Urinary Incontinence in the Pre-Menopausal Woman and Impact on Quality of Life

Jacqueline Skene Kirk
jackiekirk1@verizon.net

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Molloy College
The Barbara H. Hagan School of Nursing and Health Sciences
PhD in Nursing Program

URINARY INCONTINENCE IN THE
PRE-MENOPAUSAL WOMAN AND IMPACT ON QUALITY OF LIFE

a dissertation

by

JACQUELINE SKENE KIRK

Submitted in partial fulfillment of the requirements for the degree of

Doctor of Philosophy
Molloy College

The dissertation committee of the Barbara H. Hagan School of Nursing has examined the dissertation titled

URINARY INCONTINENCE IN THE PRE-MENOPAUSAL WOMAN AND IMPACT ON QUALITY OF LIFE

Presented by JACQUELINE SKENE KIRK, MSN, RN, MBA, RN, ANP-BC

A candidate for the degree of Doctor of Philosophy

And hereby certify that the dissertation was read and approved by the committee.

Margarita Whelan

Margaret Whelan, EdD, RN, FNP-BC (Chairperson)
Professor, The Barbara H. Hagan School of Nursing & Health Science

Judith James-Borga, PhD, RN (Committee Member)
Associate Professor, The Barbara H. Hagan School of Nursing & Health Science

Victoria Siegel

Victoria Siegel, EdD, RN (Committee Member)
Professor, The Barbara H. Hagan School of Nursing & Health Science

Veronica D. Feeg

Veronica D. Feeg, PhD, RN, FAAN (Director of the PhD Program)
Associate Dean, The Barbara H. Hagan School of Nursing & Health Science, Molloy College
Abstract

Background

Urinary incontinence (UI) is a medical condition that plagues millions of women worldwide, negatively affecting their quality of life. UI is the involuntary release of urine or what women refer to as having “accidents.” Women suffering from UI often feel embarrassed and become socially isolated. The majority of studies in the literature focus on UI in postmenopausal women. However, very few studies explore the lived experience of living with UI as a premenopausal woman, who are at a time in their lives when they are involved in their careers, having intimate relationships with their partners, and are raising their children.

Purpose

The purpose of this phenomenological qualitative study was to uncover the lived experiences of premenopausal women living with UI and how it impacted their quality of life. The participants shared their stories and were able to shed light on this seriously overlooked and underestimated problem. The knowledge gained from the findings of this research study may help inform the generation of knowledge for both the patient and the provider, nursing practice, and academia.

Methods and Participants

A qualitative hermeneutic design was used in this study to discover the essence of living life with UI on the quality of life of premenopausal women. Telephone interviews were conducted with 13 premenopausal women from May to July 2021.

Results

Five essential themes emerged from the study: (1) Fictitious Dialogue, (2) Strategic Planning, (3) A Walk in My Shoes, (4) Sailing on a Sea of Emotions, and (5) Barricades and
Barriers to Care. Excerpts from the recorded transcripts were used to elucidate and illustrate the meanings that the experience of living with UI had for these women.

Major Findings

This study yielded a deeper understanding of the lived experiences of premenopausal women living with UI and permitted greater insight as to how this phenomenon impacted their quality of life. Their stories closely paralleled findings in the literature but also illuminated quality of life issues unique to this subset of women. Impacts of UI on body image, work, anxiety and depression, and intimacy were all uncovered. Barriers to care have been uncovered in prior studies, but this study reinforced how prevalent a problem this is to treating women expeditiously. Important rich data collected from this study provide an impetus for future research to further explore this phenomenon.
Dedication

For my father who sowed the seed that anything, with hard work, is possible

For my husband who nurtured that seed

For my children who encouraged that seed to bloom
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CHAPTER 1: STATEMENT OF THE PROBLEM

Problem Statement

Urinary incontinence (UI) is a common distressing medical disorder that affects approximately 50% of American women during their lifetime and millions of women around the world. It is also known as “loss of bladder control” or “urinary leakage” and is thought to affect up to 70% of women at some point in their lives (Milsom & Gyhagen, 2019). UI is the leakage of urine before one can “make it” to a bathroom. Some women may lose a few drops of urine when they laugh, cough, or sneeze, while others may feel a sudden urge to urinate and be unable to control it. Recent studies have discovered that UI prevalence among women increases with age, from 20% to 30% in young adult women, increasing to 30% to 40% in middle-aged women, and 30% to 50% in the elderly. It is at least twice as prevalent in women as in men (Albeirs-Heitner et al., 2008). Of these women, only 25% seek care, and of those, less than half receive treatment. This condition is associated with significant decrements in function and quality of life (Aoki et al., 2017; U.S. Department of Health and Human Services, 2010).

