

ABSTRACT

HUGHES, STEPHANIE LINDSEY. An Exploration of How Individuals with an Ostomy Communicatively Manage Uncertainty. (Under the direction of Dr. Lynsey Romo).

Individuals with an ostomy (a surgical diversion of part of the digestive tract through the abdomen) face a variety of uncertainties, due to the chronic and anatomy-altering nature of living with one, as well as the perceived stigma attached to having an ostomy. However, little is known about how these individuals manage uncertainty, despite the psychological impact uncertainty can have. Thus, through 21 semi-structured interviews of individuals with an ostomy and the use of Uncertainty Management Theory as a theoretical framework, the current study found individuals with an ostomy employed a range of management strategies, opting in different situations to maintain, reduce, or adapt to uncertainty. The study recommends practical applications for medical professionals, as well as individuals with an ostomy and their support systems to facilitate better uncertainty management.

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An Exploration of How Individuals with an Ostomy Communicatively Manage Uncertainty

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DEDICATION

I dedicate this thesis to everyone who has lived with an ostomy. Those who have remained strong in the face of this life-changing experience have inspired me and helped me find my own strength to carry on and to continue to seek out the positives. Even those who have struggled since their surgery daily prove their resolve and remind me not to give up, even when times are difficult.

BIOGRAPHY

Stephanie Hughes began studying communication during her undergraduate experience at the University of North Carolina at Chapel Hill. Her interests moved toward interpersonal health communication following colorectal surgery and ostomy-placement in 2012, specifically communication among others who had been through the same or a similar surgery. These interests incited her roles as a health advocate and blogger who discusses topics of living with an ostomy. They further prompted her enrollment in the Master of Science in Communication program at North Carolina State University in 2013. Mrs. Hughes' graduate experience during her four years at North Carolina State University has deepened her understanding of communication theory and its application in the interpersonal health context. She plans to use this knowledge to influence and advance her advocacy.

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Introduction

Uncertainty is a natural occurrence for people living with a health issue (Mishel, 1988), particularly for those with a chronic or anatomy-altering condition, such as living with an ostomy (a surgical diversion of part of the digestive tract through the abdomen).

Uncertainty in illness is defined as “the inability to determine the meaning of illness-related events,” and learning to manage this uncertainty is often central to the coping process (Mishel, 1988, p. 225). Uncertainty exists for individuals living with an ostomy (Tao, Songwathana, Isaramalai, & Zhang, 2013), but little is known about how these individuals manage this uncertainty. Understanding how they manage uncertainty is essential in combatting the negative psychological impact having ostomy surgery can have on an individual (Wade, 1990; White & Hunt, 1997). Furthermore, some people refuse ostomy surgery due to reasons that include vanity, depression, and fatalism (Black, 2004; Pabst Battin, 1983), despite the fact that the surgery can be a life-saving operation, or at least may greatly improve an individual’s quality of life (Druss, O’Connor, Prudden, & Stern, 1968; Pittman, 2011). Understanding their uncertainty management processes can potentially prevent others from refusing a surgery that could better or even save their lives.

Previous research on those with an ostomy focused on active coping strategies to reduce uncertainty (Kelly, 1991; Reynaud & Meeker, 2002; Tao et al., 2013), rather than a more comprehensive view of uncertainty management strategies. Brashers’ (2001) Uncertainty Management Theory (UMT) urges the importance of not only considering attempts at reducing uncertainty, but maintaining and increasing uncertainty, as well. After all, not everyone may view uncertainty negatively (Brashers, 2001). Using UMT as a

theoretical framework, the current study seeks to more fully understand the management strategies used by individuals with an ostomy, in order to help individuals better navigate the uncertainties they experience and equip health care providers to better treat their patients.

In this paper, I will first discuss the uncertainties present for those living with an ostomy and the coping strategies previously reported in the literature, before overviewing Uncertainty Management Theory, describing the study's methodology, presenting the results of this investigation, and discussing its practical applications.

Uncertainties Faced by Individuals with an Ostomy

Before exploring the uncertainty management techniques employed by individuals with an ostomy, it is important to understand what an ostomy is, why an individual may need one, and what uncertainties he or she might face. An ostomy is a surgically created opening through which feces or urine leaves the body. An ostomy bag is worn over the opening to catch the waste and is emptied by the individual (Kelly, 1992; UOAA, n.d.). There are three main types of ostomies: A colostomy is formed from part of the colon; an ileostomy is formed by part of the small intestine or ileum; and a urostomy is formed from the urethra. Reasons for needing an ostomy are varied, and can include inflammatory bowel disease (IBD); colon, rectal or bladder cancer; diverticulitis; congenital anomalies and conditions; and, traumatic injury to the colon, small intestine, or bladder (Maydick, 2014; UOAA, n.d.).

Individuals who receive an ostomy must manage the psychological impact from the surgery, as well as struggle with the inherent uncertainty (Honkala & Berterö, 2009; Turnbull, 2005; Wade, 1990). Although generally this uncertainty is consistent with the uncertainty present for individuals living with any health issue (Mishel 1988; Mishel 1990),

those living with an ostomy face specific uncertainties. Various studies have examined individuals with an ostomy's concerns, struggles, experiences, and psychological adjustment, including anxiety about daily care and physical limitations, struggling with body image, and being unsure how to disclose its existence to others due to fear of how those others will react (Honkala & Berterö, 2009; Nicholas et al., 2008; Shipes, 1987).

Existing research indicated that many individuals felt uncertain about daily care of the ostomy bag and the physical limitations that may accompany wearing a bag. Specific concerns included learning how to change the ostomy appliance, whether or not they would be able to take part in physical exercise, eat certain foods, or maintain their position at work (Honkala & Berterö, 2009; Martins et al., 2015). Some felt the need to avoid traveling with the bag since they were not sure how to handle the bag filling up quickly or a potential leak (Honkala & Berterö, 2009; Nicholas et al., 2008; Savard & Woodgate, 2009). Leaks were one of the most commonly reported sources of anxiety in regards to the daily care of the ostomy, as many felt stressed about the possibility of one occurring, leading them to be anxious about going out in public (Honkala & Berterö, 2009; Nicholas et al., 2008; White & Hunt, 1997). Individuals found the initial days after surgery to be difficult as they learned how to care for the bag and how to deal with any issues that may arise (Nicholas et al., 2008).

