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A Preliminary Review of Effects of Bladder Integrity (Urinary Incontinence) Following Gender Affirming Surgery in Transwomen: Two Case Studies

Ingrid Van Duyne DHSC, MRC, OTR/L
University of Wisconsin-La Crosse

Abstract

Transwomen narratives about their unique living experiences are an important tool for assisting healthcare workers to better understand how to help these women gain control of their symptoms. No previous type of study could be found that focused on the meaning of transwomen's experience of living with urinary incontinence (UI) from a symptom management perspective or how the gender affirming surgery (GAS) effects bladder integrity or UI. Through a case study of two transwomen a story unfolded: the devastating informative effects of living with UI, dealing with healthcare systems and providers, the patronizing and ineffective informed consents endured to receive care, and missed healthcare issues that were not uncovered by healthcare professionals due to unasked questions on both sides. The gaps in the literature are evident, as are the effects of their transition, aside from the additional medical effects from the surgical process. The aim was to highlight the meaning of transwomen's experience with bladder integrity and potential UI issues following GAS, and to discover if any subsequent bladder issues are routinely addressed by healthcare workers; care-seeking behaviors were explored. The two 60-75 year old informants' experiences were presented in terms of inter-related themes as being in a vulnerable position with UI and striving for adjustment to being transgender while dealing with UI symptomology. UI as a potential side effect of GAS ought to be discussed as part of informed consent prior to surgery. Providers should offer education as to both the potential complications of UI and realistic outcomes prior to GAS.

Keywords: urogenital integrity, gender reassignment surgery, gender confirming surgery, transgender, urinary incontinence, bladder control self-assessment questionnaire

Meet Kai, these words of despair were written as Kai made her next attempt to find a new home and acceptance by an unaccepting society. Her words may help the reader to understand why the 2 informants' in this case study did not ask questions of providers and accepted a less than favorable surgery outcome:

> I cried as the early morning flight gained altitude out of Portland. According to the pilot we were leaving the usual soup and goop of the area. It was not a baleful wailing cry, but more like a few tears welling up at the corners of my eyes. It is hard for me to cry, but today I relived recent agony suffered at the hands of those I work with. As I headed east toward a new job opportunity, I reflected on the last two and a half years of my life in Oregon. They have been anything but happy - they should have been. I could never have imagined that dismissive slights and gawking gazes imparted by unthinking and uncaring strangers and fellow hospital employees could eviscerate so easily and lay me out like an old shag carpet.
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> In 2016, while living in Oregon I opted to reclaim my gender identity that I forfeited in 2011 for a traditional church marriage in Texas. I met a gender-blind woman in 2010 who believed in me and accepted my hybrid identity. How could I not be with her? Marriage equality was still but a dream for millions of Americans. So, in 2011, I returned to my male birth gender even though important characteristics of that gender were now missing. My first attempt at acceptance as one of feminine persuasion in 2005, even after a complete surgical, cosmetic, and hormonal transformation, was pretty much a failure, so what did I have to lose - especially knowing that I would be with the woman of my dreams. My life as Kai suffered only loss, and as an old boss had plainly told me, "That dog will never hunt." He was right. I would surely be further ahead and more pleasing to my neighbors if I gave up on the silly charade. As 2016 wore on, my gender assigned at birth could not thrive and sustain itself - even after a second try. There was clearly some nature thing at work as my internal gender compass would not line up properly - it was busted.
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> Unlike my first gender change metamorphosis in 2005 that started in the great state of Texas, I thought that the blueness and friendlier legal language of Oregon would have forecast a prettier picture for my second go around with a gender swap. How wrong was I. People are pretty much the same whether they are from red states or blue states. The last 30 months of my life in a quasi-liberal blue college town have hardened me into a numb, and repressed shell that only exists. I have come to regard my job as a daily struggle to survive the enemy's camp. I have raised my voice, sought to patiently educate and forgive the thoughtless utterings, personal slights, and gossip of my co-workers.
>
> Alas, I have given up on my current work family. The

barbs have been too numerous and deep, and they have persisted for too long. I am not sure which is worse, smug indifference, being tolerated, casual thoughtless dismissiveness or blatant and undeniable discrimination. We all like labels, especially if we can gleefully hang them around the neck of someone else. Society likes to describe me as transgender. I hate that word as it is dismissive and pejorative. It invites a brand of harsh judgement that trashes and guts the very soul. The label certainly allowed others the opportunity to inflict a fair share of hurts on me, and our current polarized political climate only encourages injurious assaults. On paper we would probably all agree that being overly judgmental and hypercritical of others is not a good thing, and we would find unity in agreement that a smile beats a fist to the face any day.

As this jet speeds through the air I know that my life is still less than and that the very people who should know better still do not. My heart was sad today as I reflected back on my last day of my stretch of seven on, seven off shifts. The stinging pronoun of "he" slammed into me once again. Reading that nurses note from Sunday that referenced me as a "he" harshly grabbed at my very being. Really? The window into her subconscious of prejudice and animus was clear and sad. She pretended to be politically correct, but her true brain thought revealed her reality as it pertained to what she thinks of me. She is representative of many of her work mates. I can only hope that a new beginning in a new state will allow me to feel something besides sadness.

I am a person like anyone else - full of life, dreams, and humanity. I bleed, hurt, laugh, and cry like anyone else. But because I am seen merely as a derisive word, transgender, I am somehow less than - the 14th amendment does not apply to me. I have been maliciously marginalized, discriminated against and even denied healthcare because of my label - a flaming moniker first attached in 2005. I have spared no expense to be outwardly regarded as female, and over the course of a decade plus the knife has carved me in Colorado, Texas, Illinois, Massachusetts, Oregon and California. It has not been enough, and gosh almighty, I wish this had not been my path or my cross to bear.

Sometime in 1964 when I was five years old something stirred inside; it was a restlessness that better defined itself at age seven. I wanted to be a girl. That realization was innate and visceral, and confusing. For heaven's sake I knew I was a boy, but there was profound sorrow in that reality. I was quick to learn that my misaligned feelings were not shared by others. The internet for the masses was 30 years in the future and there were no poster models of what I was. Since that distant time, I have struggled to be what life told me to be. Age 45 hung heavy on me and I could go no further living behind my mask. The herd and tribal mentality of my fellow beings would have preferred a bullet to my brain rather than having to comprehend and share space with one who dared to go against the binary of gender. To this day I fail to understand why and how my humanity and rights as a human being can be so easily and nonchalantly denied. There are nearly eight billion of us who breathe the same air and come from the same divinely created ancestral soup. Why is it so hard to accept and love those who are a bit different? Come to think of it - are we not all a bit different from one another? Surely, our very species can only hope to survive if we do not learn to accept one another and embrace the differences that make us all unique and human (Van Duyne, in press).