UI negatively impacts quality of life (QOL) for women, making the individual feel uncomfortable, distressed, and inadequate due to continuous wetness and irritation. In addition, UI causes negative psychosocial effects such as continuous leakage of urine and fear of smelling bad and feeling unclean. It can also result in decreased self-esteem, deterioration of body image, stigmatization, embarrassment, and decreased sexual desire. It has been reported that affected women withdraw from social activities such as exercising, shopping, and visiting friends due to the fear of odor and possibility of discovery. They see themselves as lacking and insufficient; lose their sense of attractiveness and sexual desirability; thus experiencing loneliness, depression, and distress (Gumossoy et al., 2019).
Women are often too embarrassed to talk about UI and feel that it is an inevitable part of aging. Despite what many patients believe, UI is not a normal result of aging. It is a pathological condition that affects QOL. Patients who have incontinence are more likely to have depression, limited social and sexual function, and dependence on caregivers (Khandelwal & Kistler, 2013; Saiki & Maize-Grochowski, 2019).

UI not only affects QOL, but it is also very expensive. The overall cost of UI to society, including all ages and genders, is 26.3 billion dollars annually. It is estimated that the annual cost of routine care of UI is $50 to $1,000 per person (Gumussoy et al., 2019).

In light of the magnitude of this problem, this researcher elected to study the impact of UI on premenopausal women and their QOL as they navigate through the health care system through the lens of an interpretive hermeneutic, qualitative phenomenological study to fully explicate the problem that living with UI has for these women from their perspective, so their voices can truly be heard. This population of women has not been studied extensively in terms of living with UI and how it impacts their QOL. Human science studies persons, but phenomenology seeks to understand an individual’s lived experience of a phenomenon, shedding light on the meaning the phenomenon has for the individual. Underpinned by Heidegger’s interpretive philosophy, this qualitative hermeneutic, interpretive phenomenological approach will facilitate the exploration of this phenomenon with participants’ views and experiences from their emic perspective.

This chapter attempts to showcase what continence is and what it is not, how it affects QOL in the pre-menopausal woman, and to understand her lived experience with UI.

Pre-menopausal women were chosen for this study because the literature is rich with studies on post-menopausal women, as menopause itself is a leading cause of incontinence. In
post-menopausal women, estrogen levels drop, the muscles and tissues in the pelvis lose strength and support due to the lower levels of collagen, and organs may prolapse, which for many causes incontinence (Rabin, 2008). In the literature, however, premenopausal women are often overlooked. The reported prevalence of UI is 26% to 58% in young and middle-aged women, with a paucity of epidemiological data addressing the prevalence and risk factors for UI (Luo et al., 2016; Peyrat et al., 2002).

Pre-menopausal women are an interesting subset of women with which to examine the phenomenon of UI. They are at a time in their lives when they are typically enjoying career success and satisfaction, are involved with their children and their activities, and are, for the most part, enjoying satisfying sexual relationships with their partners. Experiencing UI in this age group has, according to the literature, the potential to alter and impede their QOL and is therefore an important avenue to explore.

**UI and Premenopausal Women**

The literature is rife with documentation on UI in the post-menopausal woman, but a paucity exists on the premenopausal woman, particularly, the lived experience of living with UI and the meaning that it has for her. According to the literature, the prevalence of UI is between 44% and 57% among the middle-aged and postmenopausal women, but it is also prevalent in 25% of younger women (Luo et al., 2016), including nulliparous women. This percentage may be higher, as UI tends to be under-reported.