Body image was also frequently reported as an uncertainty, as patients had difficulty accepting their altered body, as well as felt concerned about how others would view them (Honkala & Berterö, 2009; Nicholas et al., 2008). Shipes (1987) iterates how a change in body image is usually gradual and, therefore, an individual has time to adjust to their new body; however, receiving an ostomy provokes an abrupt change in body image, which often

necessitates a lengthy process to come to acceptance of the new body. Individuals with an ostomy often abstain from intimacy with another person due to fear of how the other individual will react (Savard & Woodgate, 2009; Turnbull, 2006).

Similarly, the thought of telling others about their ostomy caused many people to feel embarrassed and afraid of being judged by their peers, due to the stigma placed on those with an ostomy (Honkala & Berterö, 2009; Nicholas et al., 2008; Savard & Woodgate, 2009). The stigma surrounding ostomies often centers on the perception that it is odorous; the ostomy being considered “gross” or dirty; the individual being disabled; the taboo of bodily functions, specifically involving feces, not being socially acceptable; and finally, the notion of simply no longer being “normal” (Briggs, Plant, & Devlin, 1977; Norton, 2004; Sinclair, 2009). An ostomy is most often concealable from others, but there is ongoing uncertainty of whether or not individuals will be able to keep the bag concealed, especially when a situation arises in which they are unable to keep it hidden, such as in a group changing room or during sexual intimacy. After all, “The tension between private self and public identity is [...] a central fact of life for the ileostomist” (Kelly, 1992, p. 391). On the one hand, individuals may desire to keep the ostomy bag private, as shown in several studies where the participants felt the need to change their wardrobe or to avoid swimwear in order to keep the bag concealed (Honkala & Berterö, 2009; Savard & Woodgate, 2009); alternatively, individuals concealing an integral part of themselves may experience negative feelings by not revealing their true self (Bosson, Weaver & Prewitt-Freilino, 2012; Kelly, 1992). The uncertainty of being able to keep the ostomy concealed and the potential for a negative reaction from others

may lead these individuals to feel a conflict of not revealing an important aspect of their lives.

Coping Strategies for Living with an Ostomy

Due to these uncertainties and the psychological impact they often have on the individual, previous research has considered ways to alleviate these uncertainties and found that information, including both social support and education, is an important part of the process (Carlsson et al., 2010; Nicholas et al., 2008; O'Connor, 2005). However, in line with UMT, situations must also be considered in which the individual does not desire to reduce their uncertainty and, therefore, may not find information or support beneficial (Brashers, 2001).

Social support can help improve the psychological and even physical health of an individual by providing opportunities for validation, ventilation, and instrumental or informational support, specifically when given without stigmatization or rejection (Brashers, Neidig & Goldsmith, 2004; Uchino, 2009). In those with an ostomy, social support advanced individuals' coping abilities and reduced uncertainty following surgery (Carlsson, et al., 2010; Nicholas et al., 2008; Sinclair, 2009). Although access to supportive others is important, social support can also lead to challenges, such as creating uncertainty regarding stigma and impression management (Brashers, Neidig & Goldsmith, 2004). This concern of a potentially negative reaction from others may supersede the desire for social support (Bosson, Weaver & Prewitt-Freilino, 2012; Martins et al., 2015; Savard & Woodgate, 2009), thus depriving these individuals of the benefits that may come from having those supportive others in their life (Brashers, Neidig & Goldsmith, 2004).

Similarly, education received both pre- and postoperatively has been shown to benefit the patient's long-term psychological adjustment and perceived quality of life (Bekkers, van Knippenberg, van den Borne, & van Berge-Henegouwen, 1996; O'Connor, 2005; White & Hunt, 1997). Living with an ostomy provides a unique situation since much of the uncertainty involves the logistics of daily care, but these uncertainties may be lessened over time as the individual learns the skills needed to care for the ostomy and behaviors that may help avoid complications (Bekkers et al., 1996; Maydick, 2014; O'Connor, 2005). However, difficulties may occur when there is a lack of available information or when an individual finds conflicting information from multiple sources (Brashers, 2001; Brashers et al., 2000). Previous research points to an information deficit for individuals undergoing ostomy surgery, often due to shortened hospital stays and a lack of preoperative education (Colwell & Gray, 2007; Walker & Lachman, 2013), but research has not specifically looked at how individuals obtain or process the information they are given or how they utilize it in managing their uncertainty. Future research must move beyond simply viewing information seeking as the appropriate response to uncertainty for those living with an ostomy and also consider the role that information maintenance and avoidance plays in that response.

Uncertainty Management Theory

Uncertainty in illness has garnered much attention in other illness contexts, with much of the research focused on uncertainty reduction. More recently, research has broadened to include the concept of managing one's uncertainty, which may include reducing, maintaining, or even increasing one's uncertainty (Babrow & Kline, 2000; Brashers, Goldsmith, & Hsieh, 2002; Case, Andrews, Johnson, & Allard, 2005). Brashers'

(2001) Uncertainty Management Theory (UMT) encourages a reconceptualization of uncertainty as inherently neutral, rather than assuming it to be a negative entity; thus, giving it the potential to lead to a range of emotional responses, including hope, anxiety, or indifference (Brashers, 2001; Mishel, 1988).

In Brashers, Neidig and Goldsmith's (2004) study of individuals living with HIV or AIDS, the authors argue, "people seek or avoid information to manipulate uncertainty to a comfortable level" (p. 306). When uncertainty is assumed to be negative, information seeking is seen as the logical response; however, when uncertainty is considered neutral, information has the potential to reduce, increase, or transform uncertainty, depending on the nature of the uncertainty and the characteristics of the individual (Barbour, Rintamaki, Ramsey, & Brashers, 2012; Brashers, 2001). Brashers, Goldsmith, and Hsieh (2002) define information as "stimuli from a person's environment that contribute to his or her knowledge or beliefs"; it may include research or social support and may come from healthcare providers, friends, social networks, others living with the same condition, or the media (p. 259). Although in some circumstances information can benefit an individual, such as by providing understanding of his or her treatment plan or prognosis, there are times it can be detrimental by overwhelming the individual or providing negative information, in which cases avoidance of the information may ultimately be more helpful (Barbour et al., 2012). Therefore, an individual must manage their uncertainty by determining whether to seek out or avoid information; learning to adapt to long-term uncertainty; building a social support network of health care providers, loved ones, and peers; and, coping with information problems through self-advocacy (Brashers, Neidig & Goldsmith, 2004; Mishel, 1988).