Introduction to and Defining the Problem

In this article, I examined how potentially living with urinary incontinence (UI) was not discussed with transwomen who were contemplating undergoing gender reassignment surgery (GAS). The effects of UI touched all aspects of their lives to include work, social, hobbies, and their sexuality (Sinclair & Ramsay, 2011). Informed consent appeared to be lacking and paternalistic. Review of literature supported this theory (Shuster, 2019). Transwomen who are considering undergoing GAS should be educated as to the potential negative consequences of this procedure. Review of literature supported this theory. The PubMed database was searched for literature specific to transgender medical education among physicians or trainees; this included "all papers that reported results of transgender specific educational interventions" (Korpaisarn & Safer, 2018, p. 271). According to Korpaisarn and Safer (2018), it was found that there is a lack of education among providers across all levels of medical education from physician trainees and medical students to primary care providers and specialists such as endocrinologist and others involved in transgender care. Eligible providers are lacking. They represented the greatest barrier to care for people who identify as transgender (Korpaisarn & Safer, 2018). Follow-up appointments ought to ask specific questions regarding UI or any other issues involving the neo-vagina such as proper hygiene and care to minimize or negate bothersome odors. This argument is grounded in the experiences of two transgender women who have undergone GAS, who have participated in this case study. The questions asked within the interview and during the survey involved their healthcare experiences going back up to five years.

Literature Review

People who identify as transgender, are becoming more visible in society. This population is forming support groups and seeking community support, yet health issues are a concern (Monaco, 2019). As more people seek GAS, issues with UI and "female problems" will need to be considered (Sifferlin, 2017). These issues ought to be highlighted for best outcomes following surgery (Dreher et al., 2017).

Research and data are limited to non-existent, as are informative evaluations of outcomes (Neto, et al., 2012). A case study is warranted. The expectation is that GAS will continue to increase in the coming years (Åhs et al., 2018; Sifferlin, 2017). A recent study found that though the number of people undergoing GAS is increasing, the estimates of those who wish to have this surgery remains unknown. Health professionals need to be prepared to care for this dynamic and shifting population with their specialized needs as more people move forward with this life-changing decision (Åhs et al., 2018).

Research on UI following GAS is limited and extensive descriptions of poor surgical outcomes is not readily publicized (Neto et al., 2012). More research is needed to address this potential health issue as such surgeries are expected to rise in the future. Health care workers (HCWs) need evidenced-based research to meet the unique needs of this growing population in health care (Monaco, 2019; Sifferlin, 2017). Research into women who have UI have found isolation behaviors, depression, anxiety, and secrecy surrounding this health issue (Hulme, 2012; Koch, 2006; Park et al., 2018; Siddiqui, et al., 2014). Couple this with studies that reveal sedentary behaviors are linked to depression (Vancampfort et al., 2018), and a cycle of secrecy surrounding this health concern is perpetuated. Compounding all of this is the data that transgender teens are more than 6 times more likely to commit suicide than their heterosexual counterparts, causes greater concern (Monaco, 2019).

GAS is becoming more accepted by the medical community and more available. There has been a 20% increase since 2015. In 2016 there were 3,200 surgeries performed in the U.S. The recent 2014 removal of a decade's long ban for GAS, and the subsequent Affordable Care Act reversal for discriminating on gender could boost such surgeries. A person who identifies as transgender in a medical center can no longer be classified by insurance companies as having a pre-existing condition as in the past. These combined variables have contributed to the rise in surgeries (Sifferlin, 2017). "The number of patients presenting for care at gender clinics is increasing, yet the proportion of adults in the general population who want gender-affirming medical treatment remains essentially unknown" (Åhs et al., 2018, para. 1). There are varied procedures to address gender affirmation for those who wish the outcome of physically transitioning to a transwoman (Kwun Kim et al., 2003). One is the modified rectosigmoid colon surgical technique. Though this surgery boasts the best outcomes for sexual outcomes (Özkan et al., 2018), research is lacking as to the overall long-term effects this surgery or other approaches have on UI (Dreher et al., 2017; Neto et al., 2012). Literature has shifted from a model of pathology to a model of minority stress (Edmiston, 2018).

Though literature is limited regarding surgical outcomes following GAS for those transitioning to transwomen, data does show that there are undeniable complication rates, even when these surgeries are performed by experienced surgeons in qualified centers. A 13-year review of surgical outcomes found a frequent surgical complication in 40% of the patients for obstructive voiding disorder; this was due to progressive meatal stenosis (narrowing of the meatus with secondary blockage of urine), according to Neto et al. (2012). Transwomen considering GAS ought to be informed preoperatively about potential lower urinary tract symptoms (Melloni, 2017). "There is a high complication rate in the reported literature" (Dreher et al., 2017, p. 191). Even so, I could not find any case studies or qualitative research on UI following GAS and its effects on work or quality of life (QoL).

UI is globally viewed with shame and effects QoL and activities of daily living (Hulme, 2012). It is viewed as a life impairment by some societies and is kept a secret by those who have this health issue. There is secrecy attached due to a perceived need of preserving self-respect (Park et al., 2018). Severity of UI and embarrassment are negatively correlated with help-seeking behaviors (Hägglund & Wadensten, 2007). Many isolate themselves to hide from the potential of having a humiliating incident (Hulme, 2012; Koch, 2006). Despite the effects that UI have on women, less than 38% seek help from HCWs, and less than 50% discuss this issue with anyone (Koch, 2006). Many will not even discuss their UI problems with family members and prefer women over men, even if the man is a physician (Siddiqui et al., 2014).

Gaps in Literature

The gaps in research are obvious. A 2018 systematic review found that people who identify as transgender display poor QoL; (Nobili et al., 2018). More research into QoL following GAS is warranted. The reasons and firmer conclusions regarding the effect GAS has on QoL remain in question (Nobili et al., 2018).

