General

Stigmatization as a Barrier to Urologic Care: A Review

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Heavy societal stigma of certain conditions has created an environment where individuals may be hesitant to seek professional care. Urology is a specialized field that focuses on many of these conditions that society has deemed taboo to discuss. In this review, we address barriers that have prevented patients from seeking urologic care in order to better understand and elucidate important concerns within development of the physician-patient relationship. Recognizing these concerns can also assist in public health outreach approaches to motivate patients for seeking urologic care. The scope of this review was limited to three highly prevalent conditions affecting both men and women, including urinary incontinence, erectile dysfunction, and genitourinary syndrome of menopause.

INTRODUCTION

A person's health is by nature a personal and sensitive topic. This is well illustrated by how society has established norms surrounding the sharing of health information. Individuals often take measures to keep their health status private. It is socially frowned upon to directly question others regarding their health status. Furthermore, numerous state and federal laws have been adopted to protect health information. Indeed, the doctor-patient privilege is widely respected and considered sacrosanct. Only in extenuating circumstances is it allowed to be broken. The personal preference and sensitive nature of the health concern heavily influence how much a condition is shared with others. Generally speaking, conditions characterized by a high prevalence and low perceived risk of stigmatization are broadly shared. These may include conditions such as acne, asthma, or even high blood pressure. Some conditions, however, are met with intense stigma. Intense social stigma has burdened individuals with an intense feeling of needing to keep their condition private. These conditions are generally associated with the urogenital system. Unfortunately, the burden may be so high as to create hesitancy in seeking professional care. Urologists treat many conditions that society has deemed taboo to discuss. Multiple barriers have hindered urologic services from providing effective treatment. In this review, we examine the barriers that have discouraged individuals from seeking care. To focus our efforts, we have limited the scope of this review to examining societal stigma and lack of access to care as barriers to seeking treatment for urinary incontinence, erectile dysfunction, and genitourinary syndrome of menopause; these are three highly prevalent conditions affecting both men and women.

EPIDEMIOLOGY

URINARY INCONTINENCE

Urinary incontinence (UI) is the involuntary leakage of urine, and is characterized by multiple subtypes, including urge, stress, mixed (urge and stress), overflow, and functional.[1] The literature reports a broad prevalence of UI, ranging from 12-50% in women and 4-21% in men.[2-7] Both men and women experience higher rates of bothersome incontinence with increased BMI and chronic conditions such as heart failure.[4] Multiparous women with 4 or more births

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also have 3-4 times higher prevalence of UI compared to nulliparous women.[8] Finally, rates of incontinence correlate with age,[4] thus the prevalence of UI is expected to further increase in the coming years due to the United States' aging population.[7,9]

ERECTILE DYSFUNCTION

Erectile dysfunction (ED), also known as impotence, is the inability to achieve or maintain an erection that is sufficient for satisfactory sexual performance.[10] ED has numerous etiologies and subsequently a wide array of treatments. Physiologically, erections are generated by blood flowing into and collecting within the penis. ED can be caused by disruptions in blood flow, such as atherosclerosis, diabetes, and declining testosterone levels.[11] Damage to the penile nervous system is also a known precipitant of ED, with etiologies such as multiple sclerosis, Parkinson's disease, or sequelae of surgery.[11] In addition to these chronic conditions, ED has been reported to occur secondary to lower urinary tract symptoms (LUTS).[12-14] It is important to note that younger men under 40 generally have different causes of ED than older men, such as subclinical endothelial dysfunction, Peyronie's Disease, side effects of antidepressants or NSAIDs, and hormonal causes such as hypogonadism.[15] Treatment options for ED range from lifestyle modifications, including healthy diet, exercise, and reduction of alcohol consumption or smoking, to medical interventions such as pharmacotherapy, injection therapy, vacuum erectile device, or penile implant surgery.[11] In addition to ED, increased age in men also presents with other sexual problems, including lack of interest in sex and inability to reach orgasm.[16,17]

The prevalence of ED in different populations around the world has been extensively explored. It is generally regarded that ED is more prevalent in older men, which is often supported by the evidence. However, wide discrepancies among all age cohorts have been reported. One major milestone study, the Massachusetts Male Aging Study, reported a prevalence of mild to moderate ED for 52% of men aged 40-70 years.[10] A United Kingdom study found similar results, reporting a prevalence of 53%[14] in men 45+ years old. Many cross-sectional surveys conducted in North America, Europe, and Australia, though, have reported lower rates for men older than 40, ranging from 21-49%.[12,16,18-20] These numbers can be contrasted with ED prevalence studies conducted for the general population, which include men under 40 years old. Here, overall prevalence ranged from 14-26%.[21-23] One German survey reported the overall prevalence of ED at 19.2%, however there was a marked age stratification, finding only 2.3% for those aged 30-39, compared to 53.4% in the 70-80 year cohort.[22] Another study conducted for men aged 18-39 years of age only saw ED reported in 5% of men in the last 6 months.[24]

