 years	86	24.4
51 – 65 years	134	38.0
66 years or older	75	21.2
Years Since Surgery *(mean = 8 years)*		
Non-US ostomy patients in the sample (n = 351)	37	10.5
Reason for Ostomy Surgery		
IBD	150	42.5
Cancer	110	31.1
Other Reasons	114	32.3

Table 2.2. Descriptive Statistics of the Quality of Clinician Communication in Ostomy Patient Care (n = 353)

	N	%
Adequate Communication	187	53.0
Inadequate Communication	166	47.0
Number of Inadequacies		
0	187	53.0
1	69	19.6
2	53	15.0
3	28	7.9
4	13	3.7
5	1	0.3
6	2	0.6
Median		0
Mean		0.92
Standard Deviation		1.22
Minimum		0
Maximum		6

Table 2.3. Descriptive Statistics of the 13 Categories of Medical Clinician Communication Inadequacies (n = 353)

	N	*%*
1. Pre-operative Information	72	20.4
2. Missing Information	72	20.4
3. Products Were Not Discussed	43	12.2
4. How to Fix Complications/Issues	32	9.0
5. Supervise Pouch Change	29	8.2
6. Support Resources	20	5.6
7. Socioemotional Exchange	18	5.1
8. See an Ostomy Nurse	16	4.5
9. Nurse Lacked Ostomy Knowledge	9	2.5
10. Clinician Attitude	6	1.7
11. Wrong Information Given	5	1.4
12. Hurried	5	1.4
13. Questions Left Unanswered	1	0.2

Table 2.4. Risk Ratios of Ostomy Patients' Characteristics on Receiving Adequate Communication from Medical Clinicians (n = 353)

	Model 1 Bivariate	Model 2 Bivariate	Model 3 Bivariate	Model 4 Bivariate	Model 5 Multivariable
Patient Characteristics					
Education (post-graduate degree as reference)					
Completed H.S. or less	1.58*				1.61†
Completed Associate's	1.30				1.36
Completed Bachelor's	1.31				1.35
Race - White		0.87			0.91
Gender - Female			0.92		0.82
Age				0.99	0.99
Control Variable					
Years Since Surgery					1.01*

†p≤.10 *p≤ 0.05; ** p≤0.01; *** p≤ 0.001
NOTE: Numbers are risk ratios.

Figure 2.1. Doctor-Patient Relationship Typologies

	Physician Control	
Patient Control	**Low**	**High**
Low	Default	Paternalistic
High	Consumerist	Mutuality

Source: Roter and Hall 2006

Chapter 3: Marginalization in the Medical Encounter: Ostomy Patients Experiencing Stigmatizing Sentiments from Medical Clinicians

Chapter 3 Abstract

Background: Ostomy stigma negatively impacts the health of people with an ostomy and contributes to health disparities. An ostomy is a surgically diverted bowel and/or bladder, resulting in bodily fluids discharged into a pouch attached to the abdomen. Living with an ostomy has been described as difficult, and produces feelings of shame, anxiety and depression. Medical clinicians[7] are the first line of support for patients; this interaction is important for new ostomy patients.

Objective: To investigate whether ostomy patients experience stigmatizing sentiments from medical clinicians. Stigmatizing sentiments is operationalized as verbal or non-verbal comments or signals from medical clinicians that may contribute to ostomy stigma.

Method: Using two cross-sectional phases of data, conducted in 2017-18 (phase one) and 2019 (phase two), I conducted a nonprobability retrospective study using a triangulation of data (quantitative and qualitative). There are 386 ostomy patients included in the study from Phase One, and 312 ostomy patients included in the study from Phase Two. I analyze three closed-ended questions and four open-ended questions, examining written comments from ostomy patients using thematic analyses.

Results: I found that 10 percent of the Phase One sample experienced stigmatizing sentiments from their medical clinician. A slightly higher percentage (16%) experienced stigmatizing sentiments from medical clinicians in the Phase Two sample. Together, for both phases of data combined, 11 percent of ostomy patients experienced stigmatizing sentiments from their medical

[7] I use the term 'clinician' as an umbrella term for medical professionals, such as physicians, nurses, ostomy-trained nurses, physician assistants, etc. I will specify which medical professional I am referring to, where applicable.

clinician. Topics exibiting stigmatizing sentiments included: clinicians explicitly stating feelings of disgust or showing visible signs of disgust when providing medical care to ostomy patients; clinicians treated the patient as if the medical condition was their fault; clinicians treated ostomy patients as less than human because of the ostomy; and finally, patients described a negative interaction with their clinician because of the ostomy or had an uncaring or rude medical clinician.

Conclusion: Ostomy patients reported being treated negatively from medical clinicians because of their ostomy. Ostomy patients experience stigmatizing sentiments from medical clinicians. The differential treatment that ostomy patients experience in healthcare likely contributes to ostomy stigmatization and impacts ostomy patients' psychosocial adjustment.

Key words: provider-patient communication, ostomy, stigma

Stigma is a pressing social issue that contributes to health disparities and the disproportioned treatment of marginalized groups (Major, Dovidio, and Link, 2018), yet it is a topic that is largely absent from mainstream media. Scholars, however, have been theorizing about stigma and stigma-related mechanisms for decades (Goffman 1963; Kleinman and Hall-Clifford 2009; Major et al. 2018). Stigma has been described as a 'mark' that separates the affected person from others, and links the person to an undesirable characteristic (Jones et al. 1984; Link et al. 1997). A large body of literature has examined stigma-related processes, such as race as a stigmatized status (Cohen 1999; Sacks 2019), obesity stigma (Fruh et al. 2016), mental illness stigma (Kroska and Harkness 2006; Link et al. 2001), cancer stigma (Chapple et al. 2004; Phelan et al. 2013; Shen et al. 2016), substance use stigma (Chang, Dubbin, and Shim 2016), inflammatory bowel disease stigma (such as Crohn's or colitis) (Taft, Ballou, and Keefer 2012), HIV stigma (Li et al. 2007), sexual orientation stigma (Williams and Mann 2017), transgender stigma (Kosenko et al. 2013; Poteat, German, and Kerrigan 2013), and to a smaller degree, ostomy stigma (Qin et al. 2020; Smith et al. 2007). An ostomy is a surgically diverted bowel and/or bladder that allows bodily waste to be rerouted and evacuated through an opening on the abdomen, called a stoma (UOAA 2018).

The current article focuses on an unanswered question in the ostomy stigma literature regarding whether ostomy patients experience stigmatizing sentiments from medical clinicians, which may contribute to ostomy stigma. While decades of research demonstrate the importance of the medical clinician-patient communication to patient health outcomes (Chang et al. 2016; Parsons 1961; Roter and Hall 2006; Sacks 2019; Shen et al. 2016), very few studies exist on how ostomy patients are treated by medical clinicians, and no known studies exist on ostomy stigma based on interactions with medical clinicians. By understanding whether ostomy patients

experience stigmatization in the medical encounter, we can begin to address ostomy stigma and health disparities for this patient population.

BACKGROUND

Ostomy Surgery

More than one million individuals in the United States live with an ostomy, and approximately 100,000 receive an ostomy each year (WOCN 2017). Ostomy surgical rates in the United States are comparable to or higher than other countries. For instance, estimates for individuals undergoing ostomy surgery in China are similar to the United States (Zhang et al. 2018), the United Kingdom has an estimated 100,000 people living with an ostomy (Colostomy Association 2016), and Canada approximates 13,000 ostomy surgeries are performed each year (Recalla et al. 2013). An ostomy is categorized as a disability under the Americans with Disabilities Act (ADA) because of the life-changing nature of eliminating bodily fluids differently and having to wear a prosthetic device (i.e., ostomy appliance) (Gleba and Mueller 2019), and is associated with high morbidity and mortality (Sheetz et al. 2014).

Ostomy surgery is not a new procedure; the first ostomy surgery was recorded in the late-18th century (Cataldo 1999). Indications for ostomy surgery include cancer, inflammatory bowel disease (IBD, such as Crohn's or colitis), diverticulitis, trauma and other reasons. There are several types of ostomies. The three most common include colostomy (surgically diverted colon to the abdominal wall), ileostomy (surgically diverted ileum to the abdominal wall), and urostomy (surgically diverted bladder to the abdominal wall). An individual may have more than one ostomy at one time depending on the medical condition, and the ostomy may be temporary or permanent.

Ostomy surgery is a life-changing operation that replaces the old way of everyday living.

Unlike many other medical conditions, an ostomy appliance requires a constant, daily, self-care regimen. Patients have described their ostomy as 'difficult' to accept their new way of life and they worry over disclosing the ostomy to others (A. K. Danielsen et al. 2013). Patients have reported experiencing high rates of leakages from the appliance (Claessens et al. 2015), which means that bodily fluids leak onto the body or clothing. Several qualitative studies have examined ostomy patients' experiences and health outcomes based on having an ostomy. For example, qualitative studies have described what it is like living with an ostomy (Claessens et al. 2015; A. K. Danielsen et al. 2013; Diebold 2016), how living with an ostomy negatively affects quality of life (Erwin-Toth 1999; Grant et al. 2011; Popek et al. 2010) and alters a patient's body image (Black 2004), results in feelings of anxiety (Richbourg et al. 2007) and shame (Colman 2014; Diebold 2016), but literature on ostomy patients' health outcomes based on interactions with medical clinicians after ostomy surgery is lacking.

For instance, one quantitative study examined ostomy patients' quality of life based on contact with an ostomy care nurse (Aronovitch et al. 2010), and another quantitative study analyzed perceptions of quality of care for an ostomy outpatient clinic in Sweden (Persson et al. 2005). In the Sweden ostomy patient study, Persson and colleagues (2005) found that the majority of respondents were dissatisfied with the quality of ostomy care they received. Recent studies support this finding in general/non-ostomy specific healthcare settings (Abadel and Hattab 2014; Batbaatar et al. 2016). Overall, research on ostomy patients' experiences at the hospital tends to focus on patients' knowledge, skills or adjustment relating to the type of ostomy care instruction they received at the hospital, such as educational materials on how to clean and care for their ostomy, video tutorial, verbal instruction, or a combination (Colwell and Gray 2007; Crawford et al. 2012; Haugen et al. 2006; WOCN 2017). The current study examines

quality of care for ostomy patients by investigating ostomy patients' experiences with medical clinicians, particularly focusing on stigmatizing messages (verbal and non-verbal communications) that patients receive from medical clinicians regarding the ostomy.

Stigma Definitions and Conceptualizations

Similar to socioeconomic status being referred to as a "fundamental cause of disease" by Link and Phelan (1995), Link and colleagues recently suggest that stigma be considered as a fundamental cause[8] of disease as well because it "affects multiple disease outcomes" (Major et al. 2018:53). The term 'stigma' originated from the ancient Greeks (Corrigan 2002) to refer to a person 'blemished;' a "bodily sign designed to expose something unusual and bad about the moral status" (Goffman 1963:1). Even though stigma was first introduced centuries prior, modern scholarly stigma research owes a great deal to Erving Goffman (1922-1982), a seminal figure in the field of sociology. Goffman defined stigma as "an attribute that is deeply discrediting," which makes the stigmatized person "not quite human" (Goffman 1963:3,5). Goffman proposed two types of stigma as the stigmatized pass from "a normal" to either: (a) a *discredited* stigma, where the stigma is known to others or assumed as known to others, such as race or physical disability, and (b) a *discreditable* stigma, where the stigma is unknown or concealable to others (i.e., passing as normal (Briggs, Plant, and Devlin 1977), such as HIV status or mental illness (Goffman 1963). While both types of stigma may result in negative psychological affects (Chaudoir, Earnshaw, and Andel 2013), there is an important difference between the two forms: the discredited (known to others) are perceived as "tainted" and may be more likely to experience stigmatization due to the inability to hide their stigma (Chaudoir et al. 2013). As this pertains to ostomy patients, an ostomy appliance is generally attached to the

[8] Link and Phelan (1995) proposed an argument that socioeconomic status and social support are "fundamental causes" of disease in their influential piece called "Social Conditions as Fundamental Causes of Disease."

abdomen and hidden under clothing; thus, ostomy stigma may (or may not) be concealable in everyday life. It can be concealable until the pouch becomes full of gas or bodily fluids and then it may become exposed or balloon up so that clothing moves away from the body, or it may be heard passing gas, or it may leak bodily fluids on the front of clothing (which is one of the main issues patients have with an ostomy appliance (WOCN 2017). However, concealability would be impossible with medical clinicians, especially considering the patient is at the hospital for ostomy surgery. Therefore, ostomy patients would not be able to conceal their stigmatized status in this scenario.

Since Goffman's influential work in the early-1960s, stigma has since been conceptualized and defined in various ways (Jones et al. 1984; Link et al. 1997; Phelan, Link, and Dovidio 2008). Similar to the ambiguity with defining health disparities discussed in chapter two, scholars have proposed several different stigma definitions. Stigma scholars generally agree, though, that stigma is a social construct that "involves pervasive cultural ideologies" (Major et al. 2018:5). The different definitions of stigma are rooted in the different sociological traditions of the scholars themselves. For example, Goffman (1963) was a symbolic interactionist, which is a micro-level approach to examining how people interact with one another in their everyday lives, and how these interactions impact them and society as a whole. His definition for stigma reflected this worldview. Building on Goffman's work, experimental social psychologists, Jones and colleagues (1984) defined stigma as a "mark that (1) sets a person apart from others and (2) links the marked person to undesirable characteristics" (Link et al. 1997:179). Jones and colleagues focused on relationships to stigma between stigmatized individuals and non-stigmatized individuals. Bruce Link and colleagues (1997), coming from social psychology and epidemiology perspectives, extend Jones et al.'s definition and include a

third dimension—rejection and isolation as consequences for the marked person once they are linked with an undesirable characteristic. Stigmatization can vary in degree and the way(s) it affects individuals, and include cognitive processes, such as labels[9] inferring an undesirable characteristic, and a behavioral component, such as rejection or a secondary deviance[10] where the marked person adapts to their status by being secret about it or withdrawing from the social world, for example (Link et al. 1997:197).

Stigma can be understood by four constructs of stigma: (a) *enacted*, (b) *felt*, (c) *internalized,* and (d) *anticipated* stigmas (Major et al. 2018). *Enacted* stigma is a stigmatizing behavior toward the stigmatized individual, from interpersonal or structural level perspectives, such as intentional discriminatory behaviors, or cultural norms or policies (e.g., Jim Crow laws). Enacted stigma can also include covert, and unintentional actions, such as clinicians spending less time in a medical interview with patients of color or low-income patients compared to white patients or high-income patients (Major et al. 2018:10); the length of a medical visit is associated with patients feeling less relaxed in discussing ailments in shorter visit lengths (Roter and Hall 2006). Studies show that individuals experience enacted stigma similarly for visible stigmas, such as African American race, as well as concealable stigmas, such as HIV status (Chaudoir et

[9] Labeling is the application of a 'mark' on an individual seen as being deviant. Labeling can result in positive or negative consequences (Rosenfield 1997). Stereotypes, which are learned from childhood, are important to the labeling process (Fletcher and Reynolds 1967; Scheff 1966). I will discuss more about labeling in the discussion on modified labeling theory.

[10] Deviance is defined as "non-normative beliefs, behaviors, and identities" in a society (Worthen 2016:4), such as behaviors that deviate from cultural norms. For example, acts associated with mental illness would be considered deviance (Scheff 1966) because these acts violate social rules. A person with an ostomy has been described as deviant for violation of social rules (Briggs, Plant, and Devlin 1977). Becker (1963) explains that society defines certain situations and behaviors as socially accepted; "specifying some actions as 'right' and forbidding others as 'wrong' (p. 1)." When an individual violates socially accepted rules by their actions, they are labeled as an 'outsider', not part of the group, not to be trusted to abide by social rules and roles. The 'outsider', then, is labeled as a deviant. Social roles are expected patterns of behavior according to what is socially accepted, such as the role of a parent is to care for their children, or the role of a patient, according to Parsons (1961), is to accept doctors' directives and get well again in order to return to being a functioning and contributing member of society. When a person violates society's definition of a social role, they are labeled as an outsider, a deviant.

al. 2013). The current study explores the enacted (behavioral) stigma construct in the way that medical clinicians treat ostomy patients in the medical interaction.