Aspects of UI have not been addressed. It is cause for speculation as to what other medial issues and gaps in research remain for the transwoman population following surgery (Monaco, 2019). The need for GAS standards and guidelines for best outcomes cannot be disputed (Dendrinos, et al., 2019). HCWs need to ask questions regarding toileting health and habits, coupled with sensitive probes as to their unique patient's general state of being. The right questions could help to mitigate both physical and emotional distress caused from these specialized surgeries and the journey of transition. July: *"I think just general, you know, knowledge, asking direct questions like, 'Will my urination change?' 'Will I have any trouble with my bowel or bladder function?' 'What kinds of negative things can I anticipate?"'*

Current Study Purpose

The purpose of this study was to determine whether people, who are transgender, and who identify as female, but are born male, have UI following GAS. The study sought to identify UI in this specific population. The aim was to

illuminate the meaning of transwomen's experience with bladder integrity and potential UI issues following GAS and to discover if any subsequent bladder issues, such as UI, are routinely addressed by HCWs.

Care seeking behavior was also reviewed. A case study of two individuals who had undergone the surgery assisted to this means of understanding. Health care providers who care for people who are transgender, who have undergone or wish to undergo this surgery, can be better prepared for such health issues, outcomes, and symptomology management, if prior knowledge of potential issues are known through such a preliminary study (Neto et al., 2012).

Study Description and Method

The experiences detailed in this article are drawn from a modified phenomenological case study of two transwomen living in Oregon. "Phenomenology focuses on describing the essence of experience" (Pitney and Parker, 2009, p. 123). In this article I focused on the experiences of Mary and July that have unfolded over the course of up to five years in the United States. The University of Wisconsin-La Crosse Ethics Review Board provided approval for this project under the expedited review category in accordance with 45CFR46, 46.110(a)(b). (Project reference 5-6892).

Interview Process

For the interview process I used a case study outline (Zucker, 2009), but approached this with a phenomenological approach. This type of research helps to focus on the meaning to a specific experience. Normally there are several informants (Pitney & Parker, 2009); in this case I had two. Gaining the trust of this population can be difficult. They are used to being objects of curiosity. Being asked to participate in surveys that ask specific questions relating to bodily functions and sexuality made finding willing participants more difficult. My two participants knew each other. I had gained July's trust over the years and was introduced to Mary by July. They both had similar issues it soon turned out, and wished to tell their stories, but in an objective means to improve, what they considered to be misconceptions and myths, involving their population. Participating in the case study served this need, as well as my research agenda; it served a dual purpose. Once we decided to move forward, I attempted to set aside my own beliefs and preconceived notions about what I was investigating. I used bracketing so that I could better learn about Mary & July's perceptions while excluding my own ideas. I used practices that have worked for me in the past: I engaged in deep self-reflection before each interview; I wrote down my own thoughts about the phenomenon. I have published twice in the *Journal of Life Care Planning* regarding the process and cost of gender transition; I have also conducted a case study for a person who is transgender and struggling to navigate the systems and processes of living as transgender and transitioning (Van Duyne, in press); (I shared Kai's poem in this article's introduction). These experiences were a wonderful way for me to bracket my own perceptions and identify my bias ahead of time so that I would recognize them. My goal was to be self-aware and therefore able to see these interviews with fresh eyes, and an open mind, with a goal to avoid making assumptions; I wished to discover the intricacies of the phenomenon. For this article, I spoke with Mary & July, collected data, analyzed it, and transformed the data into a readable story and themes. By doing this I was able to share their stories. When I collected the data, I kept in mind two things as I have in the past when interviewing this population: I wondered how they experienced the phenomenon, and then pondered what had influenced their perceptions and experiences with this phenomenon. I talked about their life histories, the details of their experiences, and asked them to reflect on the meaning using specific interviews. Last, I analyzed and transformed their data into a concise article that reflected their individual essence. I looked for themes and worked to bring the phenomenon down to its core, which was essentially bringing out the meaning of the experience. I believe that by sharing their stories, it helps bring to light a description of what they have experienced, and therefore helps to uncover events and situations which were previously unknown. I recorded the interviews and wrote Mary and July's words verbatim. The recorded tapes were sent to a professional transcriptionist as a means to compare what I have written to an actual transcribed document.

Instrumentation and Approach

Interviews were conducted 1:1 between the principal researcher and in the quiet comfort of each informant's place of choice; one was in a home and the other a frequented favorite restaurant. Debriefing was performed in a hotel room. The study began with the two women taking the Transwomen Bladder & Sexuality Survey, then a standardized questionnaire, the Bladder Control Self-Assessment Questionnaire (B-SAQ), a second non-standardized survey, The Transgendered Patient's Experience and Their Surgical Journey (El-Hadi, Stone, Temple-Oberle, & Harrop, 2018), followed by scripted open-ended questions in a semi-structured interview (Transwomen Toileting Questionnaire). The El-Hadi et al. (2018) survey consists of 21 multiple-choice and short answer questions. The aim of the El-Hadi study was to examine perceived satisfaction and barriers to care for people who identify as transgender after they had made the decision to undergo GAS (El-Hadi et al., 2018). This survey (El-Hadi et al., 2018) was provided to people in the United States and in Canada. The B-SAQ has good reliability and validity. It is known to be psychometrically robust. It allows people to self-assess bladder symptoms and the bother symptoms. The sensitivity and specificity of the questionnaire to detect patients with troublesome lower urinary tract symptoms (LUTS) is 98% and 79% (respectively); (Basra et al., 2007). The

Transwomen Bladder & Sexuality Survey was specifically made by this researcher to target bladder and sexuality issues for the population of Transwomen. It has 53 questions and is broken into 4 areas: Health /Background, Urination/Bowels & Bathroom Use, Sexuality, and an area labeled for Gender Confirmation Surgery Informants (Only). This research was its first time to be used. The Transwomen Toileting Questionnaire is an in-depth semi-structured interview guide. The areas covered are as follows: Background History, Surgery, Provider/Patient Education, Personal Reflections, Regarding Neovagina/Urination, and Society areas of inquiry. The focus of this 1:1 interview using the Transwomen Toileting Questionnaire was to gently and sensitively ask questions as to how the person feels they have been treated by not only society, but the providers who they depend upon for care and a healthy transition.