Brashers (2001) also notes that an individual's relationship with uncertainty has the potential to adapt over time, specifically when dealing with a chronic condition. Because of the chronic nature of some conditions, uncertainties that were once appraised negatively can ultimately be viewed positively, and vice versa. More research must be conducted that neither assumes uncertainty is a fundamentally negative concept, nor that all individuals have a desire to seek out more information regarding their health (Barbour et al., 2012; Case et al., 2005).

Expanding on Uncertainty Management Theory

In order to expand on previous work, research must continue to focus on a variety of conditions, with differing symptoms, prognoses, and experiences (Barbour et al., 2012). Afifi and Matsunaga (2008) address the need to expand uncertainty beyond the focus on life-threatening illnesses, such as HIV, which has garnered much of the previous research on uncertainty in illness. In addition to HIV, previous research has mainly considered illnesses that are diagnosed, such as cancer (Hope-Stone, Brown, Heimann, Damato, & Salmon, 2015) and HPV (Kosenko, Harvey-Knowles, & Hurley, 2014), but not health conditions that are the result of surgical procedures.

UMT offers an opportunity to gain understanding into how individuals living with an ostomy manage their uncertainty. Reciprocally, studying those with an ostomy can contribute to the body of research on UMT by offering a differing perspective than much of the former research, which has focused on conditions that are internal to the body and are acquired unwittingly by the individual. This study of individuals living with an ostomy considers a new illness context—one that is not only external to the body, but is created via surgical

procedure that must be approved by the individual (Kelly, 1991; Pabst Battin, 1983). Based on this framework, the following research question will be explored:

RQ1: How do individuals with an ostomy communicatively manage uncertainty?

Method

During the fall of 2016, individuals who have or have had an ostomy participated in semi-structured, in-depth interviews to discuss their experience living with an ostomy. I recruited participants through referrals from wound ostomy continence nurses and through online postings on social media channels. No incentives were provided.

Participants

After receiving approval from my university's international review board, I interviewed 21 individuals who had been through ostomy surgery. Seventeen (81%) of participants had an ileostomy, two (9.5%) had a colostomy, one (4.8%) had a colostomy and later an ileostomy, and one (4.8%) had a urostomy. Fourteen (67%) participants had a permanent ostomy, three (14%) had temporary ostomies, although two said their ostomy would become permanent eventually, and four (19%) had previously had their ostomies reversed, although one was scheduled to have surgery for a second ostomy. Twelve (57%) participants had an ostomy as a result of inflammatory bowel disease, six (29%) due to cancer (two colon, one rectal, one colon and rectal, one bladder, one anal), one (4.8%) due to cloacal exstrophy, one (4.8%) due to severe constipation, and one (4.8%) due to an intestinal perforation. Participants underwent ostomy surgery between the ages of 1 month and 60 years ($M = 37.09$ years, $SD = 15.73$). At the time of the interviews, participants had lived with an ostomy between 3 months and 37 years ($M = 3.97$ years, $SD = 8.06$). Eighty-one

percent ($n = 17$) of the participants were female and ranged in age from 21 to 63 ($M = 43.95$, $SD = 12.54$). Twenty (95%) participants self-identified as white/Caucasian and one (4.8%) self-identified as American Indian/Alaskan Native. All participants had completed some higher education; 85% had a bachelor's degree, and 50% had an advanced degree. One participant declined to provide ethnic and educational information.

Procedure

Interview length ranged from 19 minutes to 126 minutes ($M = 42$ minutes), not including initial introductions and time to complete a demographic questionnaire, which was emailed to participants following the interview. Twenty interviews occurred over the phone due to participant schedules and locations; one interview took place in person. After receiving participant consent, interviews were audio recorded for transcription and analysis. I took field notes during the interview, as well. Prior to transcription, I assigned all participants a pseudonym in order to protect their privacy.

Instruments and analysis

I conducted the interviews with a set of standardized research questions (see Appendix A) that first asked about how the participant came to have an ostomy. Subsequent questions focused on the individual's view of living with an ostomy and the uncertainties and fears they experienced during that time. I then initiated a discussion of where these individuals went to receive more information on both the ostomy surgery and life following it. Finally, the interview focused on disclosure of having an ostomy and what impact it had on their uncertainties. I asked follow up questions when appropriate to yield further data.

I began transcribing the interviews and analyzing the data concurrently with conducting other interviews in order to determine once the data was producing no new insights and saturation had been reached (Cohen, Manion, & Morrison, 2007). Using Brashers' (2001) Uncertainty Management Theory as a theoretical framework, I examined the data using thematic analysis in order to identify preliminary patterns (Braun & Clark, 2006). Through open coding of the data, I identified the general strategies participants reported using in order to manage their uncertainty (e.g. one-way information seeking; two-way communication). I next used axial coding to refocus these preliminary themes into larger, overarching patterns, as well as breaking them down into more nuanced subthemes (Corbin & Strauss, 1990; e.g. receiving information from medical professionals; speaking to others with an ostomy; avoiding information). I continued to refine the themes according to the patterns that emerged (e.g. seeking information; seeking social support; adapting to chronic uncertainty), employing in-vivo coding to support these themes. Once I identified the final themes, I performed a member check by contacting each of the participants to learn if they would corroborate the themes pulled from the data. Fourteen participants (67% of interviewees) responded and indicated the findings were consistent with their experiences.

Results

I found a wide range of strategies used to manage uncertainty. Among participants in this study, uncertainty was almost exclusively seen as a negative entity and, therefore, the most common response was to attempt to reduce that uncertainty through a variety of means, including seeking out information and social support. However, alongside an active attempt at reducing uncertainty, some participants managed their chronic uncertainty through gradual

adaptation and acceptance. A few individuals felt the need to maintain uncertainty in specific situations by initially ignoring their need for surgery and desiring to maintain uncertainty in regards to the reactions of others.

