The Importance of Responsiveness: Improving Health-Related Outcomes Among Ostomates

Carrie Reif

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ABSTRACT

More than 750,000 individuals in the United States live with an ostomy appliance, and additional 130,000 patients undergo ostomy surgery each year (United Ostomy Association of America, 2018). Although a life-saving procedure, patients confront significant physical (e.g., bowel routine and activity levels) and emotional (e.g., poor body image and depression) challenges that impede the adjustment process. When faced with health-related threats, the transactional action model of stress and coping argues that patients use strategies, such as seeking support, to effectively cope. However, because of perceptions of felt and enacted stigma and health-related uncertainty, some patients conceal ostomy-related issues and limit access to social support. Thus, patients struggle to effectively transition and adapt to life with an ostomy appliance.

While the transactional model accounts for patients’ self-disclosure practices, little theoretical development has been offered to explain the importance of others’ responsiveness in shaping health-related quality of life. The purpose of this study is to better understand the ways self-disclosure about one’s ostomy to others, and the perception of responsiveness to the disclosure affect ostomy patients’ perceptions of social support, coping, and health-related quality of life. Specifically, this study proposes a theoretical model that incorporates perceived partner responsiveness within the transactional model of stress and coping framework.

Survey data was collected from 375 ostomy patients. Path analysis was conducted to test the hypothesized model. Although the proposed model did not demonstrate adequate fit, analyses identified several direct and indirect factors influencing ostomy patients’ health-related quality of life. Most importantly, findings revealed that
ostomates’ self-disclosure and health-related quality of life is mediated by perceived partner responsiveness. This study suggests that for patients perceived reactions that are responsive are paramount in improving health-related quality of life. To account for this relationship, this study proposes the disclosure-responsiveness theory.
ACKNOWLEDGMENTS

Because writing a dissertation is the final step in a long journey, many people deserve acknowledgement. To begin, I want express thanks to Al Nua, Angela Lander, and United Ostomy Association of America’s Gulfport, Mississippi support group for inviting me to monthly meetings, helping with data collection, and being a source of encouragement. I would also like to recognize the United Ostomy Association of America’s Board of Directors for the opportunity to attend and collect data at the national conference in Irving, California. Additionally, I want to express sincere gratitude to Ostomy Canada Society, Corstrata, and Ostomyland for posting my survey on social media accounts and electronic newsletters.

To my friends and colleagues at Troy University’s Hall School of Journalism and Communication, thank you for supporting my decision to complete my education. In particular, to Drs. Jeff and Amy Spurlock and Dr. Susan Sarpin for giving guidance and encouragement when applying for programs and continuing to be sources of academic knowledge. I would also like to extend a thank you to my master’s advisor, Dr. Brigitta Brunner, for offering valuable mentorship and friendship during this critical time in my academic journey.

Furthermore, to all my professors at USM, thank you for giving me the educational tools to achieve academic and professional success. More specifically, I would like to acknowledge Dr. Jung and Dr. Meyer for serving on my committee and offering critical feedback on drafts. Additionally, Dr. Mohn and Dr. Shelly for fostering my desire to learn about statistics and answering SPSS & AMOS questions.
Most importantly, I want to express appreciation to Dr. Kathryn Anthony and my committee chair, Dr. Steven Venette. I would like to thank Dr. Anthony for providing motivation, expertise, and constructive criticism during this project. Special thanks to Dr. Steven Venette for countless hours of answering questions, running statistical analysis, and reading multiple drafts. This dissertation would not have been possible without their persistent support and academic insight. I am very honored and blessed to have them as academic mentors and lifelong friends.
DEDICATION

This dissertation is dedicated to my family and friends. Particularly, to my husband, Matt, for showing patience, kindness, and understanding during challenging times and elation with each significant milestone achieved. Thank you for standing by me and helping me to achieve this dream. Without your love and support, I would not be earning this degree. To my mom, Mary Jo, and sister, Robin, for emotional reassurances and comfort in moments of stress and uncertainty. I also want to thank my grandma and grandpa Blakey for teaching me the value of education. Most importantly, to my dad, Harvey, for providing advice and invaluable insight concerning ostomates’ health-related experiences. I will forever be grateful for your love and unfaltering support during this academic and professional endeavor. I love you all.

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<tbody>
<tr>
<td>AGFI</td>
<td>Adjusted goodness of fit</td>
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<tr>
<td>ALS</td>
<td>Amyotrophic lateral sclerosis</td>
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<td>BCI</td>
<td>Brief COPE inventory</td>
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<td>CFI</td>
<td>Comparative fit index</td>
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<td>CPM</td>
<td>Communication privacy management</td>
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<td>DDM</td>
<td>Disclosure decision model</td>
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<td>DD-MM</td>
<td>Disclosure decision-making model</td>
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<td>Disclosure responsiveness theory</td>
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<td>EFA</td>
<td>Exploratory factor analysis</td>
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<td>GFI</td>
<td>Goodness of fit</td>
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<td>HRQoL</td>
<td>Health-related quality of life</td>
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<td>IFI</td>
<td>Incremental fit index</td>
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<td>ISSB</td>
<td>Inventory of socially supportive behaviors</td>
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<tr>
<td>KMO</td>
<td>Kaiser-Meyer-Olkin</td>
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<tr>
<td>MSPSS</td>
<td>Multidimensional scale of perceived social support</td>
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<td>MUIS</td>
<td>Michel uncertainty in illness scale</td>
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<tr>
<td>NFI</td>
<td>Normal fit index</td>
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<tr>
<td>PCA</td>
<td>Principal component analysis</td>
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<td>PI</td>
<td>Problematic integration theory</td>
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<td>PPR</td>
<td>Perceived partner responsiveness</td>
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<td>QoL</td>
<td>Quality of life</td>
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<td>Acronym</td>
<td>Explanation</td>
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<tr>
<td>RMSEA</td>
<td>Root mean square error of approximation</td>
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<td>UOAA</td>
<td>United Ostomy Association of America</td>
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<td>WHO</td>
<td>World Health Organization</td>
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<td>$X^2$</td>
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CHAPTER I – INTRODUCTION

In 2014, the U.S. Centers for Disease Control and Prevention (CDC) unknowingly created controversy in the ostomy community by releasing the anti-smoking campaign *Tips from a Smoker* (Berstein, 2015a; CDC, 2018). The campaign presents formers smokers who disclose their smoking-related health issues. For example, Julia, a former smoker, discusses her battle with colon cancer and the consequence of having an ostomy. Julia holds up an ostomy pouch saying, “my tip is to get over being squeamish. You’re going to be emptying your bag six times a day” (CDC, 2018). Although ostomy surgery saved her life, Julia describes the negative aspects of her colostomy, including lack of bowel control and unpleasant smells. She also highlights experiencing ostomy-related fear and social isolation: “I was home the majority of the time because I was scared it would come loose. It would smell, and I didn’t want to be around anyone. So I was kinda, like stuck at home” (CDC, 2018). While the campaign successfully deterred people from smoking (CDC, 2016), Julia’s tips unintentionally reinforced ostomy-related stigma.

Because the CDC campaign framed ostomy surgery as a preventable and undesirable medical issue, many ostomates (the term ostomy patients use to identify themselves) felt that this sent a misleading message to the American public (Berstein, 2015a). Instead of demonstrating how ostomy surgery save lives, the campaign supported negative misconceptions of having an appliance. The message also implied that smoking was the only cause of colon cancer and ostomy implementation (Berstein, 2015a). In response, the United Ostomy Association of America (UOAA), argued that Julia’s tips undermined UOAA’s mission to empower, educate, and reduce ostomy-related stigma.
Furthermore, because of the CDC’s position as a source of medical information, patients would delay or refuse ostomy surgery (Berstein, 2015b). The CDC revised Julia’s tip by editing out excerpts the UOAA considered offensive (Berstein, 2015b).

Ostomy implementation is a life-saving surgical procedure that diverts waste by removing the diseased section of the colon or bladder. A portion of the colon (colostomy), small intestine (ileostomy), or bladder (urostomy) is then linked to an external opening in abdominal wall. The stoma enables the removal of waste from the body into an attached pouching system. Several medical conditions necessitate implementing a temporary or permanent ostomy, including colorectal cancer, Crohn’s disease, and diverticulitis (Pittman, Rawl, Schumidt, Ko, Wendel, & Krouse, 2008).

The UOAA (2019) estimates that 750,000 Americans have an ostomy appliance with 130,000 new surgeries a year. Because of the rise rates of colorectal cancer (Siegel, et al., 2017) and inflammatory bowel disease (M’Koma, 2013), the number of ostomates is projected to yearly increase at rate of 3% (Turnball, 2003). Although many ostomies are intended to be temporary, 40-60% of patients do not undergo reversal surgery (Zorcolo, Covotta, Carlomangno, & Bartolo, 2003).

When no other medical interventions are available, ostomy surgery is performed. However, despite the colon-related concerns ameliorated by ostomy, patients often experience health-related uncertainty concerning the unknown health issues surrounding their device. Brashers (2001) argued that patients experience health-related uncertainty when “details are ambiguous, complex, unpredictable or probabilistic; when information is unavailable or inconsistent; and when people feel insecure in their own states of
knowledge or the state of knowledge in general” (p. 478). Because uncertainty occurs throughout disease stages, including diagnosis, treatment, and prognosis, patients struggle to find meaning in their illness experience (Mishel, 1981).

Illness-related uncertainty adversely influences patients’ capacity to effectively transition to their appliance (Irvine, 1997; Mishel, 1981). Because of the physical and psychological challenges of ostomy implementation, patients often encounter health-related uncertainty. For example, while some ostomates experience uncertainty about bodily functions and disrupted sexual health, others encounter uncertainty about reduced physical and social activity (Krouse et al., 2009; Persson & Hellström, 2002). When ostomates fret how others perceive their device, uncertainty also occurs. Thus, to reduce uncertainty and effectively adjust, patients must rely on coping mechanisms.

**Ostomy and Disrupted Bodily Function**

Life with an ostomy presents significant challenges, which makes ostomates’ transition problematic and an additional source of anxiety. Ostomates describe being embarrassed by the unpleasant odors emitted from their appliance (Krouse et al., 2007). At least 39% of patient report frequently worrying about the lack of control over noises and passing gas (Liao & Qin, 2014). Over 50% of ostomates fear their pouch filling past capacity, leaking, or detaching from their body in public. Other ostomy-related issues delaying transition, includes uncontrollable rectal discharge, constipation, and diarrhea (Krouse et al., 2007).

Because ostomates feel overwhelmed about their altered bodily appearance, they struggle adjusting to their appliance. While transitioning, patients incorporate ostomy-management skills into their daily routines, such as learning when and how to change
their pouching system. Furthermore, ostomates also learn how to properly clean the stoma and assessing the surrounding area for disease (Dorman, 2009). However, at least, 70% of ostomy patients experience health problems caused by poor self-care practices (Ratliff, Scarano, Donovan, & Colwell, 2005). Failure to integrate proper ostomy produces serious consequences for ostomates. For example, between 18-55% of ostomates encounter skin breakdown in the area surrounding their stoma (Colwell, Goldberg, & Carmel, 2001). Over 50% of patients suffer from periosteal herniation, which is abdominal weakness near the stoma. While 2-25% of ostomates seek medical assistance for a protruding bowel, 11% undergo surgery for a retracted stoma (Colwell, Goldberg, & Carmel, 2001). Clearly, physically adjusting to an ostomy appliance is fraught with uncertainty and debilitating complications.

**Ostomy and Poor Body Image**

When ostomy implementation occurs, patients undergo radical body transformations. Specifically, the symmetry of the body is altered and an opening in the abdomen is created (Kelly, 2004). The removal of waste is “made visible in a way which when viewed from anything other than a medical perspective is odd” (Kelly, 2004, p. 397). Because of their altered body, some ostomates experience a fragmented self-identity and poor body image (Manderson, 2005; Persson & Hellström, 2002). When first seeing their appliance, ostomates report feeling embarrassed and devastated about their altered appearance. Many patients describe their post-ostomy body as abnormal, physically disfigured, and out of control (Manderson, 2005; McKenzie et al., 2006). Poor body image also adversely influences patients’ well-being and transition. For example, poor body image causes distress, anxiety, and depression for patients up to ten years after
implementation (Manderson, 2005; Mols, Lemmens, Bosscha, van den Broek, & Thong, 2014).

Loss of bodily confidence and poor body image affects how patients renegotiate their appearance. Although the medical professionals encourage ostomates to maintain their personal style, many patients discard their pre-ostomy wardrobe (Sun et al., 2013). Instead, they strategically use clothing as a tool to conceal their appliance. For example, to hide the outline of the pouch, ostomates wear multiple layers of baggy clothing, high-waisted garments, and suspenders (Savard & Woodgate, 2009). Other ostomates avoid wearing lighter colors for fear of having a leaky pouch. Because some patients face clothing restrictions (Sun et al., 2013), they may struggle to regain post-surgery body confidence and experience poor well-being.

Ostomy and Disrupted Social Activity

After implementation, 80% of ostomates undergo substantial changes to their pre-surgery lifestyle (Nugent, Daniels, Stewart, Patankar, & Johnson, 1999). Some ostomates experience social isolation for up to five years after their surgery (Fucini, Gattai, Urena, Bandettini, & Elbetti, 2008). To protect themselves from feeling shame and embarrassment, patients often socially withdraw from friends and family members (Sun et al., 2013). For example, because of increased anxiety about changing and disposing of a used appliance in public, 33% of patients avoid social activities with others (McKenzie et al., 2006). Patients also limit social interactions for fear of omitting offensive odors, passing gas, and having an appliance leak (Taft & Keefer, 2016).

Social isolation is not necessarily caused by lack of social support from others (Nichols, 2011). Because of poor body image, patients believe their ostomy determines
how others view them. Thus, patients may receive social support, but still socially withdrawal. Overall, ostomy implementation adversely impacts patients’ social live and hinder their ability to resume their pre-surgery lifestyle.

**Ostomy and Disrupted Intimacy**

Sexual dysfunction is also a consequence of ostomy surgery. Out of 70% of patients who engage in pre-surgery intercourse, 55% resume having intercourse post-operatively. Of those who resume sexual activity, only 31% of patients are satisfied with their intimate interactions (Anaraki et al., 2012). Physical complications, such discomfort and nerve damage, causes sexual dysfunction for ostomates. For example, in male patients, ostomy implementation increases erectile dysfunction and impotence (Symms et al. 2008; Nugent et al., 1999). Females also experience impaired sexual functioning, including poor libido, arousal problems, and infertility (Hendren et al., 2005).

Poor body image also negatively impact patients’ sexuality and desirability. Many ostomates perceive themselves as being less sexually attractive to their partners (Persson & Hellström, 2002). For example, 32.5% of men are ashamed of their post-surgery body and struggle engaging in intercourse (Hendren et al., 2005). When nude in front of their partner, female ostomates also report feeling undesirable (Manderson, 2005). Thus, because of their appliance, patients believe that their partners will be disgusted by their appearance and rebuff sexual advances (Sprunk & Alteneder, 2000).

Another major concern ostomates worry about is the appliance leaking during intercourse. When leakage occurs, patient report experiencing shame, embarrassment, and humiliation (Persson & Hellström, 2002). Other issues affecting intimacy are stoma activity, strong odors, and uncontrollable flatulence (Persson & Hellström, 2002).
Additionally, some ostomates limit sexual activity for fear of hurting their stoma during intercourse (Sprunk & Altender, 2000). If ostomates experience negative first time post-operative sexual encounter, they are less likely to engage in future intimate interactions (Cohen, 1991).

**Ostomy and Quality of Life**

Because of the physical complications of ostomy surgery, patients may encounter considerable psychological distress and impaired quality of life (QoL). For example, between 19-26% of ostomates report psychological issues within the first ten weeks of surgery (Wade, 1990). In a survey of 500 patients, Krouse and associates (2007) revealed 50% of participants had depression, while 10% had suicidal thoughts following implementation. While some patients feel comfortable with their stoma six months after surgery (Anaraki et al., 2012), others need at least 12 months or longer to accept their appliance (Wade, 1990).

Managing illness-related uncertainty and coping effectively is undoubtedly challenging for ostomy patients. Coping strategies, such as accessing social support from family and friend, help patients adapt to their appliance and improve well-being (McMullen et al., 2008). Unfortunately, some ostomate struggle procuring adequate support from family members, friends, and loved ones. Because of perceptions of stigma surrounding their stoma (Smith, Loewenstien, Rozin, Sherriff, & Ubel, 2007), threats to their identity (Petronio, 2002), or changes in their relationships (Little, Jordens, Paul, Sayers, & Sriskandarajah, 2009), patients may conceal ostomy-specific issues and limit access to social support. Furthermore, unsupportive responses from patients’ support network could adversely influence the adjustment process (Manne & Zautra, 1989).
However, if family members provide supportive responses after ostomy-related disclosures, patient indicate better psychological well-being (Reif, Anthony, & Venette, 2016).

In summary, some ostomates grapple with health-related uncertainty regarding the physical and psychological consequences of implementation. For example, because of their inability to control bowel function, patients encounter distress and anxiety (Krouse et al., 2007). Others avoid social situations to avoid being rejected or stigmatized (Maderson, 2005). Poor body image and depression also contributes to poor psychological well-being (Krouse et al., 2007). Because these challenges prevent or delay the transition process, health scholars need to understand how communication influences ostomates health-related quality of life (HRQoL; Greene et al., 2012).

While patients who self-disclose information regarding their chronic illness are able to effectively cope and experience HRQoL (Greene, 2009; Manne, Siegel, Kashy, & Heckman, 2014), limited research has been conducted regarding ostomates’ illness experience (Vonk-Klaassen, de Vocht, den Ouden, Eddes, & Schuurmans, 2016). Because ostomates are ‘out-of-sight’ of the healthcare system (Vonk-Klasssen et al., 2016), health communication scholars have overlooked the communicative behaviors ostomates utilize to cope with their condition. For example, patients may fail to divulge ostomy-related information fear encountering stigma, unsupportive reactions from others, and loss of interpersonal relationships (Krouse et al., 2009). However, if ostomates fail to reveal health information, coping efforts could be impeded and the transition process delayed. Thus, for patients, sharing ostomy-related information is a decision process fraught with difficulty and unpredictability.
The purpose of this study is to understand the communicative behaviors patients transition to their ostomy appliance. Specifically, this study explores how coping strategies, such as self-disclosure and social support, influence ostomates HRQoL. To examine the coping process, Lazarus and Folkman’s (1984) transactional model of stress and coping is used as a guiding framework. Furthermore, Reis and Shaver’s (1988) interpersonal process model of intimacy is also used to understand how self-disclosure and perceived partner responsiveness facilitates ostomates’ transition.

This study is comprised of four additional chapter. Chapter II provides in-depth literature review of the transactional model of stress and coping (Lazarus & Folkman, 1984) and psychosocial variable. Chapter III gives a detailed description of the operational definitions, research design, and protocols used to gather date. This chapter also overviews statistical test utilized to analyze quantitative data. Chapter IV provides a summary of statistical findings. Finally, Chapter V presents conclusions and implications drawn from statistical analysis. Limitations and areas of future research are also discussed.
CHAPTER II – LITERATURE REVIEW

While adjusting to their appliance, ostomates encounter a high degree of uncertainty and loss of normalcy. Because patients remove waste from an attached appliance, they experience negative bodily changes (e.g., inability to control bowel function, poor body image, and loss of physical and social activities). As stated earlier, these pervasive issues cause increased feelings of distress and poor well-being. For example, some patients struggle to resume post-operative activities and socially withdraw. Overall, these issues impair patients’ ability to effectively cope and transition to their appliance (Krouse et al., 2009). Thus, ostomates can experience reduced health-related quality of life (HRQoL).

This chapter provides the theoretical foundations to examine how ostomy patients use coping strategies to manage stressors and illness uncertainty. First, Lazarus and Folkman’s (1984) transactional model of stress and coping is discussed. Second, illness uncertainty is explored. Because ostomy implementation threatens patients’ identity and sense of control, illness uncertainty is an important concept in understanding patients’ perceptions of their ostomy. This literature review also investigates felt and enacted stigma. Some ostomy patients fail to resume pre-surgery activity for fear of being stigmatized (Chelvanayagam, 2014). The literature surrounding self-disclosure, coping, social support, and responsiveness are also reviewed. The disclosure of ostomy-related information and positive responses from social support networks may help patients effectively cope with stressor (Reif, Anthony, Venette, 2016). Finally, HRQoL is conceptually defined.
Transactional Model of Stress and Coping

Selye (1973) articulated stress as a “nonspecific response of the body to any demand made upon it” (p. 692). In other words, stress is a physiological or biological response to a stressor. Lazarus and Folkman (1986) rearticulated stress as a “relationship with the environment that the person appraises as significant for his or her well-being and in which the demands tax or exceed available coping resources” (p. 53). The transactional model of stress and coping outlines how coping strategies, such as social support, reduces stress and improves HRQoL. Thus, stress in not a physiological response, but a cognitive process. When stressor occur, people engage in cognitive appraisal to manage or reduce stress.

Cognitive appraisal. Laazurs and Folkman (1984) defined cognitive appraisal as the “process of an encounter, and it has various facets, with respect to its significance for well-being” (p. 19). When encountering stressors, individuals first evaluate the negative impact of stress on their personal well-being (Folkman & Moskowitz, 2004). The theory distinguished three different types of appraisal strategies: primary appraisal, secondary appraisal, and reappraisal (Lazarus, 1993).

Individuals engage in primary appraisal when assessing whether stressors directly impacts their well-being. In this stage, they evaluate the potential risks, harms, or social rewards associated with the stressors. Primary appraisal categorizes stressors into four categories: benign, harmful, threatening or challenging. Benign stressors are insignificant to one’s well-being. However, if appraised as a threat, the stressor is classified as harmful (i.e., damage has occurred), threatening (i.e., the possibility of future harm), or challenging (i.e., possibility of master the situation). For example, when the only
treatment option is an ostomy appliance, a patient might appraise the situation as threatening because of the health-related uncertainty.

When a situation is assessed as harmful, threatening, or challenging, secondary appraisal occurs. To effectively cope with stressors, individuals evaluate what potential internal (i.e., humor or behavioral disengagement) and external (i.e., social support or religion) resources are available (Folkman & Moskowitz, 2004; Lazarus & Folkman, 1984). For example, a new ostomate may appraise her social support network as insufficient in providing instrumental support and attend an ostomy-specific support group. By accessing social support from other ostomates, the patient should experience reduced uncertainty and distress.

To manage stressors, individuals are continually reappraising and altering their primary and secondary appraisals (Lazarus, 1993). Initially, a new ostomy patient could perceive attaining social support as an appropriate coping strategy. However, after receiving a negative reaction from an ostomy-specific disclosure, she might reappraise her available coping resources. Reappraisals either increase or decrease stress. If stress increases, the appraisal process until the stressors are either resolved or properly managed (Lazarus, 1993).

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Individuals engage in primary appraisal when assessing whether stressors directly impacts their well-being. In this stage, they evaluate the potential risks, harms, or social rewards associated with the stressors. Primary appraisal categorizes stressors into four categories: benign, harmful, threatening or challenging. Benign stressors are insignificant to one’s well-being. However, if appraised as a threat, the stressor is classified as harmful (i.e., damage has occurred), threatening (i.e., the possibility of future harm), or challenging (i.e., possibility of mastering the situation). For example, when the only treatment option is an ostomy appliance, a patient might appraise the situation as threatening because of the health-related uncertainty.

When a situation is assessed as harmful, threatening, or challenging, secondary appraisal occurs. To effectively cope with stressors, individuals evaluate what potential internal (i.e., humor or behavioral disengagement) and external (i.e., social support or religion) resources are available (Folkman & Moskowitz, 2004; Lazarus & Folkman, 1984). For example, a new ostomate may appraise her social support network as insufficient in providing instrumental support and attend an ostomy-specific support group. By accessing social support from other ostomates, the patient should experience reduced uncertainty and distress.

To manage stressors, individuals are continually reappraising and altering their primary and secondary appraisals (Lazarus, 1993). Initially, a new ostomy patient could perceive attaining social support as an appropriate coping strategy. However, after receiving a negative reaction from an ostomy-specific disclosure, she might reappraise her available coping resources. Reappraisals either increase or decrease stress. If stress
increases, the appraisal process until the stressors are either resolved or properly managed (Lazarus, 1993).

*Coping.* Lazarus and Folkman (1984) defined coping as “constantly changing cognitive and behavioral efforts to manage specific external and internal demands that are appraised as taxing or exceeding the resources of a person” (p. 141). More simply, coping is a set of strategies people employ to manage the negative impact of stressors (Lazarus, 1993). Because coping is not a predetermined response pattern, there is no one best coping strategy. Instead, coping is recognized as an individualistic process that employs emotion-based and problem-based strategies. While emotion-focused coping regulates emotional responses to stressors, problem-focused coping eliminates stressor by altering the situation (Lazarus, 1993; Lazarus & Folkman, 1984).

Coping is a dynamic process that changes according to the individual, the context of the situation, and available resources (Lazarus, 1993). To achieve desired outcomes, individuals engage in “goodness of fit” or matching coping strategies to appropriate stressors (Forsythe & Compas, 1987; Lazarus & Folkman, 1984). Because coping is a complex process, individuals simultaneously use emotion-based and problem-based strategies (Lazarus & Folkman, 1984). Overall, the appraisal and coping process influences adaptational outcomes. When successful, coping efforts should improve individuals’ health status, social functioning, and HRQoL (Lazarus & Folkman, 1984).

*Transactional Model of Stress and Coping*

The transactional model of stress and coping is an important framework for understanding health-related outcomes in chronically ill patients (Glanz & Schwartz, 2008). More precisely, stressor and coping behaviors are key factors in determining
patients’ HRQoL (Hulburt-Williams, Morrison, Wilkinson, & Neal, 2013; Stanton, Revenson, & Tenn, 2007). For example, the model highlights how coping strategies determine breast cancer patients’ HRQoL (Paek, Ip, Levine, & Avis, 2016). The transactional model also provides a framework for better understanding the relationship among stressors, appraisal, coping and depressive symptoms in Type II diabetes patients (Shah, Gupchup, Borrego, Raisch, & Knapp, 2012). The also model also demonstrates the importance of coping strategies in accepting adaptational outcomes in patients with rheumatoid arthritis (Trehanne, Lyons, Booth, & Kitas, 2007), multiple sclerosis (Plow, Resnik, & Allen, 2009), chronic heart failure (Yu, Lee, Kwong, Thompson, & Woo, 2008), prostate cancer (Roesch et al., 2005), ovarian cancer (Audrain et al., 1997), and sickle cell anemia (Hocking & Lockman, 2005).

The ostomy community offers an opportunity for understanding how coping efforts influence patients’ outcomes. Many ostomates experience health-related uncertainty and experience reduced HRQoL (Dabirian et al., 2010; Krouse et al., 2007; Krouse et al., 2009). Because ostomy implementation is fraught with health-related challenges, the transactional model provides a framework for better understanding ostomates’ coping experiences.