Participants

Two informants participated in this case study. Snowball sampling was used. I belong to two different groups that support people who identify as transgender, in two different states and two different cities. I attend meetings when in those cities and states. I am active and vocal in these group meetings. Most members know I am a researcher. I have participated in fund-raisers, marched in their parades, advocated on college campuses, and gradually gained their collective trusts. When I mentioned that I was hoping to do a case study, one informant offered herself and then introduced me to her friend, who became the second informant. I have written a grant and hope to conduct a group project using the case study as a springboard. I plan to do the group study with the members of the largest group but will broaden the demographics. For the case study, I was looking for a specific population: middle-age adults over age 40, some college education, GAS (male-to-female), health insurance, not recently hospitalized due to overt health issues or chronic illness. Informants excluded were anyone who was under age 40, had dropped out of high school or had not been to college, had been born female or intersex, did not have health insurance, and had a history of health issues such as cancer or chronic illness.

These demographics were chosen as the informants needed to have health insurance to be able to exercise the option for decision-making in their health care. A college degree could assist in a potential understanding of how to perform a literature search for self-education. Also, people who identify as transgender, who do not have solid jobs or education, many times turn to prostitution and this leads to AIDS/HIV and/or other genital urinary issues. People who have chronic illnesses may have UI due to the chronic illness versus the GAS or may become too sick to participate and drop out of the case study. I did not consider race or religion as inclusion/exclusion criteria. The two participants fit the inclusion criteria.

Themes and Four Study Questions

The research studied whether people who have had GAS and subsequently developed UI (as a perceived result of their surgery), after taking the B-SAQ, recognized their incontinence as a health issue. This study asked four questions and searched related themes, 1). Do people who identify as transwomen have new or worsened bladder issues, to include UI, following gender affirming surgery? 2). If bladder issues are worsened, to include UI, following gender affirming surgery, was care sought? 3). Do they recognize they had a bladder problem before taking the B-SAQ or following taking the B-SAQ?" 4). Have any bladder issues, to include UI, been routinely and independently addressed by health care providers? A 5th question could be, do people who identify as transgender and have had GAS, to become a transwoman, who have elevated symptom scores on the B-SAQ, recognize they have a problem before taking the B-SAQ?

The use of the Transwomen Bladder & Sexuality Survey, coupled with the Transwomen Toileting Questionnaire in a 1:1 semi-structured recorded interview, sought themes as to whether the informants were prepared for UI health issues prior to the surgery through education, counseled following the surgery for potential issues, and if they developed problems, what types of services were recommended, provided, or sought. If they did not seek services, the questions sought to answer why no services were pursued. Themes and correlations with prior studies with non-transgender women were studied for similarities in perceived need for care and care-seeking behaviors.

In summation, a phenomenological hermeneutic method was used to analyze and interpret the interview data. An inductive thematic approach was used; data was first analyzed, then coded as the themes presented. Mary and July were debriefed to ensure reliability of the data. An outside researcher reviewed the data to provide feedback for the coding and themes. Informed consent preceded the process. Both interviews were electronically recorded and transcribed verbatim.

Urinary Incontinence is Not a Part of Being Female

I came to know the two women described in these pages during my time as a student while learning about research. I was searching for a topic of which I could devote as my life work as a researcher. While casually talking with one of the informants, the topic of UI informally came up. I was much later introduced to the informant's friend who was contemplating GAS. The two informants, with whom I later interviewed, endured much loss as a result of UI and its effects on many integral facets of their lives. Their voices deserve to be heard. Unfortunately, there seem to be many who wish to be silent due to shame and not wanting to give poor outcomes much thought as then it becomes more of a reality. This is what July and Mary gave as reasons as they apologized for the fading away of those who initially seemed

to want to step forward with them. I understood. I am new to qualitative research yet understand its value when expressing such topics as loss, shame, and personal needs. As the opening paragraph illustrates, UI is not addressed by either the HCWs or was it brought up by the transwomen who must deal with this issue on a daily basis. UI is viewed with shame by many societies (Hulme, 2012). People who are transgender have learned to be secretive in order to survive. Remaining quiet about issues following their GAS falls in line with survival and what they have learned is "best" practice. Shame is a strong force (Giordano, 2018). Much of what is learned about surgeries and transition is found in social media. People in the transgender community share and talk within this forum. It is safe. They can be secretive. They can get answers to their questions using social media. They don't have to be ashamed. The problem with social media is that it is just that, it is social conversations. Making a life-changing medical decision based on social conversations can cause those who are trusting and desperately looking for answers to accept untruths as fact. Informant 1, Mary, believed that, *"UI is something that women all eventually endure*." Also, Informant 2, July, assumed that it was *"Normal"* for *"…women to have daily and regular odor* coming from their vaginal area." Names have been changed to respect the confidentiality of these two brave and honest women.

Taking the Final Step: The Impact of Surgery

Transwomen surviving within the United States are largely alienated from what is offered so readily to others (Golden & Oransky, 2019). Wives, children, parents and siblings turn on them. Housing and jobs become an issue (Grant et al., 2011). A steady income and stable relationships cannot be taken for granted. Depression is common and suicide is higher than the general population (Haas, et al., 2014; Valentine & Shipherd, 2018). It should not be surprising that transwomen do not ask questions of their healthcare providers and are simply grateful to be seen for care (Goldhammer, et al., 2018). Organizations do discriminate and excuses are made for paternalistic approaches to care. Transwomen many times are put in the position to educate their providers about what their unique needs are or remain quiet (Vermeir, et al., 2018).

The two informants in my case study remained quiet even though they had questions regarding their new bodies and complications. The research drawn upon here reflects my engagement with the issues of paternalistic approaches to care, poor informed consent, questions that aren't asked and the questions that need to be asked, and postsurgical complications such as UI. The center portion or theme of this article involves transwomen's part in this equation. They have learned to be quiet, ashamed, and resigned to unpleasant events, occurrences, and fate.

In these pages I did not take a stance regarding the need for transwomen to change their role with healthcare providers. My phenomenological attention focused on an emergent understanding of the devastating informative effects that healthcare providers played in not asking the right questions, or sensitivity in approaches to care, and for the need for better guidelines for managing transwomen following GAS. I hoped to raise questions about practices surrounding the care of people who are considering GAS as well as follow-up care for those who make this choice. An emergent theme that unfolded was loneliness perpetuated by stigma perceived by transwomen and the feeling that they are judged on all levels.