Maintaining Uncertainty

Among participants in this study, no one acknowledged an active desire to maintain all uncertainty; however, some participants reported maintaining uncertainty in particular situations, specifically through initially ignoring the reality of needing an ostomy and then via ongoing avoidance of disclosure of their ostomy to others.

Ignoring the reality of needing an ostomy. A few participants said they avoided thinking about or learning more about ostomies before surgery in an attempt to ignore their need for an ostomy. These individuals preferred to remain uncertain in regards to their current health situation, rather than accept the certainty of living with an ostomy. Carolyn, 63 (had a permanent colostomy due to anal cancer), explained that, prior to surgery, she preferred to maintain her uncertainty about what living with an ostomy would entail:

I think during that first six weeks when I was on chemo, I was a little bit in denial at that point. [...] I don't think I looked at living with an ostomy until afterwards. It's kind of a, "If I don't look it up, maybe it won't happen."

Some participants attempted to delay having surgery by trying other medications for a period of time. In doing so, they maintained uncertainty about whether or not they would eventually require surgery, rather than be certain about their future of living with an ostomy. Thomas, 32 (had a permanent ileostomy due to IBD), said: "We tried new drugs [...] wanted to see if maybe that would help with the inflammation itself. [...] So it took me three or four months

to finally come to grips with.” Participants eventually came to a point where their health had deteriorated and they could no longer deny their need for surgery, or they realized they would rather have control over the situation than risk the chance of needing to have emergency surgery. Thomas would later explain: “I just kind of came to grips with the fact that it was going to happen sooner or later. [...] I didn’t want it to be an emergency surgery. So it wasn’t like a, ‘Hey, we need to do this now, you don’t have a choice.’” All participants who admitted to initially avoiding the reality of needing an ostomy did eventually acknowledge their need for surgery and would later seek out other ways to reduce their uncertainty.

Avoiding disclosure. A few participants reported maintaining uncertainty about how others would respond to learning they had an ostomy. In these instances, the participants avoided telling others about their surgery due to the uncertainty of how others would react. Linda, 49 (had a permanent ileostomy for 17 years), said: “I would not want to go public with this information, again because I do think that generally there would be misunderstanding and discrimination.” She would later admit: “By not talking I have ensured that there hasn’t been any repercussions from other people.” In these instances, the participant preferred to maintain uncertainty about how the other individual would respond to their disclosure, rather than risking the potential certainty of the other person responding negatively. Those individuals who wished to avoid disclosing to others about their ostomy did seek out other ways to reduce their uncertainty about living with an ostomy.

Reducing Uncertainty

All participants acknowledged employing some sort of communication strategy to reduce their uncertainty of living with an ostomy at some point in their experience. They

commonly sought information, gained social support, and attempted to destigmatize ostomies by educating others in order to reduce their uncertainty.

Seeking information. Participants sought to reduce their uncertainty by seeking out more information; this was especially true for those who acknowledged they knew very little about ostomies before their surgery. For instance, Tammy, 44 (had what would become a permanent ileostomy due to IBD), when asked what she knew about ostomies at the time she was first told she would need one, responded: “Nothing. I didn’t know anything about it. Really, I didn’t know a thing and that’s why I had to do so much research.” Participants used different methods of seeking information, including speaking with medical professionals and reading online or print materials.

Speaking to medical professionals. Most participants obtained initial information on ostomies from their medical team, including their surgeons and dedicated wound ostomy continence (WOC) nurses, consistent with previous research looking at where individuals find their health information (Brashers, Haas, Neidig, & Rintamaki, 2002; Fox & Duggan, 2013; Massey, 2016). For those with little or no knowledge about ostomies, medical professionals provided the first glimpse of what having ostomy surgery would entail, as well as how it would affect their lives going forward. Linda (had a permanent ileostomy due to IBD) said:

Really it was that day in the hospital room where I was lying there and the colorectal surgeons came in and said, “Here’s the situation and here’s what I think is, that needs to happen,” and he explained the surgery to me. From there they had a wound and ostomy nurse come in and explain to me more

about an ostomy, where it is, how it works, so on and so forth. So, it was really when I was in the hospital that I learned about it.

Many participants mentioned the benefit of relying on a dedicated ostomy nurse to help them learn how to care for the appliance and provide encouragement for the life after surgery.

Jason, 47 (had a permanent colostomy due to rectal cancer), shared how the WOC nurses helped him learn to care for his ostomy: “They showed me the first day, I helped them the next day and I did it myself the third day, of how to change out the appliance and, you know, cut the hole for the stoma and all of that stuff.” Indeed, significant research points to the important role medical professionals, specifically WOC nurses, play in the pre- and postoperative care of ostomy patients (Bass et al., 1997; Haugen, Bliss, & Savik, 2006).

Reading literature. Participants also looked to other methods for seeking information on what an ostomy was and what life was like with one. Most participants reported going online at some point to find information on ostomies, consistent with research that shows the majority of U.S. adult internet users turn online to find health information (Fox & Duggan, 2013). Jennifer, 48 (had a permanent ileostomy due to IBD), said she did a lot of research before her surgery to understand her options: “I actually had my laptop with me in the hospital and I did a lot of research to make sure that I was comfortable with that suggestion, that the surgery really was my best and, probably at that point, my only option.” Outside of online research, some participants accessed books written about ostomies and read through the informational materials they were given at the hospital.

When asked what prompted them to seek out information, participants reported a desire to feel more certain in their decisions and in their ability to move forward after surgery

and live their lives. Jennifer said: “My nature is that I feel more empowered the more informed I am. And it helped me feel more confident about the choices I ultimately had to make about having the surgery and then living with an ileostomy.” Other interviewees specifically mentioned the uncertainties as a catalyst for seeking information. For instance, as Thomas explained: “Just the fear of the unknown. Like not knowing what, going into something not knowing what it would be like afterwards. I wanted to make sure that I didn’t have to change my lifestyle a whole lot to accommodate this procedure.” In fact, previous research has urged the importance of having information and training available to the individual before and following ostomy surgery, in order to help them move forward and regain their quality of life (O’Connor, 2005; Richbourg, Thorpe & Rapp, 2007).