Health-Related Uncertainty

The unpredictability of uncertainty plays a complicated role in one’s health. Uncertainty is described as an “inability to determine the meaning of illness-related events” (Mishel, 1990, p. 256). When diagnosed with health problem, patients experience uncertainty because the “orderliness and predictability of their lives” (Mishel, 1990, p. 256) is disrupted. Patients encounter uncertainty for a variety of internal and external
sources, including perceptions of stigma, trajectory of illness, and treatment options (Brashers, Neidig, Reynolds, & Haas, 1998). While uncertainty is central to peoples’ health experiences (Bradac, 2001), uncertainty negatively impacts coping strategies and reduces HRQoL (Brashers et al., 2003).

**Uncertainty in illness.** Mishel’s (1981) theory proposes that uncertainty occurs when individuals are unable to cognitively evaluate illness related-events and predict outcomes. Because of insufficient health-related information, patients encounter uncertainty during their diagnosis, treatment, and long-term management (Mishel, 1984). Mishel (1981) argued uncertainty is experienced in four ways: ambiguity about the illness state and symptoms, complexity regarding treatment and care, lack of information regarding seriousness of illness, and unpredictability of the disease process and prognosis. When patients utilize coping strategies, uncertainty can be reduced and eliminated. Thus, patients are able to cope and construct meaning surrounding their illness experience.

To provide further insight on how patients experience uncertainty, Mishel (1990) reconceptualized the theory. The revised framework articulates a probabilistic view of uncertainty (Mishel, 1990). Originally constructed as a threat to be eliminated, this framework presents uncertainty as a process that transforms over time. The longer patients live with uncertainty, they begin to consider it as part of the health-related experience and are able successfully manage outcomes. While illness experience is unpredictable, patients cope and construct meaning regarding their health and well-being.

**Problematic integration theory.** Communication scholars have a vested interest in the role of health-related uncertainty in patients’ communicative behaviors. For example,
Babrow’s (1992) problematic integration theory (PI) provides a lens to examine the relationship between uncertainty and the illness experience. PI frames communication as a process that explores how information is received, evaluated, and integrated into personal understanding (Babrow, 1991; 2001; 2006; Babrow & Matthias, 2009). Specifically, PI suggests that individuals construct probabilistic and evaluative orientations. While probabilistic orientations involve the likelihood of an event or issue occurring, evaluative orientations determine whether the event is positive or negative (Babrow, 1991; 2001; 2006; Babrow & Matthias, 2009). To illustrate, when a colon cancer receives news that a permanent colostomy is part of their long-term treatment plan, they experience a probabilistic orientation. They may access the ostomy information as either positive (i.e., it will save their life) or negative (i.e., my life is changing). Evaluative orientations might include patients’ feelings regarding an altered physical appearance and uncontrolled bodily functions.

The theory also posits that probabilistic and evaluative orientations are mutually exclusive but integrated into individuals’ personal experience. Thus, probabilistic and evaluative orientations are incorporated to created meaning. When conflict occurs between individuals’ expectations and desires, integration between orientation becomes problematic and uncertainty occurs (Babrow, 1991; Ford, Babrow, & Stohl, 1996). Babrow (2001) argued that communication is the source, medium, and resource in forming this nuanced relationship. For example, after receiving a poor health prognosis, a colon cancer could experience problematic integration and uncertainty. To manage uncertainty, she could utilize communication as a coping resource by accessing social support, reappraising her progress, and find meaning the diagnosis.
Uncertainty management theory. Uncertainty management theory (UMT) argues that health-related uncertainty should be effectively managed, but not necessarily eliminated. The theory posits that uncertainty is not inherently positive or negative but “multilayered, interconnected, and temporal” (Brashers, 2001, p. 481). Thus, patients appraise uncertainty as either a danger or positive opportunity (Brashers, 2001; Brasher et al., 2003). If evaluated as dangerous, patients may pursue additional health-related information to clarify experiences and reduce uncertainty (Brasher, 2007). However, because of misinformation, poor understanding, or lack of expertise, information seeking could potentially increase uncertainty and impede management efforts (Brashers et al., 2000).

Conversely, if patients appraise uncertainty as an opportunity, strategies, such as avoiding others, deception, and controlling the conversation, are used (Barbour, Rintamaki, Ramsey, & Brasher, 2012). For example, some cancer patient manage uncertainty by avoiding detailed or “unsafe information” (Leydon et al., 2000). Patients also avoid accessing new information to keep a positive outlook, avoid feeling overwhelmed, accept limits of actions, maintain boundaries, and continue their routine (Barbour, Rintamaki, Ramsey, & Brashers, 2012; Brashers et al., 2000). In a study of African American cancer patients, uncertainty was positively appraised (Matthews, Sellergren, Manfredi, & Williams, 2002). Patients chose to maintain uncertainty for fear of assessing misinformation, mistrusting the medical community, concerns about privacy, lack of insurance, religious beliefs, and emotional issues. Thus, avoidance serves as a protective buffer from distressing or overwhelming information. While avoidance
strategies work as “protective mechanisms” (Brashers et al., 2000), disregarding health-related information can exacerbate uncertainty and increase distress.

Because uncertainty spans across the illness trajectory (Brashers et al., 1998; Garofalo, Choppala, Hamann, & Gjered, 2009), patients use communication to continuously manage uncertainty through the course of their illness (Brahers, 2001). While some patients engage in information seeking immediately after diagnosis, other wait or resist to access further information about their illness (Brashers, 2001; Leydon et al., 2000). However, to attain optimal HRQoL, patients must learn how to “negotiate their identity, relationships, and levels of knowledge” (Brashers et al., 2000, p. 81). Thus, if left unmanaged, negative uncertainty determinately impacts well-being.

Unmanaged Uncertainty and HRQoL

When negative uncertainty is unmanaged, patients experience poor psychological quality of life (QoL; Bailey et al., 2009; Johnson, Afari, Zaurta, 2009; Kazer et al., 2013). Negative uncertainty is associated with mood disturbances in patients with Hepatitis C (Bailey et al., 2009), cancer (Stewart, Mishel, Lynn, & Terhorst, 2010), chronic obstructive pulmonary disease (Hoth et al., 2015; Hoth et al., 2013), and multiple sclerosis (Siegert & Abernethy, 2005). Because of the unpredictability of illness symptoms, patients experience depression, anxiety, and anger (Johnson et al., 2009; Lütze & Archenholtz, 2007). Illness uncertainty also causes feelings of anger and hopelessness in rheumatoid arthritis patients (Lütze & Archenholtz, 2007). Finally, when patients experience uncertainty, coping mechanisms and resiliency to illness-related stressors are impaired (Akkasilpa, Goldman, Magder, & Petri, 2005).
Unmanaged illness uncertainty also contributes to poor physical functioning. For example, unmanaged uncertainty is associated with increased sensitivity to pain and reduced pain tolerance (Wright et al., 2009) in patients with lung cancer (Hsu, Lu, Tsou, & Lin, 2003), fibromyalgia (Johnson, Zautra, & Davis, 2006), and renal cancer (Parker et al., 2013). Furthermore, Hepatitis C patients experience greater fatigue and musculoskeletal issues with increased uncertainty (Bailey et al., 2009). Patients also encounter reduced medication adherence (Balkrishnan, 1998), dissatisfied medical treatment (Kazer et al., 2013), and more stress-related hospitalization (Mishel, Hostetter, King, & Graham, 1984). Poor self-efficacy and resourcefulness is also linked to unmanaged uncertainty. Overall, unmanaged uncertainty reduces general health and negatively influences patients’ HRQoL.

Managed Uncertainty and HRQoL

Managed uncertainty enhances psychological and physical well-being (Wright et al., 2009). For example, a study of newly diagnosed HIV patients who communicatively managed uncertainty (i.e., seeking support, talking to healthcare providers, and disclosing to loved ones) experienced better coping and reduced depression (Brashers, Basinger, Rintamaki, Caughlin, & Para, 2017). When uncertainty is managed, patients with chronic obstructive pulmonary disease (Jiang & He, 2012), liver transplants (Bailey et al., 2017), gynecological issues (McCorkle et al., 2009), and breast cancer (Wonghongkul, Dechaprom, Phumivichuvate, & Loswatkul, 2006) also experience less depression and anxiety. Managed uncertainty is also linked to improved patient self-efficacy (LeFort, 2000) and higher life satisfaction (Mishel et al., 2005).
Several theoretical perspectives examine how individuals manage health-related uncertainty, including illness uncertainty (Mishel, 1981), problematic integration theory (Babrow, 2001), and uncertainty management (Brahers, 2001). When patients fail to find meaning in their illness experience, uncertainty occurs (Mishel, 1984). Early conceptualizes of uncertainty framed it as an attribute to be minimized or eliminated (Mishel, 1981). However, uncertainty cannot be simply be eradicated in all patients, but maintained and managed. Unmanaged uncertainty is problematic and negatively impacts psychological and physical well-being (Brashers, 2001; 2007; Brashers et al., 2017; Wright et al., 2009). To effectively manage uncertainty and improve well-being, patients must utilize coping strategies.

Stigma

Stigma is described as “deeply discrediting” (Goffman, 1963, p. 3) attributes that deviate from accepted cultural standards. Stigma delineates individuals into acceptable and unacceptable categories. When individuals’ social identity does not align with society’s expectations, that are reduced from a “whole and usual person to a tainted, discounted one” (Goffman, 1963, p. 3). More recent definitions frame stigma as a social construct composed of two key elements: recognition of difference (e.g., visibility or mark) and devaluation (e.g., controllability; Dovidio, Major, & Crocker, 2000). Stigmatization occurs when individuals have “some attribute or characteristic that conveys a social identity that is devalued in a particular social context” (Crocker et al., 1998). Thus, stigma is a cultural construct formed through values, beliefs, and social interactions (Crocker et al., 1998).
While normal individuals are positively evaluated and considered as part of the in-group, stigmatized people are negatively evaluated and placed in the out-group (Crocker & Major, 1989). Stigma also poses significant threats to individuals’ social identity and self-esteem (Crocker, 1999; Crocker & Major, 1989). However, stigma characteristics varies across social and cultural setting. Stigma is not rooted in individualists’ characteristics but depends on social situations and shared cultural meaning (Crocker, 1999). Because stigma is created through social interaction, stigmatized individuals risk significant consequences for revealing their condition to others.

Types of Stigma

Goffman (1963) identified three types of social stigma: tribal stigma, character blemishes, and abominations of the body. While triable stigma categorizes people into groups such as race, religion, and ethnicity, character blemishes (i.e., moral failings) are hidden and help individuals pass as normal (Goffman, 1963). In contrast, abominations of the body are visible deformities or disabilities (i.e., missing limbs). For example, even though ostomy patients can complete ordinary tasks, they are considered different because of their altered body. Although having an ostomy is a hidden condition, once displayed the ostomates is discredited and stigmatized.

While Goffman’s (1963) work remains widely accepted, scholars continue to debate the defining characteristics of stigma. For example, Jones and associates (1984) argued that stigma develops along six dimensions: concealability (e.g., ability to pass as healthy), origin (e.g., how condition developed), disruptiveness (e.g., how condition interferes with social relationships), course (e.g., length of stigmatization), aesthetics (i.e.,
others’ reactions), and peril (e.g., perceived fear). More recently, Frable (1995) argued that stigmatized groups are characterized in terms of dangerousness, visibility, and commonness. Conversely, Deaux, Reid Mizrahi, and Etheir (1995) framed stigma as polarizing traits of dangerousness (e.g., harmless-threatening), controllability (e.g., preventable-unpreventable), and commonness (e.g., active-passive). In other words, because ostomy appliances are hidden, patients are harmless, unpreventable, and uncommon compared to others with visible disabilities.

Corrigan and colleagues (2001) reconceptualized stigma as dimensions of stabilities (e.g., recover/benefit from treatment), pity (e.g., sympathy for disorder), and controllability. For example, people show hostility towards individuals who should be able to control their issues, such as drug addiction and mental illness. Conversely, other will display pity and sympathy to those they perceive are unable to control their symptoms (Corrigan, 2000). Stigma is a social process that involves, labeling, stereotyping, separation, status loss, and discrimination (Link & Phelan, 2001). Overall, assigning groups characteristics based on social values, separates people into hierarchal categories of “us” and “them” (Link & Phelan, 2001, p. 376). Labeled individuals risk loss of status, rejection, exclusion, and discriminations.

**Health-Related Stigma**

Stigma also impacts patients’ health-related experiences (Scrambler, 2009). Health related stigma is described as a “social process or related personal experience characterized by exclusion, rejection, blame, or devaluation that results from experience or reasonable anticipation of an adverse social judgement about a person or group identified with a particular health problem” (p. 536). Chronic illness irrevocably disrupts
persons’ identity and self-worth. Furthermore, patients are negatively stereotyped and suffer the loss of identity and social status (Charmaz, 1983; 2000). For example, some ostomy patients use layers clothing to conceal their illness and pass as healthy (Savard & Woodgate, 2009). However, by revealing their illness, ostomates can still experience felt and enacted stigma.

*Enacted Stigma.* Chronically ill patients experience episodes of decimation or enacted stigma (Phillips, 1990). Enacted stigma is articulated as a “phenomenon of large social groups endorsing stereotypes about acting against a stigmatized group” (p. 179). Specifically, enacted stigma requires individuals to experience actual instance of discrimination, prejudice, and unfair treatment. For example, patients with invisible illnesses, like an ostomy, encounter social exclusion, isolation, and abandonment by loved ones (Corrigan & Kleinlein, 2005; Smith et al., 2007). Patients also experience poor employment and housing opportunities (Page, 1995; Tak-Ying, Shiu, Kwan, & Wong, 2003). Some forms of invisible stigma, like HIV, are also linked to acts of violence, harassment, and physical harm when a person’s status is discovered (Gielen, McDonnell, Burke, & O’Campo, 2000).

*Enacted Stigma and HRQoL.* Enacted stigma, such as social exclusion or violence, causes patients to experience psychological distress. For example, enacted stigma is linked to depression and anxiety in patients with HIV (Zaho, Li, Zhao, Zhang, & Stanton, 2012), neuromuscular diseases (van der Beek, Bos, Middel, & Wynia, 2013), and Hepatitis’s C (Zickmund, Ho, Masuda, Ippolito, & LaBrecque, 2003). Furthermore, enacted stigma also impairs patients’ physical health. In a study of Parkinson’s patients, Ma, Saint-Hilaire, Thomas, and Tickle-Degnen (2016), showed that enacted stigma
reduces daily function and increases disease-related symptoms. When encountering enacted stigma, HIV patients fail to pursue medical care (Sayles, Wong, Kinsler, Martins, & Cunningham, 2009), adhere to medication (Carriero et al., 2001), and engage in risky sexual behaviors (Balaji et al., 2017). Thus, enacted stigma negatively influences patients’ physical and psychological HRQoL.

Felt stigma. In contrast, felt or perceived stigma refers to the negative attributed patients perceive others have about their illness. Felt stigma is defined as the personal shame of being different and “the fear of encountering enacted stigma (Scambler, 2004, p. 33). Patients perceive stigma more than they encounter instances stigma (Scambler & Hopkins, 1986). However, when patients experience discrimination, their perceptions of felt stigma increases (Ma et al., 2016). Because HIV fear disclosing their status to others, they experience higher levels of enacted stigma (Oolley, Ogunde, Oso, Ishola, 2016). Similarly, at least 89% of patients with inflammatory bowel disease perceive stigma during symptom flare-ups (Taft, Keefer, Leonhard, & Nealon-Woods, 2009). While 86% of neuronuclear patients described experiencing felt stigma, only 64% reported encountered discrimination. Although some patients conceal their illness, perceptions of felt stigma continues to negatively impact overall well-being.

Felt Stigma and HRQoL. Felt stigma impairs patients’ psychological well-being. For example, when dealing with felt stigma, HIV patients experience greater depression, anxiety, and loneliness (Lyimo et al., 2014). Similarly, felt stigma also causes reduced self-esteem and poor body image in patients with irritable bowel disease (Taft, Keefer, Leonhard, & Nealon-Woods, 2009). Felt stigma generates increased depression in patients with lung cancer (Gonzalez et al., 2015), breast cancer (Tripathi, Datta, Agrawal, 25
Chatterjee, & Ahmed, 2017), colorectal cancer (Phelan et al., 2013), epilepsy (Jacoby et al., 2005), and multiple sclerosis (Broersman et al., 2017). Furthermore, perceptions of stigma encourage patients to engage in maladaptive coping behaviors, such as social isolations and substance abuse (Lyimo et al., 2014).

Felt stigma also damages patients’ physical health. For example, when perceiving stigma, patients with mental illness display more psychiatric symptoms (Corrigan, 2004). Perceptions of stigma also deters HIV patients from revealing their status, accessing quality medical care, and adhering to medication (Lyimo et al., 2014). Additionally, sickle cell patients describe suffering from limited physical functioning and bodily pain when perceiving stigma (Adeyemo, Ojewunmi, Diaku-Akinwumi, Ayinde, & Akanmu, 2015). Finally, felt stigma impedes self-efficacy in patients with irritable bowel disease (Taft et al., 2009), lung cancer (Liu et al., 2016), and HIV (Li et al., 2011). Thus, the fear of stigmatization harmfully affects both physical and psychological HRQoL.

**Stigma Resistance**

More recently, scholars are examining how stigma resistance counteracts the harmful effects of stigma on HRQoL. Stigma resistance is presented as a state of being unaffected by stigmatizing attitudes (Ritsher, Otingam, Grajales, 2003: Ritsher & Phelan, 2004). Thoits (2011) articulated resistance as a set of strategies that challenge or deflect negative stereotypes. In general, stigma resistance improves patients’ abilities to combat stigmatizing encounters. More specifically, patients are empowered to reject a “social identity that is tied to stigma” (Firmin, Luther, Lysaker, Minor, & Salyers, 2016, p. 118). Several key strategies help patients resist stigma, including availability of coping
resourcing, previous experience countering stigma, multiple role-identities outside of the illness, and witnessing peers oppose stigma (Thoits, 2011).

A positive relationship exists between stigma resistance and QoL (Ritsher & Phelan, 2004). For example, stigma resistance improves patients with mental illnesses well-being and reduces feelings of stigma and depression (Firmin et al., 2016). Stigma resistance also increases patients’ perceptions of hope while promoting health self-efficacy and functioning (Firmin et al., 2016). When engaging in stigma resistance, schizophrenia patients encounter less anxiety, fewer depressive episodes, and improved QoL (Sibitz, Unger, Woppman, Zidek, & Amering, 2011). Stigma resistance also enhanced patients’ self-esteem and psychological well-being (Lau et al., 2017). Patients with depression and bipolar disorder report feeling empowered and better functioning when utilizing stigma resistance strategies (Brohan, Gauci, Sartorius, & Thornicroft, 2011).

In sum, stigmatization is the process by which society stereotypes people as different and undesirable. Patients often encounter direct or perceived stigma surrounding their health-related issues. When illnesses are invisible, like an ostomy appliance, patients choose to either self-disclose or conceal their condition. Those who pass as “normal” or “healthy” as Goffman (1963) observed, suffer from distress and poor QoL by “living a life that can be collapsed at any moment” (p. 87). By challenging or deflecting stigmatizing encounters, patients can actively resist the negative health-related consequences of stigma.
Coping Strategies

The diagnosis of chronic illnesses poses significant challenges for patients’ daily functioning. When complete recovery is unattainable, patients must adjust their lifestyle, aspirations, or employment status to accommodate their illness (Turner & Kelly, 2000). The adjustment process is described as the “presence or absence of diagnosed psychological disorder, psychological symptoms, or negative mood” (p. 586). For example, successful adaption occurs when patients perform adaptive tasks, like accepting their disability and displaying emotional stability. To successfully transition and improve well-being, patients engage in the coping process.

While some patients quickly adjust to their illness, others may struggle to accept their diagnosis and limited lifestyle. The coping process provides the foundation for patients to acclimate and adapt to their illness (Lazarus & Folkman, 1984). For example, Krouse and associates (2009) revealed that coping and acceptance are the greatest challenges facing new ostomates. When experiencing poor adjustment, patients risk poor physical and psychological health (Meyer, Springer, & Altice, 2011; Sanders, Labott, Molokie, Shleby, & Desimone, 2010). Thus, the coping strategies patients select are critical to improving well-being and determining transitional outcomes.

Problem-Focused Coping

Coping strategies are recognized as important variables in governing patients’ adjustment and health experiences. In general, coping is conceptually delineated into two dimensions: problem- and emotion-focused coping (Folkman, 1997; Lazarus, 1993). Problem-focused coping involves individuals making solution-oriented attempts to minimize or eliminate the source of the stressor (Lazarus & Folkman, 1984). These
strategies are “often directed at defining the problem, generating alternative solutions, weighing the alternative in terms of their costs and benefits, choosing among them, and acting” (Lazarus & Folkman, p. 152). When there is personal control over environmental conditions and the stressor is perceived as changeable, this form of coping is frequently employed (Folkman & Moskowitz, 2004).

Problem-focused strategies include seeking information, problem-solving, evaluating alternatives, and planning and solving the problem (Carver, Scheirer, & Weintraub, 1989; Thoits, 1995). As an example, before choosing a pouching system, a new ostomy patient might seek additional information from peers or medical professionals. When engaging in problem-focused coping, patients experience better HRQoL (Alok et al., 2014; Moslehi, Atefimanesh, & Farid, 2015).

Problem-focused coping helps patients psychologically adapt to their illness (Penley, Tomaka, & Wiebe, 2002). In a meta-analysis of prostate cancer patients, Roesch and associates (2005) revealed that problem-focused coping improves social functioning and positive affect. Problem-focused coping is also associated with reduced depression in patients with multiple sclerosis (Rabinowitz & Arnett, 2009), diabetes (Macrodimitris & Endler, 2001), and breast cancer (Ransom, Jacobsen, Schmidt, & Andrykowski, 2005). Furthermore, problem-focused strategies also lessen patients’ anxiety (Drageset & Lindstrøm 2003) and feelings of hopelessness (Swindells et al., 1999).

Problem-focused coping is also linked to improved physical functioning. For example, breast cancer patients who engage in information seeking behaviors report greater physical well-being (Ransom et al., 2005). Problem-focused coping is also associated with reduced pain and increased function in patients with fibromyalgia (Alok
et al., 2004) and prostate cancer (Roesch et al., 2005) When using problem-focused coping, patients engage in better self-care behaviors (Harvey & Lawson, 2009) For example, problem-focused coping motivates diabetes patients to diet, exercise, and engage in glycemic testing (Harvey & Lawson, 2009). Problem-focused coping also helps HIV patients better adhere to medical treatment (Heckman, Catz, Heckman, Miller, & Kalichman, 2004). Overall, problem-focused coping plays a crucial role in shaping patients’ psychological and physical well-being.

Emotion Focused Coping

When nothing can be done to modify the threatening or harmful situation, individuals employ emotion-focused coping strategies (Lazarus & Folkman, 1984). Emotion-focused coping involves individuals reducing negative feelings by managing their emotional reaction (Thoits, 1995). Examples of emotion-focused coping include behavior avoidance, cognitive avoidance, focusing on the positive aspect of the situation, and seeking social support. To illustrate, a new ostomy patient might choose to avoid looking at their stoma or seek advice when learning how to change their ostomy appliance to better understand their new medical circumstances.

When examining the use of emotion-focused coping strategies and improving HRQoL, results are mixed. Prior studies reveal use of emotion-focused strategies are less effective in minimizing patients’ health stressors compared to problem-focused strategies (Coyne & Racioppo, 2000; Penley et al., 2002). For example, when using emotion-focused coping strategies, renal cell cancer patients experience poor HRQoL (Beisland et al., 2015). Emotion-focused coping is also linked to pain and uncontrolled symptoms in prostate cancer patients (Roesch et al., 2005). Patients with multiple sclerosis
(Giovannetti et al., 2016), rheumatoid arthritis (Affleck et al., 1999), prostate cancer (Roesch et al., 2005), and renal disease (Kristofferzon, Lindqvist, & Nilsson, 2011) also encounter depression, stress, anxiety, and mood disturbance when using emotion-focused strategies.

Conversely, Lazarus (2006) argued that emotion-focused strategies fosters positive coping outcomes for patients. Diabetic patients, using emotion-focused strategies, experience lower levels of depression and anxiety (Duangdao & Roesch, 2008). Emotion-focused coping is also linked to better well-being in infertile women and fewer instances of depression (McQueeney, Stanton, & Sigmon, 1997). When employing emotion-focused coping strategies, breast cancer patients encounter less cancer-related morbidities and stress (Stanton et al., 2001). Finally, Affleck and associates (1999) documented that osteoarthritis patients’ experience less pain when employing emotion-focused coping strategies.

When managing stressors, individuals adapt their coping strategies to match the demands of the stressor (Lazarus & Folkman, 1984). To adjust to their illness, patients use a combination of emotion-focused and problem-focused strategies. For example, diabetic patients demonstrate improve self-care practices and have better glycemic control when using a combination of coping strategies (Karlsen & Bru, 2002). Krouse and colleagues (2009) argued that problem- and emotion-focused coping improves ostomates well-being.

**Adaptive and Maladaptive Coping**

Although Lazarus and Folkman’s (1984) framework is frequently cited, scholars have exposed several weaknesses in their conceptualization of coping. Because problem- and emotion-focused coping does not include a full range of responses, this
conceptualization does not accurately capture the coping experience (Duhachek, 2005). To better distinguish among coping behaviors, Skinner, Edge, Altman, and Sherwood (2003) suggested that categories be differentiated based on whether coping behaviors are beneficial or harmful. Specifically, Rippetoe and Rogers (1987) argued that individuals respond to stressors by employing adaptive or maladaptive coping strategies. Adaptive coping behaviors reduce both fear and threat by directly confronting stressors (Carver et al., 1989; Rippetoe & Rogers, 1987). Adaptive coping strategies are comprised of problem- and emotion-focused behaviors (i.e., social support, positive reframing, and planning) associated with improved well-being (Carver et al., 1989).

Maladaptive coping strategies temporarily reduces a stressor but does not completely remove the threat (Carver et al., 1989; McCrae & Costa, 1986; Rippetoe & Rogers, 1987). While these strategies provide temporary relief, such as venting or expressing negative feelings, overuse results in poor physical and psychological well-being (Carver et al., 1989; Penley et al., 2002). To maximize outcomes, patients can engage in both adaptive and maladaptive coping (Folkman & Moskowitz, 2004). However, they are more likely to select adaptive strategies over maladaptive strategies based on cognitive evaluations and past experiences (Lazarus, 2006; Tanner, Hunt, & Eppright, 1991). In other words, when attempting to cope, people rely on behaviors that previously reduced reduces stressors.

Adaptive Coping and HRQoL. Adaptive coping strategies are connected to better psychological well-being in chronically ill populations (Carver et al., 1993; Klein, Turvey, & Pies, 2007; Llewellyn, McGurk, & Weinman, 2006). Carver and associates (1993) reported that adaptive coping strategies improve optimism levels and reduce
distress in presurgical breast cancer patients. Frequent use of adaptive coping also lessens depression and anxiety in patients with head trauma (Anson & Ponsford, 2006), spinal cord injuries (Galvin & Godfrey, 2001), terminal cancer (Nipp et al., 2016), and congestive heart failure (Carels, 2004).

Patients also experience improved physical functioning when employing adaptive coping strategies. Greater use of adaptive coping strategies promotes adherence to antiretroviral medication and reduces viral load in HIV patients (Johnson, Heckman, Hansen, Kochman, & Sikkema, 2009). When engaging in adaptive coping, Parkinson’s patients experience better cognitive function and less pain (Whitworth et al., 2013). Van der Lee and Garssen (2012) showed that adaptive coping reduces fatigue and improves energy levels in cancer patients. Finally, when using adaptive coping strategies, postsurgery patients experience quicker recovery rates (Kopp et al., 2003). Adaptive coping is thus positively associated with improved QoL.