Interviews and Themes

The transgender women's experiences are presented in terms of inter-related themes as being in a vulnerable position with UI and striving for adjustment to being transgender while dealing with UI symptomology. Being vulnerable means that the woman had no control over UI or how society perceived them (Fongkaew et al., 2017). The subthemes in this case were living in an uncontrolled body, living with incontinence as taboo, and experiencing less than satisfying encounters on a daily basis with people in society who are not accepting of transgenderism or UI. The shame and embarrassment are two-fold. Striving for adjustment means that the women try to handle their incontinence in varied ways to regain control and to live as normally as they were able as transgender and with incontinence. The subthemes here were living in readiness, making urine leakage understandable, accepting living with UI, and being familiar with the situation. Assuming a proactive stance of self-education and care-seeking behavior for the UI, while feeling worthy of such care is another subtheme. This lack of perception of self-worth is due to a perceived societal and healthcare provider negativity, coupled with a lack of support due to being transgender (Monaco, 2019). Both women reported feeling unsupported and misunderstood by HCWs; this perception is not unusual (Samuels & Keisling, 2019). A Midwest survey revealed that a third of family medicine physicians do not feel qualified to treat people who identify as transgender (Monaco, 2019). Prior to GAS, health information regarding UI was not provided to the women unless they asked, however interestingly, both women were given the impression that they would experience female sexual sensation following GAS. Both women expressed this to be false and therefore an untrue expectation. During the interview, Mary and July's surgeries, scarring, lack of testosterone, increase in estrogen (through hormone therapy), and shrinking prostates, were all given as reasons for a lack of interest in sexuality. Both Mary and July said they simply assumed this was the case for their inability to meet the promises made to them before their GAS. Both said that when they found themselves to be uninterested sexually and anorgasmic, that they "filled in their own blanks to come up with reasons for this loss". According to Mary and July, none of the reasons mentioned for their post-surgery issues were

explained as potential complications by their providers prior to the GAS.

The Interviews: Portraits of Frustration and Loss

Mary:

"I am not able to hold it like I could. I just still don't feel I am able to hold it like I could before the surgery. There are other times, on the other hand, where it seems like I'm having to get up every 15 minutes: and so, the one thing I do feel very self-conscious about is going and having to excuse myself to go to the restroom again."

July:

"Out of frustration, years after the fact, of urine spraying this/that way, having to go to (the) urologist, trying to fix it. I did notify my gender change surgeon years later that this was an issue…The surgeon was somewhat defensive and certainly offered no new ideas to fix things."

Mary answered the first research question relaying that UI seemed, *"Like it became a bigger and bigger issue. It was there most of the time."* Strategies that she used to minimize the issue was to use the bathroom before performing an activity such as watching a movie or flying on an airplane. Also, she noted that she was aware of where restrooms were when she was traveling by car and would plan her rest stops along the highway accordingly. *"I am not able to hold it like I could. I just still don't feel I am able to hold it like I could before the surgery."* Mary reports (what), *"…I do feel very self-conscious about is going and having to excuse myself to go to the restroom again."* Regarding research question #2, Mary did seek care, but did not continue with the exercises that were prescribed (Kegels). She mentioned that in her later appointments with her physician that the exercises were not brought up and she did not feel pushed to do them and therefore she stopped doing them even though she noted that she probably needs to continue the exercises for the sake of her bladder health. Mary answered research question #3 when she noted that she now has an increased awareness of the severity of her symptoms and bother following taking the B-SAQ. Mary did note that her bladder health was discussed by her provider, and that it was discussed "every time" however, she believed it was because she was bringing it up herself. Regarding research question #4, Mary recognized that she had a problem with UI before taking the B-SAQ, however she noted that the high numbers revealed to her just how much of issue it was, and how she has ignored and minimized the problem in her own mind.

Mary noted that although she was pleased that she had had the surgery, that there were issues as a result. She noted that she was an anxious person before the surgery and believed that her continued anxiety may have contributed to some of her symptomology. She had not discussed this conclusion with her providers. A subtheme of this study demonstrated the increased need for HCW communication and education with patients, as well as improved sensitivity to the specific needs of this population during care. HCWs ought not to assume that their patients will bring up issues but should recognize that this patient population may unintentionally hide their symptoms due to embarrassment and/or lack of the requisite health education to recognize their symptoms as abnormal. In Mary's case, she believed that being a woman and leaking was to be expected and one of the trade-offs for having the surgery. This misconception could have been explained away by a proactive healthcare provider who understood some of the possible complications and issues following the surgery.

July answered the first research question; she had a lot of commentary regarding her new and worsening UI issues following her GAS.

"I think the most relevant postsurgical issue would be stress or urge incontinence of urine. When I have to go, I have to go and even when I sometimes think that urine has not leaked out, I later find out that it did leak out. It's a very frustrating issue. When I urinate, my urine sprays often many directions. In fact, just yesterday, I went to the bathroom and it sprayed so far off to the right side that it went underneath into the other stall, and it's humiliating and embarrassing to have to try to mop up that urine on a dirty public bathroom floor."

When asked to list the general ways that bottom affirming surgery had affected her in negative ways she replied, *"Well the incontinence issue. There're sometimes some foul odors that arise from that area that are embarrassing. I find it a difficult area to clean sometimes. If I feel I've cleaned it well one day, the next day I found out that it still is nasty. That's frustrating."* When asked if she could explain exactly what nasty meant July replied,

"Odors. I've had issues in the past where I've had some yeast type infections and some nasty discharges, but that's been years ago. Now it's just kind of a general odor, and I was checked by the gynecologist for anaerobic bacteria, and that was a negative test, so I'm not sure what the odors are."

When asked how her daily urination and toileting sequence affected her psychologically, socially, and/or physically July responded,

"I don't really see that it affects me in positive ways. It is always negative… It is usually in public that I sometimes run into issues of trying to hold it too long; and in public, it is always a matter of selecting bathrooms. At work, I try to use a unisex single stall bathroom, or I use a man's bathroom that has one toilet in it so I can lock the door. I'm still extremely self-conscious if I'm forced into using a women's bathroom."