GENITOURINARY SYNDROME OF MENOPAUSE

Genitourinary syndrome of menopause (GSM), previously referred to as vulvovaginal atrophy,[25] is a term used to describe the genital, sexual, and urinary symptoms associated with menopause. Symptoms include vaginal dryness, dyspareunia, bleeding, discharge, and increased urination.[26,27] The decline in estrogen production associated with menopause results in decreased estrogen delivery to the estrogen receptors widely expressed in the female urogenital tract. The absence of estrogen leads to loss of mucosal elasticity, inflamed epithelium, and impaired function.[28,29] Changes in the bacterial flora predispose women to recurrent urinary tract infections (UTI).[30] Estrogen therapy may be used to reverse the urogenital atrophy which may subsequently improve irritative urinary symptoms.[31] Prevalence of GSM has been reported to be present in upwards of 50-80% of post-menopausal women,[32-34] with a variable frequency of associated symptoms. Associated symptoms that have been reported include: dryness 27%,[35] discharge 18%,[35] UI 29%,[36] recurrent UTIs 13%.[36] Incremental severity of GSM symptoms is associated with significant decreases in quality of life.[32]

PREVALENCE OF NOT SEEKING CARE

The impact of stigmatization on urogenital conditions manifests before even entering a medical office. For both men and women alike, there is an appreciable prevalence of hesitancy in seeking care.

In women's health, multiple studies have reported hesitancy. A Swedish epidemiological study of women aged 60-80 years found that only 38.5% of participants with UI had sought treatment.[7] An international survey of postmenopausal women from Europe and North America, reported that 71% of interviewees who experienced vaginal discomfort did not discuss it with either their general practitioner or gynecologist.[29] Moreover, of those who did receive prescription medication for vaginal discomfort, 25% waited at least a year before discussing their symptoms with a healthcare provider.[37] Likewise, a Western European survey involving postmenopausal women reported that 33% of women did not discuss their symptoms of GSM with doctors at all.[29] Importantly, this hesitancy is not restricted to older women or those without formal medical training. A study in Western Europe that included all adult women (18+ years old) reported that only 31% had consulted a doctor about their UI symptoms.[38] In another study, researchers linked symptom reports to insurance claims in a cohort of nurses with high health literacy; this study demonstrated that only 16% of women with current UI symptoms had an outpatient appointment addressing incontinence.[39]

Men too display hesitancy in seeking care. In one multinational survey of men aged 50-80 years, researchers found that 90% of the participants reported LUTS, however only 19% sought medical help.[12] In another wide-scale survey centered across Western Europe, 52% of men with ED across all ages did not discuss their condition with their physician.[24] An Australian phone survey reported that 80% of men with no to mild erectile problems expressed concern about losing erectile function. However, only a third of those with significant ED sought medical treatment. The same study reported an age-related disparity, finding that

nearly half of participants aged 40-49 years with an erectile problem had sought medical advice for ED, whereas and only a fifth of those 70+ years of age had sought medical advice.[18]

Hesitancy in seeking care is a shared problem amongst both men and women. As noted, several medical conditions can precipitate this hesitancy. Interestingly, the hesitancy has afflicted those of all ages and educational status.

ETIOLOGY OF REDUCED CONVERSATIONS

In this section, we will present potential reasons to the social stigma surrounding patients before they reach the urologic clinic office for care. These conversation barriers to seek care for urinary and sexual health symptoms may range from macrosocial viewpoints to individual needs.

NORMAL PART OF AGING

One of the major barriers to seeking care for urinary and sexual health symptoms is a belief that it is a normal part of old age and something one must live with. This barrier is apparent in both men and women.

In an international survey study of 4246 postmenopausal women living in Sweden, Finland, the United Kingdom, the United States, and Canada between the ages of 55-65 conducted by market research institute YouGov Zapera A/S, 28% of women did not tell their partners about their vaginal discomfort because they thought it was "just a natural part of growing older".[40] There also was a report of stoicism regarding female urinary symptoms, in that women felt it was something they must put up with.[41] In a phone survey of postmenopausal women aged 45-65 who were not receiving hormone therapy, 51% agreed that they learned to live with vulvar and vaginal symptoms as a normal part of getting older.[42] As such, a majority of patients would count the symptoms as a natural process of getting older than seek urologic care.