Seeking social support. Although education and information can be valuable resources for individuals with an ostomy, significant benefits come from social support, including from those who have been through a similar situation (Peterson, Rintamaki, Brashers, Goldsmith, & Neidig, 2002) and from a close-knit support system (Uchino, 2009). Study participants sought out, accepted, and provided social support in a number of different ways, specifically by connecting to others with an ostomy for camaraderie, as well as for the opportunity to help others. Participants also relied on their family and friends for support and to not feel the stress from keeping their ostomy a secret.

Connecting to others with an ostomy. Many participants actively sought out others living with an ostomy in order to obtain advice, to feel they were not alone, and to receive and provide support through shared experience. Robin, 54 (had a permanent urostomy due to bladder cancer), was given the contact information for a WOC nurse who also had a

urostomy: “She gave me some websites and some different pouch brands. She was a wealth of knowledge. [...] That was the best thing ever to talk to somebody who actually was living it.” Like Robin, some participants connected with others with an ostomy in a one-on-one setting, while others chose to join either an in-person or online group. Carolyn explained that joining an in-person support group was one of the most important things she did after her surgery, stating: “That support group has helped to alleviate probably every fear or every uncertainty that I had.” Some participants pointed out that by going online, they were given the ability to find quick answers to questions that are not always answered by medical professionals, or that may be uncomfortable to ask someone in person. Denise, 59 (had a permanent ileostomy due to IBD), said about visiting online support groups:

I get real facts of what people are going through. [...] The Facebook groups, those are people that wear them, and they know. [...] I’ve found out how to travel with an ostomy. You find out how to have sex with an ostomy. You find out everything. Because you don’t get that from the nurses. The doctors don’t tell you that.

Several participants mentioned how knowing they were not alone helped them deal with the uncertainty of living with an ostomy. When asked why he decided to join a support group, Thomas responded: “Just to see that other people have gone through what I’ve gone through. Like just to know that I’m not by myself.”

Being in contact with others with an ostomy also gave many participants the opportunity to share their stories with others going through a similar experience. This allowed them the opportunity to not only be open about their experience in a judgment-free

setting, but to give back and to offer reassurance and advice to others, in the same way some of them had received that support early in their experience. This finding is consistent with increasing research that shows the positive impact of giving support to others with the same health condition, which at times may be even more beneficial than receiving support, by reducing feeling indebted to others who have helped them, and also by promoting feelings of control and self-esteem (Schwartz & Sendor, 1999; Warner, Schüz, Wurm, Ziegelmann, & Tesch-Romer, 2010). Participants said that sharing their stories helped them reduce their uncertainty by keeping a positive energy about living with an ostomy, making them feel they could be helpful and give back, and giving them a purpose for having an ostomy. Jennifer said:

I think that just letting people know, “Hey, I’ve been through this, I’ve successfully navigated the uncertainties,” gives people confidence to know what to say and what to do and give them that reassurance that their lives will change somewhat, but it’s just a really small facet of your bigger life. You’re not defined by an ostomy.

For participants who did not receive support during the time of their surgery, sharing their experience was a way to give to others what they had not received themselves. April, 35 (had her second and permanent ileostomy due to IBD), said: “I feel like by doing it, I’m talking to younger me who was so afraid and didn’t even know what they were. I really try and just bridge that gap because she didn’t have that, and so I like to be that for other people.” Susan, 45 (previously had an ileostomy due to IBD and was scheduled to receive a second one following the interview), explained that being able to help others made her feel that what she

had gone through was worth it: “I kind of feel like everything happens for a reason. And you know maybe this was my reason. If I can help just one person, then I’ve done my job.”

Sharing with family and friends. Outside of sharing with a group of individuals who had been through the same experience, receiving support from friends and close family was an important aspect for all participants in this study, as significant uncertainty centered on how others would react and whether or not they would be treated differently post ostomy. Despite the risk of non-acceptance, all participants had a trusted group, either large or small, whom they had told about their ostomy. By sharing with this group, they were able to reduce the uncertainty regarding others’ responses and gain the benefits that come from social support. Morgan, 21 (had a permanent ileostomy due to complications from severe constipation), explained that sharing her experience with others helped her feel that she would not be judged: “Because then I know I talk to them and then they can understand why I have it, and they won’t judge me for the reason I have it or anything. And it makes it better to deal with it.” Several participants said they received supportive messages and comments not only from friends and family after sharing about their surgery. Cindy (had a temporary ileostomy for 15 months) said:

One of the things that I did after my initial shock wore off was announce it on my Facebook page. [...] In bringing that out in the open to them, I felt like it opened up a lot of the communication for us to be able to talk about it. It was basically a really positive experience; I got a lot of support from it.

Chelsea, 21 (had a permanent ileostomy due to IBD), said she felt better being open about her ostomy with her friends: “I think keeping it private would be hard. Having no one to talk

to or vent. Like even my friends, I can vent about it or, like I said, joke about it if something, like if I were to have a leak instead of having to keep it bottled in and it's frustrating, I can just tell them and talk about it."

When asked why they wanted to share about their ostomy with others, many participants explained they felt it was better to be open about their surgery and their new way of life, rather than feeling they had to keep it a secret. Being open about living with an ostomy can potentially protect against negative health effects caused by the stress of keeping a major secret (Rodriguez & Kelly, 2006; Slepian, Masicampo, & Ambady, 2014). This is especially pertinent to individuals diagnosed with IBD, as stress is shown to cause adverse outcomes in these individuals (Cámara, Ziegler, Bégé, Schoepfer, & von Känel, 2009); meanwhile, the role of stress and cancer recurrence remains unclear (Todd, Moskowitz, Ottati, & Feuerstein, 2014). Shannon, 37 (had an ostomy since she was 1 month old due to being born with cloacal exstrophy), explained that sharing with those close to her helped her feel more comfortable in the relationship: "It's not the dark secret I have to hide. Once somebody knows that I have it, I can just be open. [...] I don't feel I have to hide something from them." April 35 (had her second and permanent ileostomy due to IBD) described it this way:

Sort of like a 'you're only as sick as your secrets' type of thing, where if you shine a light on something then you scare away the dark. [...] Like if I can talk about it with trusted people then it can't mean that it's, you know, as scary as my brain would like to make it.