July answered the second research question as to whether her bladder issues had worsened to include UI following GAS and whether care was sought as a result when she said, *"Out of frustration, years after the fact, of urine spraying this/that way, having to go to urologist, trying to fix it, I did notify my gender change surgeon years later that this was an issue."* When asked how that went, July responded, *"The surgeon was somewhat defensive and certainly offered no*

new ideas to fix things." July answered the third question as to whether she recognized she had a bladder problem before taking the B-SAQ or following completing the questionnaire. Similar to Mary, July was aware that she had a problem, but had minimized and attempted to deal with it on her own. Completing the questionnaire did help her to recognize the level of her problem as it was put into a numerical level. Her numbers were very high as were Mary's scores (see Table 1). July reported that her bladder issues, to include UI, had not been routinely or independently addressed by HCWs. When asked whether she knew that prescribed systematic estrogen could cause urinary incontinence she said, "*No*." When asked whether she knew that estrogen could cause constipation she said, "*Yes*." When asked whether she knew that constipation could cause pressure to the neck of the bladder and has been correlated with urinary incontinence, she said that she did know that, but on that issue, she had self-educated and learned this on her own. July had no education or communication as to what to expect following both of her bottom surgeries from any HCWs. When asked whether her bladder health was discussed by her provider in her follow-up appointment she said, *"I never had a follow-up appointment. It was clearly never discussed after surgery or there was no discussion that my urination would change."* When asked what she wished she would have known she responded, *"As for one, I would have liked to have known that the direction of my urination or stream would or could change; I would have liked to have known that that might become an issue."*

Some of the themes that came to light during our interview was that people who are transgender do not receive effective informed consent (Shuster, 2019), regularly have their Human Rights violated (HRC, 2018; McBride, 2017), are patronized and made to feel unimportant by healthcare providers (Shuster, 2019), find information on the Internet as healthcare providers fall down on their duties in this respect (transgender people end up educating their providers according to Grant et al., (2011), and fall prey to surgical predators who feed on their insecurities and relentless pursuits at "becoming female" (Stack, 2019). These are themes that were found through review of literature and are supported by this case study.

Analysis of Interviews: Summation of Research Questions

Both informants highlighted the need for provider (HCW) education and communication before, during, and after GAS to best prepare people for surgical outcomes, complications, and issues. With improved communication and education, potential patients could be promoted to ask informed questions and receive better follow-up care. Stress and anxiety could potentially be mitigated. Both participants spoke of living with anxiety. Interviewer: *"But it sounds like you are living in a lot of fear and anxiety because there is no control, there is nothing solid to hold onto it sounds like."*

July: *"Well it's true. I mean, to an extent it is very true; and I realize, you know, too, that I think that I will never… That I will always be something in between. And you know, maybe that would be okay if society was okay with that, but the fact that society is not in the fact that, you know, even being in public is always a bit of a challenge for me… Every day presents its own set of challenges and disappointments and anxieties… I think a lot of transgendered people are extremely lonely."*

Mary disclosed that, *"I am an anxious person. I frequently joke that I would be an insurance agent's dream because I worry about everything and if I was to try to get insurance for any and every potential problem, I would have no money left."*

This study answered the research questions. There was a difference in bladder function following GAS. Bladder function was not the same as before GAS. Also, Mary and July did recognize that they were having bladder issues before taking the standardized B-SAQ, however taking the questionnaire clarified the extent of their bladder issues and heightened their awareness of this major health issue. Talking about their bladder issues and then seeing the high number scores of their respective questionnaires appeared to help facilitate this better understanding. This was disclosed by both in the debriefing. Neither Mary or July were eager to seek health care even with this new information and understanding of their bladder issues. They disclosed that their experiences with providers, and the lack of satisfaction with outcomes, served to make them hesitant to seek care for their current problem. Both informants had sought help and felt that their concerns were either dismissed, ignored, or minimized.

Discussion

The meaning of transgender women's experience of living with UI is vulnerability compounded by being transgender in a less than accepting society (Fongkaew et al., 2017). Also, if people are considering such surgeries, it is prudent that they ought to ask questions related to sexuality, sensation, and request realistic expectations from the surgery. July was told it would, "Make me a girl." She has since realized that she is not a girl.

"My DNA is XY and I still have my 'boy parts' of a prostate and cannot have a vaginal orgasm, but only a weak prostate release and only if I am stimulated for a long period of time. These releases are getting weaker and weaker as my prostate shrinks with the feminizing medications." Further, "It is depressing. I lost my sexuality and gained incontinence when I had the surgery. It would have been good to know this trade-off. I would have had the surgery anyway, but this loss and issue has been rough. I was ill prepared for this" (July).

This supports findings by Li, Remble, Macapagal, and Mustanski (2019), that public health ought to perform more research into sexual functioning when it comes to the LGBT community. It is vital to healthy sexuality and healthy self-

esteem. Much must be done to combat the stigma attached to identifying as a part of the LGBT community (Li et al., 2019).

Mary remembers bleeding after her surgery and being frightened. She called and left a message for her surgeon. He never returned her call. Her answer came when she went in for her follow-up. July has had two surgeries. One for the GAS and the other because of the UI issues and how…

"My urine goes in many directions whenever I pee. I hoped to minimize this issue. I frequently have to change my underwear and pants, or I smell like pee at work. It is embarrassing. Since I have had the surgery, my neovagina looks better as I have less loose skin (scrotal tissue that is made into labias), but the UI is still an issue and my urine still sprays everywhere at times." (July)

In summary, education and standards are lacking. HCWs are beginning to understand the importance of specialized training when it comes to addressing the unique needs of this population in many specialties (Dendrinos et al., 2019; Ludwig et al., 2019). It is important that HCWs communicate with people who are transgender before, during, and after procedures to minimize confusion, fear, and the feeling of being alone when it comes to potential or persistent issues. This was an emerging theme as the informants were interviewed; that an issue would develop, and it was up to them to deal with it on their own: no follow-up in one situation (July) and no call-back/return call with reassurances in another (Mary). Sadly, both women relayed not reacting to this dismissive tone in their care as they have had prior histories of rejection. A Midwest survey revealed that approximately 15% of physicians polled would refuse providing care to a person who identified as transgender (Shires, et al., 2018a). Primary care providers in a Midwest health system were surveyed regarding their willingness to provide hormone therapy to people who are transgender. Only about half of the providers were willing to provide these treatments to their transgender patients (Shires et al., 2018b). These attitudes are not limited to conservative states, regions, and countries. July had this experience in a liberal town and state in the Pacific Northwest. An endocrinologist refused her care when her former provider moved out of state. The new provider would not assume the hand-off of care. As a result, July had to drive more than two hours to find the nearest provider within her healthcare network. Even Thailand, which has been performing the GAS for decades ahead of other countries, still has its negative portrayals, stereotypes, and ultimate discrimination against this population of people (Fongkaew et al., 2017).