Maladaptive Coping and HRQoL. Conversely, maladaptive coping strategies cause negative psychological outcomes. For example, the use of avoidance coping heightens anxiety and depression in women with polycystic ovary syndrome (Benson et al., 2010). Frequent use of maladaptive coping strategies also promotes depression and poor adjustment in patients with stage I and stage II breast cancer (McCaul et al., 1999), HIV (Gore-Felton et al., 2006), and rheumatoid arthritis (Vriezekolk, Lankveld, Geenen, & Ende, 2011). When using maladaptive coping strategies, patients with aneurysmal subarachnoid hemorrhage have mood disturbances (Hedlund, Ronne-Engström, Carlsson, & Ekselius, 2010) and posttraumatic stress disorder (Nobel et al., 2008).
Chronically ill patients also experience poor physical functioning when using maladaptive coping behaviors. For example, when engaging in maladaptive strategies, rheumatoid arthritis, osteoarthritis, and fibromyalgia patients encounter greater physical disability and intensified pain (Covic, Adamson, & Hough, 2000; Edwards, Bingham, Bathon, & Haythornthwaite, 2006). Reoccurring use of maladaptive strategies causes poor physical mobility, reduced energy, and increased fatigue in patients with type II diabetes (Coelho, Amorim, Prata, 2003), heart failure (Doering et al., 2004), and HIV (Vosvick et al., 2003). Finally, maladaptive coping strategies are associated with increased mortality rates among heart failure patients (Murberg & Bru, 2001).

In review, the transactional model of stress and coping (Folkman & Lazarus, 1984) employs different coping strategies to mitigate stressors and achieve optimal well-being. How chronically patients cope with their illness experience is essential in determining their HRQoL. To meet the stressors and demands associated with illnesses, patients use both adaptive and maladaptive coping strategies (Carver et al., 1980). While maladaptive coping strategies briefly minimizes stressors, long-term use can negatively reduce HRQoL. In contrast, adaptive coping strategies diminishes the long-term negative effects of stress. Because the coping process shapes patients’ HRQoL, more research is required to better understand how coping helps patients manage ostomy-related stressors (Krouse et al., 2009). More specifically, research should explore how patients use self-disclosure to access social support and effectively cope with ostomy implementation. Although self-disclosure of sensitive medical issues provides social resources, revealing sensitive information increases the threat stigmatization.
Self-Disclosure

Self-disclosure, or the revealing of sensitive information to others, is a requirement for creating, maintaining, and dissolving intimate relationship with others (Altman & Taylor, 1973; Greene, Derlega, & Matthews, 2006). Jourard (1971) described self-disclosure as an essential component in developing and maintaining healthy relationships. More recently, scholars have rearticulated self-disclosure as a complex process of information regulation of revealing or concealing sensitive information in interpersonal relationships (Altman & Taylor, 1973; Green et al., 2006, Greene, 2009).

Green and associates (2006) defined self-disclosure as “an interaction between at least two individuals where one intends to deliberately divulge something personal to another” (p. 411). To self-disclose, individuals make the decision to reveal verbally or non-verbally personal information (e.g., I have an ostomy appliance) or less sensitive information (e.g., I have a family member with an ostomy). Green and colleagues (2006) distinguished between two types of self-disclosure: personal and relational. While personal disclosure deals with information about one’s thoughts and feelings (e.g., I hate my ostomy), relational disclosure focuses on the state of one’s relationship with others (e.g., I can’t image recovering from ostomy surgery without your help).

Initially, research examined how depth (e.g., the importance of the material) and the breadth (e.g., the topics disclosed) of disclosures foster interpersonal relationships (Greene, Derlega, & Matthews, 2006b). For example, Altman and Taylor’s (1973) social penetration theory posits that, over time, relational communication shifts from superficial to more intimate discussions, reducing uncertainty and creating relational closeness. However, as the relationship develops, the level of intimate self-disclosure becomes less
important Altman & Taylor, 1973; Derlega, Harris, & Chaikin, 1973). More recently, scholars view privacy and closed communication as important factors in relational development (Finkenauer & Hazam, 2000, Goldsmith & Domann-Schlolz, 2013; Omarzu, 2000). For example, self-disclosure and closed communication increased marital satisfaction between cardiac patients and their partners (Goldsmith & Domann-Scholz, 2013).

**Communication privacy management.** Communication privacy management (CPM) is used as a theoretical framework to understand when and why open communication is advantageous in interpersonal relationships (Petronio, 2002). CPM is a rule-based theory that explains individuals’ disclosure practices regarding their public and private lives (Petronio, 2002). CPM proposes that personal boundaries regulate the amount of revealed information about the self, while collective boundaries manage information concerning the group (e.g., family members, friends, and friends; Petronio, 2002).

Petronio (2002) argued privacy rules consist of five conditions: cultural standards, gender, motivations, contextual factors, and risk-benefits. Because individuals’ privacy rules govern disclosure practices, exactly what and how much information is shared varies from person-to-person. Before disclosing, individuals negotiate privacy boundaries surrounding what they will and will not discuss. Once disclosure occurs, the receiver becomes the co-owner of the information and entangled in the sender’s privacy boundaries (Petronio, Sargent, Andea, Reganis, & Cichocki, 2004). Revealing sensitive information can place disclosers in vulnerable situations, thus, co-owners engage in a
series of negotiations that focus on boundary ownerships, linkage, and permeability (Petronio, 2007).

**Disclosure decision model.** Omarzu’s (2000) disclosure decision model (DDM) posited that individuals purposefully manage different types and levels of disclosures to achieve goals. DDM reinforces that, “individuals decide what, how, and to whom they are going disclose and that this decision is based on an evaluation of the possible rewards versus the possible risks of disclosing in any specific social situation” (Omarzu, 2000, p. 177). First, the discloser identifies situational cues that highlights potential self-disclosure rewards (e.g., intimacy, social approval, and identity clarification). Second, the discloser searches for others with whom to reveal, while assessing the subjective utility (e.g., rewards and desired outcomes) and subjective risks (i.e., rejection and stigma) of the disclosure. DDM, like CPM, maintains that individual’s evaluation of subjective utility and subjective risk shapes the breadth (i.e., topics), depth (i.e., intimacy), and duration (i.e., length) of the disclosure. The model argues, as subjective evaluation increases, individuals reveal greater amounts of information over a longer duration, but the breadth centers on the goal. In contrast, as subjective risk increases, the level of information and duration disclosure decreases.

**Model of disclosure decision making.** Greene’s (2009) disclosure decision-making model (DD-MM) incorporates components of CPM and DDM, like risk and rewards, but is inherently linked to disclosure decisions and uncertainty (Babrow, 2001; Brashers, 2001). The model explains how the disclosure process develops over time (Checton & Greene, 2012) and how patients and partners engage in topic avoidance (Venetis, Greene, Checton, & Magsamen-Conrad, 2015). Three factors are used to determine health-related
disclosures, the information, the recipient, and disclosure efficacy. Before disclosing, patients assess their health-related information for stigma, prognosis, symptoms, and relevance. Second, they evaluate relationship quality, and the receiver’s anticipated reaction and response to the information. Finally, the disclosers weigh their ability to effectively share the information and achieve desired outcomes.

Self-Disclosure and Health

During a health crisis, patients reveal sensitive health-related information to others to cope with the uncertainty (Goldsmith, 2004). Revealing health-related information can positively influence patients’ well-being. For example, when Amyotrophic Lateral Sclerosis (ALS) patients disclose about their disease, they report better psychological well-being (Averill, Kasarskis, & Segerstrom, 2013). Disclosure of chronic illness is also associated with reduced depression and anxiety in patients with Alzheimer disease (Mormont; Jamart, Jacques, 2014), rheumatoid arthritis (Kelly, 2004), and multiple sclerosis (Giordano et al., 2011).

In addition, patients experience improved physical functioning when disclosing about their chronic illness. Disclosing illness-related information improves medication and treatment adherence in patients with HIV (Kiltzman et al., 2004), type I diabetes (Osborn, Berg, Hughes, Pham, & Wiebe, 2013), and lupus (Bennett, Fuertes, Keitel, & Philips, 2011). Frequent health-related disclosure reduces pain, swelling of joints, and less disease activity over a six-month period in rheumatoid arthritis patients (Lumley et al., 2011). Illness-related disclosures also reduces fatigue and pain in patients with Fibromyalgia (Broderick; Junghaenel, & Schwartz, 2005) and lung cancer (Lheureux et
al., 2004). Finally, heart disease patients indicate feeling empowered when discussing lifestyle changes with their spouses (Goldsmith, Lindholm, & Bute, 2006).

Lack of Self-Disclosure and Health

Self-disclosure fraught is with challenges, especially for patients with hidden medical conditions, such as mental illness or ostomy. Because patients with concealed conditions can pass as normal, disclosing health-related information increases the risk of stigma, social rejection, loss of control, and decline cline of personal credibility (Afifi & Guerrero, 2000). Other reasons patients refuse to self-disclose health concerns are increased shame and guilt associated with their diagnoses (Hult, Wruble, Bränström, Acree, & Moskowitz, 2012). Patients also describe concealing illnesses for fear of overburdening family members and friends (Gonzalez et al., 2015). Concerns of privacy, self-blame, and fear of rejection can impede patients’ desire to share health-related information (Derlega, Winstead, Greene, Serovich, & Elwood, 2004). Patients may choose to conceal health-status to maintain normalcy and avoid jeopardizing their employment (Allen & Carlson, 2003). Thus, patients struggle with the decision whether to share potentially stigmatizing information.

Although patients may deliberately avoid self-disclosing about health-status, they risk poor psychological outcomes. For example, the absence of illness-related disclosure is related to internalized shame and increased use of maladaptive coping strategies in lung cancer patients (Gonzalez et al., 2015). Non-disclosure is also linked to depression and thoughts of suicide in patients with systemic lupus erythematosus (Schattner, Shahr, Lerman, & Shakra, 2010), HIV (Cook, Valera, & Wilson, 2015), and rheumatoid arthritis (Withers, Moran, Nicassio, Weisman, & Karpouzas, 2015). Among cancer patients the
absence of cancer-related disclosure is linked to low social support, decreased social functioning, and reduced emotional well-being (Figueriedo, Fries, & Ingram, 2004).

When patients do not reveal health-related, they risk decreased physical functioning. For example, self-concealment is associated with low pain tolerance and intensified pain in patients with fibromyalgia (Uysal and Lu, 2011), rheumatoid arthritis (Ryan & McGuire, 2016), and cancer patients (Cepeda et al., 2008). Lack of written emotional disclosure also increases viral load and reduce CD4+ T helper cells in HIV patients (Petrie, Fontanilla, Thomas, Booth, & Pennebaker, 2004). When emotional disclosure is low, breast cancer patients experience somatic symptom disorder and more cancer-related morbidities (Stanton et al, 2002). Smyth, Stone, Hurewitz, and Kaell (1999) revealed that when disclosure is low, asthma and rheumatoid arthritis patients’ symptoms and disease activity do not improve.

To review, scholars have conceptualized several models to understand the process of self-disclosure, including CPM (Petronio, 2004), DDM (Omarzu, 2000), DD-MM (Greene, 2009). In the context of health, self-disclosure provides patients a way to express thoughts and concerns about their illness. For patients with concealable conditions, like an ostomy, the decision to disclose is a complicated process. Although health-disclosure is risky (Petronio et al, 2004), patients who reveal medical infomation can access social support and experience better health outcomes. Conversely, when patients conceal their illness, they may encounter limited social support and suffer reduced HRQoL. Overall, self-disclosure plays is an important factor in helping patients adjust to their illness by providing patients social resources.
When people experience a health-crisis, such as ostomy implementation, they turn to others for additional care and support. Cobb (1976) described social support as information and resources that leads individuals to believe they are “care for and loved; esteemed and valued; belonging to a network of communication and mutual obligations” (p. 300). Albrecht and Adelman (1987) rearticulated social support as a reciprocal communicative process used to reduce uncertainty. More recently, Thoits (2010) defined social support as an “emotional, informational, or practical assistance from significant others, such as family members, friends, or coworkers; support actually may be received from others or simply perceived to be available when needed” (p. 543).

While some scholars articulate social support as a reciprocal process between individuals and their social networks (Cohen, 1976; Thoits, 1995), others explore the functional aspects of social support. House (1981) operationalized social support as a set of resources. Specifically, social support can be classified into four broad categories: emotional, (i.e., expression of love), informational (i.e., guidance or advice), instrumental (i.e. tangible support), and appraisal support (i.e., affirmations and validations).

Cohen and Willis’ (1985) stress-buffering model asserts that social support resources buffers against the negative effects of stress. When facing increased anxiety, individuals seek support (e.g., emotional comfort, physical assistance, and information) to mitigate stressors. Social support allows individuals to change their appraisal of the situation, cope with stressors, and experience better health outcomes. However, the buffering effect only occurs when individuals are experiencing high levels of stress (Cohen, 2004).
Perceived Social Support

Social support is either perceived or received by the recipient. Lin (1986) articulated social support as “perceived or actual instrumental and/or expressive provision supplied by the community, social networks, and confiding partners” (p. 18). Perceived support is the recipient’s subjective view about the availability of support when facing stressors. Patients’ perception of social support is formed by rating the type and quality of previous supportive interactions. More precisely, perceived support measures require individuals’ perceptions, judgement, and memory processes (Haber, Cohen, Lucas, & Baltes, 2007). For example, a newly diagnosed colon cancer patient, may rely on instances of social support to identify others who will provide tangible and emotional support. When individuals perceive social support, they are likely to indicate feeling cared for, understood, and valued (Thoits, 1995).

When patients perceive social support, they experience better psychological health (Reblin & Uchino, 2008; Uchino, 2009). Perceived social is associated with fewer depressive symptoms and mood disturbances, and better psychological adjustment (Hann et al., 2002). Patients with type II diabetes (Fortman, Gallo, & Philis-Tsimikas, 2011), burns (He, Zhou, Zhao, Zhang, & Guan, 2016), and rheumatoid arthritis (Zyrianova et al., 2006) experience reduced depression when perceiving social support. Furthermore, perceptions of social support reduce uncertainty and improves coping outcomes in HIV patients (Sajjadi, Rassouli, Bahri, & Mohammadipoor, 2015).

Furthermore, patients describe better physical health when perceiving social support. Wesley, Zelikovskey, and Schwartz (2013) maintained perceived support reduced illness-related symptoms and improved physical functioning in chronically ill
populations. When perceiving support, rheumatoid arthritis (Xu et al., 2017), multiple sclerosis (Aghaei, Karbandi, Gorji, Golkhatmi, & Alizadeh, 2016), and hemodialysis patients (Karadag, Kilikc, & Metin, 2013) have more energy and suffer from less fatigue. Type II diabetes patients demonstrate better self-care practices, disease-management, and stricter glycemic control when perceiving support (Fortmann et al., 2011; Rad, Bakht, Feizi, & Mohebi, 2013). Perceived support also improves medicine adherence (DiMatteo, 2004), reduces negative uncertainty (Neville, 1998), and better health self-efficacy (Forsythe et al., 2014). Increased perceptions of social support also reduces all-cause mortality and morbidity (Rebline & Uchino, 2008) and improves cancer recovery rates (Pinquart & Duberstein, 2010).

Lack of perceived social support has significant consequences on patients’ well-being. For example, when perceptions of social support are low, cancer patients suffer from distress and anxiety (Mehnert, Lechmann, Graefen, Huland, & Kock, 2010). Absence of perceived social support causes depression (Burgess et al., 2005), uncertainty (Lien, Lin, Kuo, & Chen, 2009), and psychological disturbances in patients with chronic illness (Curtis, Groarke, Coughlan, & Gsel, 2004). A shortage of perceived support also produces slower recovery rates and poor disease self-efficacy in patients with cardiovascular disease (Uchino, 2009), rheumatoid arthritis (Evers, Kraaimaat, Geenen, Jacobs, & Bijlsma, 2003), and type II diabetes (Strom & Egede, 2012). Patient also experience higher hospital admittance rates, usage of outpatient services, and greater morality rates (Barth, Schneider, & Kanel, 2010; Reblin & Uchino, 2008).
Received Social Support

Received social support is understood as the actual emotional, instrumental, informational, and appraisal support offered by an individual’s social network (Barrera, 1986). Goldsmith (2004) argued received support is the “things relational partners do and say with the intention of helping one another manage problems and stress” (p. 342). To illustrate, received support occurs when a loved one offers emotional support during treatment or gives financial assistance to cover medical bills. Brock and associates (2014) maintained received support occurs if patients recognize behaviors as supportive. When examining the relationship between received social support and health-related outcomes, researchers have discovered mixed findings (Goldsmith, 2004).

Because individuals may feel uncomfortable or embarrassed about their increased dependence on others, received support may hinder QoL (Chen & Feeley, 2012; Lakey & Cohen, 2000). For example, received social support is associated with poor function in elderly patients (Mendes de Leon, Gold, Glass, Kaplan, & George, 2001). When married couples receive social support, they experience higher mortality rates (Selcuk, Stanton, Slatcher, & Ong, 2017). Patients also suffer from increased depression, reduced self-esteem, and greater suicidal tendencies when receiving social support from others (Bolger, Zuckerman, & Kessler, 2000).

Brock and Lawrence (2009) argued that received support is only effective when it meets recipients’ coping needs rather than addressing the overall problem. When intended supportive behaviors are ineffective or mismatched, received support can impede coping efforts and reduce patients’ HRQoL (Reynolds & Perrin, 2004; Seidman, Shrout, & Bolger, 2006). For example, received support is linked to increased distress in
hematopoietic stem cell transplant patients (Brock & Lawrence, 2009). Breast cancer
(Reynolds & Perrin, 2004) and rheumatoid arthritis patients (Revenson, Schiaffino,
Majerovitz, & Gibofsky, 1991) encounter poor psychosocial adjustment when receiving
social support. Finally, Yan (2018) revealed that received social support from online
weight loss community hinders individuals’ ability to lose weight.

Other studies have demonstrated the importance of received social support in
improving patients’ QoL (Thorsteinsson & James, 1999). When receiving social support,
patients experience improved psychological well-being. For example, lung cancer
patients report better emotional QoL when receiving support from friends and family
members (Luszczynska, Sarkar, & Knoll, 2007). Adequate received support also reduces
depression in patients with breast (Komproe, Rijken, Ros, Winnubst, & t’Hart, 1997),
head and neck (De Leeuw et al., 2000), and lung (Akechi, Okamura, Nishiwaki, &
Uchitomi, 2001) cancer.

Received social support also positively influence patients’ physical health. For
example, Thorsteinsson and James revealed that receiving social support lowered
participants’ heart rate, systolic blood pressure, and diastolic blood pressures. Receiving
social support reduces pain and suffering in patients with rheumatoid arthritis and low-
back pain (Rzezutek, Oniszczenko, Schier, Biernat-Kaluza, & Gasik, 2016). HIV patients
also report better physical functioning and adherence to antiviral medication when
receiving social support (Luzczynska et al., 2007). Finally, receiving social support is
linked to greater health self-efficacy and physical activity in prostate cancer patients
(Hohl et al., 2016) and the elderly (Gellert, Ziegelmann, Warner, & Schwarzer, 2011).
Conversely, inadequate received social support can have harmful consequences on patients’ well-being. In a meta-analysis, Barth and associates (2010) showed that lack of received support increases disease progression and all-cause mortality in patients with pre-existing coronary heart disease. Inadequate received support strengthens individuals’ risk for developing cardiovascular disease (Horsten et al., 1999). Furthermore, cancer patients with low received social support encounter higher rates of depression, anxiety, and comorbidities (Wiesel et al., 2015).

Overall, the research on social support demonstrates its importance in shaping health outcomes. While perceived support is associated with improved well-being in chronically ill patients, scholars continue to debate the role of received support in improving QoL. Regardless, lack of perceived and received social support can have detrimental effects on patients’ psychological and physical well-being. While social support is frequently studied in patients with chronic diseases, such as cancer and HIV, little research explored on the role of perceived and received social support in helping ostomy patients transition to their device and improve their HRQoL (Krouse et al., 2009; Vonk-Klaassen, de Vocht, den Ouden, Eddes, & Schuurmans, 2016).

**Perceived Partner Responsiveness**

Because social support is an important factor in health outcomes, scholars are examining the importance of responsiveness in accessing and maintaining supportive networks. Responsiveness is defined as the “process by which individuals come to believe that relationship partners both attend to and react supportively to central, core defining features of the self” (Reis & Shaver, 1988, p. 203). Reis and Shaver’s (1998) argued that intimacy forms through a transactional process between self-disclosure and
perceived partner responsiveness (PPR). More specifically, when speakers perceive that their partners provide responses that conveys understanding (i.e., capturing the sender’s feelings and beliefs), validation (i.e., accepting the sender’s perspective and world view) and caring (i.e., showing concern and self-sacrifice for the speaker), feelings of intimacy are increased. Thus, PPR should mediate the relationship between individuals’ self-disclosure and levels of intimacy in the interaction. In other words, when a speaker perceives their partner as responsive, feelings of intimacy should strengthen (Laurenceau, Barrett, & Pietromonaco, 1998; Reis & Shaver, 1988).

Reis and Shaver (1988) suggested that the speaker’s perception of the listener’s response plays a more important role in fostering intimacy compared to the speaker’s disclosure and listener’s response. Although a partner may offer an intimate response to a disclosure, the speaker may not view the partner’s response as meeting his or her needs (Reis & Patrick, 1996). Furthermore, Laurenceau, Barrett, and Pietromonaco, (1998) revealed that emotional disclosures better predict intimacy compared to factual disclosures. For example, a loved one may provide instrumental support after an ostomy patient’s disclosure about learning how to change an appliance. While the listener’s response demonstrates concern, the ostomy patient may perceive the response as ineffective. Because the response did not provide the desired emotional support, a patient’s connection to their partner is weakened.

PPR is important in building intimacy between people in close relationships (Reis & Shaver, 1988; Lippert & Prager, 2001). For example, in a diary study of married couples, Laurenceau, Barrett, and Rovine (2005) revealed that PPR mediates the effects of self-disclosures and partner disclosure on intimacy. Manne and associates (2004) also
demonstrated the importance of partner responsiveness in couples struggling with breast cancer. When partners display responsive behaviors, patients report greater feelings of intimacy, being accepted, being understood, and feeling. Additionally, cohabitating couples also describe having better relationship connectedness when perceiving responsiveness from their significant other (Maisel & Gable, 2009). Finally, college roommates indicate a closer and more satisfying relationships when disclosures are reciprocated with responsiveness (Gore, Cross, & Morris, 2006).

Conversely, when partners demonstrate non-responsive behaviors, intimacy is reduced and relationship satisfaction decreases (Lemay Jr., Clark, & Feeney, 2007). For instance, when completing difficult tasks, individuals with inattentive partners feel less cared for and put greater distance between themselves and their partner (Kane, McCall, Collins, & Blascovich, 2012). Because partners turn to loved ones to meet the demand of stressors, lack of PPR can have a significant impact on well-being (Collins & Feeney, 2000).

**PPR and Health**

High-quality responsiveness helps individuals cope with stressors and improve HRQoL (Robles, Slatcher, Trombello, & McGinn, 2014). Specifically, when individuals face stressors, PPR mediates the relationship between self-disclosure and psychological well-being (Reis & Shaver, 1984). For example, Feeney and Collins (2015) revealed partners’ responsive behaviors reduces anxiety and stress, promotes self-efficacy, and encourages partners to achieve personal goals. When facing negative stressors, PPR is instrumental in reducing cortisol and providing long-term protective benefits (Slatcher, Selcuk, & Ong, 2015). Furthermore, Dagan and associates (2014) demonstrated when
partners display validating and understanding behaviors individuals experience reduced depression.

PPR also mediates the relationship between self-disclosure and mental well-being in chronically ill patients. When perceiving responsiveness, rheumatoid arthritis patients, indicate lower levels of depression and anxiety (Kasle, Wilhelm, & Zautra, 2008) Lupus and cancer patients also experience less depression, improved health self-efficacy, and better mental health when perceiving partner responsiveness (Fekete, Stephens, Mickelson, & Druley, 2007; Kayers, Sormanti, & Strainchamps, 1999). For example, perceived partner responsiveness lowers psychological distress, promotes relationship satisfaction, and improves psychosexual adjustment in gastro-intestinal and breast cancer patients (Kinsinger, Laurenceau, Carver, & Antoni, 2011; Porter, Keef, Hurwitz, & Faber, 2005).

Furthermore, when patients perceive responsiveness from partners, they demonstrate better physical well-being. For example, perceived partner responsiveness lowers depression and improves sleep rates in patients with sleep disorders (Selcuk, Stanton, Slatcher, & Ong, 2017). Knee replacement patients also experience better health self-efficacy and shorter recovery times when perceiving partner responsiveness (Khan et al., 2009). Perceived responsiveness also ameliorates pain and illness-related symptoms in patients with chronic pain (Papas, Robinson, & Riley, 2001), rheumatoid arthritis (Williamson, Robinson, & Melamed, 1997), and fibromyalgia (Lyons, Jones, Bennett, Hiatt, & Sayer, 2013). Finally, perceived responsiveness serves as a protective barrier against all-cause mortality risks (Selcuk & Ong, 2013).
Unsupportive responsiveness like being “overly critical” (e.g., critiquing patients’ ability to cope) or engaging in avoidance coping behaviors (e.g., changing the topic and withdrawing) is detrimental to a patient’s well-being (Manne et al., 2014, p. 201). For example, when receiving negative responses from their spouse, cancer patients suffer from distress and poor psychological well-being (Manne, Taylor, Dougherty, Kemeny, 1997. When partner-responses are destructive, controlling, and interfering, female cancer patients report depression and inadequate spiritual well-being (Coker, Follingstad, Garcia, & Bush, 2016). Lack of responsiveness also increases depression in patients with HIV/AIDS (Ingram, Jones, Fass, Neidig, & Song, 1999), breast cancer (Figueiredo et al., 2004), fertility issues (Mindes, Ingram, Kliwer, & James, 2003), ovarian cancer (Norton et al., 2005), and type 2 diabetes (Helgeson, Mascatelli, Seltman, Korytkowski, & Hausmann, 2016). Patients also suffer from reduced self-esteem, increased feelings of isolation, decreased social and behavior functioning when receiving unsupportive responses (Grange, Matsuvmana, Ingram, Lyckholm, & Smith, 2008; Manne, Ostroff, Winkel Grana, & Fox, 2005; Norton et al., 2005).

Additionally, poor responsiveness negatively influences patients’ physical health. When diabetic patients face unsupportive interactions, they engage in poor diabetic management behaviors (i.e., dietary restrictions and exercise) and experience poor health outcomes (Helgeson et al., 2016; Heymann, Kaplan, Freidman, & Baron-Epel, 2016). HIV patients also struggle to enact daily practices and engage in poor health-related behaviors when receiving low responsiveness is low (Fekete et al., 2007). Lack of partner responsiveness is also associated pain activity in patients with rheumatoid arthritis.
(Waltz, Kriegel, & Bosch, 199) and spinal cord injuries (Stroud, Turner, Jensen, & Cardenas, 2006).