Felt (also known as perceived) stigma are the perceptions of being devalued for the stigmatized group because of their stigmatized status (Van Brakel 2006). For example, a person with a mental illness or an ostomy perceives that society views their stigmatized characteristics as weak. This stigma construct can occur without the presence of the stigmatizer, and is associated with stress, and may be antecedent to other cognitive and behavioral responses that impact health, such as not seeking socioemotional support, and concealing and withdrawing (Major et al. 2018:12). *Internalized* stigma (also known as self-stigma) refers to an individual's conscious or unconscious adoption of the belief that society devalues an individual's status (i.e., the individual believes the same message; they adopt the same perspective); this stigma type reflects repeated exposure to enacted stigmas and can lead to chronic stress or unhealthy behaviors, such as social isolation (Major et al. 2018). To expand on the above example, a mental patient is aware that society views people with mental illness as weak, the mental patient then adopts or agrees with this view (e.g., "That's right. People with mental illness are weak" (Corrigan and Rao 2012:8), then applies this view (e.g., "I am mentally ill so I must be weak," p. 8), and as a result may lead to unhealthy behaviors because the person believes they are not worthy (e.g., of a job, of a relationship). Finally, the last stigma construct is *anticipated* stigma, which is the expectation of being in a situation where discrimination or bias will occur because of having a stigmatized "mark" (Major et al. 2018:11). Anticipated stigma has been described for black middle-class women and their experiences of discrimination in the healthcare system in the book *Invisible Visits* (Sacks 2019); the women in this study described that their guard is up in anticipation of experiencing discrimination when they have to see a physician because of their

previous experiences of discrimination. To try mitigating possible discrimination, the women described keeping their CDC work badge on their clothing during doctor visits in order to show that they had great jobs and were well-educated.

Taken together, individuals who have experienced negative treatment (enacted stigma), hold perceptions that they are devalued by others (felt stigma), adopt this perspective that they are devalued (internalized stigma), and may anticipate or expect being treated differently and unfairly prior to any of this treatment happening (anticipated stigma). The anticipation of being targeted with bias and discrimination may lead individuals to socially isolate, withdrawal, or avoid finding a job (Chaudoir et al. 2013; Major et al. 2018), or avoid obtaining healthcare services (Mays et al. 2017; Socías et al. 2014). These cognitive processes are particularly relevant to ostomy patients who struggle with whether or when to tell others about their ostomy (Nicholas et al. 2008). Each of these stigma processes lead to negative health outcomes in some way.

Ostomy Stigma

People learn about stigmatized identities, such as what it means to be mentally ill, through the process of socialization and they have beliefs about being devalued and discriminated against (Link et al. 1997). Based on these cultural beliefs, individuals internalize what it means to be attached to a stigmatizing label. As this pertains to ostomy stigma, culturally induced conceptions of an ostomy include a social taboo[11] regarding the excretion of bodily fluids (Black 2004; Briggs et al. 1977; Chelvanayagam 2014), and stems from an association between the threat of disease and intolerance of others—"the belief that other groups are impure and contaminating;" a "dread of parasite-borne disease, one consequence of deficient sanitation,

[11] A taboo is defined as "prohibition of an act, action, person, or object" (Chelvanayagam 2014).

appears to be a significant basis for prejudice…" (Haslam 2012:2). In Haslam's (2012) book, *Psychology in the Bathroom*, he discusses the psychological importance of excretion[12] and the tendency for people to keep these everyday practices "hidden and deeply private" even though these practices are universal to living (p. 3), and Haslam explains that "shame and disgust" are emotions associated with a "violation of norms to do with the body's cleanliness and purity" (p. 9). Thus, ostomy patients would have an expectation of being rejected once they become labeled as 'someone with an ostomy' or 'someone who will become a person with an ostomy' because of the cultural notion of what it means to have an altered and "impure" body.

Notably, anthropologists have studied the disgust phenomenon and "have even proposed a location in the brain where disgust may be seated" (Curtis and Biran 2001:17). Disgust is thought to be a universal human emotion, though it manifests in different forms between cultures. It is an adaptive response to the "threat of disease" (p. 22). Work on disgust stems from investigating hygiene behavior and the law of 'contagion', which holds that once you are in contact with a contagion then you are always in contact with the contagion (Rozin, Millman, and Nemeroff 1986). The disgust emotion is distinct from the emotion of fear; disgust involves a "suspension of activity" whereas fear "heightens activity" to prepare someone for the fight or flight response (Curtis and Biran 2001:18). Manifestations of disgust include a number of outward behaviors, such as facial expressions, explicit statements like "ew" "ick," and even neurological signs, such as low blood pressure (Curtis and Biran 2001).

Numerous studies have shown the impact of living with an ostomy, the resulting lower quality-of-life, and the emotional consequences that patients feel about their ostomy, but little attention has been given to mechanisms of stigmatization for ostomy patients. While there are no

[12] As it is understood by Erik Erikson's stages of psychosocial development (Erikson 1963; Munley 1975); Erikson "directly linked shame to the anal stage of development" (Haslam 2012:11).

known published studies on the impact of medical clinicians' communication on ostomy patients' stigmatization, there is important work on ostomy-related stigma and shame. Quantitative studies have examined ostomy patients' feelings of stigma and level of adjustment using a non-ostomy-specific social impact scale (Qin et al. 2020; Xu et al. 2019), and examined ostomy stigma relating to feelings of stigma and perceptions of attractiveness (MacDonald and Anderson 1984). Ostomy-related quantitative work has examined inflammatory bowel disease stigma (only 12% had an ostomy (Taft et al. 2012), colorectal cancer stigma (18% had an ostomy, (Phelan et al. 2013), and disgust sensitivity with respect to the idea of being in close proximity to someone with an ostomy (Smith et al. 2007). Qualitative ostomy stigma research has examined ways that ostomy patients try to combat ostomy stigma (Frohlich and Zmyslinski-Seelig 2014; Rademacher 2018), and has provided us with rich descriptions of life with an ostomy and the resulting effects (Diebold 2016; Erwin-Toth 1999; Nicholas et al. 2008; Owen and Papageorgiou 2008; Pınar, Ayhan, and Pınar 2013; Ramirez et al. 2014; Savard and Woodgate 2008). I address gaps in the ostomy stigma literature by examining ostomy patients' experiences with medical clinicians when they first receive their appliance.

RESEARCH QUESTION

The research question I investigate is: do ostomy patients experience stigmatizing sentiments from medical clinicians after ostomy surgery? I operationalize stigmatizing sentiments relating to negative communication about the ostomy, verbal or non-verbal, made by medical clinicians at the hospital.

METHODS AND DATA

I conducted two cross-sectional phases of an original data collection.[13] The study is titled *Peoples' Experiences With Pouches (P.E.W.P.) Study*. In the current study, I use data derived from both phases of data to investigate the research question. The first phase (overall n=390) was conducted between summer 2017 and fall 2018, and the second phase (overall n=353) was conducted in 2019 between April and December. In Phase One, I approached data collection as an exploratory mission because there was so little information on ostomy patients' experiences in the hospital, this topic was under-researched, and there was no information on ostomy patients' experiences with medical clinicians from a sociological perspective. The research question came to fruition inductively after conducting a preliminary data analysis of the Phase One data (detailed below) in order to identify general themes and "to provide directions for seeking future data" (Grbich 2013:21). Notably, a large majority (79%) of the Phase One sample wrote a comment in one or more of the open-ended questions included in the current study; over half (56%) of the Phase Two sample wrote a comment in one or more of the open-ended questions on the Phase Two questionnaire.

As I read the written comments from Phase One data, I used an inductive (bottom up) approach to discover themes in the data, which is a process of coding data "without trying to fit it into a pre-existing coding frame" (Braun and Clarke 2006:12). For example, in Phase One I asked general questions about ostomy patients' experiences at the hospital, but I did not directly ask ostomy patients whether clinicians said or did something that made them feel bad about their ostomy. However, upon reading the written comments from the open-ended questions in the Phase One data, I found that ostomy patients were experiencing differential and negative

[13] The P.E.W.P. Study has received media attention from the United Ostomy Associations of America, *Phoenix Magazine*, and the *Journal of Wound, Ostomy and Continence Nursing*; the editor of this journal named my sole-authored P.E.W.P. Study publication (Miller 2020) "a landmark article and a must read."

treatment by medical clinicians at the hospital because of their ostomy. This revelation prompted me to investigate this situation further and directly by explicitly asking ostomy patients in Phase Two whether medical clinicians made them feel bad about their ostomy and to please describe. I report findings from both phases of data collection; thus, the patient sample characteristics are different for each data collection and will have different N's.

Sample and Data Collection for Both Phases

Both phases. For both phases of data collection, I recruited participants through ostomy support groups in the United States affiliated with the United Ostomy Associations of America (UOAA) and I posted the questionnaire link on UOAA's discussion board. I also recruited participants through Facebook ostomy support groups, and Twitter. Eligibility to participate in both phases included: having an ostomy, be aged 18 or older, and be able to read and write English well enough to complete the questionnaire. Prior to accessing the questionnaires in both phases, respondents had to sign an online informed consent form, and the questionnaires were self-administered and comprised of closed-ended and open-ended questions.

Phase one. In Phase One, I contacted the managers of 60 ostomy support groups (in the states I had some connection to, which were Ohio, Michigan, West Virginia, Indiana, Oklahoma, Texas, North Carolina, Virginia, South Carolina, Tennessee, and Arizona), and in addition to the above recruitment processes, I recruited through the social media site, Reddit; I had to obtain approval from the moderators of the subreddits before posting about my survey. The Phase One questionnaire was pre-tested by a University faculty member with an ostomy and advanced doctoral students trained in methodology.

Phase two. For Phase Two, I received a small grant from the University to incentivize participants to fill out my survey, entering participants into a drawing for the chance to win one

of fifteen $25.00 Amazon gift cards. In this phase, I contacted the managers of 166 support groups in thirty states across the United States, some of which had participated in Phase One. I oversampled in locations of the United States that have a higher percentage of people of color living in the area. In addition to the recruitment processes outlined above, I also posted the questionnaire link on meetanostomate.org's discussion board. The differences in recruitment strategies between the two phases were: I did not recruit via meetanostomate.org in the first phase and I did not recruit via Reddit in the second phase. The Phase Two questionnaire was pre-tested by advanced doctoral students trained in methodology and went through a number of revisions with the doctoral committee.

The study and methods were approved by the University of Oklahoma, Approval #8040 on 05/04/2017 (Phase One) and Approval #10615 on 04/11/2019 (Phase Two). A total of 386 are included in the current study from Phase One and a total of 312 are included in the current study from Phase Two. The participants not included in the current study is due to missing data on key variables of interest to the current study. Analyses of the excluded respondents show similar patient sample characteristics to those included in the current study.

Variables

To answer the research question of whether ostomy patients experience stigmatizing sentiments from medical clinicians after ostomy surgery, I use a triangulation of data (quantitative and qualitative) to understand this phenomenon from multiple perspectives and to garner a deeper understanding of ostomy patients' experiences with medical clinicians and ostomy stigma.

Specifically, I analyzed *three closed-ended* questions and *four open-ended* questions. Two of the three closed-ended questions come from Phase One data and relate to disgust (Smith

et al. 2007) and being treated as less than human or "not quite human" as Goffman theorized (Goffman 1963:5). The first two questions were "Sometimes the medical provider made me feel like my ostomy disgusted them." (7-point Likert scale. 1=strongly disagree, 7=strongly agree), and "The medical provider made me feel less like a human because of my ostomy." (7-point Likert scale. 1=strongly disagree, 7=strongly agree). Both variables were coded as binary. That is, disgust behavior was present (or being treated as less than human) (coded 1) or this behavior was not present (coded 0); I included the answer choice 'neither agree nor disagree' in the 'no disgust' behavior present (coded 0) and 'not treated less than human' (coded 0). The third closed-ended question comes from Phase Two data relating to whether clinicians made patients feel bad about their ostomy. The question analyzed is "Was there a particular medical provider who made you feel bad about your ostomy?" This was coded as yes (coded 1), no (coded 2), and do not know (coded 3).

The four open-ended questions come from both phases of data collection. In Phase One I asked participants three open-ended questions included in the current study: (1) "Was there anything that the medical staff could have done to make you feel better prepared to take care of your ostomy at home?" (2) "Is there anything else that you would like to share regarding your interaction with medical providers when you first received your ostomy?" and (3) "Is there anything else that you would like to share about your experiences with your pouch?"

The fourth open-ended question comes from Phase Two data. As I mentioned previously, in Phase Two I used a prompted open-ended question to investigate whether medical clinicians made patients feel bad about their ostomy. Thus, the fourth (4) open-ended question I analyzed is "If yes to the above question [whether there was a particular medical provider who made the patient feel bad about their ostomy], what did the medical provider do to make you feel bad

about your ostomy? Please describe in the box below."

I used a thematic analyses approach to examine the written comments in order to investigate whether patients reported a negative interaction with their medical clinician because of the ostomy. Included in 'stigmatizing sentiments' is whether a medical clinician did or said something (verbal or nonverbal) that made the patient feel bad about their ostomy in some way. Thematic analysis is conducted when a dataset is complete and involves focusing on the narratives of the individuals in the data, repeated words or phrases (Grbich 2013). Thematic analysis is a flexible approach to "identifying, analysing, and reporting patterns (themes) within data." A 'theme' is an important piece about the data "in relation to the research question, and represents some level of patterned response or meaning with the data set" (Braun and Clarke 2006:10). Remaining flexible means that researchers do not have to "subscribe to the implicit theoretical commitments of grounded theory" (Braun and Clarke 2006:6,8), and they can approach analyses from different perspectives, such as essentialist, realist, constructionist or contextualist methods (Braun and Clarke 2006). Essentialist or realist methods report the meanings or experiences of participants, which is the approach I take in the current study. Constructionist method examines events, experiences, or meanings for a range of discussions within society, and contextualists analyze the data as a way to understand how individual's "make meaning of their experience, and in turn, the ways the broader social context impinges on those meanings" (Braun and Clarke 2006:9); I also draw on this approach as I contextualize the comments.

I used a latent or interpretive approach during the data analytic process as a way to find patterns and "their broader meanings and implications" (Braun and Clarke 2006:13) because I am interested in understanding whether medical clinicians did or said something about the

ostomy that likely contributes to ostomy stigma. This means that I am looking "beyond what a participant has said or...written" and examining underlying ideas or ideologies (Braun and Clarke 2006:13). I focus on messages stemming from a larger cultural thought about ostomies (Rademacher 2018), and about excreting bodily fluids, having an 'abnormal' and impure body that the prosthetic ostomy device imparts.

DATA ANALYSES

I first present patient demographic characteristics of the study samples. To analyze the closed-ended questions for being treated as less than human, disgust, and whether clinicians made the patient feel bad about the ostomy, I used STATA 15 for the analyses, and I present descriptive statistics for these three variables. To analyze the open-ended written comments, I used a thematic analysis approach of the written comments using QSR NVIVO qualitative data analysis software (QSR 2021). Once the initial thematic analysis was complete in NVIVO in identifying stigma sentiments, I examined the stigma sentiments for subthemes, and I present these subthemes.

RESULTS

Characteristics of the Study Sample

Both cross-sectional phases of data have similar patient characteristics of the study samples, despite oversampling in Phase Two in areas within the United States that have a higher number of people of color. Both patient samples are largely white, female, fairly educated, and relatively older. Table 3.1 shows frequencies and percentages of the variables describing the patient sample for Phase One, and Table 3.2 for Phase Two.

There are 386 ostomy patients in the Phase One sample, included in the current study. Three-quarters (76%) of the sample are women, a majority (87%) are white, a little less than half

of the sample (46%) completed a bachelor's degree or higher. The mean age for Phase One is 53 years old, and the mean years since ostomy surgery is eight years. Ten percent (10%) of Phase One sample had ostomy surgery outside of the United States; the non-U.S. sample largely had surgery in Canada or the United Kingdom.

[Table 3.1 here]

Three hundred and twelve (312) ostomy patients are included in the current study from Phase Two. Seventy-one (71%) percent are women, and a slightly higher majority than Phase One are white (90%), a little over half of the sample (56%) completed a bachelor's degree or higher. The mean age is 57 years old, with mean of 10 years since ostomy surgery from the date of participation. Nineteen percent (19%) had ostomy surgery outside of the United States, and similar to Phase One, the majority of the non-U.S. sample had surgery in Canada or the United Kingdom. Interestingly, while both samples include a relatively older sample, the average age of someone with an ostomy is reported as higher (66-70 years old) (Turnball 2003) than the average age in both phases of the current sample.