The premenopausal woman of today is involved in many life challenges. She is most likely in the throes of parenting her children. By age 40, 84% of women have had children (Barletta, 2007). In addition to parenting duties, most women in this age group have a very full plate, as they are the family’s health guardian, school liaison, housekeeper, vehicle upkeep
manager, home services coordinator, inventory manager, bill payer, chief purchasing officer, travel/vacation planner, and social scheduler. The demands of motherhood, which might include hours at a swim meet or soccer field, would be particularly devastating for a woman suffering from UI. She may fear discovery by her children or her peers that she suffers from incontinence. Many premenopausal women are at a time in their lives when they are enjoying satisfying careers. Living with UI might be particularly difficult for the attorney trying a case, school teacher, or an operating room nurse who may not have the opportunity to take a bathroom break, worrying about urinary leakage and embarrassment. According to Karbage et al. (2016), 68% of premenopausal women are sexually active. A young woman with UI might be so concerned about embarrassing herself by leaking urine and odor, that she might deny herself and her partner an important component of a satisfying sexual partnership. The premenopausal woman is no stranger to the barrage of advertisements promoting perfection and beauty. Our Western culture promotes the thin-young ideal via direct association of youth with beauty, acceptability, fame, and value (Kilpela et al., 2015). A young woman with UI might develop a poor sense of self and body image, as she is relegated to wearing bulky feminine undergarments under her clothing or athletic wear, as well as limiting her social interactions to avoid embarrassment.

**Purpose of Study**

The purpose of this phenomenological study was to investigate the lived experience of premenopausal women with UI, gaining a better understanding of their perceptions of QOL as they navigate through the healthcare system. According to Munhall (2012), phenomenological research is significant, as we can demonstrate its significance not by numbers, but by stating the implications for change that emerge from the interpretation on the meaning of various experiences. Results from a phenomenological study can be used for policy development and
change in practice, which increase our capacity for care and compassion, emancipation from oppression, and an increase in consciousness of what was not known or otherwise erroneous (Munhall, 2012). Information gleaned from interactions with each participant has the potential to inform change in practice that may expedite the treatment for this group of women that were otherwise overlooked.

Every woman with frequency, urgency, or urge incontinence—either premenopausal or postmenopausal—deserves to be recognized and treated. It is hoped that this study would bring clinicians and providers closer to an understanding of living with this phenomenon and the need for women to step forward and start enlisting their providers to become more familiar with their disorder and treat them more expeditiously. To quote Florence Nightingale,

In dwelling upon the vital importance of sound observation, it must never be lost sight of what observation is for. It is not for the sake of piling up miscellaneous information or curious facts, but for the sake of saving life and increasing health and comfort. (Nightingale, 1859/1946, p. 70).

An understanding of any causal relationship between UI in the premenopausal woman and QOL can hopefully lead to interventions to maintain or restore urinary continence in this age group, thus contributing to improved health and QOL.

**Research Design**

A descriptive phenomenological qualitative approach was used in this dissertation study, which centers on the common meaning of the lived experience of a phenomenon or what the participants share in common as they experience a phenomenon. The collection and analysis of the data show the essence of the phenomena as well as the *what* and the *how* of an experience. The epistemological perspective of a qualitative study involves the researcher getting as close as
possible to the participants being studied and meeting them where they live and work. The phenomenological approach used in this study was interpretive or hermeneutic, where the focus was on what humans experience rather than what they know, with the assumption that their realities are influenced by the world in which they live and their daily experiences. A phenomenological design was chosen for this study to gain a description of a human experience that is felt and seen through the eyes of the participant, which cannot be measured in quantitative terms (Creswell, 2013).

Phenomenology studies the structures of conscious experience as experienced from the first-person point of view, along with relevant conditions of experience. The central structure of an experience is its intentionality, the way it is directed through its content or meaning toward a certain object in the world. Conscious experiences have a unique feature, because we experience them, live through them, or perform them. We may observe other things in the world, but we may not necessarily experience them, in the sense of living through or performing them. Phenomenology addresses the meaning that things have in our experience—notably, the significance of objects, events, the flow of time, the self, and others, as these things arise and are experienced in our world. Essentially, phenomenology studies the structure of various types of experience, ranging from perception, thought, memory, imagination, emotion, desire, and volition, to bodily awareness, embodied action, and social activity, including linguistic activity (van Manen, 2006).