In review, the interpersonal model of intimacy proposes that responsive partners communicate feelings of understanding, validation, and caring to their partners (Reis & Shaver, 1998). For people with chronic illnesses, partner responsiveness is a key component in building intimacy and improving well-being. When responsiveness is low, patients experience poor relationship satisfaction and health. Although some chronically ill patients are in intimate relationships, others may seek support from family members, friends, co-workers, and others. While substantial attention is paid to people in intimate relationships (Manne et al., 2004; Manne & Badr, 2010), how support networks’ use of responsive behaviors shapes patients’ HRQoL is understudied. Because successful interactions require appropriate responsiveness, individuals attempting to offer support may unintentionally give unsupportive responses to illness-related disclosures. As the number of ostomy patients continues to rise, understanding the communicative process between ostomates and their support network is vital to improving health-related outcomes.

Health-Related Quality of Life

*Quality of life.* In health-related literature, quality of life (QoL) is a complex and multidimensional construct. The World Health Organization (2018) defined QoL as a “state of complete physical, mental, and social well-being and not merely the absences of disease” (p. 3); however, scholars continue to struggle providing a more comprehensive definition (Farquhar, 1995; Ferrans, 1996). While Lehman (1983) characterized QoL satisfaction and happiness of one’s life, other scholars maintain that QoL should be based
on spiritual aspects of well-being (Farquhar, 1995; Ferrans, 1996; Frayers & Machin, 2000).

Farquhar (1995) argued that most QoL definitions fall into four categories: including global, component, focused, and combination definitions. Because the global definition operationalizes QoL using satisfaction/dissatisfaction and unhappiness/unhappiness continuums, researchers commonly apply this definition to measure outcomes. Component definitions outlines QoL into different dimensions utilizing characteristics, such as self-esteem, socio-economic status, and emotional responses. Focused definitions refer to one or more number of QoL components. Finally, combination definition characterizes QoL as individuals’ responses to physical, mental, and social issues.

Because QoL relies on subjective evaluations of well-being (Karimi & Brazier, 2016), it is used to assess individuals’ health and functioning (Fayers & Machin, 2000). More recently, scholarship has pushed to delineate individuals’ health status from their overall well-being (Guyatt, Feeny, & Patrick, 1993). Guyatt and colleagues (1993) argued that removing health-related symptom from QoL helps practitioners better gauge well-being. Instead of a general measure, health is evaluated using increasements of small, moderate, and significant differences over an extended amount of time. Additionally, QoL does not capture the impact of disease patients’ functioning, such as self-esteem, personal satisfaction, and social functioning (Guyatt et al., 1993; Guyatt et al., 1997). Finally, because QoL relies on an individual’s response to their condition, it does not accurately reflect patients’ well-being and health status (Guyatt et al., 19997).
Health-related quality of life. Health-related quality of life (HRQoL) is a multidimensional construct related to an individual’s health-related functioning; however, scholars struggle to agree on a common definition and conceptual underpinnings (Karimi & Brazier, 2016). Lerner and Levine (1994) argued HRQoL is a set of health issues that impede individuals’ abilities to complete physical tasks, social functioning, and life expectancy. Revicki et al., (2000) defined HRQoL as “subjective assessment of the impact of disease and treatment across the physical, psychological, social and somatic domains of functioning and well-being” (p. 888). Similarly, Bowling (2001) argued that HRQoL should include physical and social well-being and “some assessment of the patient’s level of satisfaction with treatment, outcome and health status and with future prospects” (p. 60). Thus, HRQoL is used to describe characteristics of QoL that are influenced by health, such as illness experience or treatment, and the impact of illness on the individual’s psychological, social, and economic well-being (Karimi & Brazier, 2016; Frable, 1993).

When examining the underpinnings of HRQoL, Ferrans, Zerwic, Wilbur, & Larson (2005) revealed that health-related and non-health-related aspects are difficult to decipher. To unify biomedical (i.e., biological, physiological, and clinical outcomes) and social aspects (i.e., social structures, values, and motivation) of health, Wilson and Cleary (1994) proposed a conceptual pathway model linking traditional medical and social health indicators with HRQoL. Conceptually, the model integrates biological and physiological aspects of health into one model. The model consists of five components: physiological factors, symptom status, functional health (i.e., ability to adapt to one’
environment), general health perception (i.e., mental and physical health), characteristics of the environment, nonmedical factors, and overall QoL.

Wilson and Clearly’s model (1995) has undergone significant empirical testing to facilitate better understanding between medical outcomes and patients’ subjective well-being (Ferrans, Zerwic, Wilbur, & Larson, 2005; Sousa and Kwok, 2006). For example, in a study of elderly patients with heart disease, Yu, Lee, and Woo (2004) suggested that psychological distress, impaired functional status, poor health perception, and low educational factors negatively impact HRQoL. When applied to diabetes patients, Shiu, Choi, Lee, Yu, and Man Ng (2014) indicated that health perception, psychological distress, adequacy of income, and social support improved HRQoL. The model has also accurately captured health experiences of patients with anxiety disorders (Wyrwich, Harnam, Locklear, Syedssäter & Revicki, 2011), HIV/AIDS (Sousa & Kwok, 2006), advanced cancer (Rodriguez, May, & Gagnon, 2013), and Parkinson’s disease (Chrischilles, Rubenstein, Voelker, Wallace, & Rodnitzky, 2002).

Ferrans and associates (2005) revised the Wilson and Clearly’s (1995) HRQoL model by renaming components and improving operational definitions. In particular, biological and physiological components were combined and renamed as biological function. According to Ferrans and colleagues (2005), renaming this component was necessary because “alterations in biological function directly or indirectly affect all components of health, including symptoms, function status, perception of health, and overall quality of life” (p. 338). Most importantly, nonmedical factors were separated into individual characteristics (e.g., marriage status, self-efficacy, and motivation) and environment factors (e.g., availability of social support and interaction with doctors).
This model, unlike the original, acknowledges that individual and environmental characteristics are important components in examining HRQoL. Finally, the revised model also updates causal pathways between variables by removing unnecessary arrows and labels portraying relationships. While dominate casual relationships are depicted in the revised model, it also suggests a reciprocal relationship exists among dimensions.

Bank and colleagues (2012) argued that the revised HRQoL model (Ferrans et al., 2005) provides a solid framework for examining patient populations and developing health interventions. For example, Saban, Penckofer, Androwich, and Bryant (2007) used the revised model to assess HRQoL both preoperatively and postoperatively in lumbar spinal surgery patients. Findings indicated that HRQoL significantly improved three months following surgery. Additionally, the model has proven to be a reliable HRQoL measure in patients with breast cancer (Wyatt, Katz, & Kim, 2000), end stage renal disease (Kring & Crane, 2009), and traumatic brain injury (Daggett, Bakas, Buelow; Habermann, & Muarry, 2013).

To review, HRQoL is a construct used to assess patients’ satisfaction life satisfaction and overall health functioning. Although identified as one of the most crucial indicators of well-being, scholars continue to debate about underlying dimensions of HRQoL (Dijkers, 2007). However, the Wilson and Cleary’s (1995) model and Ferrans and colleagues’ (2005) revised model provide frameworks for understanding the basic components which shape patients’ health experiences. Evaluating these components as they relate to ostomy implementation may provide insight into the challenges of patients and how to improve HRQoL.

Hypotheses and Model
Because of the substantive physical changes to their body (Krouse et al., 2007), some ostomates struggle to find meaning in their illness experience (Mishel et al., 1984; Brashers, 2001). When experiencing negative uncertainty, chronically ill patients report reduced HRQoL (Bailey at al., 2009; Kazer et al., 2013; Johnson, Afari, & Zautra, 2009). Reduced well-being is also connected to instances of felt and enacted stigma (Goffman, 1963; Link & Phelen, 2001, Scrambler, 2009; Smith et al., 2007). Simply perceiving or encountering acts of stigma can obstruct ostomates’ abilities to successfully adapt to their device (Smith et al, 2007). Collectively, negative uncertainty and felt and enacted stigma are threats to ostomates’ HRQoL. Based on the extant literature, the following hypothesis is proposed:

H1a: Ostomates’ perceptions of negative uncertainty are negatively associated with HRQoL.

H1b: Ostomates’ perceptions of enacted stigma are negatively associated with HRQoL.

H1c: Ostomates’ perceptions of felt stigma are negatively associated with HRQoL.

When facing health-related threats, ostomates can engage in different coping strategies to improve HRQoL (Folkman & Lazarus, 1984). While some patients may avoid accessing health-related information, others will seek information to manage negative uncertainty (Brashers, 2000; Mishel et al., 1984). Because self-disclosure facilitates access to coping resources, patients potentially have to reveal sensitive information to others (Lambert & Loiselle, 2007). Although self-disclosure reduces negative uncertainty (Goldsmith, 2004; Goldsmith et al., 2006), ostomates may limit self-
disclosing ostomy-specific information for fear of being stigmatized (Smith et al., 2007).

To build upon previous research, the following hypotheses are proposed:

H2: Uncertainty is positively associated with ostomates’ disclosure.

H3a: Enacted stigma is negatively associated with ostomates’ disclosure.

H3b: Felt stigma is negatively associated with ostomates’ disclosure.

Revealing one’s health-related issues can have a substantial positive effect on patients’ well-being (Frattaroli, 2006; Goldsmith et al., 2006). Because ostomy implementation is highly stigmatized, self-disclosing ostomy-specific information is risky for patients (Petronio, 2002). When disclosing health-related information to others, some patients may perceive positive responses (e.g., understanding, validation, and closeness) and experience increased HRQoL (Reis & Shaver, 1988; Robles et al., 2014). However, others may perceive negative responses, further generating feelings of rejection and stigmatization (Corrigan, 2004). Ostomates experience higher psychological quality of life when self-disclosing to family member if they perceive the response to be validating, caring, and understanding (Reif et al., 2016). Considering this literature, the subsequent hypothesis is proposed:

H4: Perceived responsiveness mediates the positive relationship between ostomates’ self-disclosure and HRQoL.

Self-disclosing health-related information elicits received (i.e., actual instance of support) and perceived (i.e., feelings support will be provided) social support and aids in the coping process (Derlega, Metts, Petronio, Margulis, 1993; Kawachi & Berkman, 2001; Lin, 1986, Uchino, 2009). Because ostomy patients may receive negative reactions from others, revealing sensitive health-related information does not guarantee support
from others (Corrigan, 2004). When support seekers perceive that others are responsive to disclosures, they feel like they have received social support (Collins & Feeney, 2000; Maisel & Gabel, 2009). In light of this literature, the following hypothesis is proposed:

H5: Perceived responsiveness mediates the positive relationship between ostomates’ self-disclosure and received social support.

Ostomates’ disclosure intentions are largely determined by previous success or failure in eliciting a favorable response from others. Concurrently, people should see appropriate responsiveness as socially supportive. Self-disclosure is a way to garner social support, but only when the responsiveness is perceived to be positive. Thus, the following hypothesis is suggested:

H6: Perceived responsiveness mediates the positive relationship between ostomates’ self-disclosure and perceived social support.

Lazarus and Folkman’s (1984) model argues that social support and coping are critical factors in shaping patients’ health-related outcomes. More specifically, social support buffers the negative effects of stress (Cohen & Willis, 1985). Perceptions of social support positively influences patients’ HRQoL (Kawachi & Berkman, 2001; Reblin & Uchino, 2008). However, received support, unlike perceived support, is more likely to decrease patients’ physical and psychological quality of life (Chen & Feeley, 2012; Lakey & Cohen, 2000). When instance of received support do not match patients’ needs, the benefits are negible.

Adaptive coping is a critical component in negating the negative effect of stressors on psychological and physical well-being (Bucks et al., 2011; Curtis et al., 2004; Swindle et al., 1999). Although maladaptive coping can provide short-term relief
from stressors, long-term use can negatively influence patients’ HRQoL (Rabinowitz & Arnett, 2009; Whitworth et al., 2013). While coping strategies have a direct effect on health outcomes, they also mediate the relationship between social support and HRQoL (Shrestha et al., 2018). To better understand the relationships between perceived and received social support and adaptive and maladaptive coping strategies on ostomy implementation, the following hypotheses are proposed:

H7: Adaptive coping strategies mediates the positive relationship between received social support and ostomates’ HRQoL.

H8: Maladaptive coping has a negative effect on the positive relationship between received social support and ostomates’ HRQoL.

H9: Adaptive coping strategies mediates the relationship between perceived social support and ostomates’ HRQoL.

H10: Maladaptive coping has a negative effect on the positive relationship between perceived social support and ostomates’ HRQoL.

Literature suggests a complex relationship exits between the stress of ostomy implementation and improving HRQoL outcomes. Specifically, this study is designed to test a conceptual model of how perceived and received stigma, uncertainty in illness, self-disclosure, perceived responsiveness, received and perceived social support, adaptive and maladaptive coping strategies affect ostomates’ HRQoL. Taking all the hypothesis into consideration, the following model seeks to explain this relationship (Please see Figure 1).
Summary

To provide a foundation in theory, Chapter II reviews the extant literature related to coping, disclosure, responsiveness, and HRQoL. Stigmatization and uncertainty represent legitimate threats to ostomates’ well-being, and thus evoke coping strategies. The transactional model of stress and coping (Folkman & Lazarus, 1984) helps explain ostomates selection and retention of adaptive and maladaptive behaviors related to their health-related problems. Based on the reviewed scholarly work, hypotheses were proposed. In addition, a model predicting the relationships between the concepts was presented. Chapter III overviews the methodological approach of the study.
Figure 1. Hypothesized Model

Note: The path analysis model depicts the relationships proposed in hypothesis one through ten.
CHAPTER III - METHOD

The transactional model of stress and coping (Folkman & Lazarus, 1984) serves as a foundation to examine patients’ ostomy-related experiences. In particular, this study explores the role of perceived responsiveness on ostomates’ HRQoL outcomes. This chapter presents the research design to test the proposed hypothesis and model. More precisely, this chapter provides operational definitions for constructs and discusses participants, instrumentation, and procedures. Finally, data analysis methods are presented.

Research Design

This study uses a quantitative approach to assess ostomates’ well-being. Creswell (2014) noted quantitative research “employs strategies of inquiry such as experimental and surveys and collects data on predetermined instruments that yield statistical data” (p. 18). For this study, a survey design was used to better understand ostomates’ health-related experiences. Check and Schutt (2012) defined a survey as “the collection of information from a sample of individuals through their responses to questions” (p. 160). When compared to other strategies, survey research has several key advantages in accessing high-quality data. First, survey data can accumulate a sizable amount of information from a variety of respondents (Kerlinger & Lee, 1999). Online surveys also offer access to communities traditionally difficult to reach in face-to-face environments, such as stigmatized health populations (Wright, 2005).

Another advantage of survey research is the ability to gather a variety of data. For example, researchers can collect data on respondents’ attitudes, beliefs, and behaviors (Ponto, 2015). Survey research also provides an accurate reflection of communicative
phenomenon being investigated (Kerlinger & Lese, 1999). For example, in health communication, surveys offer important insight concerning patients’ knowledge of health-related information, decision-making behaviors, and health care experiences (Manary, Boulding, Staelin, & Glickman, 2013). To analyze survey information, SPSS version 24.0, PROCESS macro version 3.1 (Hayes, 2018), and AMOS version 24.0 was used.

Participants

A total of 456 ostomates voluntarily participated in the online survey. However, to improve data quality, participants were only included if 80% of the survey was completed. All patients reported currently or previously having an appliance. Overall, 81 surveys were omitted for under-completion, resulting in a sample of 375. Two hundred and ninety-five (79.1%) participants were female, and 78 (20.9%) were male. In terms of their ages, .8% reported being between the ages of 18-25, 6.7% between 26-35, 16% between 36-45, 24.8% between 46-55, and 23.7% between 56-65, and 28% were 66 or over.

Validity

Exploratory factor analysis (EFA) is an appropriate multivariate statistical procedure for assessing scale validity in communication research (Park, Dailey, & Lemus, 2006). EFA provides researchers a tool to “uncover factors in data when the structure has not been previously established” (Venette, 2015, p. 224). EFA examines a construct’s validity and reliability by investigating the relationships among items. More specifically, statistical analysis is used to identify clusters of items that correlate on the same dimension (Field, 2013). If correlation is not indicated, items failing to load
unidimensional are removed (Field, 2013). Overall, EFA reduces a large number of latent dimensions into a smaller variable, factors, or components (Fabrigar, Wegener, MacCallum, & Strahan, 1999).

Initially, a correlation matrix was constructed to determine simple relationships among items (Field, 2013, Tabachnick & Fidell, 2012). Next, Bartlett’s test of Sphericity (Bartlet, 1950) was used to protect against redundancy, ensure satisfactory interrelatedness between items. To accept or reject the null hypothesis, a chi-square matrix and corresponding correlation value was examined. For the null hypothesis to be rejected, Tabachnick and Fidell (2012) argued a significant chi-square output (p < .05) must occur. Additionally, the correlation matrix should not be an identity matrix. In other words, for the structure to be uncovered, the items must be sufficiently correlated, but not every item interrelated. For this study, the Bartlett’s Test of Sphericity was significant at the .05 level for all analyses and supported conducting an EFA. Furthermore, none of the scales’ correlation matrices had overly high average associations.

Next, Kaiser-Meyer-Olkin (KMO) was conducted to determine sampling adequacy for factor analysis (Kaiser, 1970). To yield reliable estimates, KMO examines observed items correlations to partial correlation coefficients for all variables and the model (Field, 2013; Venette, 2015). Kaiser (1974) revealed that KMO values between 0.6 and 1 signifies an adequate threshold for additional analysis. While higher values indicate that one or more factors exists among the variables, lower values suggest common factors do not exist (Field, 2013; Venette, 2015). The KMO values for this study met the required threshold for all analyses.
Because EFA and KMO met required standards, factor extraction was conducted to identify underlying dimensions in the data. Watson (2017) defined factor extraction as “the process of partitioning out the common or shared variance in each variable from its unique variance and error variance” (p. 233). This study used principal component analysis (PCA) with a Varimax rotation. Byrne (2005) defined PCA as a “procedure in which the eigenvectors (factors) are rotated in an attempt to achieve a simple structure” (p. 132). For this study, an eigenvalue of 1 was set as the factor extraction criterion and scree plots were used to interpret the adequacy of the outcome. Factor loadings represent each variables’ relationship to the underlying factor. Low loadings of a 0.30 threshold represent poor fit between the variable and factor. Items which loaded at a value of 0.40 or above were considered appropriate (Field, 2013; Venette, 2015).

**Reliability**

To determine the reliability, internal consistency analysis was conducted. Specifically, a coefficient alpha was performed to evaluate inter-relatedness among all items within the scales (Cronbach, 1951). Because Cronbach’s alpha tau-equivalent reliability provides a consistent way to identify the amount of non-random variance in multiple-item measures (Field, 2013), reporting alpha levels for reliability is highly accepted in social science research (Venette, 2015). For this study, instruments demonstrating a Cronbach’s alpha coefficient of 0.70 or above were considered reliable.

**Measures**

*Ostomy-related uncertainty.* To measure ostomy-patients’ uncertainty, an altered version of Mishel’s (1981) Uncertainty in Illness Scale (MUIS-A) was used. The MUIS-A consists of 33-items representing four dimensions of uncertainty: ambiguity (i.e., state
of illness is unclear), inconsistency (i.e., unreliable health-related information from providers), complexity (i.e., treatment options are difficult to understand) and unpredictability (i.e., lack of stability in patients’ illness outcomes). The MUIS-A has previously exhibited alpha coefficients of 0.86 for ambiguity, 0.81 for complexity, 0.78 for inconsistency, and 0.65 for unpredictability (Mishel, 1981). The total uncertainty scale indicated a Cronbach’s alpha of 0.87 (Mishel, 1981). The MUIS-A has exhibited strong validity and reliability across different disease states and cross-cultural contexts (Giammanco et al., 2014; Lin et al., 2012).

On a 5-point Likert scale (1 = strongly disagree to 5 = strongly agree), participants rated perceptions of their health status, illness, and ostomy. Sample scale items included: “I have a lot of questions concerning my ostomy without answers,” “Because of the unpredictability of my ostomy, I cannot plan for the future,” and “I have been given many differing opinions about ostomy care.” In this study, one overall composite score assessed illness uncertainty. Higher scores reflect greater illness uncertainty in areas of diagnosis, treatment, symptoms, prognosis and treatment with others (Mishel & Epstein, 1990). The uncertainty scale was found to be highly reliable (15 items; $\alpha = 0.93$). The loading matrix, Cronbach’s alpha, and KMO for the ostomy-related uncertainty scale are presented in Table 1.

**Felt and enacted stigma.** Felt and enacted stigma was examined using an altered version Stigma Scale for Chronic Illness (SSCI; Rao et al., 2009).
Table 1

Uncertainty PCA Factor Loading with Varimax

<table>
<thead>
<tr>
<th>Statement</th>
<th>EFA Final Factor Loading</th>
</tr>
</thead>
<tbody>
<tr>
<td>I have a lot of unanswered questions concerning my ostomy.</td>
<td>0.70</td>
</tr>
<tr>
<td>I was unsure if my illness was getting better or worse with my ostomy.</td>
<td>0.65</td>
</tr>
<tr>
<td>It was unclear how bad my pain would be with my ostomy.</td>
<td>0.63</td>
</tr>
<tr>
<td>The explanations they gave me about my ostomy seemed hazy to me.</td>
<td>0.63</td>
</tr>
<tr>
<td>I do not know when to expect additional medical procedures related to my ostomy.</td>
<td>0.60</td>
</tr>
<tr>
<td>Problems related to my ostomy continue to change unpredictably.</td>
<td>0.71</td>
</tr>
<tr>
<td>The doctors have said things to me about my ostomy that could have many meanings.</td>
<td>0.67</td>
</tr>
<tr>
<td>My ostomy is too complex to figure out.</td>
<td>0.69</td>
</tr>
<tr>
<td>It is difficult to know if my ostomy is helping with my illness.</td>
<td>0.69</td>
</tr>
<tr>
<td>Because the unpredictability of my ostomy, I cannot plan for the future.</td>
<td>0.76</td>
</tr>
<tr>
<td>The course of my illness keeps changing. I have good and bad days with my ostomy.</td>
<td>0.71</td>
</tr>
<tr>
<td>It's vague to me how I will manage the care of my ostomy.</td>
<td>0.82</td>
</tr>
<tr>
<td>Since my ostomy, it is not clear what is going to happen to me.</td>
<td>0.81</td>
</tr>
<tr>
<td>I usually know if I am going to have a good day or bad day with my ostomy.</td>
<td>0.73</td>
</tr>
<tr>
<td>The effectiveness of my ostomy is undetermined.</td>
<td>0.76</td>
</tr>
</tbody>
</table>

Note: The final Cronbach’s Alpha for the scale based on EFA is 0.93. KMO was acceptable at 0.94.
The SSCI scale consists of 24 items evaluated on a 5-point Likert type scale ranging from 1 (strongly agree) to 5 (strongly disagree). The SSCI was originally tested using a sample of 511 epilepsy, ALS, multiple sclerosis, Parkinson’s disease, and heart disease patients. Exploratory factor analysis showed the overall stigma scale to have a Cronbach’s alpha of 0.97 (Rao et al., 2009). The scale also showed multidimensionality with 13-items loading on felt stigma and 11-items on enacted stigma. While the two factors were highly correlated ($r = .82$), poor item loading occurred on sub categories (-0.12 to 0.53; Rao et al., 2009; Stevelink, Wu, Voorend, & Brakel, 2012). Because experts were used during the developmental process, Stevelink and associates (2012) contended that the scale showed appropriate content validity. Thus, the scale is considered an adequate measure for assessing internalized and enacted stigma (Molina, Choi, Cella, & Rao, 2013; Rao et al., 2009).

To assess enacted and felt stigma participants rated their feelings about their ostomy appliances on a 5-point Likert type scale ranging from strongly agree (1) to disagree (5). Examples of scale items include, “Because of my illness, I felt embarrassed in social situations,” “Because of my ostomy, people were unkind to me,” and “Some people act as though it is my fault I have this illness.” This study uses the enacted and felt subscales to examine the multiple facets of ostomates’ stigma experiences. Higher scores represent increased enacted and felt stigma. Cronbach’s alphas for the 12 felt stigma and 8 enacted stigma items were 0.95 and 0.95. The final factor loading matrix, Cronbach’s alpha, and KMO for the ostomy-related felt stigma are available in Table 2 and enacted stigma in Table 3.
Table 2

**Felt Stigma PCA Factor Loadings with Varimax**

<table>
<thead>
<tr>
<th></th>
<th>EFA Final Factor Loading</th>
</tr>
</thead>
<tbody>
<tr>
<td>Because of my ostomy, I feel left out of activities.</td>
<td>0.84</td>
</tr>
<tr>
<td>Because of my ostomy, I feel emotionally distant from other people.</td>
<td>0.88</td>
</tr>
<tr>
<td>Because of my ostomy, I feel embarrassed in social situations.</td>
<td>0.88</td>
</tr>
<tr>
<td>Because of my ostomy, I worry about other people's attitudes towards me.</td>
<td>0.85</td>
</tr>
<tr>
<td>I am unhappy about how my ostomy affects my appearance.</td>
<td>0.76</td>
</tr>
<tr>
<td>Because of my ostomy, it is hard for me to stay neat and clean.</td>
<td>0.75</td>
</tr>
<tr>
<td>Because of my ostomy, I worry about being a burden to others.</td>
<td>0.75</td>
</tr>
<tr>
<td>Since my surgery, I feel embarrassed about my ostomy.</td>
<td>0.87</td>
</tr>
<tr>
<td>Since my surgery, I feel embarrassed because of my physical limitations.</td>
<td>0.87</td>
</tr>
<tr>
<td>Because of my ostomy, I feel different from others.</td>
<td>0.80</td>
</tr>
<tr>
<td>Since my surgery, I tend to blame myself for my medical problems.</td>
<td>0.69</td>
</tr>
<tr>
<td>I avoid making new friends to avoid telling others about my ostomy.</td>
<td>0.83</td>
</tr>
</tbody>
</table>

*Note.* The final Cronbach’s Alpha for the scale based on EFA was 0.95. KMO is adequate at 0.95.

*Self-Disclosure.* A modified version Laurenceau and others' (1998) Perceived Self-Disclosure Scale was used to assess participants’ ostomy-specific self-disclosure. The scale consists of three items rated on a 7-point Likert type scale varying from not at all (1) to very much (7).
Table 3

Enacted Stigma PCA Loadings with Varimax

<table>
<thead>
<tr>
<th>Statement</th>
<th>EFA Final Factor Loading</th>
</tr>
</thead>
<tbody>
<tr>
<td>Because of my ostomy appliance, some people seem uncomfortable with me.</td>
<td>0.81</td>
</tr>
<tr>
<td>Since my ostomy surgery, some people avoid me.</td>
<td>0.87</td>
</tr>
<tr>
<td>Because of my ostomy, people are unkind to me.</td>
<td>0.91</td>
</tr>
<tr>
<td>Because of my ostomy, people make fun of me.</td>
<td>0.86</td>
</tr>
<tr>
<td>Because of my ostomy, I was treated unfairly by others.</td>
<td>0.88</td>
</tr>
<tr>
<td>Because of my ostomy, people tend to ignore my good points.</td>
<td>0.90</td>
</tr>
<tr>
<td>Since my ostomy surgery, some people avoid looking at me.</td>
<td>0.90</td>
</tr>
<tr>
<td>Some people acted as though it is my fault I have this stoma.</td>
<td>0.80</td>
</tr>
</tbody>
</table>

Note. The final Cronbach’s Alpha for the scale based on EFA is 0.95. KMO is acceptable at 0.95.