Men too have been reported to avoid medical attention due to attributing symptoms to a normal part of aging. Interestingly, care seeking for urinary and sexual symptoms is higher amongst men compared to women.[43] A study in Central Scotland found that men aged 50 and older associated developing urinary symptoms with aging.[44] Furthermore, the study reported that despite urinary symptom interference with daily activities, men believed it was not a sufficient reason alone to consult their general practitioner. Instead, only specific symptoms, such pain, hematuria, and acute retention warranted seeking medical care.[44] With regards to ED, a survey of Australian men demonstrated a decreasing level of concern regarding loss of erectile function with escalating age groups. This coincided with older patients being less likely to seek out treatment as compared to the younger aged cohorts.[18] Likewise, a population-based study in Minnesota showed that although ED increases with age, older men are less likely to perceive it as a problem compared to younger men,[45] a finding that was replicated in other studies.[20,21] Notably, a decline in sex drive may be a potential confounder in the findings of reduced care seeking for ED with increased age. However, an international survey of male health issues provides evidence against this. The study found that 47% of men with ED either somewhat or strongly agreed that "when you have this sort of problem, you must learn to accept it" but only 8.5% of men agreed that they were too old for sex.[46] This finding suggests that lack of sex drive was not a primary reason for accepting ED as a normal part of aging among older men.

UI, ED, and GSM are indeed associated with aging. Proper patient education on this may assist in patient understanding of onset. However, anticipatory guidance should be provided at annual well-visits that treatments are available. Addressing the belief that the conditions are a normal part of aging and therefore must be accepted is an easy area of intervention that physicians can take to reduce care avoidance.

PERCEIVED CAUSE OF PROBLEM

Another barrier that may impede conversations between physicians and patients is patients' perception of their problem's etiology. Patients may believe their symptoms are secondary to something that either does not necessitate medical attention or cannot be fixed. This phenomenon has been most widely documented with ED.

Evidence of this phenomenon has been reported with respect to prostate cancer. Treatment of prostate cancer has a significant adverse effect on erectile function.[47] However, one study found that men treated for prostate cancer may be better able to cope with ED than those without prostate cancer.[48] It was suggested that men who have received treatment for prostate cancer are able to place their ED into perspective by weighing the importance of treating their cancer. This is in comparison to men suffering from ED without prostate cancer, who may view their ED through the prism of lack of "manliness" as the source of the problem. Effectively, the cancer alleviated the burden of self-blame, as the treatment was likely responsible for the ED.[48] A second study exploring ED's burden in men with treated prostate cancer found a significant association between depressive symptoms and impaired erectile function. The authors noted that a positive treatment prognosis led to decreased worrying and concerns about the cancer, and instead increased distress related to the side effects of treatment.[49] Importantly, the latter study did not conclude distress from ED was the result of self-blame. Thus, the presence of prostate cancer does not prevent distress from ED but may allow for protection from self-blame.

Similar results have been demonstrated with other etiologies as well. An Australian telephone survey reported 25% of patients did not seek medical care for their ED due to the belief that the problem was caused by medication side effects or other disorders.[18] This finding was echoed by a study of sexually inactive couples, who attributed the inactivity to the male partner's physical health.[19] In both cases, ED was attributed to specific causes, prompting the men to disregard seeking care.

Ultimately, the burden of ED may be mitigated by a perception that ED arose secondary to causes beyond oneself. This, in effect, may provide a protective effect from believ-

ing they themselves are at fault for the problem. As a result, patients fail to seek care as they perceive the problem is due to something that cannot be fixed. Further exploration of this topic is warranted to clearly elucidate this conclusion, however.

DEGRADING

As previously mentioned, ED may result in self-blame. The degrading effects may mount a barrier to the desire to seeking medical help. In essence, patients felt stripped of their masculinity and sexual identity. It was reported that men oftentimes expressed a deep sense of disappointment, describing feelings of frustration, shame, and anxiety. As a result of their ED, they "did not feel like a man".[50] In fact, some reports suggest upwards of 69% of men deny the existence of their ED.[10,21] Moreover, even men receiving treatment for ED reported a tendency to avoid sexual situations due to fear that their treatments may fail, causing their ED to be known to others.[50]