This research studied whether people who have had GAS and have UI, as a perceived result of their surgery, and following taking the Bladder Control Self-Assessment Questionnaire or B-SAQ, recognize this as a health issue. This study asked four questions and searched related themes," 1). Do people who identify as transwomen have new or worsened bladder issues, to include UI, following gender affirming surgery? 2). If bladder issues are worsened, to include UI, following gender affirming surgery, was care sought? 3). Do they recognize they had a bladder problem before taking the B-SAQ or following taking the B-SAQ?" 4). Have any bladder issues, to include UI, been routinely and independently addressed by health care providers? The questions were answered, and new themes emerged. Transgender women do have problems with UI following surgery. Care was not sought. They recognized they had a problem with UI, but the B-SAQ clarified the issue and the amount of 'bother'. HCWs do not routinely ask questions specific to UI unless prompted. Both informants recognized UI as a health issue, but simply dealt with it using their own techniques. Both have anxiety. Both reported themselves as not having interest in sex and being either non-sexual (July) or asexual (Mary); a change since their GAS.

Result and Conclusion and Suggestions

Intimate phenomenological accounts of individual experiences unfolding over time, point out critical junctures that might be changed over the course of these two women's experiences. These accounts raised critical questions regarding conditions of a possibility for better QoL for transwomen. Marginalized populations do not receive the medical care needed; transwomen are no exception. What if Mary and July had been told that they would have had to endure UI as a consequence of surgery for the rest of their lives; would they have opted to have their surgeries? What if these two transwomen had been asked whether they were having any issues with UI or having to deal regularly with malodorous neovaginas; would they be more prepared for the confidence it requires to continue hobbies and social activities without the shame and embarrassment of this new secret? Did they fully comprehend that adopting a new gender may be fraught with grief and struggles or did they believe it would be a seamless transition? July responded,

"Well, I guess my comment would be about transgender in general, and that would be that it is a very difficult path and going through all these surgeries and trying to adopt a new gender is certainly an uphill battle. And, I think the younger generations that get this process underway sooner is probably better. So, I would say to anybody that is middle-aged or beyond 30 to try to go through this, they are going to face an uphill challenge in many ways. And overall, I am sorry I had to deal with this. I regret it. But on the other hand, I feel that I really didn't have any options because I was tired of just the incessant thought and longing to be female; and why that was, I will never quite understand, but I'm really sorry that I had to have that in my life because I feel in many ways it has ruined my life. And in general, I don't like transgendered people. I think it is an embarrassing condition. It certainly is humiliating; and again, I can't say strong enough it has ruined my life and has caused me to miss so much of life."

These questions induced recognition of the role of systems and communities in cultivating conditions favorable

to coping and better QoL. Opportunities for education are lost and transwomen are left believing that the current medical condition that they have, or are in, is how it will remain or is meant to be. They learn to adapt and survive as they have always done. Health care professionals are not educated in how to care for this population; how can they ask questions when they are not prepared to provide appropriate service (Korpaisarn, & Safer, 2018)?

Transwomen are not alone. Cis-women (women who are born female) in studies use a variety of daily-living approaches and techniques to manage UI, but they generally employ strategies to keep UI a secret. Such strategies include limitations in activities of daily living. Educational approaches are necessary to inform women with UI about more effective management skills (Park et al., 2018). This could be generalized to the upcoming transgender population as evidenced by a systematic review regarding perceptions about female UI (Siddiqui et al., 2014). The review found varied ethnic and racial groups use similar strategies and share related UI experiences. Also, women preferred speaking to other women; this included withholding medical issues from male physicians. Hispanic women had a tendency towards more secrecy than other ethnic groups studied. Non-white women saw UI as a result of prior sexual experiences and/or childbirth and blamed themselves for this issue (Siddiqui et al., 2014). Less than 38% of all women with UI do not seek help for this issue. Less than 50% talk to their healthcare provider about their symptoms (Koch, 2006). Obstructive voiding disorder is seen in 40% of transwomen patients after their 1st surgery. High follow-up loss, limited data collection, and unavailable controlled studies impede needed support to advance outcomes toward evidenced-based guidelines (Neto et al., 2012).

UI translates to lower QoL, as it impacts social and recreational activities; it has been tied to anxiety, frustration, and depression (Hulme, 2012; Koch, 2006). Isolation due to UI can lead to depression through withdrawal from former enjoyed activities and a subsequent increase in sedentary behavior (Hulme, 2012). This lack of activity has been tied to depression (Vancampfort et al., 2018), leading to a self-perpetuating negative cycle affecting multiple areas of life. Findings suggest that healthcare HCWs ought to ask specific questions when speaking to women about their experiences with UI, otherwise the women will not bring it up. Living with UI effects care-seeking behaviors (Häggland & Wadensten, 2007).

Varied ethnic and racial groups have similar experiences and share management techniques when it comes to UI. Perceptions do vary (Siddiqui et al., 2014); as a result, future educational strategies ought to consider varied approaches for best outcomes with different populations. As GASs continue to rise, education to service this population to mitigate health issues is warranted (Sifferlin, 2017). Specific questions should be asked on a routine basis to encourage care-seeking behavior and best health outcomes (Häggland & Wadensten, 2007). Bladder health management and the potential effects of UI education should begin prior to and continue post-surgery (Neto et al., 2012). More research into this area is warranted; studies are limited to rare (Neto et al., 2012). More research and employment of standards is essential to improve patient outcomes (Dreher et al., 2017). New therapy guidelines, informative evaluation of outcomes, and methods to follow-up are needed (Neto et al., 2012). "The main barrier on describing surgical outcomes is the lack of comparable publications detailing the techniques used and their complications…" (Melloni, 2017, p.3).

Limitations

The limitations of this study were the informants' ages (age 60 and age 72), number of informants (2) in the case study, and race (both were Caucasian and raised Lutheran/Catholic). One informant had a history of prostate cancer. The other informant had a history of dual bottom surgeries for aesthetic and urine stream reasons (July: "…*like a shower-head*"). These variables effect generalization to the overall population. Also, to consider, in all affirming surgeries, for those who are transitioning to a transwoman, is whether the prostate is not removed or is modified (Melloni, 2017). Lower urinary tract symptoms, or LUTS, effects 40% of older men. This term includes an extensive assortment of symptoms (bladder, prostate, and urethra). Voiding symptoms include mainly: storing of urine, voiding of urine, or a combination of both (Melloni, 2017). This variable poses a major research variable with regard to voiding and surgery outcomes, following affirming surgeries, for those transitioning to a transwoman.