Manne and colleagues (2004) revealed that when applied to breast cancer patients and their partners, the self-disclosure scale showed strong validity and reliability. Specifically, the Cronbach’s alpha for patients was 0.91 and for spouses 0.89. The scale also demonstrated Cronbach’s alphas of 0.96 for partner and 0.97 for spouses when examining self-disclosure in patients with head, neck, or lung cancer (Manne & Badr, 2010).
Respondents revealed how much they disclosed ostomy-specific thoughts, feelings, and information to others. Items were rated on a 7-point Likert scale with 1 (not at all) to 7 (very much). Some example questions include, “How much do you disclose your thoughts about your ostomy to others?,” “How much do you disclose your feelings concerning your ostomy to others?,” and “How much do you disclose information to others about your ostomy?.” Higher scores show an increase in ostomy-specific self-disclosure. The perceived ostomy-related self-disclosure scale was found to be highly reliable (3 items; $\alpha = 0.94$). Table 4 presents the final factor loading matrix, Cronbach’s alpha, and KMO for the ostomy-related self-disclosure.

Table 4

<table>
<thead>
<tr>
<th>Item</th>
<th>EFA Final Factor Loading</th>
</tr>
</thead>
<tbody>
<tr>
<td>How much do you disclose about your ostomy to your friends and family?</td>
<td>0.76</td>
</tr>
<tr>
<td>How much do you disclose information about your ostomy to your friends and family?</td>
<td>0.96</td>
</tr>
<tr>
<td>How much do you disclose your feelings concerning your ostomy to your friends and family?</td>
<td>0.93</td>
</tr>
</tbody>
</table>

Note. The final Cronbach’s Alpha for the scale based on EFA is 0.94. KMO is adequate at 0.76.

Perceived partner responsiveness. A modified version of Laurenceau and associates’ (1998) Perceived Partner Responsiveness Scale was used to measure PPR. The scale is comprised of three items rated on a 7-point Likert scale ranging from 1 to 7
(1 = not at all, 7 = very much). When applied to breast cancer patients and their partners, the PPR scale had Cronbach’s alphas of 0.93 for patients and 0.97 for spouses. Additionally, the PPR scale produced Cronbach’s alphas of 0.91 for head, neck, or lung cancer patients and 0.97 for spouses (Manne & Badr, 2010). Finally, in a study of cohabitating couples and social support, the scale revealed a Cronbach’s alpha of 0.91 (Maisel & Gable, 2009).

For this study, participants assessed how often they felt accepted, understood, and cared for by others when revealing ostomy-specific information. Response options were rated on a 7-point Likert scale ranging from not at all (1) to very much (7). Example questions include, “To what degree do you feel accepted by others after self-disclosing ostomy-specific information to others?,” “To what degree do you feel understood by others when discussing ostomy-specific information to others?,” and “To what degree do you feel cared for after disclosing your thoughts about your ostomy to others.” Higher scores show increased feelings of perceived responsiveness. The perceived ostomy-related self-disclosure scale was found to be highly reliable (3 items; $\alpha = 0.94$). Table 5 shows the final factor loading matrix, Cronbach’s alpha, and KMO for the ostomy-related responsiveness.

**Perceived social support.** This study measured perceived social support using items adapted from the Multidimensional Scale of Perceived Social Support (MSPSS; Zimet; Dahlem, Zimet, & Farley, 1988). The MSPSS consists of three subscales with four items each (a total of 12-items) that evaluate participants’ availability of support from family members, friends, and significant others.
Table 5

*Responsiveness PCA Factor Loadings with Varimax*

| To what degree do you feel accepted by your family after disclosing ostomy-specific information? | 0.91 |
| To what degree do you feel understood by other when discussing ostomy-specific information to others? | 0.89 |
| To what degree do you feel cared for after disclosing your thoughts about your ostomy to others? | 0.92 |

*Note.* The final Cronbach’s Alpha for the scale based on EFA is 0.94. KMO is adequate at 0.77.

Zimet and colleagues (1988) argued the scale, when tested on college students, demonstrated a strong reliability and validity with a coefficient alpha of 0.88. The three subscales also revealed good internal consistency: $\alpha = 0.87$ for friends, 0.85 for family, and 0.91 for significant others. A confirmatory factor analysis of the MSPSS, using both college students and psychotic patients, showed acceptable goodness-of-fit indicators in both populations (Clara, Cox, Enns, Muarry, & Torgrudc, 2003). The three subscales also demonstrated suitable Cronbach alphas: friends $\alpha = 0.94$ (psychiatric sample) and 0.93 (university sample), family $\alpha = 0.92$ (psychiatric) and 0.92 (university), and significant others $\alpha = 0.94$ (psychiatric) and 0.93 (university).

In this study, participants rated their perceptions of social support since ostomy implementation on a 7-point Likert-type scale. Response choices varied from very
strongly disagree (1) to very strongly agree (5). Examples of questions include “There is a special person with whom I can share my joys and sorrow,” “My family really tries to help me,” and “I can count on my friends when things go wrong.” Higher scores demonstrate greater perceived support from friends, family members, and significant others. Although the MSPSS provides three subscales, only the overall total score was used for analysis. The modified scale was found to be highly reliable (11 items; α = 0.95). Table 6 offers the final factor loading matrix, Cronbach’s alpha, and KMO for the perceived social support.

Received social support. A tailored version of Short-Form Inventory of Socially Supportive Behaviors (ISSB) was used to evaluate ostomates’ perceptions of received social support (Barrera & Baca, 1990; Barrera, Sandler, & Ramsey, 1981). While the original ISSB consists of 40-items (Barrera, Sandler, & Ramsay, 1981), the short-form scale has 19-items designed to capture how often individuals’ received support (Berra & Baca, 1990). The ISSB captures four dimensions of social support: directive guidance (e.g., giving advice and feedback), nondirective support (e.g., listening and expressions of intimacy and trust contemplating), positive social interaction (e.g. expressing encouragement), and tangible assistance (e.g., providing money; Barrera et al., 1981).

Both the ISSB and the short form exhibit strong internal consistency and reliability. The ISSB long form had a Cronbach’s alpha of 0.93, and a test-rest reliability coefficient of 0.88 (Barrera et al., 1981). Similarly, in a test-rest reliability over a one-month period, the scale presented Cronbach’s alpha of 0.92 and 0.94. Additionally, when tested on mental outpatients, the ISSB exhibited a coefficient alpha of 0.84 (Berra & Bacathe, 1991).
Table 6

Perceived Social Support PCA Factor Loadings with Varimax

<table>
<thead>
<tr>
<th>Statement</th>
<th>EFA Final Factor Loading</th>
</tr>
</thead>
<tbody>
<tr>
<td>There will be a special person who is around in case I am in need.</td>
<td>0.81</td>
</tr>
<tr>
<td>I will have special person with whom I can share my joys and sorrows.</td>
<td>0.82</td>
</tr>
<tr>
<td>My family will try to help me if I am in need.</td>
<td>0.79</td>
</tr>
<tr>
<td>I will get the emotional help and support I need from family.</td>
<td>0.86</td>
</tr>
<tr>
<td>My friends will try to help me.</td>
<td>0.73</td>
</tr>
<tr>
<td>I can count on others when things go wrong.</td>
<td>0.87</td>
</tr>
<tr>
<td>I will be able to talk about my problems with family.</td>
<td>0.89</td>
</tr>
<tr>
<td>I have other people with whom I can share my joys and sorrows.</td>
<td>0.84</td>
</tr>
<tr>
<td>There will be a special person in my life who will care about my feelings.</td>
<td>0.86</td>
</tr>
<tr>
<td>My family will be willing to help me make decisions.</td>
<td>0.82</td>
</tr>
<tr>
<td>I will be able to talk about my problems with other people in my life.</td>
<td>0.87</td>
</tr>
</tbody>
</table>

Note. The final Cronbach’s Alpha for the scale based on EFA was 0.95. KMO was acceptable at 0.92.

To assess received support, ostomates recalled how often people helped or tried to help make life more pleasant in the past month. The scale contained six items from the 40-item ISSB long form. Participants reported the amount of support received on a 5-point scale ranging from 1 (not at all) to 5 (about every day). Some example items are, “Told you that he/she feels close to you,” “Expressed interest and concern in your well-being,” and “Comforted you by showing you some physical affection.” Higher scores
implied receiving actual instances of social support. In this study, only the total received support score was evaluated. The modified scale indicated to be highly reliable (6 items; \( \alpha = 0.92 \)). Table 7 provides the final factor loading matrix, Cronbach’s alpha, and KMO for the received social support scale.

Table 7

*Received Social Support CPA Factor Loadings with Varimax*

<table>
<thead>
<tr>
<th></th>
<th>EFA Final Factor Loading</th>
</tr>
</thead>
<tbody>
<tr>
<td>Others have told you that they feel close to you.</td>
<td>0.85</td>
</tr>
<tr>
<td>Someone has let you know that he/she will always be around if you need help.</td>
<td>0.88</td>
</tr>
<tr>
<td>People tell you that you are ok just the way you are.</td>
<td>0.91</td>
</tr>
<tr>
<td>People have expressed interest and concern for your well-being.</td>
<td>0.87</td>
</tr>
<tr>
<td>People have comforted you by showing you some physical affection.</td>
<td>0.88</td>
</tr>
<tr>
<td>Someone has told you that he/she would keep things you talk about private.</td>
<td>0.73</td>
</tr>
</tbody>
</table>

*Note.* The final Cronbach’s Alpha for the scale based on EFA was 0.92. KMO was acceptable at 0.92.

*Adaptive and maladaptive coping.* A modified version of the Brief COPE Inventory Scale (BCI) was used to capture ostomates’ coping reaction. BCI is the shorted version of the original 60-item COPE Inventory Scale (Barrera & Baca, 1990). The 28-item self-report instrument has 14 subscales with two items each: instrumental support, behavioral disengagement, venting, positive reframing, planning, humor, acceptance, religion, and self-blame. Carver (1997) showed that 11 of the 14 Brief COPE subscales had Cronbach’s alphas surpassing 0.60, while the other three
exceeded 0.50. Test-retest reliability estimates ranged from 0.46 to 0.86 and 0.42 and 0.99 (Carver et al., 1989). EFA with oblique rotations of the BCI revealed a factor structure comparable to the COPE (Carver, 1997). Overall, the BCI is used and across different patient populations, including breast cancer (Yusoff, Low, & Yip, 2010), multiple sclerosis (McCabe, McKern, & McDonald, 2004), and heart disease (Carles, 2004).

Although Carver (1997) discouraged creating an overall coping index from the BCI, researchers have aggregated subscales into high order factors using EFA (Bellizzi & Blank, 2006; Su et al., 2015). More specifically, maladaptive and adaptive coping categories were created from the 14 subscales. For example, in a study of breast cancer patients, Bellizzi and Blank (2006) classified self-distraction, active coping, seeking emotional and instrumental support, venting, positive reframing, planning, acceptance, and religion as adaptive coping strategies. Conversely, items like alcohol abuse, denial, and behavioral engagement identified as maladaptive coping behaviors. While adaptive coping items ranged from 0.55 to 0.83, maladaptive coping items varied from 0.47 to 0.77. Because coping is an individualistic process, items loadings may fluctuate between adaptive and maladaptive categories (Carver, 1997).

Participants indicated the extent to which they used specific coping strategy when handling ostomy-related stressors. Some sample questions include “I’ve been turning to work or other activities to take my mind off things,” “I have been using alcohol or drugs to make myself feel better,” and “I’ve been concentrating my efforts on doing something about the situation I am in.” Items were rated on a 4-point Likert-type scale with ratings
from 1 (I haven’t been doing this at all) to 4 (I’ve been doing this a lot). Coping strategies with higher scores are used more frequently compared to strategies with lower scores.

For this study, EFA was used to categorize items into adaptive and maladaptive coping strategies. Specifically, self-distraction, active coping, emotional support, instrumental support, positive reframing, venting, planning, acceptance, humor, and religion were identified as adaptive coping. Conversely, self-blame, substance abuse, self-blame, and denial were categorized as maladaptive strategies. Cronbach’s alphas for the 16 adaptive and 8 maladaptive items were 0.91 and 0.81. The final factor loading matrix, Cronbach’s alpha, and KMO for the ostomy-related adaptive coping is presented in Table 8 and maladaptive coping in Table 9.

*Health-related quality of life.* HRQoL was evaluated using an adapted version of the RAND 36-Item Health Inventory 1.0 (Hays, Sherbourne, & Mazel, 1993; Hays & Morales, 2001). The RAND-36 is a generic measure that is widely used to examine patients’ well-being (Hays & Morales, 2001). The scale is comprised of 36-items exploring eight different dimensions of health that can be delineated into physical and psychological health scores.

Specifically, physical health consists of physical functioning, role-physical, bodily pain, and general health subscales. In contrast, psychological health is comprised of vitality, social functioning, role-emotional and mental health subscales. When originally tested, the eight health dimensions exhibited a Cronbach’s alpha ranging from .78 to .93 (Hays et al., 1993).
### Adaptive Coping PCA Loadings with Varimax

<table>
<thead>
<tr>
<th>Item</th>
<th>EFA Final Factor Loading</th>
</tr>
</thead>
<tbody>
<tr>
<td>I've been concentrating my efforts on doing something about the situation I'm in.</td>
<td>0.70</td>
</tr>
<tr>
<td>I've been taking action to try to make the situation better.</td>
<td>0.72</td>
</tr>
<tr>
<td>I've been getting emotional support from others.</td>
<td>0.65</td>
</tr>
<tr>
<td>I've been getting comfort and understanding from someone.</td>
<td>0.66</td>
</tr>
<tr>
<td>I've been getting help and advice from other people.</td>
<td>0.74</td>
</tr>
<tr>
<td>I've been trying to get advice or help from other people about what to do.</td>
<td>0.69</td>
</tr>
<tr>
<td>I've been trying to see my problems in a different light, to make it seem more positive.</td>
<td>0.79</td>
</tr>
<tr>
<td>I've been looking for something good in what is happening.</td>
<td>0.76</td>
</tr>
<tr>
<td>I've been trying to come up with a strategy about what to do.</td>
<td>0.80</td>
</tr>
<tr>
<td>I've been thinking hard about what steps to take.</td>
<td>0.77</td>
</tr>
<tr>
<td>I've been making jokes about my problems.</td>
<td>0.52</td>
</tr>
<tr>
<td>I've been making fun of the situation.</td>
<td>0.48</td>
</tr>
<tr>
<td>I've been accepting the reality that I have problems.</td>
<td>0.63</td>
</tr>
<tr>
<td>I've been learning to live with my problems.</td>
<td>0.65</td>
</tr>
<tr>
<td>I've been trying to find comfort in my religion or spiritual beliefs.</td>
<td>0.49</td>
</tr>
<tr>
<td>I've been praying or mediating about my problems.</td>
<td>0.48</td>
</tr>
</tbody>
</table>

**Note.** The final Cronbach’s Alpha for the scale based on EFA is 0.91. KMO is adequate at 0.84.
Table 9

Maladaptive Coping PCA Loadings with Varimax

<table>
<thead>
<tr>
<th></th>
<th>EFA Final Factor Loading</th>
</tr>
</thead>
<tbody>
<tr>
<td>I've been saying to myself &quot;this isn't real.&quot;</td>
<td>0.65</td>
</tr>
<tr>
<td>I refuse to believe that I have problems.</td>
<td>0.32</td>
</tr>
<tr>
<td>I've been using alcohol or other drugs to make myself feel better.</td>
<td>0.60</td>
</tr>
<tr>
<td>I've been using alcohol or other drugs to help me get through it.</td>
<td>0.63</td>
</tr>
<tr>
<td>I've been giving up the attempt to cope.</td>
<td>0.77</td>
</tr>
<tr>
<td>I've been giving up trying to deal with it.</td>
<td>0.77</td>
</tr>
<tr>
<td>I've been criticizing myself for negative events that have</td>
<td>0.74</td>
</tr>
<tr>
<td>happened.</td>
<td></td>
</tr>
<tr>
<td>I wear clothes I do not like to conceal my ostomy.</td>
<td>0.75</td>
</tr>
</tbody>
</table>

*Note.* The final Cronbach’s Alpha for the scale based on EFA is 0.81. KMO is adequate at 0.72.

Additionally, the underlying physical and mental health subscales are conceptually distinct (Simon, Revicki, Grothaus, & Vonkorff, 1998). For example, in a study of primary care patients, Ware and colleagues (1995) highlighted the internal consistency and estimated alpha for coefficients for the physical subscale as .92 and .91 for the mental subscale.

In this study, ostomates’ were asked to rate their current physical health and mental well-being using 17-items from the RAND-36. Following EFA, two questions were removed due to poor loading. Example questions include, “Do you feel full of pep?,” “Have you felt so down in the dumps that nothing could cheer you up?,” and “Do
you feel tired?.” Each score of the subscales ranged from 0 to 100, with a higher score indicating better functioning. Although items could be categorized into the eight dimensions, this study uses the mental and physical health scores. The modified scale indicated to be highly reliable (15 items; α = 0.94). The final factor loading matrix, Cronbach’s alpha, and KMO for health-related quality of life are in Table 10. Finally, the complete instrument used in this study is found in Appendix B.

Data Collection Procedure

After receiving Institutional Review Board approval (see approval letter in Appendix B), participants were recruited using purposive sampling. To collect a wide range of responses, the survey was distributed both electronically and face-to-face. First, an electronic survey, administered through Qualtrics was posted to ostomy-specific online support groups. Because patients join online support groups to give and receive social support (Gustafson et al., 2001), an online approach was appropriate for this study. More specifically, the Pew Research Center (2013) estimates that over 36 million people in the United States are members of online support groups. For many patients, especially those living in rural and remote areas, online support groups offer an accessible alternative to face-to-face sessions (Cline & Haynes, 2001).

Furthermore, Turner, Grube, and Meyers (2001) argued that online support networks offer members anonymity and a supportive outlet away from family. Patients are able to connect with others facing similar challenges and freely share illness-related feelings, frustrations, and sensitive information (Fox, 2011; Turner et al., 2001).
<table>
<thead>
<tr>
<th>Question</th>
<th>EFA Final Factor Loading</th>
</tr>
</thead>
<tbody>
<tr>
<td>Did you feel full of pep?</td>
<td>0.81</td>
</tr>
<tr>
<td>Have you been a nervous person?</td>
<td>0.67</td>
</tr>
<tr>
<td>Have you felt so down in the dumps that nothing could cheer you up?</td>
<td>0.77</td>
</tr>
<tr>
<td>Have you felt calm and peaceful?</td>
<td>0.80</td>
</tr>
<tr>
<td>Do you have a lot of energy?</td>
<td>0.80</td>
</tr>
<tr>
<td>Have you felt downhearted and blue?</td>
<td>0.79</td>
</tr>
<tr>
<td>Do you feel worn out?</td>
<td>0.77</td>
</tr>
<tr>
<td>Have you been a happy person?</td>
<td>0.70</td>
</tr>
<tr>
<td>Do you feel tired?</td>
<td>0.69</td>
</tr>
<tr>
<td>Cut down the amount of time you spent on work or other activities.</td>
<td>0.79</td>
</tr>
<tr>
<td>Accomplished less than you would like.</td>
<td>0.80</td>
</tr>
<tr>
<td>Were limited in the kind of work or other activities.</td>
<td>0.76</td>
</tr>
<tr>
<td>Had difficulty performing work or other activities.</td>
<td>0.78</td>
</tr>
<tr>
<td>Didn’t do work or other activities as carefully as usual.</td>
<td>0.69</td>
</tr>
<tr>
<td>How much has your stoma interfered with your normal work?</td>
<td>0.79</td>
</tr>
</tbody>
</table>

Note. The final Cronbach’s Alpha for the scale based on EFA is 0.94. KMO is adequate at 0.93.
The online survey was administered to ostomy-specific Facebook support groups. Facebook, a popular social networking site, offers a place and space for support groups to form, proliferate, and help users cultivate interpersonal relationships. Specifically, individuals can connect with others by sending messages, posting comments, and sharing images on the support groups page (Farmer, Holt, Cook, & Hearing, 2009). For example, patients with hypertension (Mamum, Ibrahim, & Turnin, 2015), diabetes (Zhang, He, & Sang, 2013), and breast cancer (Bender, Jimenez-Marroquin, & Jadad, 2011) use Facebook as a tool to provide and receive social support, gather health-related information, and cultivate relationships (Bender et al., 2011). Because many ostomates conceal their condition (Savard & Woodgate, 2009), ostomy-specific Facebook social support groups offer access to many patients who might otherwise be unavailable.

A list of all Facebook ostomy support groups was compiled using a key word search of ostomy, colostomy, ileostomy, stoma, and urostomy support. Because results indicated over 200 support groups, only groups with 1,000 or more members were considered. Additionally, Libermann and Goldstein’s (2006) four conditions of online support networks were also used to determine group inclusion for this study. First, groups message boards contain posts allowing for members to read about others’ ostomy-related experiences. Second, group members must receive ostomy-related support, information, and advice. Third, users post messages that offer ostomy-specific support, information, and advice on the group’s page. Finally, posts show emotional disclosures regarding ostomates’ experiences. In total, six ostomy Facebook groups met the selection criteria.

A letter requesting permission to recruit participants was sent to the pages’ moderators (See letter in Appendix C). Overall, four moderators agreed to let the group
participate in the study. To recruit participants, an announcement outlining the purpose of the study and a link to the survey was posted on their Facebook pages. The post specified that participants had to be at least 18 years or older and currently have or have had an ostomy. Respondents were asked to take the survey only once. Qualified participants simply clicked the link, verified their age, and proceed with the survey (See Appendix C).

Two non-profit and one for-profit ostomy-specific companies were also contacted about participating in the study. To increase response rate, the UOAA and Ostomy Canada Society, ostomy-specific non-profit organizations, and Corstrata, a wound care and ostomy management solution company, were emailed the Qualtrics link, IRB approval letter, and explanation of the study. UOAA and Ostomy Canada Society advertised the link on their Facebook page, monthly newsletter (July, 2017), and website. Corstrata also posted the survey link to its website and Facebook page.

Ostomates were also recruited through UOAA affiliated local social support groups along the Gulf Coast Region. Initially, the UOAA support group in Gulfport, Mississippi, was contacted about participating in the study. After receiving permission, the survey was distributed during monthly meeting from July-August 2017. In addition, the researcher attended and circulated a paper version of the survey at UOAA’s sixth national conference (August 2017) in Irvine, California. Interested conference participants signed an informed consent letter and completed the survey.

Data Analysis

Missing data. To conduct path and mediation analysis, several preliminary analyses were conducted. Missing values for each variable were also addressed. Because the sample size was adequate and less than ten percent of data were missing answers, this
study uses the pairwise deletion technique (Bennett, 2001; Marsh, 1998). Although there are disadvantages to this technique (i.e., underestimated or overestimated sample sizes and can produce a nonpositive definite matrices), pairwise deletion accounts for all data and can increase statistical power (Marsh, 1998).

Additionally, the skewness and kurtosis of each variable were examined to check whether constructs met the assumption of normality. A normally distributed construct shows a skewness value of ±2.0 and kurtosis of ±3; however, Tabachnick and Fidell (2012) argued that with a large sample, skewness does not “make a substantive difference in the analysis” (p. 74). Furthermore, when a sample contains 200 or more cases, the risk of underestimating the variance significantly decreases (Tabachnick and Fidell, 2012). Because this study contains 362 cases, the violation of normality and kurtosis is unlikely to distort results (Altman and Bland, 1995).

KMO and Bartlett’s Test of Sphericity were calculated for each variable in the model. KMO was great than .5 and Bartlett’s Test was significant in each instance. Field (2013) suggests that skewness and kurtosis are unlikely to be problematic in such cases.

Assumptions

Data were also checked for the assumptions of multiple regression. Initially, graphs were plotted for each construct (i.e., box plots and scatter plots) to ensure that the relationship between the predictors and outcome variable is linear, to check for potential outliers, and to evaluate the distribution of residuals (Field, 2013). As mentioned, each Bartlett Test reflected that indices are not identity matrices. Multicollinearity was also assessed using Pearson Bivariate correlations (See Table 12), variance inflation factors, and tolerance (Field, 2013). The correlations did not exceed 0.80, variance inflation
factors were between one and ten, and tolerance scores were above 0.2 (meeting standards suggested by Field, 2013) Thus, the data did not demonstrate multicollinearity. Finally, the Durbin-Watson statistic was close to 2 (d = 1.9) indicating that values of the residuals are independent (Field, 2013). Because data met all the assumptions of a multiple regression, SEM and path analysis was warranted.

Descriptive Statistics

Univariate analysis was calculated for each continuous variable in the data set. Specifically, the mean and standard deviation for enacted and received stigma, uncertainty, disclosure, responsiveness, perceived and received social support, adaptive and maladaptive coping, and HRQoL are reported. See Table 11 in Chapter 5 for descriptive statistics. Frequencies for categorical variables age and sex are also described in the participants section of this chapter.

Path Analysis

Path Analysis with AMOS 24.0 was used to test hypotheses and the proposed model. Path analysis is described as “the part of SEM that represents the researcher’s explicit theory of the pattern of variation and/or correlation among the variables” (Lee, Cai, & MacCallum, 2012, p. 197). Although multiple regressions can test sections of theoretical relationships, this statistical analysis fails to simultaneously evaluate all variables in the model (Meyers, Gamst, & Guarino, 2012). Instead, path analysis, a multivariate analytical technique, provides a better way to analyze relationships among observed variables (Meyers, Gamst, & Guarino, 2012). Because path analysis examines correlational links between variables by combining confirmatory factor analysis and multiple regression analysis (Byrne, 2016), observed constructs can be measured
Simultaneously to determine how consistent the model is to parameter estimates. Specifically, path analysis uses multiple tests to evaluate model fit, such as comparative fit index (CFI), chi-square. In other words, if test reveal statistical goodness-of-fit, the model reflects the relationships between the variables and proposed model. In health communication, path analysis testing is useful for understanding communication as a process and identifying complex relationships among variables (Stephenson, 2006).

For this study, path analysis-testing was used to examine how well the data fit the model proposed in the literature review. The full model proposed for this study is shown in Figure 1. Before analyses were conducted, all measures were verified using EFA, mean centered, and transformed into Z-scores. Several absolute fit indices were used to examine how well the model fit the sampled data. Initially, model fit was examined using the chi-square index ($\chi^2$). According to Hu and Bentler (1999), the chi-square test is used to determine the “magnitude of discrepancy between the sample and fitted covariances matrices” (p. 2). For chi-square to demonstrate acceptable fit, the value must meet a .05 threshold (Bryne, 2010). However, chi-square fit index has some limitations as a fit statistic, such as being sensitive to sample sizes (Hooper, Coughlan, & Mullen, 2008). While larger sample sizes causes distortion of the chi-square statistic, smaller sample sizes do not offer enough power to differentiate between good and poor fitting model (Kenny & McCoach, 2003). Because of these drawbacks, other measures were considered to evaluate the model. To test the absolute fit of the proposed model to the data several absolute fit indices were examined: $x^2/df$, the root mean square error of approximation (RMSEA), the goodness of fit index (GFI), and the adjusted goodness of fit index (AGFI). Additionally, to better compare the chi-square value to a baseline
model, incremental fit indexes were observed (Hooper et al., 2008), such as the normal fit index (NFI), the comparative fit index (CFI), and incremental fit index (IFI).