KNOWLEDGE OF EXISTING SOLUTIONS

Lack of medical awareness may play a major role in care seeking. For instance, patients who do not realize treatments are available may subsequently be less likely to seek treatment. In 1999, it was reported that as many as 76% of patients were concerned that there was no medical treatment for their sexual problems.[51] With the high accessibility of internet services and engagement with social media, these rates have likely decreased. However, one study from 2010 showed as many 42% of women did not know there was treatments available for vaginal atrophy.[40] An international study of postmenopausal women suggested that most women used over-the-counter treatments for vaginal atrophy, with 46% of respondents noting they were unaware of local estrogen therapy.[52] The low awareness of available treatments may be connected to a stigmatization of discussing vaginal conditions.[40]

Without conversations amongst family, friends, and physicians, patients miss opportunities to learn from others' experiences. Ultimately, this results in poor awareness of treatment availability and in turn, lack of care seeking.

EMBARRASSMENT

Embarrassment was cited amongst the most common reasons as to why patients did not seek care. Across different countries in North America and Europe, between 47-66% of postmenopausal women reported embarrassment as the main reason for not discussing vaginal atrophy with their physicians.[40] Another survey conducted in British women aged 55 and older demonstrated that 13% of women who did not seek medical care for painful intercourse or vaginal dryness attributed it to embarrassment. The same study also reported 10% of women said they would be too embarrassed to discuss vaginal itching or soreness, and painful intercourse.[41] Notably, this barrier extended beyond the patient-physician relationship. One survey reported that 5.9% of women with vaginal discomfort did not tell their partners due to embarrassment.[53]

Men too expressed a sense of embarrassment. In an Australian telephone study of men older than 40, approximately 19% of survey respondents cited the inability to talk about their erection problems as their reason for not seeking medical care.[18]

Another manifestation of embarrassment was in relation to provider characteristics, more specifically, the physician's gender. Most sources have reported a majority (54-80%) of patients have no preference in the gender of their urologist. However, when gender preference was expressed, the desire was for a gender concordant urologist.[54-57] Interestingly, it was also reported that certain situations were associated with a gender preference. For instance, it was found that patients with UI expressed a gender preference,[57] as did patients who had a condition they considered embarrassing.[56]

SOCIETAL VIEWS

While many health-related issues are generally perceived to be personal, a societal stigmatization regarding the open dialogue of genitourinary conditions fuels communication barriers. Indeed, a strong belief that certain conditions are inappropriate to discuss has resulted in hesitancy seeking care and poor dissemination of reliable health resources. These issues are well illustrated in women's health. It was reported that 47% of women agreed that acknowledging they were experiencing menopausal symptoms was a societal taboo.[42] The physician's office has not been immune to the consequences of these feelings. An online survey across 13 countries found that 25% of women felt uncomfortable discussing vagina-related issues with their healthcare providers.[58] These findings have been unintentionally created through teaching young girls it is inappropriate to discuss conditions of the vagina. This is best highlighted by the finding that 33% of women admitted to receiving negative vagina-related messages during childhood.[58] The consequences of this messaging have also manifested as poor availability of resources on the topic. Less than 40% of women said they had read an informative article about the vagina. Because of this, the International Vagina Dialogue Survey concluded that young women felt societal taboos surrounding the vagina contributed to their ignorance about urogenital and sexual health.[58] Patient hesitancy in raising issues has been worsened by physicians also neglecting to address the topic. A European survey reported that only 11-12% of healthcare providers initiated a discussion on GSM with patients, with a finding as low as 5% in the United Kingdom.[53] Discussion of the topic generally relied upon the patient initiating the discussion.

Because of the existence of a significant societal stigmatization on certain issues, a strong patient-physician bond is critical toward generating comfort in discussing sensitive topics. Unfortunately, however, it was reported in one European study that only 48% of participants felt a close relationship with their physician.[24] An unintended consequence of this impaired relationship may be a fear of dismissal by the physician, perpetuating a possible hesi-

tancy in seeking care. One study found women were hesitant to raise their concerns of vaginal atrophy symptoms as they believed healthcare providers will be dismissive of them.[42] A poll in the United States found that 71% of survey respondents felt their doctors would dismiss their concerns about sexual problems if brought up. Despite this, however, 85% of the respondents also said they would still raise the topic even if they felt they would not receive treatment.[51] Fortunately, this finding provides hope physicians may still be able to address concerns, though improvements in creating a safe environment to raise the issues is still needed.

Building a trustworthy connection between patients and physicians may assist in decreasing the communication barriers surrounding urogenital conditions. Reducing the societal stigma remains a difficult feat, yet a significant area capable of bettering healthcare.