The philosopher, Martin Heidegger, who greatly influenced qualitative phenomenological research, advocated for the interpretation of experiences. He rejected the notion of the human being and subject as a spectator of objects espousing that both subject and object were inseparable. For Heidegger, “being” was thus the descriptions or accounts that “Dasein” (being
there or man’s existence) provided of their everydayness or ordinary existence (Heidegger, 1927/2011, p. 38). From the Heideggerian perspective, the meaning of being human in an experienced situation can be answered in the participant’s own words, as they form expressions of meaning, which will then bring into play the life-worlds, the situated context, and contingency (Munhall, 2007).

With the interpretive or hermeneutic phenomenological approach espoused by Heidegger, presuppositions or expert knowledge on the part of the researcher are valuable guides to inquiry and make it more meaningful (Creswell, 2013).

In phenomenological studies, the researcher often brackets oneself out of the study by discussing personal experiences with the phenomenon, which often help to guide the questions. The researcher is not taken completely out of the study but sets personal experiences aside to better focus on the participant’s experiences (Creswell, 2013). The researcher’s knowledge base leads to specific ideas about how the inquiry needs to proceed to produce useful knowledge.

This research study used the philosophical underpinnings of Merleau-Ponty (2014), which focuses on the human in the lived experience, embodiment, and meshing of the individual and the world. The philosophical underpinnings provide a framework for researchers to seek understanding of the content of experiences in the abstract way individuals experience living in the world. The perception of the human experience is not just a mental state but also how individuals ascribe meaning to tangible things, according to Merleau-Ponty (2014) who is an advocate for phenomenological reduction in order to reach an original awareness. To help us view our experience in a new light, not relying on the categories of our reflective experience, a pre-reflective experience is necessary (Dowling, 2005).
Methods

The research methods of van Manen were utilized in this study. According to van Manen, the purpose of phenomenological research is to establish a reconnection with the original experience and give individuals an opportunity to look at the world and re-examine the meaning of the event (Creswell, 2013). Also, van Manen believed from a research perspective that phenomenological questions are meaning questions (Munhall, 2007). According to van Manen (1990),

Natural science studies objects of nature, things, natural events, and the way that objects behave. Human science, in contrast, studies persons or beings that have consciousness and that act purposefully in and on the world by creating objects of meaning and that are expressions of how human beings exist in the world. (p. 4)

This study used hermeneutic interviews for data generation. In this method, the researcher is the primary instrument for collecting data (Pezalla et al., 2012). For hermeneutic interviews, van Manen (1990) suggested developing a conversational relationship with each participant about the meaning of the experience. Beginning questions with “What is it like…” was suggested by van Manen (2006, p. 40) as a way to gather data and develop relationships.

Qualitative Approach

Phenomenological studies explore the lived experiences of individuals regarding a particular phenomenon and provide a greater understanding and awareness of the meaning such individuals attribute to their experiences (Creswell, 2013). In phenomenological research, it is essential that researchers decenter themselves and adopt a perspective of unknowing. Decentering involves reflecting on one’s own beliefs, preconceptions, intuitions, motives, and biases. Paradoxically, unknowing is another form of knowing. Knowing that you do not know
something or that you do not understand someone is critical to the evolution of understanding meaning. Unknowing is an art and calls for a great amount of introspection. It is essential to understand ourselves and each participant in our study as two distinctive beings, one of whom the researcher does not know. Each of us has a unique perspective of our situated context and a unique perspective of who we are as individuals in the world. This is our perspective, our worldview, and our reality. When the researcher and the participant meet, two perspectives of a situation need to be recognized (Munhall, 2012).

It has been said that phenomenology can liberate one from preconceptions. The researcher in a phenomenological study is, to use a metaphor, the “research tool” or the “research instrument” (Munhall, 2012). To be truly authentic and effective, the researcher is asked to do something that is impossible to do but to do it to the greatest extent that is possible. Researchers are tasked with clearing their vision and thinking from assumptions, prior knowledge, belief systems, and any other noise that might prevent the clear listening to others about the meaning of the experience. Usually, we assume that we knew something about what we were seeing, only to find out that we had misperceived (Munhall, 2007, p. 170).