To better account for a larger sample size and correct for inflated effect, $\chi^2/df$ fit index was initially examined (Bryn, 2010). The chi-square is divided by degrees of freedom within the model, and the accepted ratio for this statistic is below 5.0 (West et al., 2015). In addition, the RMSEA, a widely used and accepted fit index, offers a better understanding of the relationship between parameter values and the population covariance matrix (Kelley & Lai, 2011). A RMSEA value should be less than 0.60 (Kelley & Lai, 2011) to be considered a good fit. GFI and AGFI also serve as alternative statistical indices to chi-square. While the GFI analyzes the proportions of variance accounted for in the covariance matrix, AGFI adjusts the GFI using degrees of freedom to prevent model overfitting (West et al., 2015). Values for both tests range from 0 to 1.0, where values 0.9 or over represent good fit (West et al., 2015).

The NFI uses fit function values or $\chi^2$ value to compare a specified model to the fit of a null model (West et al., 2015). Because the null model specifics all measured variables are uncorrelated, the hypothesized model cannot have a larger $\chi^2$ value (West et al., 2015). Scores for the NFI vary between 0 and 1 with 0.90 or higher value indicating acceptable fit (Hooper et al., 2008). Although an accepted incremental fit index, the NFI is sensitive to small sample sizes and can under estimate model fit for samples that are less than 200 (Hooper et al., 2008). To improve the NFI, the CFI measure (Bentler, 1990) and IFI measures (Bollen, 1990) were introduced. The IFI and CFI, unlike NFI, are not sensitive to sample size (Hooper et al., 2008). The CFI and IFI assume all variables are uncorrelated and tests the hypothesized model against the null with values varying from
0.0 to 1.0. A coefficient of .90 or higher is thought to demonstrate good fit (West et al., 2015). While the CFI is bounded by 1, IFI can potentially exceed 1 when the specified model’s $x^2$ is lower than its $df$ (West et al., 2015). Results of goodness-of-fit analyses are presented in Chapter IV.

Mediation Analysis

Mackinnon, Fairchild, and Fritz (2007) described mediation as the influence of an external variable on the causal relationship between two variables. Mediation models provide a better understanding of theoretical relationships among variables. Baron and Kenny (1986) argued that for mediation analysis to occur four conditions must be met. First, the predictor must be significantly related to the outcome variable. Second, the predictor and the mediating variable must demonstrate a significant relationship. Third, when the indirect effect is statistically significant, the mediator must have a significant relationship with the outcome variable. Finally, when the mediator variable is controlled, the relationship between the predictor variable and outcome variable should significantly diminish. If all four requirements are met, a complete mediation is indicated. However, analysis only meets the first three steps, only a partial mediation has occurred.

While Baron and Kenny’s (1986) framework is widely applied in social science research (MacKinnon, Fairchild, & Fritz, 2007), other statistical approaches to mediation analysis exist (MacKinnon, Lockwood, & Williams, 2004; Preacher & Hays, 2004, Sobel, 1982). For this study, the Preacher and Hayes’ (2004) non-parametric bootstrapping method of modeling was used to conduct analyses. Specifically, Hayes’ (2013) PROCESS (version 3.0) macro in SPSS (version 23) was used to test mediation. With this approach, data observations are subsampled to compute 95% bias-corrected
confidence intervals. Bootstrapped confidence intervals were constructed using 5,000 subsamples (as recommended by Preacher & Hayes, 2008). These confidence intervals were used to examine the statistical significance of the extent to which perceived responsiveness mediated three relationships: self-disclosure and HRQoL, self-disclosure and perceived social support, and self-disclosure and received social support. The nature of the relationships (i.e., strength and direction) is interpreted using the calculated beta coefficients. Additionally, bootstrapping was also employed to examine the statistical significance of the extent to which adaptive and maladaptive coping mediated the relationship between two pairings: perceived social support and HRQoL and received social support and HRQoL. Again, beta coefficients reveal the nature of the relationships.

Summary

To review, Chapter III overviews the methods used to conduct this study. While the research model and hypotheses are introduced in the review of literature, this chapter details the survey research design, explained data collection procedure, and described participants. Additionally, statistical analyses are outlined and justified. Chapter IV presents results from analyses of the proposed model and all hypotheses.
CHAPTER IV – RESULTS

The purpose of this study is to examine relationship among negative uncertainty, enacted and felt stigma, self-disclosure, perceived responsiveness, received and perceived social support, and adaptive and maladaptive, and HRQoL. While Chapter II shows the review of literature, ten hypotheses, and the proposed model, Chapter III overviews the methods and statistical tests used to conduct the investigation. This chapter reveals the results from the statistical analysis in two sections. First, results of the analyses for all hypotheses are discussed. Next, tests of the hypothesized model are reported.

Preliminary Analysis

Descriptive statistics. Overall, a total of 456 ostomates completed the survey but only 375 are included in the final analysis after data cleaning. Before results are reported for each hypothesis, a better understanding of the descriptive statistics for each variable in the proposed model is needed. See Table 11 for descriptive statistics for each construct.

Table 11

Descriptive Statistics for the Sample (N = 375)

<table>
<thead>
<tr>
<th>Variable</th>
<th>Mean</th>
<th>SD</th>
</tr>
</thead>
<tbody>
<tr>
<td>Enacted Stigma</td>
<td>4.14</td>
<td>1.03</td>
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<tr>
<td>Felt Stigma</td>
<td>2.62</td>
<td>1.21</td>
</tr>
<tr>
<td>Uncertainty</td>
<td>2.46</td>
<td>0.94</td>
</tr>
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<td>1.08</td>
</tr>
<tr>
<td>Responsiveness</td>
<td>3.62</td>
<td>0.94</td>
</tr>
<tr>
<td>Received SS</td>
<td>3.16</td>
<td>1.21</td>
</tr>
<tr>
<td>Perceived SS</td>
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<td>1.06</td>
</tr>
<tr>
<td>Adaptive Cope</td>
<td>2.56</td>
<td>0.68</td>
</tr>
<tr>
<td>Maladaptive Cope</td>
<td>1.66</td>
<td>0.47</td>
</tr>
<tr>
<td>HRQoL</td>
<td>2.85</td>
<td>0.85</td>
</tr>
</tbody>
</table>

Note: Sex and age are nominal variables and not included in this table.
Bivariate correlation results. To assess the relationships between the proposed model’s constructs, Bivariate Pearson correlations were performed. Results show that there is a significant negative correlation between disclosure and enacted stigma $(r = -0.35, p < .01)$, received stigma $(r = -0.43, p < .01)$, and uncertainty $(r = -0.30, p < .01)$. However, self-disclosure is positively correlated to responsiveness $(r = 0.56, p < .01)$ and HRQoL $(r = 0.31, p < .01)$. Enacted stigma $(r = -0.61, p < .01)$, received stigma $(r = -0.75, p < .01)$, and uncertainty $(r = -0.72, p < .01)$ are also negatively correlated with HRQoL. Although responsiveness is also positively correlated with perceived social support $(r = 0.31, p < .01)$ and HRQoL $(r = 0.58)$, it is negatively correlated with received social support $(r = -0.40, p < .01)$. Received social support is also positively correlated with maladaptive coping $(r = 0.31, p < .01)$ and negatively correlated with adaptive coping $(r = -0.42, p < .01)$. Conversely, perceived social support is positively correlated with adaptive coping $(r = 0.36, p < .01)$ and negatively correlated with maladaptive coping $(r = -0.50, p < .01)$. Finally, HRQoL is correlated with adaptive coping $(r = 0.20, p < .01)$ and maladaptive coping $(r = -0.60, p < .01)$. Overall, all variables in the model were statistically significant. See Table 12 for all correlations among study variables.

Hypotheses Results

$H1a$. Hypothesis 1a predicted ostomates’ perceptions of uncertainty are negatively associated with HRQoL. Findings from the path analysis reveals that negative uncertainty predicted a decline in patients’ HRQoL $(\beta = -.28, SE = .05, p < .001)$.

$H1b$. Hypothesis 1b predicted that perceptions of enacted stigma are negatively associated with HRQoL. Results show that enacted stigma did not predict ostomates’
HRQoL ($\beta = .05, SE = .05, p = .329$). Thus, ostomates who reported increased felt stigma and uncertainty were most likely to experience reduced HRQoL.

$H1c$. Hypothesis 1c articulated that ostomates’ perceptions of felt stigma are negatively associated with HRQoL. Findings demonstrated that felt stigma was negatively associated with ostomates’ HRQoL ($\beta = -.42, SE = .06, p < .001$).

$H2$. Hypothesis two argues uncertainty is positively associated with ostomates’ ostomy-specific self-disclosure levels. Results of the analyses indicate that uncertainty did not confidently predict patients’ self-disclosure practices ($\beta = .14, SE = .08, p = .09$). Given the size of the sample, the size of the effect should be small, even if the direction is unknown. Thus, uncertainty’s impact on self-disclosure appears to be negligible for ostomates.

$H3a$. Hypothesis 3a proposed felt stigma is negatively associated with patients’ ostomy-specific self-disclosure levels. Results showed felt stigma has negative relationship with ostomates’ self-disclosure practiced ($\beta = -0.46, SE = .09, p < .001$). Consequently, ostomates who perceive higher levels of anticipated stigma are less likely to disclose ostomy-specific issues to others.

$H3b$. Hypothesis 3b argued enacted stigma is negatively associated with ostomates’ disclosure. Analysis revealed that enacted stigma did not predict patients’ ostomy-specific self-disclosures ($\beta = -0.11, SE = 0.07, p = .14$).
Table 12

*Bivariate Correlation Coefficients*

<table>
<thead>
<tr>
<th>Variable</th>
<th>1</th>
<th>2</th>
<th>3</th>
<th>4</th>
<th>5</th>
<th>6</th>
<th>7</th>
<th>8</th>
<th>9</th>
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<td>1. Enacted Stigma</td>
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<td></td>
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<td></td>
<td></td>
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<tr>
<td>2. Received Stigma</td>
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<td></td>
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<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>3. Uncertainty</td>
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<td>.77**</td>
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<td>4. Disclosure</td>
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<td>-.43**</td>
<td>-.30**</td>
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<tr>
<td>5. Responsiveness</td>
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<td>-.67**</td>
<td>-.62**</td>
<td>.56**</td>
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<td></td>
<td></td>
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<td></td>
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<tr>
<td>6. Received Support</td>
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<td>.33**</td>
<td>.32**</td>
<td>-.40**</td>
<td>-.50**</td>
<td></td>
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<td>7. Perceived Support</td>
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<td>-.47**</td>
<td>-.46**</td>
<td>.31**</td>
<td>.58**</td>
<td>-.60**</td>
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<tr>
<td>8. Adaptive Cope</td>
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<td>-.18**</td>
<td>-.12*</td>
<td>.33**</td>
<td>.36**</td>
<td>-.42**</td>
<td>.36**</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>9. Maladaptive Cope</td>
<td>.61**</td>
<td>.60**</td>
<td>.54**</td>
<td>-.24**</td>
<td>-.53**</td>
<td>.31**</td>
<td>-.50**</td>
<td>-.22**</td>
<td></td>
<td></td>
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<tr>
<td>10. HRQoL</td>
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<td>-.75**</td>
<td>-.72**</td>
<td>.31**</td>
<td>.58**</td>
<td>-.31**</td>
<td>.48**</td>
<td>.20**</td>
<td>-.60**</td>
<td></td>
</tr>
</tbody>
</table>

*Note. *p < 0.05; **p < 0.01; Pearson correlation coefficients (N = 375).*
**H4.** Hypothesis four used mediation analysis to explore if responsiveness mediates the effect of disclosure on HRQoL. Analysis specified that a complete mediation occurred. Findings are summarized in Table 13. Results highlighted that self-disclosure is a significant predictor of responsiveness, $\beta = 0.56$, $SE = 0.04$, $p < .001$, BCCI [0.47, 0.65], and responsiveness significantly predicts HRQoL, $\beta = 0.59$, $SE = 0.05$, $p < .001$, BCCI [0.49, 0.69]. However, after controlling for responsiveness, disclosure is no longer a significant predictor of HRQoL, $\beta = -0.02$, $SE = 0.05$, $p = 0.68$ BCCI [-0.12, 0.08]. Thirty-three percent of the variance is accounted for by the predictors ($R^2 = 0.33$). The indirect effect is significant, $\beta = 0.33$, $SE = 0.04$, 95% BCCI [0.26, 0.41]. Thus, when mediated by responsiveness, the effect of disclosure on HRQoL is .33 standard deviations higher than average.

Table 13

<table>
<thead>
<tr>
<th>Path</th>
<th>β</th>
<th>SE</th>
<th>P</th>
<th>LLCI</th>
<th>ULCI</th>
</tr>
</thead>
<tbody>
<tr>
<td>a Disclosure ---&gt; Responsiveness</td>
<td>0.56</td>
<td>0.04</td>
<td>&lt;.001</td>
<td>0.47</td>
<td>0.65</td>
</tr>
<tr>
<td>b Responsiveness ---&gt; HRQoL</td>
<td>0.59</td>
<td>0.05</td>
<td>&lt;.001</td>
<td>0.49</td>
<td>0.69</td>
</tr>
<tr>
<td>c' Disclosure ---&gt; HRQoL</td>
<td>-0.02</td>
<td>0.05</td>
<td>0.68</td>
<td>-0.12</td>
<td>0.08</td>
</tr>
<tr>
<td>c Total Effect</td>
<td>0.31</td>
<td>0.05</td>
<td>&lt;.001</td>
<td>0.21</td>
<td>0.41</td>
</tr>
<tr>
<td>ab Indirect Effect</td>
<td>0.33</td>
<td>0.04</td>
<td></td>
<td>0.26</td>
<td>0.41</td>
</tr>
</tbody>
</table>

*Notes. $R^2_{\text{Total}} = 0.09$ p < .001; $R^2_{\text{predictor}} = 0.31$ p < .001; $R^2_{\text{mediator}} = 0.33$ p < .001.*

**H5.** Hypothesis five required a mediation analysis to examine whether perceived responsiveness mediates the positive relationship between ostomates disclosure and received social support. Results revealed a partial mediation. Findings are summarized in Table 14. Analysis indicated that self-disclosure is a significant predictor of
responsiveness, $\beta = 0.56$, $SE = 0.04$, $p < .001$, BCCI [0.47, 0.65], and responsiveness significantly impacts received social support, $\beta = 0.40$, $SE = 0.05$, $p < .001$, BCCI [0.29, 0.51]. However, disclosure also significantly influenced received social support, $\beta = 0.17$, $SE = 0.05$, $p = <.001$, BCCI [0.06, 0.28]. Twenty-seven percent of the variance is accounted for by the predictors ($R^2 = 0.27$). The indirect effect is significant, $\beta = 0.22$, $SE = 0.04$, 95% BCCI [0.15, 0.31]. Overall, the effect of disclosure on received social support is .22 standard deviations higher than average when mediated by responsiveness. Thus, perceived responsiveness affects the positive relationship between disclosure and received social support in a meaningful way.

Table 14

*Mediation Analysis Effect of Responsiveness on Disclosure and Received Social Support*

<table>
<thead>
<tr>
<th>Path</th>
<th>$\beta$</th>
<th>$SE$</th>
<th>$P$</th>
<th>LLCI</th>
<th>ULCI</th>
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</thead>
<tbody>
<tr>
<td>a Disclosure --- &gt; Responsiveness</td>
<td>0.56</td>
<td>0.04</td>
<td>&lt;.001</td>
<td>0.47</td>
<td>0.65</td>
</tr>
<tr>
<td>b Responsiveness --- &gt; Received SS</td>
<td>0.40</td>
<td>0.05</td>
<td>&lt;.001</td>
<td>0.29</td>
<td>0.51</td>
</tr>
<tr>
<td>c’ Disclosure --- &gt; Received SS</td>
<td>0.17</td>
<td>0.05</td>
<td>&lt;.001</td>
<td>0.06</td>
<td>0.28</td>
</tr>
<tr>
<td>c Total Effect</td>
<td>0.39</td>
<td>0.05</td>
<td>&lt;.001</td>
<td>0.30</td>
<td>0.49</td>
</tr>
<tr>
<td>ab Indirect Effect</td>
<td>0.22</td>
<td>0.04</td>
<td>&lt;.001</td>
<td>0.15</td>
<td>0.31</td>
</tr>
</tbody>
</table>

Notes. $R^2_{Total} = 0.15$ $p < .001$

$R^2_{predictor} = 0.31$ $p < .001$

$R^2_{mediator} = 0.27$ $p < .001$

**H6.** Hypothesis six employed mediation analysis to test whether perceived responsiveness mediates the positive relationship between ostomates disclosure and perceived social support. Results indicated that a complete mediation. Findings are summarized in Table 15. Analysis highlighted that self-disclosure predicts responsiveness, $\beta = 0.56$, $SE = 0.04$, $p < .001$, BCCI [0.47, 0.65], and responsiveness significantly influences perceived social support, $\beta = 0.59$, $SE = 0.05$, $p < .001$, BCCI
When controlling for the effect, disclosure did not significantly predict perceived social support, $\beta = -0.02, SE = 0.05, p < .72, \text{BCCI} [-0.12, 0.08]$. Thirty-four percent of the variance was accounted for by the predictors ($R^2 = 0.34$). The indirect effect was significant, $\beta = 0.33, SE = 0.05, 95\% \text{BCCI} [0.25, 0.42]$. When mediated by responsiveness, the effect of disclosure on perceived social support is .33 standard deviations higher than average.

Table 15

**Mediation Analysis of Responsiveness Effect on Disclosure and Perceived Social Support**

<table>
<thead>
<tr>
<th>Path</th>
<th>$\beta$</th>
<th>$SE$</th>
<th>$P$</th>
<th>LLCI</th>
<th>ULCI</th>
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</thead>
<tbody>
<tr>
<td>a</td>
<td>Disclosure --</td>
<td>--</td>
<td>Responsiveness</td>
<td>0.56</td>
<td>0.04</td>
</tr>
<tr>
<td>b</td>
<td>Responsiveness --</td>
<td>--</td>
<td>Perceived SS</td>
<td>0.59</td>
<td>0.05</td>
</tr>
<tr>
<td>c'</td>
<td>Disclosure --</td>
<td>--</td>
<td>Perceived SS</td>
<td>-0.02</td>
<td>0.05</td>
</tr>
<tr>
<td>c</td>
<td>Total Effect</td>
<td>--</td>
<td>--</td>
<td>0.31</td>
<td>0.05</td>
</tr>
<tr>
<td>ab</td>
<td>Indirect Effect</td>
<td>--</td>
<td>--</td>
<td>0.33</td>
<td>0.05</td>
</tr>
</tbody>
</table>

Notes. $R^2_{\text{total}} = 0.10 \ p < .001$; $R^2_{\text{predictor}} = 0.31 \ p < .001$; $R^2_{\text{mediator}} = 0.34 \ p < .001$

**H7.** Hypothesis seven claimed adaptive coping strategies mediates the positive relationship between received social support and ostomates’ HRQoL. The relationship was tested using mediation analysis. Results showed that adaptive coping strategies did not mediate the relationship between received social support and HRQoL. Findings are highlighted in Table 16. Received social support is a significant predictor of adaptive coping, $\beta = -0.42, SE = 0.04, p < .001, \text{BCCI} [-0.51, -0.30]$. Interestingly, perceptions of current support are negatively associated with the use of positive coping strategies. Additionally, adaptive coping did not significantly predict received HRQoL, $\beta = 0.08, SE = 0.06, p = 0.13, \text{BCCI} [-0.03, 0.19]$. Moreover, received social support was a significant
negative predictor of HRQoL, \( \beta = -0.27, SE = 0.06, p < .001, BCCI [-0.38, -0.16] \). The predictor accounts for ten percent of the variance \( (R^2 = 0.10) \). Furthermore, the indirect effect was insignificant, \( \beta = -0.03, SE = 0.04, 95\% \ BCCI [-0.09, 0.01] \). Overall, adaptive coping did not mediate the relationship between received social support and HRQoL.

Table 16

Mediation Analysis of Received Social Support on Adaptive Coping and HRQoL

<table>
<thead>
<tr>
<th>Path</th>
<th>( \beta )</th>
<th>( SE )</th>
<th>( P )</th>
<th>LLCI</th>
<th>ULCI</th>
</tr>
</thead>
<tbody>
<tr>
<td>a</td>
<td>Received SS ---&gt; Adaptive Cope</td>
<td>-0.42</td>
<td>0.05</td>
<td>&lt;.001</td>
<td>-0.51</td>
</tr>
<tr>
<td>b</td>
<td>Adaptive Cope ---&gt; HRQoL</td>
<td>0.08</td>
<td>0.06</td>
<td>0.13</td>
<td>-0.03</td>
</tr>
<tr>
<td>c'</td>
<td>Received SS ---&gt; HRQoL</td>
<td>-0.27</td>
<td>0.06</td>
<td>&lt;.001</td>
<td>-0.38</td>
</tr>
<tr>
<td>c</td>
<td>Total Effect</td>
<td>-0.31</td>
<td>0.05</td>
<td>&lt;.001</td>
<td>-0.40</td>
</tr>
<tr>
<td>ab</td>
<td>Indirect Effect</td>
<td>-0.03</td>
<td>0.03</td>
<td>-0.09</td>
<td>0.01</td>
</tr>
</tbody>
</table>

Notes. \( R^2_{\text{total}} = 0.09 \ p < .001; \)
\( R^2_{\text{predictor}} = 0.17 \ p < .001 \)
\( R^2_{\text{mediator}} = 0.10 \ p < .001 \)

**H8.** Hypothesis eight argued maladaptive coping has a negative effect on the positive relationship between received social support and ostomates HRQoL. Findings indicated maladaptive coping partially mediates the relationship between received social support and HRQoL. Results are available in Table 17. Received social support is a significant positive predictor of maladaptive coping, \( \beta = 0.31, SE = 0.05, p < .001, BCCI \ [0.21, 0.41] \). Furthermore, maladaptive coping (\( \beta = -0.56, SE = 0.04, p < .001, BCCI \ [-0.65, -0.41] \)) and received social support (\( \beta = -0.22, SE = -0.05, p < .001, BCCI \ [0.21, 0.41] \)) significantly influences HRQoL. Because the indirect effect was significant (\( \beta = -0.17, SE = 0.03, 95\% \ BCCI [-0.23, -0.11] \), maladaptive coping only partially mediates the relationship between received social support and HRQoL. Overall, the predictor accounts for 38 percent of the variance predictor \( (R^2 = 0.38) \).
Table 17

Mediation Analysis of Received Social Support on Maladaptive Coping and HRQoL

<table>
<thead>
<tr>
<th>Path</th>
<th>β</th>
<th>SE</th>
<th>P</th>
<th>LLCI</th>
<th>ULCI</th>
</tr>
</thead>
<tbody>
<tr>
<td>a Received SS ---› Mal Cope</td>
<td>0.31</td>
<td>0.05</td>
<td>&lt;.001</td>
<td>0.21</td>
<td>0.41</td>
</tr>
<tr>
<td>b Mal Cope ---› HRQoL</td>
<td>-0.56</td>
<td>0.04</td>
<td>&lt;.001</td>
<td>-0.65</td>
<td>-0.41</td>
</tr>
<tr>
<td>c’ Received SS ---› HRQoL</td>
<td>-0.22</td>
<td>-0.05</td>
<td>&lt;.001</td>
<td>0.21</td>
<td>0.41</td>
</tr>
<tr>
<td>c Total Effect</td>
<td>-0.31</td>
<td>0.05</td>
<td>&lt;.001</td>
<td>-0.40</td>
<td>-0.21</td>
</tr>
<tr>
<td>ab Indirect Effect</td>
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<td>0.03</td>
<td></td>
<td>-0.23</td>
<td>-0.11</td>
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</table>

Notes. \( R^2_{\text{total}} = 0.38 \ p < .001 \)
\( R^2_{\text{predictor}} = 0.09 \ p < .001 \)
\( R^2_{\text{mediator}} = 0.38 \ p < .001 \)

**H9.** Hypothesis nine stated adaptive coping strategies mediates the positive relationship between perceived social support and ostomates’ HRQoL. Analysis did not support mediation. Findings are highlighted in Table 18. Perceived social support significantly predicts adaptive coping, \( \beta = 0.36 \), \( SE = 0.05 \), \( p < .001 \), BCCI [0.26, 0.46]. However, adaptive coping did not significantly predict HRQoL, \( \beta = 0.09 \), \( SE = 0.05 \), \( p = 0.60 \), BCCI [-0.07, 0.12]. In addition, a direct relationship exists between perceived social support and HRQoL, \( \beta = 0.47 \), \( SE = 0.05 \), \( p < .001 \), BCCI [0.30, 0.57]. The indirect effect was also insignificant \( \beta = 0.01 \), \( SE = 0.02 \), 95% BCCI [-0.03, 0.05]. Adaptive coping did not mediate the relationship between received social support and HRQoL.

**H10.** Hypothesis ten predicted maladaptive coping has a negative effect on the positive relationship between perceived social support and ostomates’ HRQoL. Mediation analysis revealed a partial mediation. See Table 19 for summary of result.
Findings demonstrated that perceived social support significantly influences maladaptive coping, $\beta = 0.17$, $SE = 0.03$, $p < .001$, BCCI [0.12, 0.23]. Similarly, maladaptive coping, $\beta = -0.99$, $SE = 0.08$, $p < .001$, BCCI [-1.14, -0.84], and perceived social support, $\beta = -0.13$, $SE = 0.04$, $p < .001$, BCCI [-0.22, -0.05], are negative predictors of HRQoL. Thirty-eight percent of the variance was accounted for by the predictors ($R^2 = 0.38$). The indirect effect was significant, $\beta = -0.17$, $SE = 0.03$, 95% BCCI [-0.23, -0.11]. Thus, when mediated by maladaptive coping, the effect of perceived social support on HRQoL was 0.17 standard deviations lower than average.
Model Results

The proposed theoretical model was evaluated using several criteria, including $X^2$, $X^2/df$, RMSEA, GFI, AGFI, NFI, CFI, and IFI. The results demonstrate that hypothesized structural model provided an adequate fit to the data. The $X^2$ test of the model was statistically significant, ($df = 18$) = 389.07, $p < .001$. With large sample sizes, significant $X^2$ is not surprising. Because chi-square is influenced by sample sizes (Hooper et al., 2008), other measures were used to assess the model. The RMSEA (0.24, $p < .001$) and AGFI (.55) indicated unacceptable fit. However, the NFI (0.82) demonstrated acceptable fit, GFI (0.85), CFI (0.83) and IFI (0.83) showed marginal fit. The value of $X^2/df$ was 21.62 at 18 degrees of freedom, which is above the often-used target value of five. All fit indices of the observed model are available in Table 20. To better understand the observed model, Table 21 outlines a list of all the regression weight loadings for each path. In addition, Figure 2 provides a graphical presentation of the model with all regression loadings for each path.