[Table 3.2 here]

Quantitative Representation of Stigmatizing Sentiments from Medical Clinicians

Table 3.3 presents percentages of patients reporting being treated as less than human from medical clinicians because of their ostomy, whether clinicians seemed disgusted by the patient's ostomy, and whether patients reported that medical clinicians made them feel bad about the ostomy.

A small percentage of ostomy patients reported being treated as less than human because of their ostomy and that the medical clinician seemed disgusted by the ostomy in Phase One. Specifically, seven percent (7%) of ostomy patients reported that they were treated as less than

human from their medical clinician and similarly reported (7%) that the medical clinician seemed disgusted by the ostomy. Patients who reported that they experienced less than human messaging *and* disgust messaging from their clinician was five percent (5%) of the sample.

[Table 3.3 here]

Qualitative Representation of Stigmatizing Sentiments from Medical Clinicians

The thematic analyses of the respondent's written comments identify stigmatizing sentiments from medical clinicians and from these sentiments, I identified nine subthemes reflecting cultural mores attached to ostomies. The following subthemes were identified as they relate to medical clinicians' sentiments: (a) age-related, (b) patient at-fault, (c) body-specific, (d) disgust, (e) medical gaze, (f) negative experience or projection, (g) shame, (h) treated as less than human, and (i) uncaring or rude. I will present patient quotes for each of these themes. Note that many quotes can fall under multiple themes.

Age-related. While it has been cited that ostomy surgery occurs more in older populations compared to younger (AgingInPlace 2021), people of all ages can have ostomy surgery (Anon 2019). Interestingly, there is a movement among younger ostomy patients to combat the stigma attached to ostomies using social media and pictures of themselves in bikini's with the ostomy device exposed (Frohlich and Zmyslinski-Seelig 2014). Comments from medical clinicians portray a mindset about ostomies and age, reflecting social mores that ostomies are more appropriate or socially acceptable for older people than younger:

> "He said that I was too young to have one and that as an 18-year-old, it would negatively impact my quality of life."

> "A pre-operative nurse made comments about being too young to have an ostomy and have had cancer (which I hadn't had she just assumed!)"

> "Was told that I did not want to live with a permanent ostomy when I was young and as an adult."

> "The two nurses with me said, 'such a shame, she's so young to have a bag.' Those words are burned into my mind forever! It hurt me badly."

The above comment about being too young to have cancer is also an outdated age-related idea that only older people have cancer. While the probability of developing cancer increases as we age, cancer is the second-leading cause of death for children between the ages of one to 14, and overall incident rates of cancer have increased over time for children and adolescents, depending on the type of cancer (ACS 2021a). Also, the clinician's assumption that the patient had cancer as the reason for the ostomy was incorrect. While cancer is an indication for ostomy surgery, inflammatory bowel disease has been reported as a more common preoperative diagnosis (Sheetz et al. 2014). The clinician's assumption about the preoperative diagnosis also reflects that he/she/they were not familiar with the patient's medical history.

Patient at-fault. The next theme found was the patient was treated as at-fault. There has been a long history of victim blaming in matters of illness, which are rooted in the Bible describing illness "as the wages of sin" (Gunderman 2000:7). There are accounts of blaming lung cancer patients for their illness or patients feeling at fault for their cancer diagnosis (Chapple et al. 2004; Shen et al. 2016) and obese patients being discriminated against and treated like their illness is their fault (Fruh et al. 2016). I found that ostomy patients were treated like their ostomy or their medical condition was their fault. Comments reflecting this at-fault perception:

> "Spilt ostomy contents and blamed me."

> "The nurse in my home town said that I had given up and that was why I needed an ostomy... that I hadn't tried hard enough. I think she insinuated that because I am overweight."

In this comment, we not only see that the patient felt like they were blamed for needing to

get an ostomy appliance, but also the stigmatizing message regarding obesity mentioned above.

> "When I had my stitches become infected around my stoma this provider blamed me for not taking care of it."

In this situation, the clinician assumed that the patient had not taken care of the skin surrounding the stoma (the intestinal piece that protrudes out from the abdomen and where bodily fluid evacuates) and commented this assumption, subsequently making the patient feel at fault for their condition.

> "After surgery I was put in a two piece that was not done correctly so when I stood up it fell off and the person who had to clean it up was not happy at all even though it was not my fault."

To put this comment into context, after surgery patients are fitted with a wafer that has an adhesive backing that sticks directly to the abdomen. The bag (aka pouch) connects to the wafer, similar to a Rubbermaid plastic ring. There are one-piece appliances (the wafer and bag are produced in a way that they are connected and cannot be separated) or a two-piece appliance where the wafer and pouch can be connected and disconnected as needed (for emptying or letting out gas). The patient in the above comment was fitted with a two-piece appliance system that was not adhered to the abdomen correctly (by the clinician) and the patient stood up and the appliance fell off of the body. It sounds like bodily fluids spilled out when the pouching system fell off and the clinician acted upset by the mess of bodily fluids being spilled. I included this comment in this subtheme because the patient describes an experience with the clinician and explicitly mentioned that the situation was not the patient's fault, but seemed to be treated as if it were. The last comment in this subtheme portrays another obesity stigma message:

> "[The clinician] [t]old me my ileostomy was my fault because I was too fat!"

While people who are obese do have a higher risk of wound complications and a higher incidence of "comorbid conditions affecting surgical outcomes" (Colwell and Fichera 2005),

explicitly stating that a patient's current situation is because of his/her/their weight is unhelpful and stigmatizing.

Body-specific. There are three patient reports regarding something the clinician said to the patient the reflected comments about the body or body image. One respondent wrote "body image" as a problem they experienced with their medical clinician and did not go into details. The remaining comments for this subtheme include:

> "My Ostomy nurse! She told me that I needed to be careful because lots of her Ostomy patients smell bad."

Comments about smelling bad may result in patients worrying about being around others and that others may be able to smell them and, as a consequence, patients will end up isolating themselves (Pınar et al. 2013).

> "A female nurse said 'well you can kiss that flat abdomen goodbye forever.'"

This comment reflects a cultural norm of what a body should look like, unblemished, a "bodily difference and impairment as abnormal, deformed, or deficient" (Blum 2020:175), and "particular standards of attractiveness" (Vartanian 2012:712), especially for women (the above patient was a woman). Not surprisingly, body image is reported as a concern for people with an ostomy (Aronovitch et al. 2010). An ostomy may change the patient's self-meaning (or personal identity) (Black 2004). A qualitative study on people with cancer described a change in self-meaning after diagnosis, which included "loss of personal control, threats to self-esteem or self-worth, and changes in body image" (Fife 1994:312). The final comment in this subtheme includes:

> "She asked me how I will have sexual relations with my husband [n]ow that you have a rectovaginal fistula and a loop ileostomy."

There are a couple of problematic assumptions that the medical clinician made about this

patient. The patient may not have been married to a 'husband', for example, or the sexual relations that occur in the patient's private life may not include sexual intercourse. A study examining patterns of asexuality found that five percent and six percent of women and men, respectively, have not had sexual intercourse in their lifetime (Poston and Baumle 2010). Assumptions about sexual relations may stem from a sexualized culture that the United States portrays in media and messaging (de Melker 2013).

Disgust. The below comments reflect what I discussed prior about outward manifestations of the emotion of disgust and these quotes elucidate the quantitative representation of disgust reported above:

> "My GP [general practitioner] needed to see me remove my bag so he could see the abscess beside my stoma. The GP could barely stand to look at it and was also useless at helping me find an appropriate place to arrange my things so I could do this bag change. It was upsetting and unhelpful."
>
> "Made a face, appeared disgusted by a leaking pouch."
>
> "Grimaced."
>
> "They looked disgusted about emptying the pouch."
>
> "Since it had not been changed for quite a few days it broke loose and leaked. The nurse just looked at my mess and left the room." (Important to note that bags should not wait "quite a few days" to be changed.)
>
> ""Doctors' – most doctors' attitudes toward the ostomy (one actually looked at the pouch and said 'ewww') [is an obstacle I have dealt with]."
>
> "I had one nurse who absolutely hated to change my ostomy bag. She always said, 'you need to change it so you will [know] how to when you get home.' … she sticks out in my memory more than all the great nurses I had because of such an awful feeling she gave me."

Medical gaze. In Michel Foucault's (1973) seminal work, *The Birth of the Clinic*, he introduced the term 'medical gaze' to describe a medical clinician's practice of "striving to 'gaze' into the deeper recesses of that body" (Philo 2000:12) in order to understand a patient's

ailment. The ‘gaze’ is about “the act of seeing” (Foucault 1973:ix) in an objectified way. In this sense, patients are not seen as a whole person with feelings, values or opinions, but rather, they become numbers, allowing clinicians to keep at a distance from patient’s personal problems outside of the medical situation and observe and diagnose. This approach to medicine has changed over time; the modern version of the Hippocratic oath highlights that clinicians need to treat patients as if they are humans, and not just a symptom to address, which is unlike the classic version of the oath (Chaney 2018; Tyson 2001). Comments describing patients feeling like ‘just a number’:

> “I felt like I was just a "number" to her. I was shocked that she was supposed to be a specialist in this field.”
>
> “Just another patient – no empathy or sign of caring at all.”
>
> “They ignore it. If there’s no pressing issue most seem reluctant to talk about it.” (This comment was in response to the question, “Was there a particular medical provider who made you feel bad about your ostomy?” I assume the patient is referring to their ostomy when they write ‘it’.)
>
> “Ignored concerns.”
>
> “I was in a teaching hospital. One or more of the resident physicians seemed to carry an attitude that the ostomy was a technical medical procedure, separate from a person. The ostomy was of interest, the person was not.”
>
> “A nurse on night duty would not help me change my bag when it was leaking, during the night. I was not well enough to get out of bed and do it myself. So [I] lay in poo for many hours, which caused my skin to break down.”

The last comment was included in the medical gaze subtheme due to the nature of how the clinician treated the patient; the patient was forgotten. Although this quote could fall under other themes as well, such as ‘less than human.’

Negative experience or projection. The below comments depict a negative experience with medical clinicians regarding the ostomy, or clinicians projecting onto the patient their own ideas or feelings about having an ostomy:

> "I had several appointments with the Gastroenterologist at [blinded for anonymity]. He told me how much I would hate living with an ostomy for the rest of my life. Sadly, he's the 3rd GI to tell me this; one in Indianapolis, one in Chicago and one in San Diego. Consequently, I put off having the surgery 20 years! My quality of life is so much better with an ostomy. Wish I would have had the surgery 20 years ago."

> "Said they could not live with one."

> "Said that no one would ever choose to have an ostomy."

> "I don't like it when I hear comedians or health professionals make jokes about having one [an ostomy]. Some nurses are very blunt in their feelings about not wanting to work with a patient who has one."

> "Nurses do not need to be scared nor do doctors of body waste with bag changes. This makes the patient scared and emotionally feeling rejected."

> "Asked whether it was permanent and when it would be reversed. Said they felt "sorry for me" and "that it must be the most terrible thing ever" and "would rather die that live with such a thing."

> "My GP was surprised that my skin was in such good shape and that my ostomy doesn't limit my activities. She clearly thought that an ostomy was a bad thing."

> "I was treated like I was drug seeking despite it being my third separate colostomy in as many years with severe complications totaling about 35+ procedures and surgeries over a four-year period and still on a wound vac. Horrific experience."

In a few of the above comments, clinicians appear to be under the impression that no one would choose to have ostomy surgery. That is, they are projecting their own beliefs about having an ostomy, but in actuality, patients have described getting a second chance after ostomy surgery

and have expressed how that their situation could have been worse (Frohlich and Zmyslinski-Seelig 2014).

Shame. As mentioned previously, the emotion ‘shame’ is associated with a violation of a norm with respect to cleanliness. This theme includes comments that either mention ‘shame’ or a comment from the medical clinician to the patient that could make the patient feel shame:

> “Tried to do things I knew were wrong and then tried to shame me.”

> “A nurse at my GP's office made a comment that at least I could have a reversal and get rid of my "icky ostomy" at my follow up visit after discharge from the hospital.”

> “When I said I had an ostomy, her immediate reaction was pity. She said that she was sorry, and said a well, at least it’s temporary, right?”

> “A very elderly nurse felt the need to empty my ostomy into a kidney shaped bowl. She made a HUGE mess & caused me to have an anxiety attack concerning my new ostomy.”

Treated as less than human. Goffman (1963) theorized about stigma and defined it as an attribute that is deeply discrediting, where the marked person is “not quite human” (p. 5). The following comments illuminate the quantitative results reported above and reflect this attitude of treating the patient as if they are not quite human, or the patient explicitly mentions ‘less than human’:

> “She did not support me or make me feel confident in my own abilities to change my appliance. I felt belittled if I attempted to ask for help.”

> “After emptying ostomy for me, nurse did not wipe it at all.”

The last comment above means that bodily fluids were left on the patient after the clinician emptied the pouch. Leaving bodily fluids on the abdomen can result in skin irritation. The last two comments for this subtheme include:

> “I had a leak while I was in the hospital and still needing to have it changed by someone and it did not seem like the nurses were concerned

> with getting it changed timely. I had the leak for an entire day before it was changed."
>
> "the one [nurse] I have now is disrespectful and does make me feel less than human."

Uncaring or rude. As mentioned previously, many of the quotes presented can fall under several themes. The following quotes depict an uncaring encounter with the clinician, or the clinician acted rude or like they did not care:

> "They were very insensitive, did not answer my questions."
>
> "Mine were rude."
>
> "The ostomy nurse i had was HORRID. She was not helpful and very degrading to me."
>
> "My ostomy nurse was so rude, I left feeling totally depressed and ill prepared. Emotional support was very much needed."
>
> "WOC nurse was uncaring about my needs/wants for my future lifestyle and refused to give me help with irrigation."
>
> "Lack of empathy."
>
> "She was curt, dismissive, and harsh."
>
> "Verbally ridiculed me, neglected my care (and care of others)."

Both Phases

For the Phase One sample, when examining the number of stigma sentiments from the open-ended reports and those who experienced 'disgust' or 'less than human' messages from medical clinicians in the closed-ended reports, I found that ten percent (10%) of the Phase One sample reported experiencing stigmatizing sentiments from clinicians. For the Phase Two sample, a higher percentage (16%) of ostomy patients reported that their medical clinician made them feel bad about their ostomy (i.e., a stigmatizing sentiment). Taken together, for both phases of data, eleven percent (11%) of the overall sample (both samples combined) experienced a

stigmatizing sentiment from their medical clinician.

DISCUSSION AND CONCLUSION

The current study investigates stigmatizing interactions with medical clinicians for ostomy patients, from both quantitative and qualitative perspectives. I analyzed two cross-sectional phases of data and found that ostomy patients experience stigmatizing sentiments from medical clinicians because of their ostomy. Results show that 10 percent of the Phase One sample experienced medical clinicians acting disgusted by the ostomy or were treated as less than human because of their ostomy or the clinician said something to the patient that contributes to ostomy stigma. Results of the Phase Two sample show that 16 percent of the sample reported that their medical clinician made them feel bad about their ostomy. Taken together, for both phases of data, 11 percent of the combined samples experienced stigmatizing sentiments from their medical clinician.

The qualitative analyses elucidate this process of stigmatization for ostomy patients. There were several notable subthemes identified in stigmatizing sentiments that medical clinicians made to ostomy patients, such as visible signs of disgust or explicitly stating their feelings of disgust when providing medical care to ostomy patients; the patient was treated as if the ostomy or medical situation was their fault because of being overweight; statements about the patient's age and being too young to have an ostomy or how the ostomy will negatively impact their quality of life as they grow older; patients were treated as less than human because of their ostomy or treated as just a number; finally, patients described a negative encounter with their clinician or had an uncaring or rude medical clinician.

While the findings help to understand ostomy patients' experiences with medical clinicians after ostomy surgery, there are a few limitations of the study to consider. Both phases

of data are largely white and female and were recruited from ostomy support groups. A more diverse sample would allow us to make comparisons across races and genders. Both samples make it appear that white women participate in ostomy support groups more than other demographic characteristics, but this may not be the actual case. Perhaps ostomy patients of color draw socioemotional support from kinship networks or churches instead of an organized ostomy support group. Future work should investigate this. Ostomy support groups affiliated with the United Ostomy Associations of America are generally held once a month and are largely conducted in free locations, such as white-attending churches. These topics are critical areas that needs investigated; ostomy patients of color experiences with medical clinicians are unknown, and perhaps there is a stratification in support mechanisms for ostomy patients due to support meetings being held in white-attending churches.