Phenomenological inquiry does, however, have suppositions. The suppositions are clearly articulated in the foundation of the phenomenological approach to being-in-the-world. We do not decenter ourselves from phenomenology; in fact, it guides us through the entire study. What we do decenter from are presuppositions, beliefs, values, knowledge, thoughts, and ideas about the experience we are studying and attempting to understand without the overlay of prior knowledge (Munhall, 2012).

In this study, the researcher embraced the task of becoming introspective and attempted to block out the noise about the meaning that the experience of living with UI has for each
participant so that authentic meanings and understanding evolve. She decentered herself from prior knowledge gleaned from her experience as a clinician and an exploration of the literature and instead adopted a perspective of unknowing (Munhall, 2012).

Research Question

The interview question, based on van Manen’s phenomenological search for the lived experience, was: “What is your lived experience of living with UI and how does it impact your quality of life?” The researcher also used probes such as: “How does having UI affect your quality of life?” Other probes were derived from QOL surveys that were tailored to women with UI and concepts related to UI found in the literature. The thread of questioning was led by the responses given by the participants as they discussed the phenomenon of living with UI and its importance to them. Interviews began after gaining verbal, then written consent from the participants. The interviews were recorded using two digital voice recorders (one as backup), with the participants’ permission. At the conclusion of each interview, each participant verbalized that they had shared everything to their satisfaction. Several participants were asked in the office setting to discuss findings and validated their earlier responses.

Probes:
The participants were asked to describe feelings that come to mind when thinking about UI.

- Describe how living with UI impacts how you feel about yourself.
- Describe how UI has impacted your lifestyle in terms of travel, socializing with friends, work, physical activity, and interacting with others.
- Describe how living with UI has impacted your social relationships.
- Describe your medical journey getting treatment for your UI.
- Describe if and how UI has affected your sexual relationships with your significant other.
Philosophical Perspective

In qualitative studies, theory is a way of asking or inquiring that is guided by a reasonable answer. If you have a reasonable answer in mind for your research question that is being proposed, then you can proceed with a specific theory as a focus. Although theories and conceptual models help to stimulate research and the extension of knowledge by providing both direction and impetus, this researcher opted to not try to predict the evolving phenomena with a priori conceptualizations or impose any restrictions that might bias the collection and analysis of data. Preconceived views of the phenomenon were held in check. However, this researcher was guided in her inquiries by a framework or philosophy that focused the analysis on certain aspects of a person’s life, such as those found in the literature. That framework is based on the premise that human experience is an inherent property of the experience itself, not constructed by an outside observer (Polit & Beck, 2012).

Definition of Terms

Urinary continence: The voluntary loss of urine from the urethra.

Urinary incontinence (UI): The involuntary loss of urine from the urethra. UI is defined by the International Continence Society as the complaint of any involuntary leakage of urine (Wiers & Keilman, 2017). It is the lack of urinary control or the inability to control urination. According to E. Stewart (2018), UI is experienced by an estimated 200 million women worldwide. There are several types of UI. Many women do not report their symptoms to healthcare providers due to embarrassment, their misconception that it is a normal part of aging, and their low expectations of successful treatment. The frequency of urine loss can be characterized as less than once per month, 1 to several times per month, 1 to several times per week, 1 or 2 times per day, or 3 or more times per day. The amount of urine lost can be quantified as a few drops, small amount,
moderate amount, or large amount. UI can be defined as any urine loss or leakage that occurs at least monthly. Symptoms are classified as stress, urge, or mixed, based on the description of events preceding leakage (Wiers & Keilman, 2017).

**Menopause:** The cessation of menses for at least 12 consecutive months. During this time in a woman’s life, the body makes progressively less of the hormones progesterone and estrogen. Menopause onset is typically between the ages of 45 and 55 (Centers for Disease Control and Prevention, 2011; Taebi et al., 2018). Changing hormones contribute to a woman experiencing symptoms that include hot flashes, mood swings, forgetfulness, vaginal dryness, weight gain, insomnia, and UI (Prairie et al., 2015).

**Pre-menopause:** This refers to the time period before menopause, when the ovaries stop functioning, resulting in the loss of the menstrual period uninterrupted for 12 months (Bener & Falah, 2014; Rathnayake et al., 2019). Premenopausal women are, for the most part, at a time in their lives when they are still raising their children, enjoy being active, are involved in satisfying work and careers, and are enjoying intimate relationships with their partner. According to an article by Karbage (2016), 68% of premenopausal women were sexually active.