Table 20

Fit Indices of the Observed Model

<table>
<thead>
<tr>
<th>Fit Index</th>
<th>Observed Model</th>
</tr>
</thead>
<tbody>
<tr>
<td>$X^2$</td>
<td>389.07</td>
</tr>
<tr>
<td>$X^2/df$</td>
<td>21.62</td>
</tr>
<tr>
<td>RMSEA</td>
<td>0.24</td>
</tr>
<tr>
<td>GFI</td>
<td>0.85</td>
</tr>
<tr>
<td>AGFI</td>
<td>0.55</td>
</tr>
<tr>
<td>NFI</td>
<td>0.82</td>
</tr>
<tr>
<td>CFI</td>
<td>0.83</td>
</tr>
<tr>
<td>IFI</td>
<td>0.83</td>
</tr>
</tbody>
</table>
Figure 2. Hypothesized Model with Regression Weights

Note: The path analysis model with weight regression loadings.
### Table 21

<table>
<thead>
<tr>
<th>Antecedent variable</th>
<th>Sequent variable</th>
<th>β</th>
<th>S.E.</th>
<th>p</th>
</tr>
</thead>
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<td>Disclosure</td>
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<td>0.07</td>
<td>0.14</td>
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Notes. *p < .001

**Summary**

In review, this chapter details the results for each hypothesis and the overall model proposed in the review of literature. In the following chapter, implications of the findings for each hypothesis are discussed. The next chapter will also highlight limitations of the current study and make recommendations for future research.
CHAPTER V – CONCLUSION

The present research seeks to better understand ostomates’ health-related issues. Specifically, this study seeks to identify the role responsiveness plays in the transactional model of stress and coping (Lazarus & Folkman, 1984). Analysis of the proposed model generated a number of interesting results. In this chapter, conclusions and implications are drawn for each hypothesis and the overall model. Next, limitations and areas of future research are presented. Finally, a concluding summary of the study’s purpose, findings, and contributions to health communication scholarship are offered.

Discussion

To begin, hypothesis 1a predicted ostomates’ perceptions of uncertainty are negatively associated with HRQoL. Uncertainty revealed to significantly decrease patients’ HRQoL. When patients fail to find meaning in illness-related experiences and are unable to predict health outcomes, they often experience negative uncertainty (Mishel, 1981). Some patients maintain uncertainty to temporarily sustain well-being (Brashers, 1998, 2000, 2007). However, unmanaged uncertainty can negatively influence HRQoL. Specifically, patients experience poor physical and mental health outcomes (Hsu et al., 2003; Johnson et al., 2009; Lütze & Archenhotlz, 2007). For ostomates, increased negative uncertainty is linked to poor reduced appliance adaptation and coping practices (Riemenschneider, 2015).

Respondents demonstrate that ostomy implementation creates a substantial emotional burden. For patients, stoma creation produces feelings of negative uncertainty and ambiguity about living with an appliance (Danielsen, Soerensen, Burcharth, & Rosen
berg, 2013). In the context of this investigation, negative uncertainty significantly contributed to lower health-related quality of life. While 2.2% of patients reported never experiencing negative uncertainty, 39.8% indicated often confronting negative uncertainty. This finding is consistent with previous work (Danielsen et al., 2013; Righter, 1995). Because this relationship highlights the ambiguity surrounding an ostomy implementation, the direct effect of negative uncertainty is important to quality of life. Ostomy patients appear to be affected by unmanaged uncertainty in the same way that people do when experiencing other health concerns.

Hypothesis 1b predicted that ostomates’ perceptions of enacted stigma are associated with poor HRQoL. Enacted stigma, or actual observed discrimination, is a key determinate of HRQoL in chronically ill patients (Scambler, 2009). Overt episodes of enacted stigma, such as avoiding, making fun, and unfair treatment, increases physical and psychological distress and reduces HRQoL among patients with HIV (Lekas, Siegel, & Leider, 2011), Parkinson’s disease (Ma et al., 2016), and multiple sclerosis (Broersma et al., 2017).

For these ostomates, results show that enacted stigma is not associated with HRQoL. A major explanation of this finding is that 32% of respondents strongly disagreed that they had experienced instances of enacted stigma from others. Furthermore, 68% of surveyed patients also disagreed or somewhat disagreed. In other words, if a respondent did not experience instances of enacted stigma their HRQoL was not impacted.

Several potential explanations exist for ostomates’ perceptions of enacted stigma and HRQoL. Chaudoir, Earnshaw, and Andel (2013) argued that individuals with visible
conditions often encounter stigma compared to patients with concealable conditions. For example, HIV patients with visible symptoms (e.g., lipoatrophy, rashes, and lipodystrophy) report experiencing stigma and health-related issues more often than those with invisible symptoms (Stutterheim et al., 2011). Not all respondents display visible characteristics of their appliance or condition, thus affecting responses. Additionally, to mitigate the effects of enacted stigma, ostomates could be concealing their appliance from others.

Another potential reason enacted stigma was insignificant may be ostomates, through social media and non-profit organizations (e.g., UOAA and Ostomy Canada), are creating more social awareness about having an ostomy appliance. For example, some ostomates are using social media share their ostomy story and post images revealing their appliance (Frohlich & Zmylinski-Seelig, 2016). The UOAA and International Ostomy Association also promote multiple events, such as World Ostomy Day, Ostomy 5k runs, and national/international conferences, to encourage positive dialogue regarding ostomy implementation (United Ostomy Association of America, 2018).

Finally, the transactional model of stress and coping argues that to cope with stressors individuals must successfully engage in a secondary appraisal process (Lazarus & Folkman, 1984). Because most respondents were actively participating in ostomy-specific social support groups, they may have already effectively coped and built resilience against enacted stigma. Thus, overt act of stigma may be less impactful in shaping patients’ HRQoL.

Hypothesis 1c maintained that ostomates’ perceptions of felt stigma are associated with poor HRQoL. While enacted stigma was not statistically significant, felt stigma did
negatively impact ostomates’ HRQoL. Felt stigma is a patients’ perceptions that others have negative attitudes or beliefs toward them or their illness (Scambler, 2009). Felt stigma, unlike enacted stigma, is more disruptive in patients’ lives and influences their desire to conceal illness symptoms (Scambler, 2009). Felt stigma negatively impacts HRQoL in patients with epilepsy (Scambler, 2009), HIV (Jiménez et al., 2012), and lung cancer (Else-Quest, Lo Conte, Schiller, & Hyde, 2009). Similarly, this study shows enacted stigma is more influential (compared to felt stigma) in lowering patients’ HRQoL.

Ostomates often experience feelings of being different and disgust toward their appliance (Smith, et al., 2007). Patients’ perceptions of stigma did contribute to reduced HRQoL. Of the 375 respondents 41.7% were fearful that they would encounter future form of stigma. Because the public’s perception of ostomy appliances is negative (Kessler, 2016), ostomates worry that others might discover their appliance and view them differently (Krouse et al., 2007; Krouse et al., 2009). In this case, internalized feelings of stigma and fear of non-acceptance considerably lowered respondents’ well-being. Similar to other patient populations (Tripathi et al., 2017), these ostomates suffered reduced health outcomes due to increased feelings of stigma.

The second hypothesis projected that uncertainty is positively associated with ostomates’ disclosure. Ostomy patients face a great deal of uncertainty concerning appliance care and management, physical limitations, and lifestyle challenges (Sun et al., 2013). When grappling with chronic illness, patients use self-disclosure as a tool to access support and manage uncertainty (Brasher, 2001; Folkman & Lazarus, 1984). In this study, the distribution of responses shows that participants, on average (\(M = 2.46, SD\))
faced moderate uncertainty; however, ambiguity is not predictive of increased self-disclosure ($\beta = .14, SE = .08, p = .09$).

The relationship between uncertainty and self-disclosure is insignificant. While not predicted, this finding might be attributed to various explanations. As mentioned earlier, in this study, many respondents were involved in ostomy social support communities. To mitigate uncertainty surrounding their illness experience, patients may seek social support networks to access ostomy-related information (Babrow, Kasch, & Ford, 1998; Brasher, 2007). Furthermore, although uncertainty fluctuates throughout the illness experience (Mishel, 1984, 1998), ostomates report experiencing negative uncertainty within the first year of implementation (Haugen, Bliss, & Savik, 2006; Riemenschneider, 2015; Wade, 1990). Because the survey did not have a question regarding time elapsed since surgery, many participants could have undergone surgery long ago and by now transitioned to their ostomy. Thus, respondents may have learned to manage their uncertainty and feel little need to disclose to others about ostomy-related issues.

Hypothesis 3a predicted that perceptions of enacted stigma are negatively associated with patients’ ostomy-specific self-disclosures. Findings show respondents, on average ($M = 1.86, SD = .04$), suffered from low levels of enacted stigma, and enacted stigma did not predict self-disclosure ($\beta = -0.11, SE = 0.07, p = 0.14$). Because enacted stigma is not a significant predictor of patients’ HRQoL, these findings are not unexpected. As previously stated, to mitigate the effects of enacted stigma, ostomates can conceal their appliance from others. Reduced instances of enacted stigma may decrease ostomates need to engage in ostomy-related self-disclosure. Furthermore, when
encountering stigma, patients could have effectively coped limiting their need to self-disclose ostomy-related information to others. Ultimately, responses from this group do not support an association between stigma and disclosure behaviors.

Hypothesis 3b argued that perceptions of felt stigma are negatively associated with ostomates’ disclosure. Unlike enacted stigma, results indicated a significant relationship between felt stigma and self-disclosure. The range of responses demonstrate that participants, on average ($M = 2.62, SD = 1.22$) suffer from felt stigma compared to enacted stigma ($M = 1.86, SD = .04$). Furthermore, when experiencing felt stigma, patients are less likely to reveal ostomy-specific information ($\beta = -0.46, SE = 0.09, (p < .001)$).

Findings are consistent with previous literature on felt stigma and ostomy-specific disclosure practices (Nicholas et al., 2008; Savard & Woodgate, 2009; Smith et al., 2007). Life with an ostomy greatly impedes patients’ abilities to disclose health-related information to others. For example, adolescent ostomates often struggle to reveal their ostomies to friends due to increased apprehension of negative responses (Nicholas, Swan, Gerstel, Allan, & Griffiths, 2008). Because ostomates fear being stigmatized (Savard & Woodgate, 2009), they use concealment as form of non-disclosure.

Hypothesis four argues that perceived responsiveness mediates the positive relationship between ostomates’ self-disclosure and HRQoL. Mediation analysis was used to analyze the relationship between ostomy-specific self-disclosure, responsiveness, and HRQoL. Findings showed that self-disclosure does not directly influence HRQoL. Instead, HRQoL only improves when mediated through responsiveness ($\beta = 0.22, SE = 0.04, 95\% \text{ BCCI} [0.47, 0.65]$). Overall, results demonstrate a complete mediation.
Although similar to Reif et al., (2016) findings regarding the effect of ostomy-specific disclosure and responsiveness on ostomates’ psychological QoL, results from this study conflicted with previous literature regarding self-disclosure practices and HRQoL in chronically ill patient populations. Self-disclosing one’s medical condition has is connected to improved HRQoL outcomes, including lower depression, reduced anxiety, and improved physical well-being (Broderick et al., 2005; Giordano et al., 2011; Kelly, 2004). In contrast, this study’s findings revealed the act of self-disclosing ostomy-specific information to others does not directly improve patients’ HRQoL. Instead, findings suggested ostomates experience no direct health-related benefits from revealing intimate details about their appliance (i.e., changes in bodily appearance, altered bowel function, and waste removal procedures). Thus, following implementation, individuals’ HRQoL is not dependent on self-disclosure alone.

Self-disclosure only improved HRQoL when ostomates perceive responses from others as conveying caring, understanding, and validating undertones (the three responsiveness categories established by Reis and Shaver, 1988). In other words, ostomates experience improved HRQoL by revealing ostomy-specific information to others they feel are supportive and understanding. Therefore, patients’ health outcomes do not solely rely on the act of expressing health-related information, but rather on how others react to the disclosures.

While the transactional model of stress and coping accounts for the direct link between self-disclosure and HRQoL (Broderick et al., 2005; Giordano et al., 2011; Kelly, 2004), the model fails to consider the significance of responsiveness on health outcomes. For this study’s respondents, self-disclosure did not directly improve HRQoL. However,
when mediated through responsiveness, self-disclosure improved HRQoL. Either the concept of secondary appraisal needs to be adjusted to reflect that disclosure alone might not be an effective tool, or more beneficially, a specific theory of disclosure responsiveness should be constructed. In essence, this theoretical perspective would articulate the combined effect of responsiveness and disclosure on relevant outcome variables, such as quality of life, coping behaviors, self-perceptions, stigma, or relationship status. Disclosure is a coping tool, as current theory suggests; however, the relative positive or negative effect is dependent on the partner’s responsiveness to that disclosure. I propose this theory be called disclosure responsiveness theory (DRT).

Hypothesis five argued that perceived responsiveness mediates the positive relationship between ostomates’ self-disclosure and received social support. To examine the relationship between ostomy-specific self-disclosure, responsiveness, and received social support, mediation analysis was used. Results showed the direct effect of disclosure on received social support (β = 0.17, SE = 0.05, p = .006, BCCI [0.06, 0.28]), indirect effect (β = 0.22, SE = 0.04, 95% BCCI [0.15, 0.31) are significant. Thus, responsiveness partially mediates the relationship between disclosure and received social support.

Self-disclosure has a direct effect on ostomates’ perceptions of received social support. When patients reveal ostomy-specific information, they are likely to perceive obtaining instances of social support. These findings align with previous research that self-disclosure performs an essential role in patients’ experiencing received social support (Cohen & Willis, 1985; Goldsmith, 2004; Lazarus & Folkman, 1984). Actual occurrences of social support accessed through self-disclosure is an essential component in helping
patients adapt to stressors (Folkman & Lazarus, 1988). However, in previous literature, the importance of responsiveness in accessing social support has been overlooked as a theoretical component of the transactional model of stress and coping.

Although there was a significant direct effect between self-disclosure and received social support, when mediated through responsiveness the relationship strengthened. When ostomates reveal ostomy-specific information and receive understanding, supportive and validating feedback (the three tenants of responsive behavior established by Reis and Shaver, 1988), they indicate higher occurrences of social support. These findings support previous research finding regarding disclosure and the importance of responsiveness (Manne et al., 2004; Manne et al., 2010; Maisel & Gable, 2009).

These results again highlight the significance of responsiveness in shaping patients’ perceptions of received social support. Because the Lazarus and Folkman’s (1984) model does not include responsiveness, in the least, an adjustment to this conceptualization is warranted. DRT provides an alternative framework for understanding the complex relationship between self-disclosure and received social support. This framework highlights the importance of positive responsiveness in contributing to patients’ evaluations of actual instances of received social support from others.

Hypothesis six stated that perceived responsiveness mediates the positive relationship between ostomates’ self-disclosure and perceived social support. Mediation analysis was conducted explore the relationship between ostomy-specific disclosure, responsiveness, and perceived social support. Results show that self-disclosure was not a
significant predictor of perceived social support ($\beta = -0.02, SE = 0.05, p < .001, \text{BCCI} [0.49, 0.69])$. Because the indirect effect was significant ($\beta = 0.33, SE = 0.05, 95\% \text{BCCI} [0.25, 0.42]$), findings exhibit that responsiveness fully mediated the relationship between self-disclosure and perceived social support.

Health-related disclosures are known to determine patients’ assessment of available social support (Kalichman, DiMarco, Austin, Luke & DiFonzo, 2003; Lueger-Schuster et al., 2015; Martins et al., 2013). Patients who disclose illness concerns are likely to feel confident about the availability of support when needed. Contrary to prior research, this study’s findings highlight the act of disclosing ostomy-specific information does not influence patients’ perceptions of available support. When patients feel others positively respond to potentially stigmatizing disclosures, their feelings of available support significantly increase.

These findings further validate the significance of responsiveness in influencing patients’ assessment of accessible social support. Although the transactional model of stress and coping identifies a direct link between self-disclosure and perceived social support (Cohen & Willis, 1985), the effect of responsiveness has been overlooked, this nuanced relationship appears. Overall, DRT demonstrates as a theoretical framework for better understanding patients’ evaluation of perceived and received support from others.

Hypothesis seven implied that adaptive coping mediated the positive relationship between received social support and ostomates’ HRQoL. Mediation analysis was performed to examine the relationship between received social support, adaptive coping, and HRQoL. Received social support is a significant predictor of HRQoL ($\beta = -0.27, SE = 0.06, p < .001$), but the indirect effect was insignificant ($\beta = -0.03, SE = 0.04, 95\%$
Analysis demonstrates that adaptive coping did not mediate the relationship between received social support and HRQoL.

Although the transactional model argues that coping mediates the relationship between secondary appraisals and the long-term effects on HRQoL (Folkman & Lazarus, 1984; 1988), findings show adaptive coping did not significantly influence the relationship between received social support and patients’ HRQoL. Contrary to the proposed hypothesis, results exhibited a negative relationship between social support and adaptive coping. In other words, patients’ who receive social support are less likely to engage in adaptive coping behaviors and report better health outcomes.

These findings suggest ostomates do not view received social support as beneficial. A large body of literature has documented mixed findings regarding the impact of received social support on HRQoL (Thorsteinsson & James, 1999). For some patients, received social support is linked to improved well-being (DiMatteo, 2004; Helgeson, 2003; Uchino, 2006; however, received support can also result in poor HRQoL for others (Bolger et al., 2000). More specifically, studies highlight that received support causes depression and decreased emotional well-being (Bolger, Zuckerman, & Kessler, 2000; Kaul & Lakey, 2003).

A possible explanation for these finding could be that social support networks are providing inadequate support to meet patients’ needs. Instead of positively impacting patients’ well-being, received social support can be detrimental to their well-being. More specifically, when receiving social support, ostomates are less likely to engage in adaptive coping behaviors and experience lower levels of HRQoL. Although ostomates’ social support network may attempt to offer genuine support, patients do not view the...
interaction supportive. For example, social networks could be offering emotional support when ostomates require more instrumental support (i.e., tips for stoma care tips, type of appliance to use, and foods to avoid).

Received social support may also be ineffective because social support networks are offering instances of invisible social support (Bolger et al., 2000; Maisel & Gable, 2009). While providers report enacting instances of social support, ostomates do not perceive that social support is occurring. For example, family members could change dietary habits to accommodate a patient’s stoma restrictions; however, without the ostomate’s knowledge the supportive actions could go unnoticed. Finally, these findings could be the result of the sampled population. As mentioned earlier, patients could have subsequently engaged in adaptive coping behaviors and effectively transitioned to their appliance. Thus, current instances of received support are not needed to improve well-being.

Hypothesis eight predicted maladaptive coping has a negative effect on the positive relationship between received social support and ostomates’ HRQoL. To test the proposed relationship, mediation analysis was used. The direct effect of received social support on HRQoL is significant ($\beta = -0.13, SE = 0.05, p < .001, BCCI [0.21, 0.41]$), the indirect effect is also significant ($\beta = -0.17, SE = 0.03, 95\% BCCI [-0.23, -0.11]$). Maladaptive coping partially mediated the association between received social support and HRQoL, noting that the direct effect was negative.

Scholarship examining the impact of maladaptive coping on HRQoL has revealed mixed findings. While some maladaptive coping strategies are associated with temporarily improving well-being, long-term use can significantly reduce health
outcomes in chronically ill patient populations (Tugade & Fredrickson, 2004; Tugade, Fedrickson, & Barrett, 2004). Results assert that maladaptive coping significantly mediates the negative relationship between received social support and patients’ HRQoL. Specifically, when patient receive social support, they engage in maladaptive coping behaviors and experience poor well-being.

Again, these findings demonstrate that received social support is negatively linked to ostomates’ well-being. Because patients often use maladaptive strategies as a tool to divert attention from illness related concerns (Klein et al., 2007), a high volume of received social support could serve as a reminder of their condition. The more social support patients receive, the chances of engaging in maladaptive behaviors increases. Furthermore, as mentioned earlier, provided support may not meet patients’ needs. For example, ostomates may interpret offered support as nagging or controlling and further engage in maladaptive behaviors. Because optimal physical and psychological functioning is critical for ostomy patients’ successful transition, these findings should be further studied.

Hypothesis nine suggested that adaptive coping strategies mediates the positive relationship between perceived social support and ostomates’ HRQoL. To examine the relationship between adaptive coping strategies, perceived social support, and HRQoL, mediation was conducted. Results indicated no mediation occurred. The direct effect of perceived social support on HRQOL is significant ($\beta = 0.47$, $SE = 0.05$, $p < .001$, BCCI [0.30, 0.57]), and the indirect effect is insignificant ($\beta = 0.01$, $SE = 0.02$, 95% BCCI [-0.03, 0.05]). Adaptive coping did not influence the relationship between perceived social support and HRQoL.
The results showed that a direct relationship existed between perceived social support and HRQoL. Ostomates who believe that help is available when needed, may experience improved well-being. Thus, perceived social support buffers against the damaging effects of ostomy-related stressors on patients’ HRQoL (see Cohen & Willis, 1985). Further, perceived social support is also positively associated with the use of adaptive coping strategies. More specifically, ostomy patients who think support is readily available are more likely to engage in adaptive coping efforts. These findings are consistent with previous literature highlighting the importance of perceived support in shaping patients’ health-related outcomes (Bekele et al., 2013; Cohen, Underwood, & Gottlieb, 2000; Jalai-Farahani et al., 2018).

Hypothesis ten proposed maladaptive coping has a negative effect on the positive relationship between perceived social support and ostomates’ HRQoL. Mediation analysis explored the relationship between perceived social support, maladaptive coping, and HRQoL. Results maintained perceived social support negatively influences HRQoL ($\beta = -0.13$, $SE = 0.04$, $p < .001$, BCCI [-0.22, -0.05]), the indirect effect is also significant ($\beta = -0.17$, $SE = 0.03$, 95% BCCI [-0.23, -0.1]). Maladaptive coping partially mediates the relationship between perceived social support and HRQoL.

Perceived social support did not buffer against the negative stressors of ostomy implementation for all patients (see Cohen & Willis, 1985; Lazarus & Folkman, 1984). Findings show perceptions of social support encourage some ostomates to engage in maladaptive coping behaviors. Because perceived social support is subjective and depends on patients’ assessment of received support (Lin, 1986; Zimet et al., 1988), ostomates could have previously identified high levels of support while engaging in
maladaptive coping. These instances of support may have set a precedent that participating in maladaptive strategies would garner future support. Subsequently, patients could feel social support will be available even when displaying negative coping behaviors. To better understand this relationship, investigating the type of maladaptive strategy that is most influenced by perceived support could be useful. Although maladaptive coping may temporarily improve HRQoL (Tugade & Fredrickson, 2004; Tugade, Fredickson, & Barrett, 2004), these findings show that engaging in maladaptive behaviors significantly reduces ostomates’ HRQoL.

Prior literature indicates adaptive coping can not only directly influence health-related outcomes (Carels, 2004; Carver et al., 1993), but also operates as a mediating variable between secondary appraisals and HRQoL (Lazarus & Folkman, 1984). Contrary to expectations, adaptive coping did not mediate the relationship between perceived social support and HRQoL. Adaptive coping strategies also failed to significantly impact ostomates’ HRQoL. Although perceived social support drives ostomates to engage in adaptive coping behaviors, results suggest adaptive strategies do not necessarily shield against ostomy-related stressors.

These surprising results could be attributed to how the adaptive coping scale was constructed. Specifically, confirmatory factor analysis of the Brief COPE scale was used to differentiate adaptive strategies from maladaptive behaviors. Several strategies were combined to create an overall adaptive coping scale. Because coping is a multifaceted process, patients may be relying on a specific adaptive strategy, such as humor, acceptance, or positive reframing to improve well-being. Examining whether a particular
adaptive coping strategy is more frequently used by ostomates could provide better insight into improving patients’ HRQoL.

Additionally, these unexpected findings may once again be the result of the sampled population. While some respondents may still be adjusting to life with an ostomy, others could have already adopted positive coping behaviors and successfully adjusted. For patients, who have already confronted and learned to manage ostomy-related stressors, engaging in adaptive coping behaviors could have little influence on their HRQoL outcomes. Because coping styles change over the course of an illness experience, these findings should be further examined.

*Model Results*

Results of the path analysis revealed the proposed model is a poor fit for the data. Enacted and felt stigma significantly lowered patients’ HRQoL. In particular, felt stigma was more pervasive and detrimental to well-being compared to enacted stigma. Because felt stigma drastically reduces ostomates’ willingness to disclose ostomy-related information, patients are likely to experience poor outcomes. These findings support associations revealed in prior literatures. For example, higher levels of felt and enacted stigma can greatly impede health outcomes in patients with Parkinson’s disease (Ma et al., 2016), HIV (Lekas et al., 2011; Olley et al., 2016) and breast cancer (Tripathi et al., 2017). Furthermore, feelings of stigma can lessen patients’ exposure to enacted stigma by impacting patients’ health-related disclosure practices (Lekas et al., 2011; Olley et al. 2016).

The model also revealed that uncertainty by itself does not reduce HRQoL. In this study, when ostomates experience uncertainty, the likelihood of health-related disclosure
increases. Thus, ostomates are using disclosure as a tool to manage uncertainty and maintain well-being (Brashers, 2001; 2007). However, contrary to previous literature, self-disclosure does not directly improve patients’ HRQoL (Averill, Kasarskis, & Segerstrom, 2013; Giordano et al., 2011; Mormong, Jamart, & Jacques, 2014). Instead, ostomates’ HRQoL improves if people provide caring, understanding, or validating responses to the disclosed information. Furthermore, when perceiving social support, patients are less likely to engage in maladaptive coping behaviors that negatively impacts HRQoL.

While previous research implies that received social support reduces well-being (Kaul & Lakey, 2003; Bolger, 2007), Maisel and Gable (2009) showed that received support is more beneficial when responsiveness is present. Surprisingly, this model demonstrates that responsiveness has a negative relationship with received social support. Although patients acquire validating, caring, and understanding responses from support networks, they may not consider the interaction supportive. After receiving instances of social support, ostomates are likely to engage in maladaptive coping behaviors and experience reduced well-being.

The lack of a significant relationship between adaptive coping behaviors and HRQoL is another interesting finding. Previous research has linked adaptive coping with improved outcomes in patients with terminal cancer (Nipp et al., 2016), endometriosis (Gonzalez et al., 2015), and spinal cord injuries (Galvin & Godfrey, 2001). In this study, ostomy patients did not experience improved HRQoL when engaging in adaptive coping behaviors. However, as expected, the model reveals a significant relationship between
maladaptive coping behaviors and HRQoL. Ostomates who engage in maladaptive coping behaviors experience reduced well-being.

Although the model was not significant, further analysis demonstrated an exceptionally well-fitting model. Figure 3 provides a graphical representation of the trimmed model with regression loadings for each path. The trimmed model showed significant fit indices (See Table 22). The regression weights for each path is also presented in Table 23.