The sample for both phases is also nonprobability and retrospective in design. Thus, it is difficult to discern whether the findings can extend to ostomy patients' experiences not included in the current study. A retrospective study design has the potential to introduce recall bias, which is remembering an experience as "better or worse than it actually was" (Blome and Augustin 2015:112); however, events that hold an emotional significance are more likely to be recalled with more accuracy than more mundane events (Kensinger 2011).

In conclusion, this study demonstrates that ostomy patients experience stigmatizing sentiments and negative treatment in the medical encounter because of their ostomy. This differential treatment likely contributes to ostomy stigma. Future research should investigate ostomy stigma further by examining it quantitatively in order to understand whether there is a statistically significant relationship between medical clinician communication and ostomy stigma. This is the topic that I turn to next in the dissertation: the relationship between medical

clinician communication and ostomy patient stigmatization.

Tables for Chapter 3

Table 3.1. Patient Characteristics in the Sample - Phase One (n = 386)

	N	*%*
Gender		
Female	293	76
Male	93	24
Race		
White	337	87
Non-White	49	13
Education		
Completed H.S. or less	62	16
Completed Associate's or some college	148	38
Completed Bachelor's	107	28
Completed Postgraduate	69	18
Age *(mean= 53 years)*		
18 – 25 years	11	3
26 – 35 years	47	12
36 – 50 years	96	25
51 – 65 years	145	38
66 years or older	87	22
Years Since Surgery *(mean = 8 years)*		
Non-US ostomy patients in the sample (n=351)	37	10

Table 3.2. Patient Characteristics in the Sample - Phase Two (n = 312)

	N	*%*
Gender		
Female	223	71
Male	89	29
Race		
White	281	90
Non-White	31	10
Education		
Completed H.S. or less	35	11
Completed Associate's or some college	104	33
Completed Bachelor's	102	33
Completed Postgraduate	71	23
Age *(mean= 57 years)*		
18 – 25 years	6	2
26 – 35 years	29	9
36 – 50 years	64	21
51 – 65 years	109	35
66 years or older	104	33
Years Since Surgery *(mean = 10 years)*		
Non-US ostomy patients in the sample	59	19

Table 3.3. Quantitative Representation of Stigmatizing Sentiments from Medical Clinicians Toward Ostomy Patients

	N	*%*
Treated Less than Human (n=386)		
Not treated less than human	361	93
Treated less than human	25	7
Disgust About the Ostomy (n=385)		
No disgust behavior present	358	93
Disgust behavior present	27	7
Patients Reporting Disgust and Less than Human Combined (n=385)	18	5
Clinician Made the Patient Feel Bad About Their Ostomy (n = 312)	49	16

Chapter 4: The Role of Medical Clinician Communication in Ostomy Patient Stigma

Chapter 4 Abstract

Background: Decades of research shows that medical clinician communication has tangible consequences, both positive and negative, on patient health outcomes in general patient populations. What is less clear is whether medical clinician communication impacts ostomy patients' health outcomes. Studies show that ostomy patients experience feelings of being stigmatized, feelings of anxiety, shame, and depression because of their ostomy. The first line of support after ostomy surgery is medical clinicians; how this interaction unfolds is particularly critical for ostomy patients.

Objective: To provide a measurement tool to examine ostomy stigma and to quantitatively investigate whether there is a relationship between medical clinician communication and ostomy patient stigma.

Method: I use original data that I collected in 2019 where I recruited participants from ostomy support groups. Using a nonprobability national sample of 315 ostomy patients, I conducted a retrospective quantitative study. Clinician communication (for both nurses and surgeons) is operationalized using a validated provider-specific scale adopted from the Agency for Healthcare Research and Quality. Ostomy stigma is measured using a modified version of Link and colleagues' devaluation and discrimination scale, originally created to test mental illness stigma. I modified the scale statements to reflect ostomy patients instead of mental patients and included new ostomy stigma statements.

Results: A majority (74%) of the patients reported moderate to high feelings of ostomy stigma. Results show a significant and negative relationship between medical clinician communication and ostomy stigma. That is, as the quality of medical clinician communication increases, ostomy

patient stigma decreases. Both nurse communication and surgeon communication were significantly related to ostomy patient stigma.

Conclusion: This study demonstrates that medical clinician communication impacts ostomy patients' health outcomes. Nurse and surgeon communication is significantly associated with ostomy patient stigma. Future research should investigate this relationship further to test other consequences of clinician communication with ostomy patients.

Key words: provider-patient communication, ostomy, quality health care, stigma

As reported in the previous chapter, I found that medical clinicians contribute to ostomy[14] stigma[15] in the way(s) that they communicate with ostomy patients. In the current chapter, I test this relationship quantitatively using an ostomy-specific and validated stigma scale from Link and colleagues (1997). I examine this relationship through the lens of patient-centered care, and the modified labeling theory as theorized by Link et al. This is the first study of its kind; no known studies have examined the relationship between ostomy stigma and medical clinician communication, nor have previous stigma studies used Link and colleagues' devaluation and discrimination scale to examine ostomy stigma. The original scale was created to investigate mental illness stigma; I adapted the original scale to reflect statements pertaining to ostomy patients instead of mental patients. I discuss this in detail in the methods section.

Approximately one million people in the United States live with an ostomy, with roughly 100,000 ostomy surgeries performed annually (WOCN 2017). Indications for ostomy surgery are inflammatory bowel disease (IBD), cancer, trauma and other reasons. An individual with an ostomy is protected under the Americans with Disabilities Act (ADA) because of the life-changing nature of eliminating bodily fluids into a prosthetic device (i.e., ostomy appliance). Unlike many other medical procedures, ostomy surgery disrupts previous ways of living and impacts patients' self-image about their body (Black 2004). Living with an ostomy has been described as difficult (A. K. Danielsen et al. 2013), is associated with a number of negative health outcomes, such as lower quality-of-life (Erwin-Toth 1999; Grant et al. 2011; Popek et al.

[14] An ostomy is a surgically diverted bowel and/or bladder that allows bodily waste to be rerouted and evacuated through an opening on the abdomen, called a stoma.

[15] Stigma is defined as "an attribute that is deeply discrediting" (Goffman 1963:3) and often results in negative health effects (Chaudoir, Earnshaw, and Andel 2013; Major, Dovidio, and Link, 2018). Stigma is not only a pressing social issue that contributes to health disparities, but stigma also affects several disease outcomes (Major et al. 2018).

2010), higher morbidity and mortality (Sheetz et al. 2014), feelings of anxiety (Richbourg et al. 2007) and feelings of shame (Colman 2014).

Quantitative ostomy stigma studies have largely been conducted outside of the United States and these studies have used stigma measurement tools not designed with the social stigma of ostomies in mind. That is, scale statements do not mention ostomies specifically, but rather, they capture a general feeling of shame or avoidance. For example, Qin and colleagues (2020) and Xu and colleagues (2019) used the Social Impact Scale to examine ostomy stigma created originally for examinations of HIV or cancer patients' stigma; both studies found moderate levels of feelings of stigma relating to the ostomy in each of their Chinese ostomy patient samples. This 24-item scale includes statements, such as "I feel others think I am to blame for my illness" or "I feel I have been treated with less respect than usual by others." An older quantitative study on ostomy stigma conducted in the United Kingdom (MacDonald and Anderson 1984) used a stigma measurement tool that the authors created to investigate avoidance, self-conscious and unattractiveness feelings, and feelings about being different from others. They found significant associations between feelings of stigma and age (younger patients felt more stigma than older), gender (men felt more stigmatized than women), and presence of a colostomy (versus patients that were left with a functioning rectum). The five-item scale used in MacDonald and Anderson's study includes statements, such as "I avoid other people these days" or "I feel less attractive than I used to." While all three of these ostomy stigma studies provide us with valuable information about the general feelings of ostomy patients, the current study investigates ostomy stigma further by using ostomy-specific statements modified from Link and colleagues' (1997) devaluation and discrimination scale.

Other ostomy-related stigma quantitative work has examined colorectal cancer stigma (only 18% had an ostomy, (Phelan et al. 2013), IBD stigma (only 12% had an ostomy, (Taft et al. 2012), and the relationship between disgust sensitivity and the idea of being in close proximity to someone with an ostomy (Smith et al. 2007). Qualitative work on ostomy stigma has provided a deep understanding of what it is like living with an ostomy (Diebold 2016; Pınar et al. 2013), patients' experiences in everyday life (Savard and Woodgate 2008), and ways patients have tried to combat ostomy stigma (Frohlich and Zmyslinski-Seelig 2014; Rademacher 2018). The current study addresses gaps in the ostomy stigma literature by investigating the relationship between medical clinician communication and ostomy stigma by focusing on the social stigma surrounding ostomies, in particular.

BACKGROUND

Ostomy Stigma

Ostomy stigma stems from a cultural belief about what it means to have a nonnormative body, which occurs through a process of socialization. Cultural concepts of an ostomy appliance include a social taboo[16] pertaining to excreting bodily fluids (Black 2004; Briggs et al. 1977; Chelvanayagam 2014). This notion comes from a relationship between a threat of disease and intolerance of others——"the belief that other groups are impure and contaminating;" a "dread of parasite-borne disease, one consequence of deficient sanitation, appears to be a significant basis for prejudice…" (Haslam 2012:2). As a consequence of this taboo, people tend to keep the everyday practice of excretion "hidden and deeply private" (Haslam 2012:3). As this pertains to ostomy patients, they struggle with whether or when to disclose their stigma (Nicholas et al.

[16] A taboo is defined as "prohibition of an act, action, person, or object" (Chelvanayagam 2014).

2008). Of course, ostomy patients would be unable to conceal their stigmatized status when they interact with medical clinicians while at the hospital for ostomy surgery.

Ostomy Patients' Experiences in Healthcare

A majority of research studying ostomy patients' experiences in healthcare have focused on examinations of patients' understanding or level of adjustment to the ostomy appliance in relation to the type of instruction received at the hospital from nurses (e.g., reading materials, video tutorial) (Colwell and Gray 2007; Crawford et al. 2012; Haugen et al. 2006), and level of adjustment in relation to how often patients communicated with medical staff (Xu et al. 2019). To a smaller extent, studies have examined perceptions of the quality of ostomy care received (Persson et al. 2005), and ostomy patients' quality of life based on contact with an ostomy care nurse (Aronovitch et al. 2010). As such, very few studies have examined the impact of medical clinicians' communication with ostomy patients. The current study addresses this gap using patient-centered care and modified labeling theory as frameworks to examine the relationship between clinician communication with ostomy patients. By examining clinicians' communication with ostomy patients, we can begin to understand its impact on ostomy patients' health outcomes, and address ostomy stigma.

Patient-Centered Care and Communication

Patient-centered care (PCC) is considered to be the preferred clinician-patient interaction because it produces a meaningful exchange between parties (Roter and Hall 2006) and results in positive patient health outcomes (Epstein and Street 2011). PCC was formally recommended in 2001 by the Institute of Medicine (IOM)[17] and is defined as care that includes patients' perspectives, values and needs in decision making (Bertakis 2009; Street 2013). Clinician

[17] IOM has been renamed to Health and Medicine Division (HMD), a division of the National Academies of Sciences, Engineering, and Medicine (the National Academies).

communication that negatively impacts patient health outcomes would deviate from the essence of a PCC medical interaction, such as clinician communication that contributes to the stigmatization of patients. Examples of areas where clinician communication has contributed to patient stigma include: substance use stigma (Chang et al. 2016), lung cancer stigma (Hamann et al. 2014; Shen et al. 2016), and obesity stigma (Fruh et al. 2016).

Clinician communication refers to communication from multiple medical professions, such as nurses, surgeons or physicians, nurse's aide, and physician's assistant. In the current chapter, I focus on communication from nurses and surgeons and compare differences as they relate to ostomy patient stigma. Both nurses and surgeons are trained to provide patient-centered care to patients (Burney 2017; Newell and Jordan 2015). The interaction between nurses and patients is a "core component of nursing science and high quality nursing care" with the intention of interacting in a way that "influences the patient's health status and state of well-being" (Newell and Jordan 2015:78). The nurse-patient interaction relates to positive patient health outcomes, such as a significant relationship between nurse communication and patients' meaning-in-life (Haugan 2014). Similarly, the surgeon-patient interaction may also affect patient health outcomes, such as patient satisfaction or treatment adherence (Burney 2017), and physicians have a long history of holding a prestigious status and having high influence and authority (Parsons 1951; Starr 1982), especially as influence relates to patients (Roter and Hall 2006).

Modified Labeling Theory

The stigmatization process that occurs for patients is best explained by Link and colleagues' (1989, 1997) modified labeling theory (MLT), which was originally used to explain mental illness stigma. MLT is derived from Thomas Scheff's (1966) labeling theory. Scheff

hypothesized that negative consequences of a label[18] occur when others start treating the labeled person as if they have a stigmatized condition and in turn, the labeled person adopts the role associated with the stigmatized condition. Link and colleagues (1989) place emphasis on an individual's response to a labeled status based on his/her/their belief of how others will react. Link et al. (1989, 1997) hypothesize that negative consequences of a label occur because the labeled person has expectations of being rejected and in turn, they engage in coping behaviors, such as secrecy or withdrawal, that are ultimately detrimental to them, such as lower self-esteem, lower earning potential, or diminished social networks.

The modified labeling approach has *five main steps* in the MLT model (Figure 4.1). The five steps are broken into *three general components* of the stigmatization process (Link et al. 1997:179). The three general components of MLT include (1) the labeled person has "culturally induced expectations of rejection" (Step One of MLT) (2) the labeled person "experiences rejection" and the labeled status become personally relevant (Step Two of MLT), and (3) the labeled person makes an effort at coping with stigma as a response to their labeled status (Step Three of MLT). Steps Four and Five of the MLT Model demonstrate how the coping behaviors cause harm as a consequence (Step Four of MLT), and as a result, the labeled person is vulnerable to future or repeat disorders because of the harm caused by coping mechanisms (Step Five of MLT). I discuss each of the five main steps in detail below.

[Figure 4.1 here]

First, expectations of rejection are "culturally induced," which means that people learn about stigmatized identities, such as what it means to be mentally ill, through the process of

[18] Labeling is the application of a 'mark' on an individual seen as being deviant. Labeling can result in positive or negative consequences (Rosenfield 1997). Stereotypes, which are learned from childhood, are important to the labeling process (Fletcher and Reynolds 1967; Scheff 1966).

socialization and they have beliefs about being devalued and discriminated against (step one of MLT). Step one is what I examine in the current study and how medical clinician communication may impact it. Second, based on these cultural beliefs, individuals internalize what it means to be attached to a stigmatizing label (i.e., the meaning attached to the label becomes personally relevant, which is step two of MLT), and experiences rejection, such as "major exclusions to 'putdowns' and slights" (Link et al. 1997:179). In this step of MLT, Link et al. (1989) explain that the stigmatized person receives their official label through treatment contact (e.g., getting help for a mental illness or having ostomy surgery) and this is important because this official label "brings personal relevance to a labeled person's views about the attitude of the community toward mental patients" (p. 403) (or attitudes about ostomy patients, for instance).

The third step of MLT focuses on responses to the stigmatized status (step three of MLT). Link et al. (1997) outline responses for coping with stigma, which are secrecy, withdrawal, or educating others as a means of preventing stigmatization. Similar to someone with a mental illness who contemplates whether to conceal their diagnosis, ostomy patients may decide not to tell others that they have an ostomy (i.e., secrecy) (Chelvanayagam 2014). Withdrawal means that people may avoid interacting with others so that they do not face possible rejection, which has been demonstrated for people with inflammatory bowel disease (Taft et al. 2012), an indicator for receiving an ostomy. Finally, steps four and five of MLT explain consequences of the stigma process. For instance, the labeled person may experience negative outcomes such as higher levels of shame, lower self-esteem, limiting their life chances by having a lower-paying job or smaller social network due to a fear of interacting with people outside of their household. Step five of MLT explains that the resulting negative outcomes happen when steps one through four occur and as a result, the labeled person is susceptible to repeat episodes of a stigmatized

condition or is vulnerable to a new stigmatizing disorder.

Taken together, for illustrative purposes of ostomy patient stigma, an ostomy patient holds beliefs about being devalued or discriminated against by others because of the labeled status (step one), the labeled status becomes personally relevant to self when the patient seeks treatment or has ostomy surgery; the patient learned about this stigmatization through socialization (step two), the ostomy patient responds to this status through concealing their labeled identity (e.g., having an ostomy), not partaking in social interactions, or they attempt to educate others about ostomies as a way to mitigate the stigma attached to ostomies (step three). As a result, the patient experiences consequences of this stigma process, such as lower self-esteem or diminished social networks (step four) and is vulnerable to a new stigmatizing disorder or repeat of an existing disorder, such as subsequent issues with their ostomy or medical condition that caused them to have ostomy surgery initially (step five).