**Perimenopause:** This refers to the time when the ovaries gradually begin to make less estrogen that usually starts in a woman’s 40s but can start in her 30s or even earlier. Perimenopause lasts up until menopause, the point when the ovaries stop releasing eggs. It begins with the first onset of menstrual irregularity and ends after one year that amenorrhea has occurred, or the last menstrual period (Santoro, 2016). In an article by Cipullo et al. (2014), estrogen hormones may have a role in the mechanism of continence. Estrogens increase urethral blood flow and induce the maturation of urethral and bladder cells (Cipullo et al., 2014; Kolodynska et al., 2019).

**Quality of Life (QOL):** This refers to the standard of health, comfort, and happiness
experienced by an individual or group. According to Yates (2017), UI significantly affects quality of life. Patients may become depressed, experience sexual dysfunction, or loss of respect or self-esteem.

**Self-esteem:** The affective evaluation of one’s self concept, which is the cognitive evaluation of oneself or how one feels about oneself. Sanford and Donovan (1984) described *self-esteem* as “the reputation you have with yourself.” In a study by Gumussoy (2019), it was found that the majority of women with UI had moderate or low self-esteem. There was a correlation between self-esteem and the amount and frequency of urine leakage.

**Body image:** Body image is made up of perceptions, thoughts, and feelings a person has about one’s body (Cash & Smolak, 2011; Kilpela et al., 2015) and is thus an important component of an individual’s self-concept and identity. It is influenced by interactions with other people, media, and advertisements, and shapes an individual’s understanding of how society expects them to look and act (Kilpela et al., 2015; Wertheim & Paxton, 2011). Conversely, negative body image has been described as negative thoughts about one’s body and the discrepancy between a person’s ideal and current body image (Cash & Smolak, 2011; Kilpela et al., 2015). A young woman with UI may suffer behavioral responses that can severely and negatively impact her psychological and physical health (Gumussoy et al., 2019; Patrick et al., 1999).

**Sensuality:** The enjoyment, expression, or pursuit of physical, especially sexual pleasure.

**Intimacy:** There are multi-dimensional aspects to intimacy. It is referred to as the depth of exchange, both verbally and/or nonverbally, between two persons, which implies a deep form of acceptance of the other as well as a commitment to the relationship (Schafer & Olson, 1981). Although this definition is dated, it remains a classic. For partnered women, managing chronic
UI occurs in the context of an intimate partnership and affects the quality of the relationship (Saiki & Maize-Grochowski, 2019).

**Economic Burden**: A term used to describe problems a patient has related to the cost of medical care. According to Health Care Financing Review (1997), the costs related to the diagnosis and treatment of UI in the US exceeded $26 billion by Medicare expenditures for the population over age 65 in 1995. In 1998, Medicare spent less on dialysis and coronary bypass grafting combined than for costs related to UI. The costs for absorbent products are usually not covered by private or government programs, so costs are assumed by individuals. Data for costs per year of these products are not easily tracked, for they are not covered by insurance or Medicare, and many adults elect to treat their condition privately, relying on pads, diapers, and frequent clothing changes. However, in 2009, women spent $70 per case of 14, resulting in an annual cost of $1,825 (Smith et al., 2009). Kimberly Clark, the manufacturer of Depends and Poise, estimates that more than 65 million Americans experience some type of bladder leakage, with a 12% continued growth for 2019 in product sales (Kimberly-Clark, 2020). A newswire by Global Market Insights predicts the disposable incontinence products market to cross $15 billion by 2025 (Global Market Insights, 2019). The cost to the environment from disposable diaper use is also high. The amount of adult diapers entering the waste stream in Japan, for example, cites an increase of nearly 13%, to almost 1.5 million tons annually in the past five years, according to data from the Environment Ministry. It is projected to grow a further 23% by 2030, when those 65 and older will represent close to a third of the population (Rich & Inoue, 2021).