Educating others in attempt to reduce stigma. Outside of their inner circle of family and friends, many participants were open to speaking to others about their ostomy as a means of educating them and working to destigmatize the condition. In doing so, participants were able to reduce their uncertainty regarding how others would respond to their ostomy and ensure that others understood what living with an ostomy entails and the positive impact it can have on the lives of those who have one. Tammy (had what would become a permanent ileostomy due to IBD) shared: “There’s such a terrible stigma about ostomies and that they’re dirty, and they’re gross and you smell [...] I let people ask me questions. Because then I can educate them on it, what it is, why I have it.”

Even when participants were not going out of their way to teach people about their ostomy, many found that others were curious and wanted to learn more. Thomas shared this story about telling his coworkers about his ostomy:

They were asking, you know, just what it’s like to have an ostomy, what all I have to do, is there any changes from real life. [...] And it wasn’t that they were judging me, at that point, they just wanted to know more, and that was a good feeling for me.

When asked about sharing about her ostomy with others, Kelly, 34 (had two separate ileostomies due to IBD), responded: “I think it’s important to talk about it because it doesn’t get talked about and then there’s like no education. You know there’s all the stigma and people have no clue what it is and what it’s not.” Jennifer explained how educating others helped her: “If I talk out loud it makes it more real and it helps me accept it. [...] I feel like

everybody who is educated and informed even a little bit, that helps chip away at the stigma just a little bit more.”

Adapting to Chronic Uncertainty

Some participants found the best option to manage ostomy-related uncertainty was simply coming to terms with living with the ostomy on a daily basis. These participants found what several called a “new normal” by managing the ongoing uncertainty of living with an ostomy through the realization that some of their original uncertainties were not as big of an issue as they had thought, through adaptation to life with an ostomy and through finding acceptance in their new life.

Feeling like uncertainty was not an issue. When asked how they dealt with some of the uncertainties they had prior to their surgery, several participants shared that many of the issues resolved themselves. Carolyn said: “After I recovered from all the pain from surgery and all the things, there were, I’d say most of the fears that I had prior, were gone. I can’t think of any of the fears that I continued to have.” Larry, 57 (had a potentially reversible ileostomy due to IBD), had a similar experience: “It has not been as bad as I thought it would be. That the anxiety and fear initially was far worse than the reality.” Most interviewees acknowledged that having the ostomy was not ideal, but recognized that it helped them achieve a more normal life. Jennifer said: “Once I healed and started to gain weight again and everything recovered, it really has been just a mild nuisance. It’s just something I have to deal with, but my life is more or less gone back to normal.”

Regulating one’s self. Many participants dealt with the ongoing uncertainties through self-regulation, incorporating simple trial and error and learning to adapt to a change

in lifestyle to accommodate living with an ostomy bag. These changes included learning what foods to eat or to avoid, keeping ostomy supplies and a change of clothes on hand, altering the way they dressed (e.g. removing form fitting clothing from their wardrobe; no longer wearing a bathing suit in public), and planning ahead to ensure they were always prepared for any uncertainties. A couple of the participants, mostly males, explained that they would rather figure out how to live with an ostomy on their own than to spend time researching. Charles, 41 (previously had an ileostomy due to colorectal cancer), shared: “I don’t think I had many questions. I was probably more, ‘You just give me a little spiel and then I’ll figure it out’ kind of thing for me. [...] It was mostly trail by error to just kind of figure it out.” Larry simply said: “I didn’t think it was that much of an information intensive kind of thing. People have lived with it for hundreds of years now. It’s a change and you adapt to it.”

Finding acceptance. Finally, many participants were able to find acceptance of their life with an ostomy, despite the uncertainties, by altering their view of their ostomy. As Rachel, 38 (previously had a colostomy and later an ileostomy due to colon cancer), said: “[Having an ostomy] can either be a daily or an hourly frustration, or I can just realize that this is [...] just part of my every day now.” Some interviewees felt so much healthier following their surgery that it made dealing with the ostomy easier to accept. April said: “Sometimes that does freak me out, like the fact that this is forever, [...] but for me it’s so worth it with the improvement in my health. And I will continue to be a proud advocate because I never imagined my life could be like this. It’s really exciting.”

Other participants acknowledged that having ostomy surgery likely saved their lives, which led them to accept their new way of life. Jennifer said: “I don’t love having an ostomy, but I recognize that having an ostomy saved my life. And, I guess, I’m very accepting of it. I wouldn’t have chosen this for myself, but I can live with it.” Still others spoke of the positive impact having an ostomy made on their lives and what having one taught them. Cindy said: “What came out of it was something very positive and that was basically for me not to take a day for granted.” And Carolyn put it this way: “I, in retrospect, think God answered my prayers because I, my life was so miserable that this was, I think, heaven-sent in that I had to pull the trigger. For me, I look at my ostomy as the biggest blessing in my life.” By viewing their ostomy as a positive change in their life, individuals were able to manage ongoing uncertainty through acceptance of a new way of life.

Discussion

This study explored the uncertainty management techniques utilized by individuals with an ostomy finding that, depending on how they viewed the uncertainty, participants used communication to maintain, reduce, or adapt to this ambiguity. Uncertainty Management Theory explains that not all uncertainty is appraised negatively, and therefore, there may be instances where individuals prefer to maintain their uncertainty, rather than work to reduce it (Brashers, 2001). In the current study, a few participants reported attempts to ignore the reality of needing an ostomy, and to maintain uncertainty regarding their current health status. Other participants avoided disclosing to others about their ostomy, therefore, maintaining uncertainty about the reactions of others. Indeed, a few interviewees shared how they became more comfortable speaking about their ostomy the longer they lived with it.

Others maintained this lack of disclosure, even after many years.