RESEARCH QUESTION

While I do not test MLT directly in the current study, MLT helps to understand the mechanisms at work when clinicians communicate with ostomy patients and how their communication may contribute to ostomy stigma. The interaction between clinician and patient is an exogenous variable to the MLT model. MLT predicts the patient's perspective and behaviors. I propose a modification to the MLT model to include an additional step for medical clinician interactions with patients (see Figure 4.2). This additional step could be considered Step .5 in the model—which would come right before step one (patients' stigma) in order to study the impact of medical clinician communication on ostomy patient stigma.

[Figure 4.2 here]

The research question being investigated in the current study is as follows: is there a

relationship between clinician communication and ostomy patients' stigmatization? Based on previous quantitative studies demonstrating a relationship between clinician communication and obesity stigma (Fruh et al. 2016), substance use stigma (Chang et al. 2016), and lung cancer stigma (Shen et al. 2016), I expect to find that clinician communication will significantly affect ostomy stigma. I examine both nurses' communication with ostomy patients and the patient's surgeon's communication in order to see if there are differences in the effect on ostomy stigma between actors. Considering that surgeons only see patients once or twice a day (ACS 2021b) and nurses have more opportunities to communicate with patients than the surgeon who performed the surgery, I expect that nurse communication will have a significant effect on ostomy stigma. On the other hand, even though surgeons may not have as much direct contact with patients as nurses who see patients, one could argue that surgeons' communication would also significantly impact ostomy stigma considering that physicians have held professional authority for decades (Parsons 1951; Starr 1982) and hold high influence in the medical interaction (Roter and Hall 2006).

METHODS AND DATA

Sample and data collection

I use original data that I collected from ostomy patients in 2019 between April and December. Using a non-probability approach, I contacted and sent a questionnaire link to 166 ostomy support groups affiliated with the United Ostomy Associations of America (UOAA), posted the questionnaire link on the UOAA's discussion board, and Facebook ostomy support groups. I also recruited through Twitter and meetanostomate.org discussion board. The majority of the questionnaire questions were closed-ended questions with a couple of open-ended

questions. The questionnaire was pre-tested by advanced doctoral students trained in methodology and it went through a number of revisions with the doctoral committee.

The questionnaire was self-administered by ostomy patients after respondents signed an online consent form. To be eligible to participate, respondents had to have an ostomy appliance, be 18 years old or older, and understand English well enough to fill out the questionnaire. I incentivized participation by providing participants the opportunity to enter a drawing for the chance to win one of fifteen $25.00 Amazon gift cards. The information collected for the drawing was not connected to the questionnaire so that participants would remain completely anonymous from their responses. The study and methods were approved by the University of Oklahoma, Approval #10615 on 04/11/2019.

A total of 353 ostomy patients filled out the questionnaire. Of this total, 315 ostomy patients are included in the current study. The excluded participants did not answer pertinent questions of interest in the current study; therefore, I do not include the excluded participants in any calculations reported. Analyses of the excluded participants show that they were similar in demographic characteristics to the overall patient characteristics in the study.

Variables

Stigma dependent variable. I conceptualize ostomy stigma as culturally induced beliefs about the extent to which ostomy patients feel they will be devalued and discriminated against because of their ostomy. I created and used a modified version of Link and colleagues' (1991) stigma scale. There are 13-items included in the scale (see Table 4.1 for the 13-scale items in order as they appeared on the questionnaire and the inter-item correlation Cronbach alpha scores, and see Appendix A for the comparison of Link and colleagues' scale and my modified version). The response choices ranged from one to six and were: strongly disagree (1), disagree, somewhat

disagree, somewhat agree, agree, and strongly agree (6). I reverse coded four statements so that all statements were in the same direction. I summed the 13 items and subtracted the variable from 12 so that one represented less stigma and 66 represented more stigma. Thus, the scale ranged from one to 66. Examples of the statements I used in the modified version are "Most people would willingly accept a person with an ostomy as a close friend," "Most people would have no problem being intimate with a person with an ostomy," and "Most people believe that a person with an ostomy is just as clean as the average person." The mean score of the ostomy stigma scale was 27.4 with a standard deviation of 11.2. The internal consistency was high with a Cronbach's alpha of .90.

In Table 4.1, I also present frequencies and percentages of the participants' agreement of each ostomy stigma item included in the modified scale. The percentages ranged from ten percent agreement to close to 75 percent agreement. A few notable findings—only 16 percent of the respondents agreed with the statement that most people would have no problem being intimate with a person with an ostomy; about a third (34%) of the respondents agreed with the idea that a person with an ostomy is just as dirty as the average person, and more than a third (36%) agreed with the idea that a person with an ostomy smells the same as the average person.

[Table 4.1 here]

Independent variables. Clinician communication was measured using a reliable and broadly used (Hays et al. 1999) clinician communication scale derived from the Agency for Healthcare Research and Quality, which is part of the Department of Health and Human Services in the United States. The survey name is called CAHPS® Clinician & Group Survey (AHRQ CAHPS 2020), Version 3.0 for the Adult Population and Language English. This is a tool used to examine medical clinician communication with patients.

I used 6-items for both the nurse communication scale and the surgeon communication scale; the only word changed between scales was the provider's designation (i.e., "nurse" and "surgeon"). I asked respondents to think about "the nurse at the hospital who cared for you and your ostomy after your surgery…" and to think about "the surgeon who did your ostomy surgery…" and then I asked respondents, (a) your hospital nurse (or surgeon) explained things in a way that was easy to understand, (b) your hospital nurse (or surgeon) listened carefully to you, (c) your hospital nurse (or surgeon) seemed to know important information about your medical history, (d) your hospital nurse (or surgeon) showed respect for what you had to say, (e) your hospital nurse (or surgeon) spent enough time with you, and (f) your hospital nurse (or surgeon) treated you with courtesy and respect. I provided a slider scale for the statements with answer choices ranging between zero (0) (never or less patient-centered) to 100 (always or more patient-centered). I summed the items together for each scale and divided by six to create an average index ranging from 0 to 100. The measure for both scales shows high internal consistency—The nurse communication scale had a mean of 72.7 (*SD*=26.2) with a .95 Cronbach's alpha. The surgeon communication scale had a mean of 81.7 (*SD*=22.3) with a .96 Cronbach's alpha.

Control variables. I use a number of control variables for patient demographic characteristics in the full models. These variables include self-reported patient race, gender, age, educational attainment, and number of years since ostomy surgery. Race was coded as white or nonwhite. Gender was coded as female or male. Age was a continuous variable, which ranged from 22 to 92 years old. Educational attainment was categorized as (a) high school degree or fewer years, (b) some college or Associate degree, (c) Bachelor's degree or Professional certificate, and (d) postgraduate degree, which includes a Master's degree or above. Number of

years since surgery ranged from zero years since surgery, from the time respondents filled out the study survey (2019), to 67 years since surgery.

ANALYSES

I first present descriptive statistics of the study sample. To test the research question, I present standardized coefficients from OLS regression models, both bivariate relationships and multivariate relationships for the association between nurses' communication and ostomy patient stigma and the association between surgeons' communication and ostomy patient stigma. I use OLS regression models instead of ordered logistic regression models because my dependent variable is normally distributed and the MLT scale that I am using is commonly treated as a continuous variable in the literature (Link et al. 1991; Mingus and Burchfield 2012; Ray and Dollar 2014); By using similar techniques to what others have done, I am able to draw comparisons to their work. Finally, I ran ordered logistic regression models for comparison and received similar results as the OLS regression models. All analyses were conducted using STATA 15.

RESULTS

Characteristics of the Study Sample

Table 4.2 shows frequencies and percentages of the demographic variables describing the patient sample. Three hundred fifteen (315) ostomy patients are included in the current study. The sample is largely women (71%), white (89%), with some college or more (88%). The sample is relatively older with a mean age of 55 years old. The mean years since ostomy surgery is ten years with 72% of the sample having had surgery within the last ten years. Less than a quarter of the sample (19%) had ostomy surgery outside of the United States; the majority of this subsample had surgery in the United Kingdom (42%), Canada (30%), and elsewhere. Reasons

for ostomy surgery ranged from inflammatory bowel disease (IBD) (33%), cancer (29%), and other reasons (these categories are not mutually exclusive since respondents could choose more than one reason for surgery).

I also assessed the percentage of patients who perceived high ostomy stigma (top 75%), moderate ostomy stigma (middle), and low ostomy stigma (bottom 25%) and found that almost three-quarters (74%) of participants scored above the midpoint of 28. In other words, three-quarters reported moderate to high ostomy stigma with only a little more than a quarter (26%) of the sample reporting low ostomy stigma.

[Table 4.2 here]

Descriptives of the Key Variables

Table 4.3 provides descriptive statistics for the dependent variable and the key independent variables. The stigma scale (dependent variable) ranged from 1 (low stigma) to 66 (high stigma), with a median of 28 and a mean of 27.4 (*SD* = 11.2). As mentioned above, only a quarter of the sample reported low ostomy stigma.

The nurse communication scale ranged from zero (low patient-centered) to 100 (high patient-centered), with a median or midpoint of 81 and a mean of 72.7 (*SD* = 26.2). Half of the sample (50%) reported patient-centered nurse communication above the midpoint of 81, and only 13% of the sample reported nurse communication as 100/100 (high patient-centered).

The surgeon communication scale ranged from three (low patient-centered) to 100 (high patient-centered), with a median or midpoint of 91 and a mean of 81.7 (*SD* = 22.3). Surgeon communication was rated similarly to nurse communication with almost half of the sample (49%) reporting patient-centered surgeon communication above the midpoint of 92. A little more than a quarter of the sample (28%) rated surgeon communication as 100/100; as mentioned

above, only 13% of the sample rated 100/100 for nurse communication. The *Z*-test for the analysis of differences in ratings shows a statistically significant difference between rated nurse and surgeon communication (z = -4.64, p = .000).

[Table 4.3 here]

Ostomy Patient Stigma and Clinician Communication

The research question being investigated is whether there is a relationship between clinician communication and ostomy patients' stigmatization. I examined both nurses' communication with ostomy patients and surgeons' communication with ostomy patient stigma. Table 4.4 presents standardized coefficients from OLS regression models, both bivariate relationships and multivariable relationships where I control for patient demographic characteristics. Standardized coefficients positions measurement units on the same scale in standard deviation units (Menard 2004; Wooldridge 2013). Using standardized coefficients in OLS regression models is more meaningful than unstandardized coefficients because it allows for comparisons to be drawn between independent variables (Wooldridge 2013).

I found statistically significant relationships between clinician communication and ostomy patient stigma. In the bivariate nurse model (Model 1), I found that as nurse communication becomes more patient-centered, ostomy patient stigma decreases by 0.23 ($P \leq .001$). The direction and effect of this association remains the same in Model 2 (the nurse full model) where I control for patient demographic characteristics. Another notable finding in Model 2 is a significant relationship between years since surgery and ostomy stigma. That is, as years progress in time, ostomy stigma decreases ($P \leq .05$). This is not surprising considering that the longer you have an ostomy appliance, the more likely you are to adjust to the change in the body and new lifestyle.

I found similar relationships in the surgeon models as I found in the nurse models, though the magnitude was slightly smaller in the surgeon models than nurse models. The directions were the same and all models achieved statistical significance. Specifically, the bivariate surgeon Model 3 achieved significance at $P \leq .01$. Model 4 is the full model for surgeon communication and ostomy patient stigma, controlling for patient demographic characteristics. The direction remains the same in Model 4 and achieved statistical significance at $P \leq .001$. Interestingly, years since surgery achieved statistical significance at $P \leq .01$ in the surgeon full model. Comparing the surgeon models (Model 3 and 4), I found a slight magnitude difference between the two models and the effect is larger in Model 4.

Models 5 and 6 are bivariate and full models, respectively, with nurse communication and surgeon communication included. The directions of the coefficients remained the same and nurse communication stayed statistically significant in each model. Notably, surgeon communication in Model 5 did not achieve significance and only achieved marginal significance in the full model (Model 6).

Comparing model fit (*R-squared*) between Model 2 (nurse communication) and Model 4 (surgeon communication), I found that the nurse *R-Squared* is slightly higher than the surgeon model. *R-squared* (multiplied by 100) is the percentage of the sample variance in the dependent variable that is explained by the independent variable (Wooldridge 2013:38); the *R-squared* is a valid goodness-of-fit measure that explains how well the model fits the data where a value equal to zero indicates a poor model fit and a one indicates a perfect fit (Wooldridge 2013).

I conducted an *F*-test for the restricted nurse model (Model 1) compared to the unrestricted model (Model 5), calculating the increment to *F* (also referred to as increment to *R-squared*) to see if the difference between the nurse and surgeon communication is significant. I

found no significant difference (*F-statistic* = 1.64, p = .20), indicating that surgeon communication does not contribute significantly to the model beyond nurse communication. I also conducted the F-test for the models with patient controls (Models 2 and 6). Again, I found no significant difference, although the p-value was marginally significant (*F-statistic* = 2.85, p = .09), which indicates that surgeon communication does not contribute significantly to the model beyond nurse communication and patient control variables.

[Table 4.4 here]

DISCUSSION AND CONCLUSION

Close to three-quarters (74%) of the ostomy patients in the current study reported moderate to high feelings of ostomy stigma. Previous work using different measurement tools to examine ostomy stigma found comparable results. Using the discrimination-devaluation scale from Link and colleagues (1991) as part of the modified labeling theory, I created a modified version to examine ostomy stigma, which is the first ostomy-specific stigma scale of its kind. Using this modified stigma scale, I examined the association between medical clinician communication and ostomy patient stigma for both nurse communication and surgeon communication. Results demonstrate a highly significant and negative relationship between clinician communication and ostomy patient stigma. That is, as medical clinician communication becomes more patient-centered (for nurses or for surgeons), ostomy patient stigma decreases. Other notable findings included a significant association between years since ostomy surgery and a decrease in ostomy stigma the longer the patient has had the appliance.

While the current study offers a new tool to measure ostomy stigma, and the findings answer important questions about ostomy stigma and the role of clinician communication, the study has limitations that we should consider. The sample is nonprobability, which makes it

difficult to know whether the findings are representative of other ostomy patients' perspectives about stigma and experiences with medical clinicians. The sample is also a majority white and female. Future studies on ostomy stigma need to include a more diverse sample of ostomy patients. There are no known studies that have been conducted in the United States on the experiences of patients of color with medical clinicians. Also, ostomy patients answered questions retrospectively, which could introduce a bias in their recall (remembering their experiences are better or worse than they actually were) (Blome and Augustin 2015). To address this potential issue, I controlled for the number of years since surgery in the multivariate regression models. Future studies, however, should examine these issues prospectively, and while patients are at the hospital for ostomy surgery. Future studies could also assess ostomy stigma and medical clinician communication immediately after discharge from the hospital.

In conclusion, this study demonstrates that medical clinician communication matters for ostomy patients' health outcomes. Medical clinician communication is significantly associated with ostomy patient stigma. Future research should investigate mechanisms contributing to differences in medical clinician communication for ostomy patients. A majority of ostomy patients feel stigmatized because of their appliance. Studies should examine ostomy stigma as predicted by the modified labeling theory, such as the endorsement of coping mechanisms of education, withdrawal and secrecy in response to their stigmatized status. Also, an examination of the role of clinician communication on patients' endorsement of coping mechanisms would also be valuable information and a step toward addressing ostomy stigma. Finally, future work should investigate the relationship between medical clinician communication with ostomy patients further in order to test other consequences of clinician communication with ostomy patients, such as feelings of lower self-esteem or demoralization.