The Vital Role of the Life Care Planner in Transgender Health

Life care planners are in an exceptional position to ask the right questions at the right time. Their unique roles as a combination of healthcare worker, counselor, and financial planner could prove vital in an area for those who are transgender and either contemplating or who have had the surgery and need assistance in navigating subsequent emotional and financial complications. As said, GAS is proposed to increase in coming years. Gaps in research cause many of the needs of this emerging population to remain unknown. Strong guidelines and standards are lacking. Life care planners are in an inimitable position to be pioneers in addressing the needs of this deserving and misunderstood population. The issue of UI following GAS is an area of need which cannot be ignored by those who hope to provide comprehensive care to people who identify as transgender. Basic care for cis-gender women who have severe UI is conservatively $900.00/year (Sudak et al., 2006). The cost for caring for this particular issue for those who have had GAS can only be speculated at this time, but one thing is certain; ignoring the problem will not cause it to go away. UI can not only affect everyday tasks, but work performance due

to worry of feeling uncomfortably wet or smelling of urine (Sinclair & Ramsay, 2011), July mentioned this as bothersome while working. July: *"Well the incontinence issue. There're sometimes some foul odors that arise from that area that are embarrassing…"*

A study revealed that there is symptomology that effect specific areas of work performance: loss of ability to perform duties (29%), loss of concentration (19%), and interrupted work due to necessary toilet breaks (34%) (Sinclair & Ramsay, 2011). Ignoring a problem such as UI can only cause it to worsen, become more expensive to manage, and ultimately cause more cost in financial and emotional damages from loss of work, wages (Sinclair & Ramsay, 2011), and societal participation at a minimum (Sudak et al., 2006). Knowledgeable healthcare providers are a major barrier to care for people who identify as transgender. A recent thorough PubMed database search for all literature that assessed the level of knowledge of physicians, medical students, physician trainees, primary care providers, and other specialists found services were lacking. It was proposed that specialty appropriate content was needed for proficiency in addressing the needs of the transgender population (Korpaisarn & Safer, 2018). Life care planners can meet this challenge. They can work to mitigate these circumstances through their unique roles in holistic provision of care to adequately address this populations' unique current and future services.

Table 1

B-SAQ Results for Mary and July*			
BSAQ Question Category	Questions	Mary	July
Symptom	Is it difficult to hold urine when you get the urge to go?	3	3
Bother	How much does it bother you?	3	3
Symptom	Do you have a problem with going to the toilet too often during the day?	2	2
Bother	How much does it bother you?	3	2
Symptom	Do you have to wake from sleep at night to pass urine?	2	3
Bother	How much does it bother you?	2	3
Symptom	Do you leak urine?	2	2
Bother	How much does it bother you?	3	3
	Total Symptom Score	9	10
	Total Bother Score	11	11
*See Figures 1 and 2 for an explanation on how the BSAQ is scored			

BLADDER CONTROL SELF-ASSESSMENT QUESTIONNAIRE

ARE YOU: MALE ○ FEMALE ○

Please put the NUMBER that applies to you in the boxes shown by the arrows based on the following:

NOT AT ALL = 0 A LITTLE = 1 MODERATELY = 2 A GREAT DEAL = 3

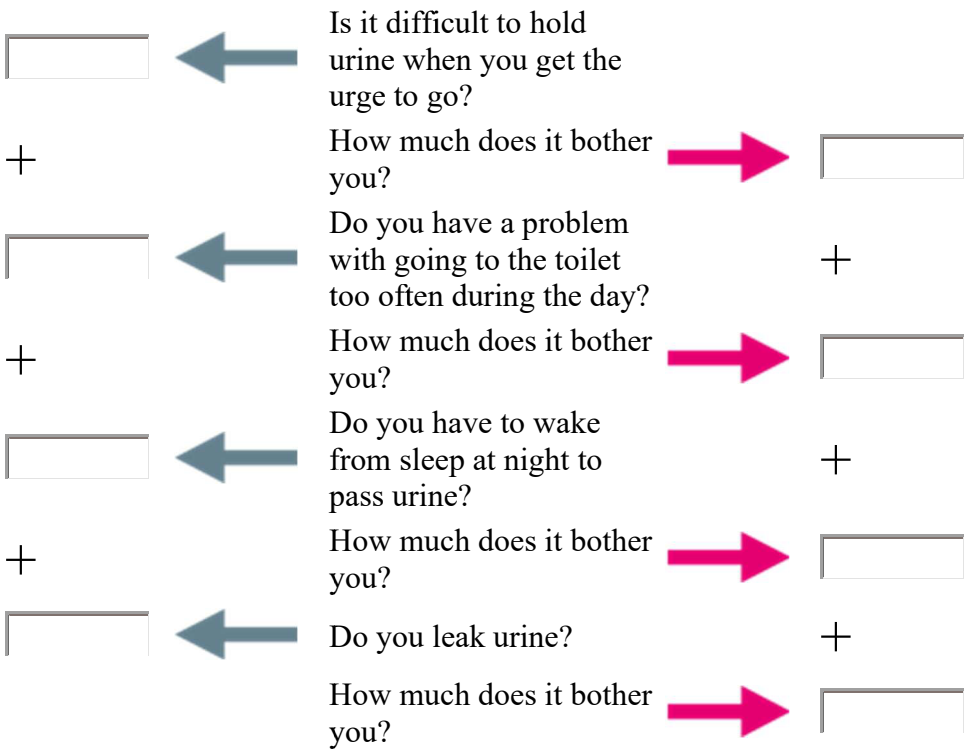

Figure 1.

SYMPTOM SCORE	This symptom score means:	This "bother" score means:	"BOTHER" SCORE
0	You are fortunate and don't have a urinary problem	You aren't bothered by a urinary problem	0
1-3	Your symptoms are mild	You are bothered slightly by your symptoms	1-3
4-6	You have moderate symptoms	You are moderately bothered by your symptoms	4-6
7-9	You have significant symptoms	Your symptoms are of significant bother for you	7-9
10-12	You have very significant symptoms	Your symptoms are a major problem for you	10-12

If your symptoms score (above) is 4 or over you should seek help.

If your bother score (above) is 1 or over you may benefit by seeking help.

IMPORTANT If you have blood in your urine, have difficulty passing urine, or pain on passing urine, you MUST talk to your doctor about it.

Figure 2.

Disclosure Statement

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