THE DIGITAL AGE

In this current digital age, marked by high engagement with social media and an extensive availability of resources (i.e. google), patients may feel more inclined to seek answers privately than to seek professional help. One study examined patients with and without chronic gynecologic pain. The authors found that patients with pain were more likely to use social media and the internet to understand and manage their condition. Additionally, these patients were significantly more likely to trust information on social media, other women with the same condition, informal health resources, and personal sources more than physicians and formal health resources.[59] Both males and females were equally likely to engage in social media and internet searches for answers. A report of the most common social media queries for urogenital conditions by gender included low sex drive by females and low sex drive and premature ejaculation by males.[60] Women were reported to have a stronger social motive for and experience greater enjoyment in health-related information searches. In contrast, men were more open to engaging in virtual visits with general practitioners.[61] These findings provide great insight in how targeting health information may be most effective from a policy perspective. Indeed, as the power of information transmission grows and engagement with social media strengthens, it is imperative that physicians recognize how patients are consuming information. Social stigmas surrounding genitourinary conditions may encourage information seeking from less reliable sources.

CONSEQUENCES

If left untreated, genitourinary conditions are associated with a poor quality of life[62] and may significantly impact mental health, including precipitation of depression or anxiety. For example, an inability to control urine can result in frequent bathroom trips and public accidents. This in turn may generate embarrassment with an avoidance of social settings. This was highlighted by a cross-sectional internet survey of men and women in the United States, United Kingdom, and Sweden conducted to estimate the prevalence of LUTS on health-related quality of life, mental health, care utilization, work productivity, and sexual functioning; this study showed a significant correlation between LUTS and worse mental health. Patients with mixed UI (stress and urgency) had the worst rates of anxiety, with 47% of men and 49% of women reporting clinically relevant anxiety. Additionally, 42% of men and 34% of women with mixed UI had clinically relevant depression.[43] Indeed, other studies have also noted the toll of UI, including high rates of depression, less work productivity, and lower sexual satisfaction.[63] Moreover, UI has a high economic burden[64] and severe UI may lead older patients to need placement in a long-term care facility.[7]

Similarly, the negative personal and social reactions surrounding ED can lead to avoidance of sexual activity.[65, 66] Unsuccessful sexual episodes may activate negative schemas related to incompetence.[67] Anxiety regarding sexual performance can then further perpetuate ED, creating a vicious cycle.[68] Avoidance of sexual activities can be correlated with higher rates of depression. Several studies have established a link between ED and depression.[49,69-71] While social stigma may hinder conversation around the topic, ED can perpetuate various mental health concerns; given that anxiety and depression surrounding ED can further perpetuate the problem, it is important to recognize and treat mental health quickly as a negative feedback loop may occur. In fact, treatment of ED with PDE5 inhibitors has been shown to improve quality of life scores.[24] Unfortunately, reports show that most patients with distressing ED do not seek help.[66]

CONCLUSION

Genitourinary conditions have been heavily stigmatized by society. The result of this has created an environment where patients are hesitant to seek help. As noted in the review, this hesitancy has manifested in numerous ways, including embarrassment, a belief of having to live with it, and even a lack of knowledge of existing solutions. Importantly, this stigmatization has led patients to seek information privately, which may not be reliable. Oftentimes, patients will not be seen in clinic for treatable genitourinary concerns because of social stigma such as embarrassment or mischaracterizing it as a natural process of aging. It is imperative physicians understand which patients may be hesitant to seek help, how patients are consuming information, and methods that can effectively target patients. Indeed, many solutions have been proposed to address this disparity. The easiest solution physicians can implement is being proactive in generating discussion. For example, men presenting with cardiac or metabolic disease should prompt physicians to screen for ED.[24,72] Additionally, identifying patients who are not likely to self-initiate discussion can expedite evaluation and management. This can be accomplished by identifying their tendency to be proactive or reserved.[73] Finally, implementing purposeful questioning and screening surveys would potentially benefit all patients.[74] Outside of the medical office, public health sur-

veys and approaches calling for normalization of urologic care can also be beneficial. Working with mass media, social media, and the Internet promoting genitourologic care through interviewing and media personalities can allow for enhanced exposure of the topic and reduced stigma to approach such care. Positive exposure on top of more trustworthy sources online may allow for an easier transition for patients to seek office based care. Working to reduce societal stigmatization is the best, yet most difficult solution. However, while trying to change societal perceptions, implementing these simple solutions can provide immediate help to at-risk patients. Normalizing discussions surrounding genitourinary conditions in society can help mitigate and improve the mental health concerns surrounding stigma for urologic care.

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