Even though study participants reported specific situations in which they preferred to remain uncertain, in general, they showed little preference towards actively maintaining uncertainty and no evidence of attempting to increase their uncertainty. This is likely due to the nature of living with an ostomy. For most participants, surgery was a last-resort; although some may have wanted to maintain uncertainty initially, as their health continued to deteriorate, they had no choice but to face the reality of living with an ostomy, realizing they did not want to be forced to undergo emergency surgery. Likewise, once the individual underwent surgery, they had no choice but to acknowledge the physical presence of the ostomy and take part in the daily care and maintenance required. Even if an individual preferred to avoid actively seeking more information on ostomies, they were still likely to reduce their uncertainty simply by having to care for it daily. In this scenario, there was ultimately no option of ignoring their condition.

By far, the most commonly reported strategy for managing uncertainty was seeking out a means to reduce it. Uncertainty was largely appraised negatively, and participants reported a desire to find ways to actively lessen it, which was most often accomplished through communicative means. Participants sought out information, social support, and opportunities to help others and share their stories. These methods helped reduce their uncertainty by finding answers to questions, gaining informational and emotional support, while also challenging the stigma of living with an ostomy through education of others.

The process of actively reducing uncertainty has garnered the most attention in research, with less focus given to how individuals are able to reduce their uncertainty through

adaptation (Babrow & Kline, 2000; Brashers, Neidig, Reynolds, & Haas, 1998; Mishel, 1999). However, participants in the current study revealed the following ways in which they adapted to their uncertainty: realizing the uncertainty was not an issue, learning how to deal with the ostomy, and finding acceptance of their new normal. Through adaptation to the ongoing uncertainty, these individuals were able to more efficiently manage some of the uncertainties they experienced.

Practical Applications

The following practical applications emerged from this study: supplying patients with quality information; appreciating the significant role of social support; encouraging the use of education and disclosure in working to reduce the stigma surrounding ostomies; and understanding an individual's need to turn inward.

This study demonstrates the importance of quality information. Nearly all participants reported doing research online, but with the enormity of information available on the Internet, these individuals may come across resources that are inaccurate or misleading, as the credibility of sources of health information has little or no effect on the individual's perception of the quality of information (Bates, Romina, Ahmed, & Hopsno, 2006). Medical professionals should provide patients with access to reputable, beneficial, and up-to-date information on what having an ostomy entails. This information can come from a variety of sources, including current and easy-to-understand literature, as well as credible websites.

Beyond the need for reliable information, these findings illuminate the importance of ensuring those who undergo ostomy surgery are made aware of the benefits of having a strong support system. This support system should include close family and friends, as well

as peers who have been through a similar experience. Programs do exist at some hospitals that connect individuals with others who are living with an ostomy, but these programs need to expand in order to connect more individuals through their shared experience and provide a safe place for them to seek advice and camaraderie. For those locations where there may not be a network of individuals with an ostomy, providing information about reputable support groups or individuals online can help to bridge the gap.

Family and friends also provide valuable support for individuals going through a life-altering operation such as ostomy surgery (Carlsson, et al., 2010; Nicholas et al., 2008; Sinclair, 2009). Medical professionals, specifically WOC nurses, can encourage individuals to cultivate a supportive group of people to help them not only transition to their new life, but also provide emotional support throughout their experience with an ostomy. It is also important that not only the patient understands the role of social support in managing uncertainty, but that the family understands its importance, as well. The family or close friend support system should be given resources and taught support strategies for helping the patient as they adapt to their new life, including an understanding that more information is not always desired.

As having support without stigmatization was found to be significant in managing uncertainty, there may be some who wish to go a step further and work to actively combat the stigma against ostomies. For those who take this approach, education and preparation is paramount. Many individuals feel uncertain when considering telling others about their ostomy, due to the fear of being stigmatized. The stigma of an ostomy often lies in the perception that it is odorous or dirty, or that the individual is disabled or “not normal”

(Briggs, Plant, & Devlin, 1977; Norton, 2004; Sinclair, 2009). However, these perceptions can be refuted by the use of facts and education and by providing an explanation of what living with an ostomy actually entails. For those who desire to dispel the stigma in this way, it is important they feel communicatively comfortable explaining how their ostomy functions and how it can positively impact one's health. By educating others on the facts of living with an ostomy, these individuals can, in essence, decrease the stigma surrounding ostomies and, in turn, reduce their own uncertainty about living with one. Research shows that education-based (information) and contact-based (personal story) anti-stigma interventions lead to a reduction in personal stigma for mental illness (Kosyluk et al., 2016) and has the potential to apply to such conditions as living with an ostomy. Individuals with an ostomy should be encouraged to educate themselves and to understand the facts of living with an ostomy in order to more easily speak about it with others. In this scenario, the individual with the stigmatized condition is taking the initiative to work to destigmatize ostomies one person at a time, rather than relying on a more formal education initiative.

Many individuals will likely gravitate towards seeking outside information and support to manage their uncertainty, but there will be some who feel the need to turn inward, and manage their uncertainty through internal adaptation. Since these methods of dealing with chronic uncertainty focus on the individual finding ways to adapt on their own, either through self-regulation or a shift in perspective, there is little outside individuals, such as medical professionals and patient support systems, can do beyond encouraging these individuals to remain positive and to find ways to make having an ostomy fit into their daily life. These findings highlight the importance of understanding that not all individuals manage

their uncertainty similarly. Those in a supportive role may feel the desire to help the patient work to reduce their uncertainty, but there will be some individuals who prefer to adapt to the uncertainty and the change in lifestyle, which, in turn, may lead to an eventual reduction in uncertainty, even though some uncertainty may remain indefinitely.

Limitations and Future Directions

Several limitations to this study should be taken into account. First, it should be noted that I have an ostomy and am active in the online ostomy community (I host a blog). I did not mention my ostomy status when recruiting and posted some of the recruitment materials anonymously. I was also careful to not identify myself as having an ostomy during the interview, unless I was asked directly by the participant, in which case I answered briefly and did not go into detail. However, it is possible some of the participants were aware of my having an ostomy prior to the interview, due to my activity among the ostomy community. Therefore, interviewer effects cannot be ruled out (Babbie, 2007). Further, since this study recruited some of its participants through online social media, it is clear these individuals were already involved in some sort of ostomy network, either by belonging to a group or following an ostomy-related page or hashtag, which shows they were not completely avoiding information regarding ostomies. Finally, since participants were asked to contact me in order to set up an interview, their willingness to reach out to a researcher suggests they are more likely to be comfortable living with and speaking about their ostomy in general.