**Urinary Incontinence**

The etiology of incontinence is not fully understood, as this problem affects both men and women of all ages and can be the result of many changes in the human body. By definition,
it is the involuntary loss of urine via the urethra, which can develop as the result of many risk factors including immobility associated with chronic degenerative disease, diminished cognitive status and delirium, medications, smoking, fecal impaction, low fluid intake, environmental barriers, high-impact physical activities, diabetes, stroke, estrogen depletion, pelvic muscle weakness, pregnancy, vaginal birth, and episiotomy (Aoki et al., 2017; Fantl et al., 1996). It can be initially evaluated by primary care providers (PCPs) without a urologic or gynecologic examination (Khandelwal & Kistler, 2013).

Continence results when the organs of the kidneys, bladder, and brain, the ureters and urethra, sphincter and pelvic floor muscles, as well as the spinal cord function properly. The upper urinary tract consists of the kidneys and their attached ureters. The lower urinary tract consists of the bladder and the urethra. This fine interplay of lower urinary tract support and normal functioning of the sphincter muscles results in continence (Rabin, 2008; Samuels et al., 2019).

The bladder is essentially a storage tank. The front part of the brain, the cerebral cortex, controls when and where to urinate, coordinating with the back part of the brain, or pons, which allows the bladder, urethra, and pelvic floor muscles to work together effectively and efficiently. The bladder is located in the lower abdomen and is responsible for the storage and elimination of urine. As urine enters the bladder via the ureters, the bladder relaxes, continually allowing an increasing amount of fluid without a significant increase in internal bladder pressure. When it empties, it resembles a deflated balloon. As it fills again, it begins to resemble a pear. The detrusor muscle, located within the bladder wall, expands as urine is stored, and deflates when it is eliminated. During storage, a ring of muscles at the bottom of the bladder, the urethral sphincter, holds the urine. This remains closed and increasingly tightens as the bladder fills with
urine. As the bladder fills, signals are sent to the receptors in the cerebral cortex, telling it what is occurring, while other inhibitory signals are sent from the brain to prevent the premature emptying of the bladder (Rubin, 2008; Samuels et al., 2019).

The bladder neck, an opening located at the bottom of the bladder, connects to the urethra. It is surrounded by muscles that keep it closed so that urine remains in the bladder until it is released during voluntary urination, where the bladder muscles contract and the bladder neck muscles relax. After urination, the urethra closes and the bladder relaxes again. Continence is reliant on several active and passive properties of the detrusor muscle and the urethra. The detrusor is passive when it is filling and active when it is emptying. The urethra is active when it is filling and passive when it is emptying. Normal detrusor function allows the bladder to fill with little or no change in pressure. Detrusor overactivity is characterized by involuntary detrusor contractions during the filling phase. During urination, sphincters relax and open as a result of signals from the brain and pelvic floor muscles. The internal and external sphincters control the storage and elimination of urine. The internal sphincter squeezes the urethra closed, while the external sphincter is controlled by the individual, so that coughing, sneezing, and laughing will not result in bladder leakage. These sphincters work together, expanding and contracting as the bladder fills and empties. Nerves automatically are sent to the muscles, ensuring that the sphincters remain closed and therefore one remains continent (Rubin, 2008; Samuels et al., 2019).

When enough urine has collected in the bladder and it has filled to where its internal pressure has increased and its bladder wall has stretched, the nervous system sends a message to the brain to signal the detrusor muscle to relax the internal sphincter muscle. The external sphincter muscle then tightens, resulting in an urge to void. Then, the external sphincter relaxes,
resulting in the flow of urine. There is a unique interplay among messages between the brain and spinal cord, which control the bladder, bladder neck, urethra, and pelvic floor muscles, and are responsible for one’s continence or incontinence. When each system involved in bladder control receives and responds appropriately to these messages, continence is achieved. A breakdown, however, in communication among these systems, which may be caused by a physical or mental condition, results in incontinence (Rubin, 2008; Samuels et al., 2019).