Tables and Figures for Chapter 4

Table 4.1. Miller-Modified Version of Link and Colleagues' Stigma Scale for Ostomy Stigma, Cronbach alphas, and Frequencies (n = 315)

			Strongly Agree and Agree	
	Direction	Inter-Item Correlation alpha	*N*	*%*
1. Most people would willingly accept a person with an ostomy as a close friend.	+	.906	224	71.1
2. Most people would have no problem being intimate with a person with an ostomy.	+	.899	53	16.7
3. Most people believe that a person with an ostomy smells the same as the average person.	+	.902	114	36.1
4. Most people would treat a person with an ostomy just as they would treat anyone.	+	.898	157	49.7
5. Most people would accept a person with an ostomy to serve or cook food in a restaurant.	+	.899	153	48.5
6. Most people believe that a person with an ostomy is just as clean as the average person.	+	.895	153	48.5
7. Most people would be willing to help a person with an ostomy if they needed help.	+	.905	146	46.2
8. Most people would have no issues with inviting a person with an ostomy into their home.	+	.900	235	74.6
9. Most people would be reluctant to date a person with an ostomy.	-	.903	84	26.6
10. Most people would be reluctant to marry a person with an ostomy.	-	.902	70	22.2
11. Most people believe that having an ostomy makes a person less attractive.	-	.901	87	27.6
12. Most people think less of a person who has an ostomy.	-	.900	34	10.8
13. Most people believe that a person with an ostomy is just as dirty as the average person.	+	.912	109	34.6
Test Scale Alpha Score		**.909**		

Table 4.2. Patient Characteristics in the Sample (n = 315)

	N	*%*
Gender		
Female	224	71
Male	91	29
Race		
White	283	89
Non-White	32	11
Education		
Completed H.S. or less	36	12
Completed Associate's	105	33
Completed Bachelor's	101	32
Completed Postgraduate	73	23
Age *(mean= 55 years)*		
18 – 25 years	6	2
26 – 35 years	29	9
36 – 50 years	65	21
51 – 65 years	111	35
66 years or older	104	33
Years Since Surgery *(mean = 10 years)*		
Non-US ostomy patients in the sample	60	19
Reason for Ostomy Surgery		
IBD Only	106	33
IBD Plus One or More Reasons	122	38
Cancer Only	94	29
Cancer and Other Reasons	100	32
Other Reasons	97	30

Table 4.3. Descriptive Statistics for the Dependent Variable and Key Independent Variables (n = 315)

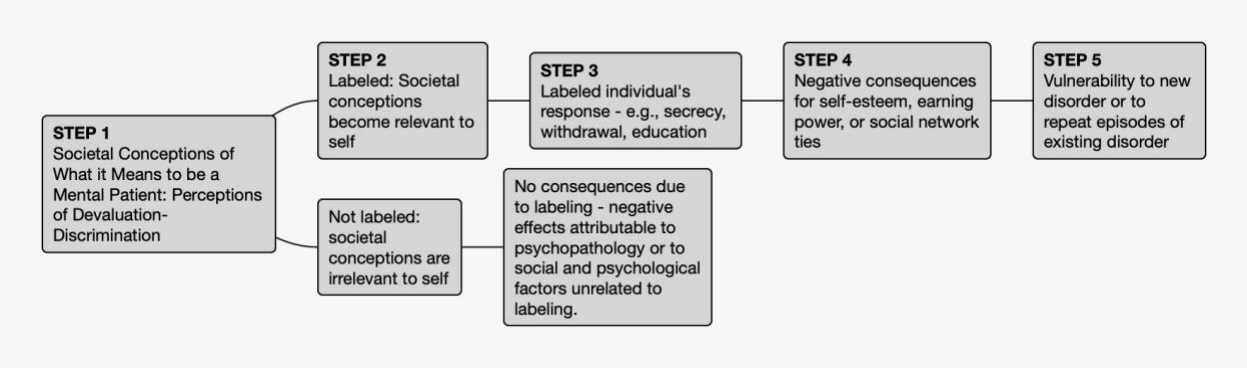
	Stigma Scale	Nurse Communication Scale	Surgeon Communication Scale
Scale Statistics			
Median	28	81	91.6
Mean	27.4	72.7	81.7
Standard Deviation	11.2	26.2	22.3
Minimum	1	0	3
Maximum	66	100	100

Table 4.4. OLS Regression Predicting Ostomy Stigmatization by Patient-Centered Nurse and Surgeon Communication (n = 315)

	Nurse Model 1	Nurse Full Model 2	Surgeon Model 3	Surgeon Full Model 4	Nurse / Surgeon Model 5	Nurse / Surgeon Model 6
Clinician Communication						
Patient-Centered Nurse Communication	-0.23***	-0.23***			-0.19***	-0.19**
Patient-Centered Surgeon Communication			-0.16**	-0.18***	-0.08	-0.10†
Patient Characteristics						
Education (post-graduate degree as reference)						
Completed H.S. or less		0.01		0.05		0.02
Completed Associate's		-0.08		-0.05		-0.08
Completed Bachelor's		-0.07		-0.05		-0.07
Race - White		-0.07		-0.08		-0.07
Gender - Female		-0.10†		-0.08		-0.10
Age		-0.11†		-0.11†		-0.11†
Years Since Surgery		-0.13*		-0.15**		-0.14**
R-squared	*0.05*	*0.10*	*0.02*	*0.08*	*0.05*	*0.10*

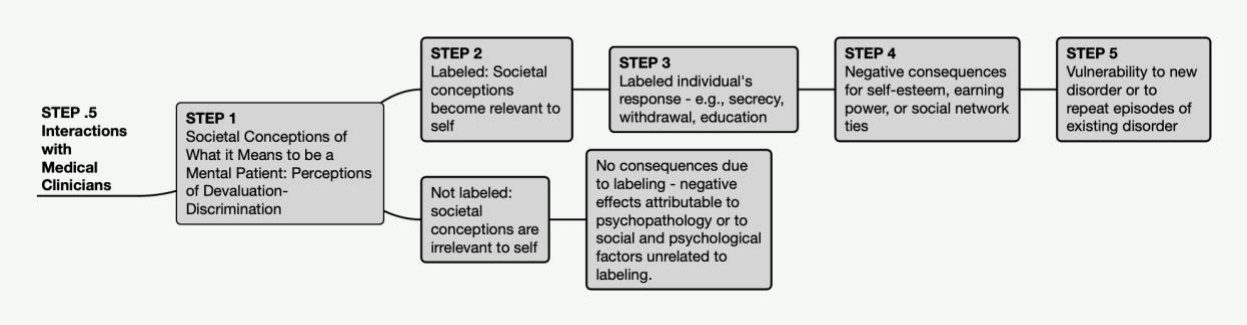
†p≤.10 *p≤ 0.05; ** p≤0.01; *** p≤ 0.001
Note: coefficients are standardized

Figure 4.1. Modified Labeling Theory Map



Source: Link and colleagues (1989)

Figure 4.2. Modified Version of the Modified Labeling Theory Map



Chapter 5: Conclusion

This dissertation examined the role of medical clinician communication in ostomy patient health outcomes. Each chapter focused on different aspects of medical clinician communication. I used patient-centered care as a baseline for quality of medical clinician communication, which is care that includes the patient in decision-making, taking the patients' needs, wants and values into consideration. Chapter 2 quantitatively assessed whether medical clinician communication adequately prepared ostomy patients to care for their new appliance, and whether the quality of communication differed by patient demographic characteristics. Using a triangulation of methods (quantitative and qualitative), Chapter 3 investigated whether ostomy patients experienced stigmatizing sentiments from medical clinicians. Finally, chapter 4 further assessed ostomy stigma by examining whether there was a quantitative relationship between medical clinician communication and ostomy patient stigma. In the coming paragraphs, I briefly describe and summarize the findings in each of these studies. Table 5.1 shows a summary of all of the research questions and findings. I conclude with a discussion on the implications of the findings in this dissertation.

[Table 5.1 here]

Summary of Studies and the Findings

Chapter 2: An Examination of the Quality of Medical Clinician Communication with Ostomy Patients. The first study, detailed in chapter 2, examined the quality of medical clinician communication with ostomy patients after surgery, and whether there were differences by ostomy patient race, gender, age, or educational attainment. Previous studies have demonstrated the important role that medical clinicians play in patient health outcomes. However, there are no known studies examining the impact of medical clinician communication on ostomy patient

health outcomes. I found that only a little over half (53%) of patients rated clinician communication as adequate, which is low in comparison to other measures of clinician communication showing that patients are generally satisfied with their medical care (Macadam et al. 2010; Peck 2011). I examined the categories of inadequate clinician communication and found that the highest percentage category was not receiving pre-operative information about what to expect after surgery, or not receiving information that they needed or wanted, and patients reported not being informed about the ostomy appliance products available to them. I also found that high school education is significantly related to reported adequate clinician communication. That is, ostomy patients with a high school degree or fewer years of schooling were significantly more likely to report receiving adequate communication compared to ostomy patients with a post-graduate degree. This finding supports previous research showing a relationship between patients with lower-socioeconomic status and rating clinicians' communication as high or having higher trust in their clinician (Coats et al. 2018). The inverse relationship of education may relate to patient health literacy[19], which has been shown to be related to educational attainment and age (Sorensen et al. 2012). On the other hand, the findings could be related to patients' expectations; there is a growing demand for quality health care in more recent years (AHRQ 2018) and expectations in care received is increasing (Lateef 2011). Perhaps ostomy patients in the sample with higher educational attainment are expecting more from their medical clinicians and less educated ostomy patients in the sample.

Chapter 3: Marginalization in the Medical Encounter: Ostomy Patients Experiencing Stigmatizing Sentiments from Medical Clinicians. The second study, detailed in chapter 3, assessed whether ostomy patients experienced stigmatizing sentiments from their medical

[19] Health literacy is an individual's ability to "process, and understand the basic health information and services they need to make appropriate health decisions" (Shim 2010:6).

clinicians. I used triangulation (both quantitative and qualitative) to answer this question. Stigma is a pressing social issue that contributes to health disparities. Only a couple known studies have examined ostomy patient stigma (Qin et al. 2020; Smith et al. 2007); no known studies have examined the role of medical clinician communication on ostomy patient stigma. Ostomy stigma is rooted in a social taboo regarding the excretion of bodily fluids and the cultural conception of a body that is 'clean and pure;' an ostomy appliance alters the body in such a way that violates this norm (Black 2004; Briggs et al. 1977; Chelvanayagam 2014; Haslam 2012). I found that 11% of respondents reported that medical clinicians communicate with them in ways that are stigmatizing, such as showing visible signs of disgust because of the ostomy, treating the patient as less than human, or verbally saying stigmatizing sentiments. Several subthemes were identified as they related to medical clinicians' communication and I detail these themes in chapter 3 and provide quotes from patients. These findings demonstrate a departure from patient-centered care and contribute to ostomy patients' feelings of stigmatizing.

Chapter 4: The Role of Medical Clinician Communication in Ostomy Patient Stigma. In the third study, detailed in chapter 4, I investigate the relationship between medical clinician communication and ostomy patient stigma from a quantitative perspective. I also provide a newly created, first of its kind, ostomy-specific stigma scale to examine this relationship. I found that almost three-quarters of the respondents (74%) reported moderate to high feelings of ostomy stigma. I also found a significant and negative association between medical clinician communication and ostomy patient stigma. That is, as the quality of medical clinician communication increases, ostomy patient stigma decreases. Both nurse communication and surgeon communication were significantly related to ostomy patient stigma. The comparisons between nurse and surgeon communication shows that the nurse *R-squared* is slightly higher

than the surgeon *R-squared*, and the *F-test* found no significant difference between nurse and surgeon communication, indicating that surgeon communication did not contribute significantly to the model beyond nurse communication.

Implications of Findings

Delivering quality health care is one of the three main goals of the United States' healthcare system (Budrys 2016). The Agency for Healthcare Research and Quality (2017) outline elements that reflect 'quality health care'-- care that increases positive health outcomes, effectiveness, efficiency, equity, patient-centeredness, safety and timeliness. Patient-centered care is considered the optimal type of patient care because it produces not only a meaningful exchange between clinician and patient (Roter and Hall 2006), but also it consists of communication between clinician and patient aimed to include the patient's perspectives, values, and involve the patient in decision making (Street 2013). Lower quality health care has been cited as a reason why health disparities exist (AHRQ 2017; Smedley et al. 2003).

In the dissertation I examine quality health care as it relates to ostomy patient care and whether clinicians deviate from patient-centered care or are in-line with a patient-centered approach. I found that ostomy patients experience care that is not in line with patient-centered care. Specifically, ostomy patients need better quality clinician communication after surgery so that they are adequately prepared to care for their new appliance, adjust to their new lifestyle, and the change to their body. The interaction between medical clinicians and ostomy patients has a tangible impact on ostomy patients when clinicians say or do something that makes the patient feel bad about their ostomy. These negative feelings may result in patients withdrawing from the social world, and having a diminished social network (Link et al. 2001). The findings help to understand ostomy patients experiences with medical clinicians, but also, the findings can help to

inform hospital processes and clinician-patient interactions, as well as address and ameliorate ostomy patient health disparities.

In addition, chapter 4 also contributed to the literature on modified labeling theory (MLT), using MLT as a guide to understand the cultural conceptions of what it means to have a labeled status, such as an ostomy, for this patient cohort. I provide a newly created ostomy-specific stigma scale to assess ostomy patient stigma in various settings. Previous ostomy stigma research used non-ostomy specific measurement tools to assess ostomy stigma, which provided a narrow understanding of ostomy patients' feelings about their new identity. The ostomy-specific scale that I created can be used broadly and, in many settings, from medical encounters to ostomy patients' everyday experiences. I examined whether there was a relationship between patients' feelings of stigmatization and how clinicians communicate with ostomy patients. I found a significant relationship here; when clinicians deliver high-quality communication (i.e., patient-centered care), ostomy stigma decreases. This finding will help move forward the care that ostomy patients receive, and, I hope, eliminate ostomy stigma.

Tables for Chapter 5

Table 5.1. Summary of Research Questions and Results

Research Questions	Result
Chapter 2	
1. Do ostomy patients receive quality communication from medical clinicians while at the hospital?	Yes, although only slightly
2. Does the quality of clinician communication differ by ostomy patients' demographic characteristics?	Yes, by education
Chapter 3	
1. Do ostomy patients experience stigmatizing sentiments from medical clinicians after ostomy surgery?	Yes, 11% of the sample
Chapter 4	
1. Is there a quantitative relationship between clinician communication and ostomy patient stigma?	Yes, a significant and negative relationship for both nurse and surgeon

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Appendix A: Perceived Devaluation/Discrimination Stigma Scale

Appendix A. Perceived Devaluation/Discrimination Stigma Scale	
Link et al.	Most people would willingly accept a former mental patient as a close friend.
Miller	Most people would willingly accept a person with an ostomy as a close friend.
Link et al.	Most people would accept a fully recovered former mental patient as a teacher of young children in a public school.
Miller	Most people would accept a person with an ostomy to serve or cook food in a restaurant.
Link et al.	Most people think less of a person who has been in a mental hospital.
Miller	Most people think less of a person who has an ostomy.
Link et al.	Most people in my community would treat a former mental patient just as they would treat anyone.
Miller	Most people would treat a person with an ostomy just as they would treat anyone.
Link et al.	Most women would not marry a man who has been a patient in a mental hospital.
Miller	Most people would be reluctant to marry a person with an ostomy.
Miller	Most people would be reluctant to date a person with an ostomy.
Miller	Most people would have no problem being intimate with a person with an ostomy.
Miller	Most people believe that having an ostomy makes a person less attractive.
Remainder of the statements that I included:	
	Most people believe that a person with an ostomy smells the same as the average person.
	Most people believe that a person with an ostomy is just as clean as the average person.
	Most people would be willing to help a person with an ostomy if they needed help.
	Most people would have no issues with inviting a person with an ostomy into their home.
	Most people believe that a person with an ostomy is just as dirty as the average person.

Note: I do not list all of Link et al.'s scale statements above; I list those that I based my statements from. I excluded seven of their statements, and instead, I created statements pertaining to close contact with an ostomy patient. Also, the above statements are not in the order that I placed them on my questionnaire; see Table 4.1 for the ordering of the statements and alpha score.

Appendix B: Survey Instrument Phase One

Would you like to be involved in research at the University of Oklahoma?

I am Leslie Miller from the University of Oklahoma's Department of Sociology and I invite you to participate in my research project entitled Peoples' Experiences With Pouches (P.E.W.P.) Study. This research is being conducted at your local ostomy group meeting. You were selected as a possible participant because you have an ostomy. You must be at least 18 years of age to participate in this study. Participants are anyone with an ostomy over the age of 14. For participants under the age of 18, parents will have to consent prior to participation.

Please read this document and contact me to ask any questions that you may have BEFORE agreeing to take part in my research.

What is the purpose of this research? The purpose of this research is that we are interested in understanding the mechanisms of issues that impact people with ostomies. We are gathering data on experiences and obstacles that ostomates face in their everyday lives. We examine perceptions of medical provider communication, and patient education upon receiving the pouch, as well as obstacles at work or school. Short-term goals for this project are gaining a deeper understanding of how ostomates process and adapt to living with the pouch. Long-term goals for this project are policy implications, such as the installation of shelves in bathroom stalls, and/or changes to discharge procedures from hospitals.