Future research could solely include participants recruited from outside of online channels, ideally directly through a healthcare provider's office, where no outside information or relationships are inherently present. Future studies could also include more

variety in participants, including the reason for needing an ostomy, the type of ostomy, and the length of time living with an ostomy, in order to draw comparisons among groups. Finally, looking specifically at those who have dealt with health complications since receiving an ostomy could provide a valuable comparison to those who have not experienced health complications following ostomy surgery and varying uncertainty management techniques.

Conclusion

This study supports and extends Uncertainty Management Theory (Brashers, 2001) by revealing the complexity in how individuals with an ostomy seek to manage their uncertainty. Some participants preferred to maintain uncertainty in specific situations, but all participants reported taking steps to actively reduce their uncertainty in some capacity; still some preferred a more passive adaptation to the chronic uncertainty. The uniqueness of applying UMT in this study lies in its consideration of individuals who live with an external device that is created via surgical procedure that often must be approved by the individual, and the uncertainty present that could deter them from wanting to move forward with the procedure. By understanding the complex methods used by these individuals to manage their uncertainty, medical professionals, patient support systems, and even the individuals themselves can become better equipped to help them find appropriate ways to deal with the uncertainties that come with living with an ostomy, and potentially move towards a better quality of life.

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APPENDICES

Appendix A

Interview Questions

INITIAL EXPERIENCE & CONCERNS

1. What type of ostomy do you have?
2. What diagnosis or event led to your getting an ostomy?
3. How long had you had that diagnosis / ago had that event occurred before getting an ostomy?
4. Is your ostomy permanent or temporary or reversed?
 - a. If temporary: What plan is in place to take down the ostomy?
 - b. If reversed: Can you tell me a little about the process you went through in getting the ostomy and having it reversed?
5. What was your health like prior to getting an ostomy?
6. How did you learn you would need an ostomy?
7. What was your initial reaction when you learned you would need an ostomy?
8. What actions did you take in response to this?
9. Tell me about the conversation you had with your surgeon prior to surgery.
 - a. If necessary, prompt by asking: Who did most of the talking? Did he/she ask questions of you? Did you ask questions of him/her? Did you receive answers? Were you satisfied with the conversation?
10. Do you feel you were given adequate information prior to your surgery?
11. What did you know about ostomies at the time?
12. Outside of living with one, where has your knowledge about ostomies come from?
13. What uncertainties did you have about getting an ostomy?
14. What did you do about this uncertainty?
15. Were your initial uncertainties more focused on having surgery? Or on life after surgery?
16. How did the uncertainty impact your decision to go through with surgery?

17. Tell me more about your decision to go through with the surgery.
 - a. If necessary, prompt by asking: Was it an immediate decision? Did you put it off for a period of time? Did you try other options beforehand?
18. Tell me about your postoperative hospital stay.
19. Who, if anybody, did you tell about your decision to go through with the surgery?

CURRENT EXPERIENCES AND HANDLING OF INFORMATION

20. What has your health been like since getting your ostomy?
21. To what extent have you found the uncertainty you had prior to your surgery to continue to be an issue after your surgery?
22. Since having your surgery, how do you feel your uncertainty has changed?
23. Specifically now, what uncertainty do you have?
24. What have you done about that uncertainty?
25. What, if anything, have you felt has stopped you from addressing this uncertainty?
26. How do you feel the uncertainty you felt would be different if your ostomy had been / had not been reversible?

These next questions can apply to both before and after your surgery...

27. Have you specifically sought out information about ostomies?
 - a. If YES: How?
 - b. Why?
28. Have you purposefully avoided information about ostomies?
 - a. If YES: How?
 - b. Why?
29. Have you specifically sought out interaction with others who have an ostomy?
 - a. If YES: How?
 - b. Why?
30. Have you specifically avoided interaction with others who have an ostomy?
 - a. If YES: How?

- b. Why?
31. Have you ever been involved in an in-person support group?
 - a. If YES: What made you decide to take part?
 - b. If YES: What do you feel you got out of the group?
 - c. If NO: What made you decide to not take part?
 32. Have you ever been involved in an online support group?
 - a. If YES: What made you decide to take part?
 - b. If YES: What do you feel you got out of the group?
 - c. If NO: What made you decide to not take part?

CONVERSATIONS ABOUT YOUR OSTOMY

33. Are many people in your life aware of your ostomy?
34. Who specifically, if anybody, have you told about your ostomy?
 - a. *If THEY ANSWER: ask below question; if NO ONE: go to next question*
 - b. Who brought up the topic in each situation?
35. What factors influence your decision to tell others or not about your ostomy?
36. How comfortable would you say you are with talking to others about ostomies?
37. How would you respond if someone you had not told about your ostomy pointed it out?
38. Have you had specific conversations about your ostomy with someone who DOES NOT have an ostomy?
 - a. *If YES: ask below questions; if NO: go to next question*
 - b. Tell me about a positive interaction about your ostomy you had with someone who does not have an ostomy.
 - c. Tell me about a negative interaction about your ostomy you had with someone who does not have an ostomy.
39. Have you had specific conversations about your ostomy with someone else who DOES have an ostomy?
 - a. *If YES: ask below questions; if NO: go to next question*

- b. Tell me about a positive interaction about your ostomy you had with someone who does have an ostomy.
 - c. Tell me about a negative interaction about your ostomy you had with someone who does have an ostomy.
40. Have you ever felt looked down on by someone else because of your ostomy?
- a. *If YES:* Tell me about that experience.
41. Have you had an experience where you have wanted to talk about your ostomy, but the other person did not?
- a. *If YES:* Tell me about that experience.
42. Have you had an experience where someone else wanted to talk about your ostomy, but you did not?
- a. *If YES:* Tell me about that experience.
43. Do you feel that talking about your ostomy with others has helped you cope with having an ostomy?
- a. Why / Why not?
44. Do you feel that NOT talking about your ostomy with others has helped you cope?
- a. Why / Why not?
45. Overall, has your experience living with an ostomy been a positive one or negative?
46. What else would you like to add about your experience living with an ostomy?