Limitations

Although this study seeks to contribute to the health communication literature, there are limitations that need to be addressed. One limitation of the current study is that data is derived from several self-report measures. While the data provides vital insight into ostomates’ experiences, this methodological approach does not completely capture the complexity of patients’ ostomy-specific disclosure practices. In particular, this study asks patients to reflect on their perceptions of others’ responsiveness to revealed information. While the receiver may intend to demonstrate responsive behavior, ostomates may perceive the interaction as unresponsive and stigmatizing. Future researchers could incorporate other procedures to better capture this dynamic process. For example, the diary method could facilitate the opportunity to examine whether friends, family members, and others’ supportive attempts are identified by patients as supportive actions. Potential studies could also measure and observe self-disclosed information and perceived responsiveness between ostomates and their support network to minimize the self-response bias.
Table 22

Trimmed Model Fit Indices

<table>
<thead>
<tr>
<th>Fit Index</th>
<th>Observed Model</th>
</tr>
</thead>
<tbody>
<tr>
<td>$X^2$</td>
<td>33.05</td>
</tr>
<tr>
<td>$X^2/df$</td>
<td>2.75</td>
</tr>
<tr>
<td>RMSEA</td>
<td>0.70</td>
</tr>
<tr>
<td>GFI</td>
<td>0.98</td>
</tr>
<tr>
<td>AGFI</td>
<td>0.94</td>
</tr>
<tr>
<td>NFI</td>
<td>0.98</td>
</tr>
<tr>
<td>CFI</td>
<td>0.97</td>
</tr>
<tr>
<td>IFI</td>
<td>0.97</td>
</tr>
</tbody>
</table>

Table 23

Trimmed Model Regression Weights

<table>
<thead>
<tr>
<th>Antecedent variable</th>
<th>Sequent variable</th>
<th>$\beta$</th>
<th>S.E.</th>
<th>$p$</th>
</tr>
</thead>
<tbody>
<tr>
<td>Responsiveness</td>
<td>---&gt; Disclosure</td>
<td>0.56</td>
<td>0.44</td>
<td>&lt;0.001</td>
</tr>
<tr>
<td>Felt Stigma</td>
<td>---&gt; Responsiveness</td>
<td>-0.67</td>
<td>0.40</td>
<td>&lt;0.001</td>
</tr>
<tr>
<td>Adaptive Coping</td>
<td>---&gt; Disclosure</td>
<td>0.19</td>
<td>0.06</td>
<td>0.002</td>
</tr>
<tr>
<td>Maladaptive Coping</td>
<td>---&gt; Responsiveness</td>
<td>-0.30</td>
<td>0.04</td>
<td>&lt;0.001</td>
</tr>
<tr>
<td>Maladaptive Coping</td>
<td>---&gt; Disclosure</td>
<td>0.18</td>
<td>0.05</td>
<td>0.017</td>
</tr>
<tr>
<td>Maladaptive Coping</td>
<td>---&gt; Felt Stigma</td>
<td>0.45</td>
<td>0.05</td>
<td>&lt;0.001</td>
</tr>
<tr>
<td>Responsiveness</td>
<td>---&gt; Perceived SS</td>
<td>0.59</td>
<td>0.05</td>
<td>&lt;0.001</td>
</tr>
<tr>
<td>Responsiveness</td>
<td>---&gt; Responsiveness</td>
<td>-0.62</td>
<td>0.05</td>
<td>&lt;0.001</td>
</tr>
<tr>
<td>Expected Social Support</td>
<td>---&gt; Maladaptive Coping</td>
<td>-0.25</td>
<td>0.06</td>
<td>0.01</td>
</tr>
<tr>
<td>Received Social Support</td>
<td>---&gt; Responsiveness</td>
<td>0.39</td>
<td>0.06</td>
<td>&lt;0.001</td>
</tr>
<tr>
<td>Expected Social Support</td>
<td>---&gt; Adaptive Coping</td>
<td>0.17</td>
<td>0.06</td>
<td>&lt;0.001</td>
</tr>
<tr>
<td>HRQoL</td>
<td>---&gt; Maladaptive Coping</td>
<td>-0.019</td>
<td>0.04</td>
<td>&lt;0.001</td>
</tr>
<tr>
<td>HRQoL</td>
<td>---&gt; Felt Stigma</td>
<td>-0.100</td>
<td>0.05</td>
<td>0.045</td>
</tr>
<tr>
<td>HRQoL</td>
<td>---&gt; Perceived SS</td>
<td>0.037</td>
<td>0.04</td>
<td>0.305</td>
</tr>
<tr>
<td>HRQoL</td>
<td>---&gt; Uncertainty</td>
<td>0.037</td>
<td>0.04</td>
<td>0.305</td>
</tr>
</tbody>
</table>

Notes: *$p < .001$
Figure 3. Trimmed Model

Note: Trimmed model with regression weights.
Another potential limitation is the amount of time elapsed since patients’ ostomy surgery. Patients report poor physical and psychological functioning in the weeks immediately following surgery (Krouse et al., 2009). However, with the passage of time, most ostomates are able to effectively cope and successfully adapt to life with an appliance (Anaraki et al., 2012; Wade, 1990). Because this study did not include a question regarding length of time since surgery, the sample potentially contains a mixture of patients still struggling to adjust and those who have effectively transitioned. To better understand the role of responsiveness in helping ostomates cope and improve HRQoL, future researchers should conduct a longitudinal study from pre-surgery to one-year post-surgery. While a longitudinal study cannot provide definitive causal inference, this type of research would be ideally suited to uncover reciprocal relationships among self-disclosures, responsiveness, social support, coping behaviors, and HRQoL.

Because this study only examines ostomy patients, a purposive sampling strategy was used. While purposive sampling provides a range of perspectives regarding ostomy implementation, results from this study may not be generalizable to all ostomy patients. The majority of respondents were women who were 66 years or older. Although the UOAA (2018) estimates there are over 750,000 ostomy patients living in the United States, no conclusive gender or age data exists (Turnbull, 2003). A recent study conducted by ostomy appliance manufacture Coloplast (2016) revealed males and females have roughly the same rate of ostomy implementation; however, the type of type of stoma (i.e., regular, inward, or outward) varies between sex. Additionally, in this study, Coloplast (2016) highlighted a majority of ostomates’ are 60 years or older. To provide a more accurate picture of ostomates’ experiences, future studies should use
random sampling to access a more diverse population. Because ostomy specific self-disclosure and perceived responsiveness may differ depending on sex and age, researchers should include a higher number of male participants and a more disperse age range. Furthermore, the impact of sex and age on the model should be evaluated.

Additional limitations to consider are survey fatigue and social desirability. Overall, this study’s survey contains over 100 questions and took between 20-30 minutes to complete. Galesic and Bosnajk (2009) revealed surveys that last approximately ten minutes, compared to 30 minutes, have a better response rate, less variability of answers, and reduced non-item response rates. Because of the excessive amount of questions and time commitment, participants may have suffered survey fatigue and opted not to complete the survey. Although the survey demonstrates acceptable response rate, a shorter survey could possibly help lower nonresponse rate (Sahlqvist et al., 2011). Specifically, some of the survey instruments could be replaced with shorter versions. For example, this study uses the 24-item SSCI Scale (Rao, et. al, 2009) to examine ostomates’ perceptions of felt and enacted stigma. However, the more recent 8-item SSCI scale may be an accurate measure regarding the impact of stigma on patients’ well-being (Molina et al., 2013).

Future Research

Because this study asks questions some might view as socially taboo (i.e., stigma) and sensitive (i.e., health status), respondents may have withheld personal information or answered questions in a socially desirable manner. Krumpal (2013) implied that survey respondents tend to misreport socially undesirable activities or not answer at all for fear sensitive information becoming public. For example, respondents
could have avoided answering questions regarding drug or alcohol use since ostomy surgery. In addition, respondents may provide desirable responses as a way to manage self- and social- perceptions. Patients may have felt embarrassed revealing embarrassing details about their physical and/or psychological well-being.

While this study sheds new insight into ostomy patients’ experiences and the role of responsiveness in the transactional model of stress and coping, additional areas of research need to be addressed. For example, this study’s model frames stress and coping as a one-way linear process. In contrast, Lazarus and Folkman’s (1984) transactional model indicates stress and coping as a circular process with a feedback loop. Because the model assumes the individual and environment are constantly in flux, cognitive evaluation is continually changing and adapting. Specifically, when coping attempts are unsuccessful, patients are likely to initiate reappraisal process using newly obtained environmental and personal information (Lazarus, 1993). For example, in the beginning new ostomates could struggle changing their appliance and suffer increased distress. During initial coping attempts, patients may seek ostomy care tips from healthcare professionals. If the information is inadequate, the reappraisal process will continue until patients access a sufficient source of information, like a social support group, to successfully manage ostomy issues and alleviate stressors. To better clarify the complex relationship between responsiveness and HRQoL, future research projects need to examine the proposed model as a circular process.

Another possible area of research is to examine the individual direct effects of physical and psychological domains on patients’ health outcomes. Although the RAND-36 (Hays, 2001) measures multiple dimensions of health, this study only examines
ostomates’ overall health functioning. Distinguishing between physical and psychological aspects of health will provide an enhanced understanding of these domains on ostomates’ well-being.

While patients with high levels of uncertainty and stigma (felt and enacted) self-disclose to others, this study did not explicitly examine whether patients reveal more to significant others, family members, friends, or co-workers. Although high quality relationships play a key role in helping patients adapt to chronic illness (Manne, Badr, Zaider, Nelson, & Kssane, 2010), increased uncertainty can hinder patients’ abilities to effectively communicate to loved ones about health-related conditions (Boehmer & Clark, 2001; Checton & Greene, 2012; Brashers, Neidig, & Goldsmith, 2004). For example, in a study of elderly heart-disease patients, Checton and Greene (2012) revealed illness-related uncertainty was negatively associated with talk about illness symptoms with significant others. Similarly, HIV patients are more likely to disclose health status to friends compared to family members (Kalichman et al., 2003). Because ostomy disclosure is risky, ostomates could make disclosure decisions based on relationship types. Future research needs to further examine how barriers and support needs shape ostomates’ disclosure decisions.

Summary

In the final chapter, conclusions and implications for each hypothesis are presented. This chapter also highlights research limitations and potential avenues of future research. Overall, the purpose of this dissertation was to investigate the role of responsiveness in helping patients cope with ostomy-related issues. To achieve this research goal, theoretical underpinnings, relevant literature and methods of investigation
are outlined. Results, implications, and limitations are also presented. Understanding the complex relationship between enacted and felt stigma, negative uncertainty, self-disclosure, responsiveness, received and perceived social support, and HRQoL provides important insight in efforts improve health and well-being for over 1.3 million ostomy patients.

Ostomy patients encounter issues, such as poor body image, depression, and stigma, that can create negative health-related uncertainty and impair well-being. While the transactional model of stress and coping (Lazarus & Folkman, 1984) provides a framework for evaluating how patients cope with stressors, the model is insufficient in understanding ostomates’ experiences. In particular, the transactional model overlooks the role perceived responsiveness in influencing patients’ health-related quality of life. This dissertation addresses the transactional model’s shortcoming by proposing the disclosure responsiveness theory (DRT). More specifically, results show that the simple act of revealing ostomy-related information does not improve patients’ well-being. Instead, when support networks display understanding, validating, and caring behaviors to ostomy-related disclosures, patients report better health outcomes. Furthermore, they feel like social support is more readily available and experience more instances of social support when responsiveness is high. Perceptions of responsiveness also promotes ostomates to engage in adaptive coping behaviors. Thus, responsiveness is the key to making ostomates’ lives better.

Although ostomy implementation is a life-changing surgery, the transition process should not be a negative experience for ostomates. Because the number of patients is steadily increasing, healthcare providers must better address the physical and
psychological needs of patients. The results of this study suggest that providers should recognize the importance of responsiveness and create interventions to help patients effectively manage ostomy-related stressors. Most importantly, social support networks should receive communication training on how to provide effective responses to ostomy-related disclosures. In the future, this research may help to facilitate communicative practices between ostomates and their supportive networks and significantly improve well-being. Through improved communication, ostomates might one day be free from stigmatization and misunderstanding that undermines their quality of life.
NOTICE OF COMMITTEE ACTION

The project has been reviewed by The University of Southern Mississippi Institutional Review Board in accordance with Federal Drug Administration regulations (21 CFR 21, 111), Department of Health and Human Services (45 CFR Part 46), and university guidelines to ensure adherence to the following criteria:

- The risks to subjects are minimized.
- The risks to subjects are reasonable in relation to the anticipated benefits.
- The selection of subjects is equitable.
- Informed consent is adequate and appropriately documented.
- Where appropriate, the research plan makes adequate provisions for monitoring the data collected to ensure the safety of the subjects.
- Where appropriate, there are adequate provisions to protect the privacy of subjects and to maintain the confidentiality of all data.
- Appropriate additional safeguards have been included to protect vulnerable subjects.
- Any unanticipated, serious, or continuing problems encountered regarding risks to subjects must be reported immediately, but not later than 10 days following the event. This should be reported to the IRB Office via the "Adverse Event Report Form".
- If approved, the maximum period of approval is limited to twelve months. Projects that exceed this period must submit an application for renewal or continuation.

PROTOCOL NUMBER: 17000802
PROJECT TITLE: Social Support and Responsiveness: Improving Osiomates' Health-Related Quality of Life
PROJECT TYPE: New Project
RESEARCHER(S): Carrie Reif
COLLEGE/DIVISION: College of Arts and Letters
DEPARTMENT: Communication Studies
FUNDING AGENCY/SPONSOR: N/A
IRB COMMITTEE ACTION: Exempt Review Approval
PERIOD OF APPROVAL: 06/15/2017 to 06/14/2018
Lawrence A. Hosman, Ph.D.
Institutional Review Board
APPENDIX B - ONLINE RECRUITMENT LETTER

Hello,

My name is Carrie Reif-Stice and I am doctoral candidate at the University of Southern Mississippi with an emphasis in health communication. For my dissertation, I am looking at the role of self-disclosure and social support in helping reduce stigma and improve health-related quality of life for ostomates. With permission from the group moderator, I am seeking participants from the support group to take my survey.

Survey results will be used for my dissertation and shared with the support community. This study is not being funded by medical groups and the survey is completely voluntary. Because the questions cover sensitive information that may cause emotional distress, once started the survey can be stopped. Please understand this survey uses questions/measures from previous nursing studies of ostomy patients. I did not make up the questions and do not have a negative perception of Ostomates.

I appreciate your support in completing this project. My motivations to conduct this research are not only academic, but also personal. My dad is a double ostomate with a colostomy and a permanent nephrostomy.

If you have additional questions, please email me at carrie.reif@usm.edu, or my advisor, steven.venette@usm.edu.

Thanks,
Carrie Reif-Stice
APPENDIX C – PERMISSION LETTER

Dear Participant,

You are invited to participate in a research study entitled: Social support and responsiveness: Improving ostomates’ health-related quality of life. Your input can help increase understanding about how ostomy patients adjust to their device. You were selected as a possible participant in this study because of your affiliation with ostomy support groups.

You must be 18 or older to participate in this study. If you decide to participate, please take 15-20 minutes to complete the following electronic questionnaire. No tangible benefits accrue to you for answering the survey questions, but your responses will be used as a guide to help family members and friends provide appropriate social support. Any discomfort or inconvenience to you derives only from the amount of time taken to complete the survey.

Your participation in this research project is completely voluntary. Please read the IRB consent form before completing the survey. By agreeing to conditions and completing this survey, indicates voluntary consent to participate in this study. The information gained from this survey will be reported as group data only, and at no time will your name be identified with any response. All research data will be stored in a locked file cabinet and electronic data will be password protected.

If you have any questions about the study, please contact either Carrie Reif (carrie.reif@usm.edu) or Dr. Steven Venette (steven.venette@usm.edu). Any questions regarding your rights as a research subject, please contact the IRB (irb@usm.edu)

You can return the survey to the table or mail to:
Carrie Reif
118 College Dr. Box #5131
Hattiesburg, MS 39406
Thank you for your time.

Thanks,
Carrie Reif
## Section 1: Uncertainty

This section presents several statements regarding uncertainty related to your ostomy. Select the response that most closely reflects your level of agreement (or disagreement) with each statement.

<table>
<thead>
<tr>
<th>Statement</th>
<th>Strongly agree</th>
<th>Somewhat agree</th>
<th>Neither agree nor disagree</th>
<th>Somewhat disagree</th>
<th>Strongly Disagree</th>
</tr>
</thead>
<tbody>
<tr>
<td>I have a lot of unanswered question concerning my ostomy.</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>I was unsure if my illness was getting better or worse with my ostomy.</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>It was unclear how bad my pain would be with my ostomy.</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>The explanations they gave about my ostomy seemed hazy to me.</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>The purpose of my ostomy as a treatment is clear to me.</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>When I have pain, I know what this means about my ostomy.</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>I do not know when to expect additional medical procedures related to my ostomy.</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Problems related to my ostomy continue to change unpredictably.</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>I understand everything explained to me about my ostomy.</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>
The doctors have said things to me about my ostomy that could have many meanings.

My ostomy is too complex to figure out.

It is difficult to know if my ostomy is helping with my illness.

Because of the unpredictability of my ostomy, I cannot plan for the future.

The course of my illness keeps changing, I have good days and bad days with my ostomy.

It’s vague to me how I will manage to care for my ostomy.

I have been given many differing opinions about ostomy care.

Since my ostomy, it is not clear what is going to happen to me.

I usually know if I am going to have a good day or bad day with my ostomy.

The effectiveness of my ostomy is undetermined.

Because of my ostomy, what I can do and cannot do keeps changing.

Since my ostomy, I’m certain they will not find anything else wrong with me.
Ostomy implementation has a known probability of success. 

My physical distress is predictable; I know when it is going to get better or worse. 

I can depend on others to be there when I need them. 

The doctors and nurses use everyday language when discussing my ostomy, so I can understand what they are saying.

**Section 2: Stigma**

This section seeks to uncover your feelings regarding stigma related to your ostomy appliance. Please indicate your level of agreement with each of the items listed below.

<table>
<thead>
<tr>
<th></th>
<th>Strongly agree</th>
<th>Somewhat agree</th>
<th>Neither agree nor disagree</th>
<th>Somewhat disagree</th>
<th>Strongly disagree</th>
</tr>
</thead>
<tbody>
<tr>
<td>Because of my ostomy appliance, I feel left out of activities.</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Because of my ostomy, I feel emotionally distant from other people.</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Because of my ostomy, I worry about other people’s attitudes towards me.</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>I am unhappy about how my ostomy affects my appearance.</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>
Because of my ostomy, it is hard for me to stay neat and clean.

Because of my ostomy, I worry about being a burden to others.

Since my ostomy surgery, I feel embarrassed because of my physical limitations.

Because of my ostomy, I feel different from others.

Since my surgery, I tend to blame myself for my medical problems.

I avoid making new friends to avoid telling others about my ostomy.

Because of ostomy appliance, some people seem uncomfortable with me.

Since my ostomy surgery, some people avoid me.

Because of my ostomy, people are unkind to me.

Because of my ostomy, people make fun of me.

Because of my ostomy, I was treated unfairly by others.

Because of my ostomy people tend to ignore my good points.
Since my ostomy surgery, some people avoid looking at me.  
Some people acted as though it is my fault I have this stoma.

Section 3: Self-Disclosure

In this section, you are asked to reflect on how much you self-disclose about your ostomy to other people (e.g., family member, co-workers, significant others, support groups).

<table>
<thead>
<tr>
<th>How much do you disclose thoughts about your ostomy to others?</th>
<th>Not at all</th>
<th>Very little</th>
<th>Little</th>
<th>A great deal</th>
<th>Very much</th>
</tr>
</thead>
<tbody>
<tr>
<td>How much do you disclose information to others about your ostomy?</td>
<td>Not at all</td>
<td>Very little</td>
<td>Little</td>
<td>A great deal</td>
<td>Very much</td>
</tr>
<tr>
<td>How much do you disclose your feelings concerning your ostomy to others?</td>
<td>Not at all</td>
<td>Very little</td>
<td>Little</td>
<td>A great deal</td>
<td>Very much</td>
</tr>
</tbody>
</table>

Section 4: Responsiveness

In this section, you are asked to reflect on your feelings regarding others’ reactions to your ostomy-specific disclosures.

<table>
<thead>
<tr>
<th>To what degree do you feel accepted by others after self-disclosing about your ostomy?</th>
<th>Not at all</th>
<th>Very Little</th>
<th>Little</th>
<th>A Great Deal</th>
<th>Very Much</th>
</tr>
</thead>
<tbody>
<tr>
<td>To what degree do you feel understood by others when you discuss your ostomy?</td>
<td>Not at all</td>
<td>Very Little</td>
<td>Little</td>
<td>A Great Deal</td>
<td>Very Much</td>
</tr>
</tbody>
</table>
To what degree do you feel cared for by others after you disclose your thoughts about your ostomy?

Section 5: Received Social Support

Below is a list of items that assess the amount of received social support you may, or may not, have received from others. For each item, select a response that closely reflects your level of received social support.

<table>
<thead>
<tr>
<th>Item</th>
<th>Not at all</th>
<th>Once or twice</th>
<th>About once a week</th>
<th>Several times a week</th>
<th>About every day</th>
</tr>
</thead>
<tbody>
<tr>
<td>Other have told you that they feel close to you.</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Someone has let you know that he/she will always be around if you need help.</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>People tell you that you are OK just the way you are.</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>People have expressed interest and concern for your well-being.</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>People have comforted you by showing your some physical affection.</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Someone has told you that he/she would keep things you talk about private.</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>
Section 5: Perceived Social Support

Below is a list of items that assess the amount of perceived social support you may, or may not, have received from others. Choose a response for each item that closely displays your level of received social support.

<table>
<thead>
<tr>
<th>Item</th>
<th>Not at all</th>
<th>Once or twice</th>
<th>About once a week</th>
<th>Several times a week</th>
<th>About every day</th>
</tr>
</thead>
<tbody>
<tr>
<td>There will be a special person who is around in case I am in need.</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>I will have a special person with whom I can share my joys and sorrows.</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>My family will try to help me if I am in need.</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>I will get emotional help and support I need from family.</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>My friends will try to help me.</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>I can count on others when things go wrong.</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>I will be able to talk about my problems with family.</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>I have other people with whom I can share my joys and sorrows.</td>
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<tr>
<td>There will be a special person in my life who will care about my feelings.</td>
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<tr>
<td>My family will be willing to help me make decisions.</td>
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<tr>
<td>I will be able to talk about my problems with other people.</td>
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</tbody>
</table>
Section 6: Coping

In this section, you are asked to determine your ability to cope with stressful issues associated with your ostomy. Select the response that represents your efforts to manage, reduce, or minimize stressors.

<table>
<thead>
<tr>
<th>I’ve been turning to work of other activities to take my mind off things.</th>
<th>I haven’t been doing this at all</th>
<th>I’ve been doing this a little bit</th>
<th>I’ve been doing this a medium amount</th>
<th>I’ve been doing this a lot</th>
</tr>
</thead>
<tbody>
<tr>
<td>I’ve been doing something to think about my stressors less, such as going to movie, watching TV, reading, daydreaming, sleeping, or shopping.</td>
<td></td>
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<tr>
<td>I’ve been concentrating my efforts on doing something about the situation I’m in.</td>
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<tr>
<td>I’ve been taking action to try to make the situation better.</td>
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<tr>
<td>I’ve been saying to myself “this isn’t real.”</td>
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<tr>
<td>I refuse to believe that I have problems.</td>
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<tr>
<td>I’ve been using alcohol or other drugs to make myself feel better.</td>
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<td></td>
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<td></td>
</tr>
<tr>
<td>I’ve been using alcohol or drugs to help me get through it.</td>
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<tr>
<td>I’ve been getting emotional support from others.</td>
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<tr>
<td>I’ve been getting comfort and understanding from someone.</td>
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</tr>
</tbody>
</table>
I’ve been giving up the attempt to cope.
I’ve been saying thing to let my unpleasant feelings escape.
I’ve been expressing my negative feelings.
I’ve been getting help and advice from other people.
I’ve been trying to get advice or help from other people about what to do.
I’ve been trying to see my problems in a different light, to make it seem more positive.
I’ve been looking for something good in what is happening.
I’ve been trying to come up with a strategy about what to do.
I’ve been thinking hard about what steps to take.
I’ve been making jokes about my problems.
I’ve been making fun of the situation.
I’ve been accepting the reality that I have problems.
I’ve been trying to find comfort in my religion or spiritual beliefs.
I’ve been praying or meditating about my problems.
I’ve been criticizing myself.
Section 7: Health-Related Quality of Life

In this section, you are asked to assess your health-related quality of life. Select the response that best represents your physical health.

<table>
<thead>
<tr>
<th>Activity</th>
<th>Yes, limited a lot</th>
<th>Yes, limited a little</th>
<th>No, not limited at all</th>
</tr>
</thead>
<tbody>
<tr>
<td>Cut down the amount of time you spent on work or other activities.</td>
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<tr>
<td>Accomplished less than you would like.</td>
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<tr>
<td>Were limited in the kind of work or other activities</td>
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<tr>
<td>Had difficulty performing work or other activities (for example, it took extra effort).</td>
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<tr>
<td>Didn’t do work other activities as carefully as usual.</td>
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</tbody>
</table>

These questions are about your well-being since your surgery. For each question, please give the answer that best describes your mental well-being.

<table>
<thead>
<tr>
<th>Question</th>
<th>All of the time</th>
<th>Most of the time</th>
<th>A good bit of the time</th>
<th>Some of the time</th>
<th>A little of the time</th>
<th>None of the time</th>
</tr>
</thead>
<tbody>
<tr>
<td>Do you feel full of pep?</td>
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<tr>
<td>Have you been a nervous person?</td>
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<tr>
<td>Have you felt so down in the dumps nothing could cheer you up?</td>
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<tr>
<td>Have you felt calm and peaceful?</td>
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<tr>
<td>Do you have a lot of energy?</td>
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<tr>
<td>Question</td>
<td>Options</td>
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<td>-------------------------------------------------------------------------</td>
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<tr>
<td>Have you felt down hearted and blue?</td>
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<tr>
<td>Do you feel worn out?</td>
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<tr>
<td>Have you been a happy person?</td>
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<tr>
<td>Do you feel tired?</td>
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</tbody>
</table>

In general, would you say your health is:
A. Excellent  
B. Very Good  
C. Good  
D. Fair  
E. Poor

Compared to before your ostomy implementation, how would you rate your health now?
A. Much better than before my stoma  
B. Somewhat better now than before my stoma  
C. About the same as before my stoma  
D. Somewhat worse now than before my stoma  
E. Much worse now than before my stoma

To what extent has your stoma interfered with your normal social activities with family, friends, neighbors, or other groups?
A. Not at all  
B. Slightly  
C. Moderately  
D. Quite a bit  
E. Extremely

Since your surgery how much has your stoma interfered with your work (including both work outside the house and house work)?
A. Not at all  
B. Slightly  
C. Moderately  
D. Quite a bit  
E. Extremely

How much bodily pain associated with your ostomy have you had?
A. None  
B. Very Mild  
C. Moderate  
D. Severe  
E. Very Severe
Section 8: Demographics

What is your age?
A. 18-25
B. 26-35
C. 36-45
D. 46-55
E. 56-65
F. 65 or older

What is your biological sex?
A. Male
B. Female

What type of stoma do you have?
__________________________________________

What medical do you have that required ostomy surgery?
__________________________________________

Where are you most likely to seek support from (e.g. friends, family members, co-workers)?
__________________________________________

How many months or years since your ostomy surgery?
__________________________________________

Additional Comments:
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