How many participants will be in this research? About 200 people will take part in this research.

What will I be asked to do? If you agree to be in this research, you will fill out a questionnaire.

How long will this take? Your participation will take approximately 15 minutes.

What are the risks and/or benefits if I participate? There are no risks and no benefits from being in this research.

Will I be compensated for participating? You will not be reimbursed for your time and participation in this research.

Who will see my information? In research reports, there will be no information that will make it possible to identify. Research records will be stored securely and only approved researchers and the OU Institutional Review Board will have access to the records.

Data are collected via an online survey system that has its own privacy and security policies for keeping your information confidential. Please note no assurance can be made as to the use of the data you provide for purposes other than this research.

Do I have to participate? No. If you do not participate, you will not be penalized or lose benefits or services unrelated to the research. If you decide to participate, you don't have to answer any question and can stop participating at any time.

Who do I contact with questions, concerns or complaints? If you have questions, concerns or complaints about the research or have experienced a research-related injury, contact me at lamiller@ou.edu or (405) 325-1751 (office). Also, feel free to write comments on the survey (if in paper form) or in the boxes (for the online survey) if you would like to do so. You may also contact the PI, Dr. B. Mitchell Peck at bmpeck@ou.edu or (405) 325-1751 (office).

You can also contact the University of Oklahoma – Norman Campus Institutional Review Board (OU-NC IRB) at 405-325-8110 or irb@ou.edu if you have questions about your rights as a research participant, concerns, or complaints about the research and wish to talk to someone other than the researcher(s) or if you cannot reach the researcher(s). IRB Number: 8040. Approval date: 5/5/2017

Please print this document for your records. By providing information to the researcher(s), I am agreeing to participate in this research.

o I agree to participate (1) o I do not agree to participate
You must be 18 or older to participate.
o I am aged 18 or older (1) o I am under aged 18

Today's date _____

1. **When did you receive your ostomy? _____**
   (month/year)

2. **What type of ostomy do you have? (select all that apply)**

   Colostomy
   Ileostomy
   Urostomy
   Other (please specify): _____

3. **What was the reason you received an ostomy? (select all that apply)**

   Inflammatory bowel disease (IBD, such as: ulcerative colitis or Crohn's disease)
   Cancer
   Trauma or accident
   Other (please specify): _____

4. **What is the name of the hospital where you received your ostomy? _____**

5. **What is your gender? _____**

6. **What is your age? _____**

7. **What city and state do you currently live in? (If you're outside of the USA, in what country do you reside?) _____**

8. **What is your ethnic or racial background?**

   Hispanic White
   Hispanic Black
   American Indian or Alaska Native
   Black/African American
   Asian
   White/Caucasian
   Native Hawaiian or Other Pacific Islander
   Other (please specify): _____

9. **What is the highest level of education that you have completed? (select one)**

   Completed some high school
   Completed some postgraduate
   High school graduate

Master's degree
Completed some college
Doctorate (non-medical; e.g., Ph.D., J.D.)
Trade/vocational certification
Doctorate (medical; e.g., M.D., D.O., DNP)
Associate degree
Bachelor's degree
Other (please specify): _____

10. **What is your marital status? (select one)**

    Married
    Never married
    Divorced or Separated
    Not married, but living with partner
    Widowed/Widower

11. **Think of how you handle the emotional aspect of living with a pouch. Do you have someone in your life who helps you emotionally with this? (select all that apply)**

    Yes, spouse
    Yes, pets (e.g., dog, cat)
    Yes, parent or mother/father in-law
    Yes, online support group(s)
    Yes, partner (girlfriend, boyfriend)
    Yes, local face-to-face support group(s)
    Yes, friend
    Yes, sibling or other relative
    Yes, other (please specify): _____
    No, I do not have anyone who helps emotionally

12. **How difficult is it for you to live on your <u>total</u> household income right now? (select one)**

    Not at all difficult
    Very difficult
    Somewhat difficult
    Extremely difficult or impossible
    Difficult or can barely get by

13. **How many times in the <u>last six months</u> have you been to the doctor for any reason?**

    Zero
    1-5
    6-10
    11-20
    More than 20 times

The following questions are about when you <u>first received your ostomy</u> (whether temporary or permanent), while still at the hospital.

14. **Which medical provider gave you <u>initial</u> instructions regarding how to care for your ostomy? (select one)**

    Nurse – Ostomy-specific (aka ET Nurse)
    Nurse Practitioner (NP)
    Physician's Assistance (PA)
    Physician
    Non-nurse ostomy/wound technician
    Other (please specify): _____
    Do not know

15. **What method of instruction did you receive regarding how to care for your ostomy? (select all that apply)**

    Hands-on instruction
    Video tutorial
    Reading materials
    Other (please specify): _____

16. **To what extent do you feel the medical provider's instruction helped your ability to take care of your ostomy once at home? (select one)**

    Helped a lot
    Helped a little
    Did not help at all

17. **Was there anything that <u>the medical staff</u> could have done to make you feel better prepared to take care of your ostomy at home? (even if the instruction helped from the provider above)**

    [text box here]

18. **If you expressed concerns, did the medical provider offer you guidance on those concerns?**

    No
    Yes
    Do not know
    N/A – did not express any concerns

19. **Did the medical provider give you information about support groups in your area and/or online resources?**

    No
    Yes
    If no, I would have liked them to
        ---------> Yes
        ---------> No

20. **Did the medical provider give you information about whom you should contact once you were released from the hospital if you had any questions/issues?**

    No
    Yes

Do not know

21. **Did the medical provider address any of the following matters with you about your ostomy? (select all that apply)**
    Medical concerns
    Preoperative education (e.g., review surgery, expected results, appliance introduction)
    Gas/odor management
    Intimacy concerns
    Signs of potential complications
    Other (please specify): _____
    Tips to fix any complications
    None of the above

22. **Before you left the hospital, did the medical provider supervise you as you changed your appliance for the first time?**

    No
    Yes
    Do not know

23. **Is there anything else that you would like to share regarding your interaction with medical personnel when you first received your ostomy?**
    [text box here]

Still thinking about the medical provider who gave you initial instructions regarding how to care for your ostomy. (select what best represents your feelings).

[How strongly do you agree/disagree…1-7 strongly disagree(1), disagree, somewhat disagree, neither agree nor disagree, somewhat agree, agree, strongly agree(7)]

24. The medical provider was polite to me.
25. I was satisfied with how the medical provider treated me.
26. Sometimes the medical provider made me feel like my ostomy disgusted them.
27. The medical provider made me feel less like a human because of my ostomy.

Now, tell me about your feelings regarding your pouch. (select what best represents your feelings)

[How strongly do you agree/disagree…1-7 strongly disagree(1), disagree, somewhat disagree, neither agree nor disagree, somewhat agree, agree, strongly agree(7)]

28. When I <u>first received</u> my ostomy, I felt fearful about doing normal activities because of my ostomy.
29. <u>Currently</u>, I still feel fearful about doing normal activities because of my ostomy.
30. What things did/do you fear doing because of your ostomy?
    [text box here]

Now, tell me about your experiences/feelings about day-to-day life with a pouch. (select what best represents your feelings)

[How strongly do you agree/disagree…1-7 strongly disagree(1), disagree, somewhat disagree, neither agree nor disagree, somewhat agree, agree, strongly agree(7)]

31. When I first received my ostomy, I felt feelings of shame because of my ostomy.
32. Currently, I still feel feelings of shame because of my ostomy.
33. Upon release from the hospital, I felt prepared to care for my new ostomy.
34. I don't travel as much because of the hassle of having the ostomy to worry about.
35. I find it difficult to take care of my pouch while at work or school (e.g., changing it, emptying it).

Now, tell me how helpful the following would be with living with your ostomy. (select what best represents your feelings)

36. Having a shelf in a bathroom stall to set your equipment on.
37. Having a flexible schedule at work or school.
38. Being able to work from home or attend class from home.
39. Having a private bathroom at work or school.
40. During the hospital stay, having had an ostomate visit you so you could ask questions and gain insight from a fellow ostomate.
41. Upon release from the hospital, having a way to keep in contact with the medical professional in case you have questions about your ostomy.
42. Upon release from the hospital, being connected to a local or online support group.
43. Upon release from the hospital, having someone from a local ostomy support group contact you.
44. Other (please specify) _____

45. **Have you experienced anything at work or school with your ostomy that made you feel uneasy?**
    No
    Yes
    If yes, what happened that made you feel uneasy? [text box here]

46. **Have you ever missed work or school because of issues with your ostomy (whether it be for emotional reasons or physical reasons)?**
    No
    Yes
    If yes, please explain what happened and any negative consequences you may have experienced.
    [text box here]

47. **In general, what (if any) obstacles have you experienced regarding your pouch?**
    [text box here]

48. **Is there anything else that you would like to share about your experiences with your pouch?**
    [text box here]

Lastly, here are some final questions about *yourself*.

49. **How likely are you to actively seek medical information when a medical issue directly affects you? (for examples: online sources, books) (select one)**

Unlikely
Extremely unlikely
Neutral
Likely
Extremely likely

50. **How likely are you to ask a medical provider questions when you have any? (select one)**
    Unlikely
    Extremely unlikely
    Neutral
    Likely
    Extremely likely

51. **On a scale of 1 to 10, how confident are you in making your own health decisions? (choose one)**
    [1-10, 1=not at all confident, 5= neutral, 10=very confident]

52. **On a scale of 1 to 10, how strongly do you agree with the statement "I feel like I go to the doctor many more times, overall, than the average person." (choose one)**
    [1-10, 1=strongly disagree, 5= neutral, 10=strongly agree]

53. **Do *you* – or – an immediate family member (including significant others) work in the medical field/health care industry?**
    No
    Yes
    If yes, what is the occupation? _____

54. **Do you personally have any medical or health care training?**
    No
    Yes
    If yes, what is the occupation? _____

55. **With regard to paying for your ostomy supplies, are they a significant financial burden for you?**

    No, my insurance covers all the costs
    No, I receive help from others to pay
    No, my insurance covers most of the costs
    Yes, I somewhat have issues affording
    No, I receive supplies from a local organization
    Yes, I have an extremely difficult time affording

56. **Do you consider yourself to be: (select one)**
    Heterosexual or straight
    Gay or lesbian
    Bisexual
    Other (please specify) _____

Thank you so much for your time.

END OF QUESTIONNAIRE - ***Thank you very much for your participation!***

Appendix C: Survey Instrument Phase Two

PEWP2 - Peoples' Experiences With Pouches Phase II

I am Leslie Miller from the University of Oklahoma's Department of Sociology and I invite you to participate in my research project entitled Peoples' Experiences With Pouches (P.E.W.P.) Study Phase II. You were selected as a possible participant because you have an ostomy. You must be at least 18 years of age to participate in this study, and read and understand English.

Please read this document and contact me to ask any questions that you may have

BEFORE agreeing to take part in my research.

The purpose of this research is to understand issues that impact people with ostomies, especially as it relates to ostomy patients' experiences at the hospital when they received the ostomy. We are also interested in understanding your general perceptions about health and culture.

How long will this take? It will take approximately 25 minutes to complete the questionnaire. How many participants will be in this research? There will be about 3,000 people who will take part in this study.

Do I have to participate? No, your participation is voluntary and your responses are confidential. Even if you decide to participate, you can stop participating at any time.

What are the risks or benefits? Although we do not anticipate any risks, recalling your ostomy negative experiences may be upsetting. Should you experience any of these risks while participating, please contact your local ostomy support group or nurse in your area or please contact us and we can provide you with additional contact information. There are no benefits from participating in this study.

Will I be compensated for participating? No, you will not be compensated for participating. However, you may choose to enter a lottery drawing to win one of fifteen $25 Amazon giftcards. Who will see my information? Data are collected via an online survey system that has its own privacy and security policies for keeping your information confidential. No assurance can be made as to their use of the data you provide.

To increase the confidentiality of your data, the researchers are not collecting your IP address. We do ask, at the end of the survey, that you provide contact information if you are willing to be contacted by us in the future. However, if you wish to maintain your anonymity, you can skip/decline to provide this information.

Finally, we will not share your data or use it in future research projects. Who do I contact with questions, concerns or complaints? If you have any questions, please contact me at lamiller@ou.edu or (405) 325-1751 (office). You may also contact the PI of this study, Dr. B. Mitchell Peck at bmpeck@ou.edu or (405) 325-1751 (office).

You may also contact the University of Oklahoma – Norman Campus Institutional Review Board (OU-NC IRB) at 405-325-8110 or irb@ou.edu if you have questions about your rights as a research participant, concerns, or complaints about the research and wish to talk to someone other than the researcher(s) or if you cannot reach the researcher(s). By providing information to the researcher(s), I am agreeing to participate in this research. This research has been approved by the University of Oklahoma, Norman Campus IRB. IRB Number: 10615 Approval date: 4/11/2019 (You may print this document for your records. By providing information to the researcher(s), I am agreeing to participate in this research.)

o I agree to participate (1) o I do not agree to participate (2)
You must be 18 or older to participate.
o I am aged 18 or older (1) o I am under aged 18 (2)

Instructions for Logging Off and Resuming Work Later If you need to log off and take a break before you have completed the survey, you can save your work and pick up where you left off as long as: (1) you resume work on the same computer using the same web browser, and (2) you do not clean your browser history or cookies before resuming work. As long as you follow these steps, you are free to take a break and resume the survey where you left off.

This questionnaire has two parts:

Part 1: is about your ostomy-related experiences and Part 2: is to gather your perceptions in general I appreciate your participation!

1. When did you receive your ostomy? (month/year) Please write in the box below. [box]
2. What was the reason you received an ostomy? (select all that apply)
   - Inflammatory bowel disease (IBD, such as: ulcerative colitis or Crohn's disease)
   - Cancer
   - Trauma or accident
   - Diverticulitis
   - Other (please specify) _____
3. What is the city/state (or country) of the hospital where you received your ostomy? Please write it in the box below. [box]
4. What is the name of the hospital where you had your ostomy surgery? Please write it in the box below. [box]
5. What is your gender? (select one)
   - Female
   - Male
   - Other (please specify) _____
6. What is your age? (years) _____
7. In what country do you currently reside? Please write it in the box below. [box]
8. What is your ethnic or racial background? (may select more than one)
   - Hispanic White
   - Hispanic Black
   - American Indian or Alaska Native
   - Black/African American

Asian
Asian American
White/Caucasian, not Hispanic
Native Hawaiian or Other Pacific Islander
Other (please specify) _____

9. What is the highest level of education that you have completed? (select one)
   Less than high school
   High school graduate or equivalent
   Completed some college, no degree
   Associate degree
   Bachelor's degree
   Master's degree
   Professional degree/certificate beyond a bachelor's degree (e.g., CFP)
   Doctorate (non-medical; e.g., PhD, JD, EdD)
   Doctorate (medical; e.g., MD, DO, DNP)
   Other (please specify) [box]
10. What is your marital status? (select one)
   Married
   Divorced or Separated
   Widowed/widower
   Never married
   Not married, but living with partner
11. How difficult is it for you to live on your total household income right now? (select one)
   Not at all difficult
   Somewhat difficult
   Difficult or can barely get by
   Very difficult
   Extremely difficult or impossible

The following questions are about your general perceptions and experiences about ostomies...(select one per statement)

Make sure to pay attention to each statement...

12. How strongly do you disagree/agree with the following statements…
   [1-6, strongly disagree (1), disagree, somewhat disagree, somewhat agree, agree, strongly agree (6)]
   a. Most people would willingly accept a person with an ostomy as a close friend.
   b. Most people would have no problem being intimate with a person with an ostomy.
   c. Most people believe that a person with an ostomy smells the same as the average person.
   d. Most people would treat a person with an ostomy just as they would treat anyone.
   e. Most people would accept a person with an ostomy to serve or cook food in a restaurant.
   f. Most people believe that a person with an ostomy is just as clean as the average person.

g. Most people would be willing to help a person with an ostomy if they needed help.
h. Most people would have no issues with inviting a person with an ostomy into their home.
i. Most people would be reluctant to date a person with an ostomy.
j. Most people would be reluctant to marry a person with an ostomy.
k. Most people believe that having an ostomy makes a person less attractive.
l. Most people think less of a person who has an ostomy.
m. Most people believe that a person with an ostomy is just as dirty as the average person.

Now, thinking about your experiences with your ostomy… (select one per question)

13. How strongly do you disagree/agree with the following statements…
[1-6, strongly disagree (1), disagree, somewhat disagree, somewhat agree, agree, strongly agree (6)]
    a. Some of my friends treated me differently after I received an ostomy.
    b. I have been avoided by people because they knew I had an ostomy.
    c. People have used the fact that I have an ostomy to hurt my feelings.
    d. I have been refused an apartment or room because of my ostomy.
    e. I sometimes avoid people because I think they might look down on people with an ostomy.
    f. After receiving my ostomy, people were uncomfortable around me.
    g. Some of my friends rejected me after they found out I have an ostomy.
    h. Some of my family rejected me after they found out I have an ostomy.
    i. Some people are afraid to be around me because of my ostomy.
    j. People have treated me unfairly because of my ostomy.
    k. Some employers have paid me lower wages because of my ostomy.
    l. Some employers have given me fewer work hours because of my ostomy.

Now, the following questions relate to your behaviors and perceptions because of your ostomy…(select one per statement)

14. How strongly do you disagree/agree with the following statements…
[1-6, strongly disagree (1), disagree, somewhat disagree, somewhat agree, agree, strongly agree (6)]
    a. In order to get a job, a person with an ostomy would have to conceal having an ostomy.
    b. If I had a close relative who had an ostomy, I would advise him or her not to tell anyone about it.
    c. If you have an ostomy, the best thing to do is keep it a secret.
    d. I wait until I know someone well enough before I tell them about my ostomy.
    e. There is no reason for a person to hide the fact that he or she has an ostomy.
    f. I rarely feel the need to hide the fact that I have an ostomy.
    g. I don't tell most people about my ostomy, but I am always conscious of it or worried about it while interacting with others.

Continuing the previous set of questions as they relate to your behaviors and perceptions because of your ostomy… (select one per statement)

15. How strongly do you disagree/agree with the following statements…
    [1-6, strongly disagree (1), disagree, somewhat disagree, somewhat agree, agree, strongly agree (6)]
    a. It is easier for me to be friendly with people who have an ostomy.
    b. If I thought that someone I knew held negative opinions about people with ostomies, I would try to avoid him or her.
    c. If I was looking for a job and received an application which asked about medical history, I wouldn't fill it out.
    d. If I thought an employer was reluctant to hire a person with an ostomy, I wouldn't apply for the job.
    e. If I believed that a person I knew thought less of me because I had an ostomy, I would try to avoid him or her.
    f. When I meet people for the first time, I make a special effort to keep the fact that I have an ostomy to myself.

Continuing the previous set of questions as they relate to your behaviors and perceptions because of your ostomy… (select one per statement)

16. How strongly do you disagree/agree with the following statements…
    [1-6, strongly disagree (1), disagree, somewhat disagree, somewhat agree, agree, strongly agree (6)]
    a. I've found that it's best to help the people close to me understand what having an ostomy is like.
    b. If I thought a friend was uncomfortable with me because of my ostomy, I would take it upon myself to educate him or her about my ostomy.
    c. If I thought an employer felt uneasy hiring a person with a medical condition, such as an ostomy, I would try to make him or her understand that people with ostomies are good workers.
    d. After I received my ostomy, I often found myself educating others about what it means to have an ostomy.
    e. I would participate in an organized effort to teach the public more about ostomies and the problems of people with an ostomy.

The following set of questions are about <u>medical providers who cared for you and your ostomy</u>.

Thinking about the <u>nurse at the hospital</u> who cared for you and your ostomy after your surgery...

17. Please provide your opinion on each of the following questions by clicking and dragging the slider to the position that corresponds to your judgment.
    [slider scale 0 (never) to 100 (always)]

    a. Your hospital nurse explained things in a way that was easy to understand.
    b. Your hospital nurse listened carefully to you.

c. Your hospital nurse seemed to know important information about your medical history.
d. Your hospital nurse showed respect for what you had to say.
e. Your hospital nurse spent enough time with you.
f. Your hospital nurse treated you with courtesy and respect.

18. For the nurse described above, using any number from 0 to 10, where 0 is the worst provider possible and 10 is the best provider possible, what number would you use to rate this provider? [zero (worst) to 10 (best)]

19. For the nurse just described, was this provider:
    a. Male
    b. Female
    c. Do not know

20. For the nurse just described, was this provider:
    a. White
    b. Non-white
    c. Do not know

Now <u>thinking about the surgeon</u> who did your ostomy surgery...

21. Please provide your opinion on each of the following questions by clicking and dragging the slider to the position that corresponds to your judgment.
    [slider scale 0 (never) to 100 (always)]

    a. Your surgeon explained things in a way that was easy to understand.
    b. Your surgeon listened carefully to you.
    c. Your surgeon seemed to know important information about your medical history.
    d. Your surgeon showed respect for what you had to say.
    e. Your surgeon spent enough time with you.
    f. Your surgeon treated you with courtesy and respect.

22. For the surgeon described above, using any number from 0 to 10, where 0 is the worst provider possible and 10 is the best provider possible, what number would you use to rate this provider? [zero (worst) to 10 (best)]

23. For the surgeon just described, was this provider:
    a. Male
    b. Female
    c. Do not know

24. For the surgeon just described, was this provider:
    a. White
    b. Non-white
    c. Do not know

Thinking about your medical providers who cared for you and your ostomy at the hospital after surgery…

25. Did your medical providers talk with you about whether you would have the help you needed when you left the hospital? (select one)
    a. Yes, always
    b. Yes, sometimes
    c. No
    d. Do not know

26. Did your medical providers give you information in writing about what symptoms or health problems to look out for after you left the hospital? (select one)
    a. Yes, always
    b. Yes, sometimes
    c. No
    d. Do not know

27. Sometimes in the hospital, one medical provider will say one thing, and another will say something else. Did this happen to you? (select one)
    a. Yes, always
    b. Yes, sometimes
    c. No
    d. Do not know

28. When you had important questions to ask a medical provider, did you get answers you could understand? (select one)
    a. Yes, always
    b. Yes, sometimes
    c. No
    d. Do not know

29. When you needed help and pressed the call button, did you get help in time? (select one)
    a. Yes, always
    b. Yes, sometimes
    c. No
    d. Do not know

30. If you had any anxieties or fears about your treatment or condition, did a medical provider discuss them with you? (select one)
    a. Yes, always
    b. Yes, sometimes
    c. No
    d. Do not know

Still thinking about ostomy providers who helped you initially after surgery or another time when you received care for your ostomy, and your experiences…

31. Was there a particular medical provider who made you feel bad about your ostomy? (select one)
    a. Yes
    b. No
    c. Do not know

32. If yes to the above question, what did the medical provider do to make you feel bad about your ostomy? Please describe in the box below. [text box]

33. For the provider just described, was this provider:
    a. Male
    b. Female
    c. Do not know

34. For the provider just described, was this provider:
    a. White
    b. Non-white
    c. Do not know

35. For the provider just described, was this provider:
    a. Ostomy-specific nurse
    b. Physician
    c. Home Health Nurse
    d. Other (please specify) _____
    e. Do not know

36. Was there a particular medical provider who made you feel less worried about your ostomy? (select one)
    a. Yes
    b. No
    c. Do not know

37. If yes to the above question, what did the medical provider do to make you feel less worried about your ostomy? Please describe in the box below. [text box]

38. For the provider just described, was this provider:
    a. Male
    b. Female
    c. Do not know

39. For the provider just described, was this provider:
    a. White
    b. Non-white
    c. Do not know

40. For the provider just described, was this provider:

a. Ostomy-specific nurse
b. Physician
c. Home Health Nurse
d. Other (please specify) _____
e. Do not know

In this section, I would like to know how you are adjusting to your ostomy…

Please provide your opinion on each of the following questions by clicking and dragging the slider to the position that corresponds to your judgment.

41. How strongly do you disagree/agree with the following statements…
[0 strongly disagree to 100 strongly agree, slider scale]
a. I feel that I have recovered from my stoma operation.
b. I don't like to touch or see my stoma.
c. I have a meaningful life even with a stoma.
d. I enjoy food and drinks as much as I did before my stoma.
e. My stoma inhibits me from having a proper bath or shower.
f. I sleep well without worrying about my stoma.
g. Because of my stoma I feel I am no longer in control of my life.
h. I am reluctant to mix socially since having my stoma.
i. I have now accepted my stoma as part of my body.
j. I cannot get over the shock of having a stoma.
k. Because of my stoma I limit my range of activities.
l. Because of my stoma I feel that I will always be a patient.
m. I am always conscious that my stoma may leak, smell or be noisy.
n. I have accepted the changes in my appearance which were caused by the stoma.
o. I am grateful that the stoma has given me a new lease of life.
p. Caring for my stoma is difficult.
q. I feel that I am less sexually attractive because of my stoma.
r. I feel angry about having a stoma.
s. Despite my stoma I feel I have a rewarding life.
t. I will be able to manage my stoma in the future.
u. I am always anxious about my stoma.
v. With my stoma I feel that my life-threatening experience has passed.
w. I can engage in a variety of activities despite having a stoma.

Thank you for continuing your participation! Reminder that you can log off and come back if you need a break!

If you need to log off and take a break before you have completed the survey, you can save your work and pick up where you left off as long as: (1) you resume work on the same computer using the same web browser, and (2) you do not clean your browser history or cookies before resuming work. As long as you follow these steps, you are free to take a break and resume the survey where you left off.

The second half of the questionnaire is about Health & Culture

The following questions are unrelated to your ostomy experiences, but will help me understand your perceptions. I am interested in knowing how you feel and behave in your everyday life.

42. In the past two weeks, how often have the following statements been true for you…(select one per statement) [Never 1, sometimes 2, often 3]
    a. There is little value in what I can offer others.
    b. My life is valuable.
    c. My role in life has been lost.
    d. I no longer feel emotionally in control.
    e. There are people who can help me.
    f. I feel that I cannot help myself.
    g. I feel irritable.
    h. I cope well with life.
    i. I have a lot of regret about my life.
    j. I feel hopeful.
    k. I tend to feel hurt easily.
    l. I feel distressed about what is happening to me.
    m. I am a worthwhile person.
    n. I would rather not be alive.
    o. I feel quite isolated or alone.
    p. I feel trapped by what is happening to me.
    q. I can offer value to others

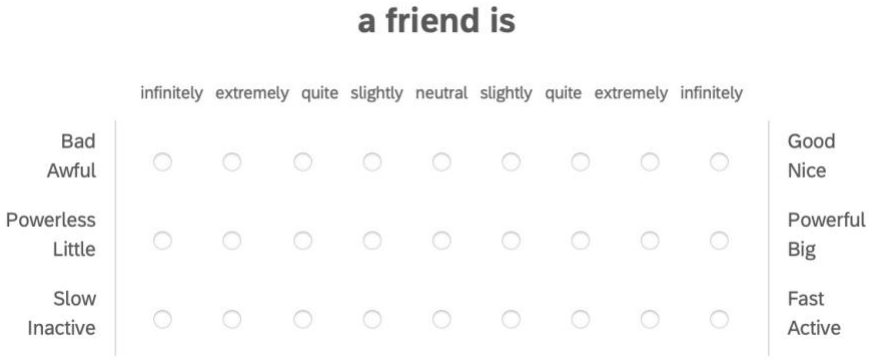
In this section, I would like to know about your <u>understanding of different types of identities, people and behaviors</u>. Again, this is unrelated to your ostomy experiences, but will help me understand your perceptions.

On the scale below, choose which best fits your understanding of the given identity. Each row of circles is like a ruler for measuring how you feel.

Select a circle that indicates how close something is to the description at one end of the ruler or the other. If something is not close to either description, select the middle circle (neutral). For example, if you were rating "a grandfather," you might rate it like this:

EXAMPLE: This example rates a grandfather as "extremely good" "quite powerful" and "neutral" for inactive/active. You will follow this example for the rest of the identities shown.

43. a friend is
    [each statement below looked like the 'a friend is' picture and the question answers were randomized.]



44. an athlete is
45. a person with a physical disability is
46. a nurse is
47. a person with an ostomy is
48. a hero is
49. a physician is
50. a person with a mental illness is
51. a criminal is
52. myself as I really am
53. myself as others see me
54. a health person is
55. a college graduate is

Now, I would like to know about your behaviors in everyday life…(select one per statement)

56. How willing are you to do the following…
    [definitely not (1), probably not (2), very probably (3), definitely (4)]
    a. Move next door to a person with an ostomy.
    b. Spend an evening socializing with a person who has an ostomy.
    c. Make friends with a person with an ostomy.
    d. Start working closely with a person with an ostomy.
    e. Have a person with an ostomy marry into the family.

Last set of questions! Almost finished!

Lastly, I am interested in how you're feeling in everyday life…

Please provide your opinion on each of the following questions by clicking and dragging the slider to the position that corresponds to your judgment.

57. How strongly do you disagree/agree with the following statements…

[0 strongly disagree to 100 strongly agree, slider scale]

a. On the whole, I am satisfied with myself.
b. At times I think I am no good at all.
c. I feel that I have a number of good qualities.
d. I am able to do things as well as most other people.
e. I feel I do not have much to be proud of.
f. I certainly feel useless at times.
g. I feel that I'm a person of worth, at least on an equal plane with others.
h. All in all, I am inclined to feel that I am a failure.
i. I take a positive attitude toward myself.

58. **Are there other characteristics that you think played a role in your interactions with your <u>medical providers</u>?** (e.g., LGBTQ status, disability, weight) If so, please explain in the box below. **[text box]**

59. **Are there other characteristics that you think played a role in your interactions with <u>people other than your medical</u> providers (e.g., family, friends, other)?** (e.g., LGBTQ status, disability, weight) If so, please explain in the box below. **[text box]**

Thank you very much for your participation!

Appendix D: IRB Approval Letter Phase One

Institutional Review Board for the Protection of Human Subjects Approval of Initial Submission – Expedited Review – AP01

Date: May 05, 2017

Study Title: Peoples' Experiences With Pouches (P.E.W.P.) Study

Principal Investigator: Dr Bob M Peck, PHD

IRB#: 8040 Approval Date: 05/04/2017 Expiration Date: 04/30/2018

Expedited Category: 7 Collection/Use of PHI: No On behalf of the Institutional Review Board (IRB), I have reviewed and granted expedited approval of the above referenced research study. To view the documents approved for this submission, open this study from the My Studies option, go to Submission History, go to Completed Submissions tab and then click the Details icon.

As principal investigator of this research study, you are responsible to:

 Conduct the research study in a manner consistent with the requirements of the IRB and federal regulations 45 CFR 46.

 Obtain informed consent and research privacy authorization using the currently approved, stamped forms

and retain all original, signed forms, if applicable.

 Request approval from the IRB prior to implementing any/all modifications.

 Promptly report to the IRB any harm experienced by a participant that is both unanticipated and related per

IRB policy.

 Maintain accurate and complete study records for evaluation by the HRPP Quality Improvement Program

and, if applicable, inspection by regulatory agencies and/or the study sponsor.

 Promptly submit continuing review documents to the IRB upon notification approximately 60 days prior to

the expiration date indicated above.

 Submit a final closure report at the completion of the project.

If you have questions about this notification or using iRIS, contact the IRB @ 405-325-8110 or irb@ou.edu.

Cordially,

Fred Beard, Ph.D.

Vice Chair, Institutional Review Board

Appendix E: IRB Approval Letter Phase Two

Institutional Review Board for the Protection of Human Subjects Approval of Study Modification – Expedited Review – AP0

Date:
May 02, 2019

IRB#: 10615 Reference No: 691750

Principal Investigator: Leslie Ann Miller Study Title: Phase II of Peoples' Experiences With Pouches (P.E.W.P.) Study Approval Date: 05/01/2019

Modification Description:

Updated the confidentiality language in the consent form as well as posting on an additional ostomy discussion board.

The review and approval of this submission is based on the determination that the study, as amended, will continue to be conducted in a manner consistent with the requirements of 45 CFR 46.

To view the approved documents for this submission, open this study from the My Studies option, go to Submission History, go to Completed Submissions tab and then click the Details icon.

If the consent form(s) were revised as a part of this modification, discontinue use of all previous versions of the consent form.

If you have questions about this notification or using iRIS, contact the HRPP office at (405) 325-8110 or irb@ou.edu. The HRPP Administrator assigned for this submission: Nicole A Cunningham.

Cordially,

Ioana Cionea, Ph.D.

Vice Chair, Institutional Review Board