Incontinence occurs as a result of anatomic abnormalities or a disruption in any point of the micturition process. It is usually caused by problems with muscles and nerves that help to hold or pass urine. A diagnosis of UI is based on assessment of incontinence type. The most common types of incontinence are stress urinary incontinence (SUI), urge urinary incontinence (UUI), and mixed urinary incontinence (MUI). SUI is the involuntary leakage of urine that occurs with increased intra-abdominal pressure, such as coughing, laughing, bending, lifting, straining, sneezing, or jumping. Urge incontinence is described as the involuntary leakage of urine accompanied or immediately preceded by a sudden uncontrollable urge to urinate. This type of incontinence can often include large-volume urine loss at socially inconvenient and unpredictable times, particularly compared to SUI, which occurs with more predictability (Aoki et al., 2019; Schimp et al., 2009). MUI is when leakage occurs with both symptoms of stress and urgency (Wiers & Keilman, 2017). SUI is seen more in younger women, UUI steadily increases with age, and MUI is from a combination of the two (Blaseck-Smith et al., 2019). About a third of adults with UI have MUI, which is often more severe than SUI and UUI (Aoki et al., 2019; Norton & Brubaker, 2006).

SUI is an involuntary loss of urine on effort, physical exertion, sneezing, and coughing that affects 200 million people worldwide, with the median prevalence of female UI being 27%.
It is age dependent, more common in the younger age group, but also occurs in older women. SUI often remains undetected and undertreated due to embarrassment, lack of knowledge about treatment options, fear of surgery, or belief that it is an inevitable part of aging. Although not associated with increased mortality, SUI affects physical activity; social contacts; sexual contacts; emotional state; sleep; physical, psychosocial, and economic well-being; as well as health-related QOL. According to Shaikh et al. in 2018, SUI adversely impacts QOL by contributing to depression, anxiety, and social isolation.

Urodynamically, SUI is defined as occurring when intravesical pressure exceeds maximal urethral closure in the absence of detrusor activity. SUI can be divided into two types: First, anatomic is described as the inability of the urethra to close due to the displacement of the urethra below the pelvic floor during periods of increased intra-abdominal pressure. Second, intrinsic sphincter deficiency is most often described as incompetence of the urethral sphincter mechanism (Aoki et al., 2019; Bradway, 2004).

Much of the pathophysiology of SUI could be due to muscle, nerve, and connective tissue injury from childbirth. Direct muscle damage results in an inability to augment support to the bladder neck and symphysis pubis. Vascular damage as a result of compression of the fetal head could affect both muscle and nerve components (Norton & Brubacker, 2006). A woman’s history of a vaginal delivery increases her risk of developing SUI over the course of her life. Only one vaginal delivery is sufficient to increase the risk. An episiotomy, use of forceps, or vacuum assist, can damage the muscles of the pelvic floor, altering the support of the urethra and bladder. The number of vaginal deliveries does not come into play, as one alone is enough to cause trauma. Most problems with bladder control during pregnancy dissipate after the muscles have time to heal, and some women who have had vaginal births never develop incontinence, but
some women continue to suffer due to weakened pelvic floor support and damage to nerves that control the bladder (Ducarme et al., 2019; Kaveler, 2006).

Family history is also noted as a key determinant in the risk of developing UI. No studies have been done on this link directly, but women report that their mothers had the same problem but never talked about it. Many mothers of the previous generation would never talk to their doctors about their problem and would certainly not discuss it with their families (Kaveler, 2006; Milsom & Gyhagen, 2019).

UUI is defined as the inability to inhibit detrusor contractions, leading to urine loss. The pathophysiology of urge incontinence is complex and has several categories as a result. Detrusor hyperreflexia occurs in the presence of a neurological disorder. Detrusor instability or idiopathic detrusor instability is characterized by urinary urgency, normal, or increased bladder sensation; and premature, spontaneous, detrusor contractions during bladder filling. As mentioned earlier, during childbirth, the urethral sphincter can become damaged, resulting in UI. Another important concept with these women is that they may undergo an anatomical or neuromuscular injury during childbirth but remain clinically asymptomatic as long as there is compensation by other components of the continence mechanism. After childbirth, trauma, and loss of pelvic floor muscles, a woman might not have incontinence until she loses a small percentage of muscle strength and innervation to the urethral sphincter because of aging or other injuries, and that small loss could alter the balance in favor of UI instead of continence (Norton & Brubaker, 2006). Clinical and epidemiological studies have shown increased risk of pelvic floor disorder, particularly UI, among women who delivered vaginally as compared to women who did not, with the first vaginal delivery most injurious to the pelvic floor (Lipschuetz et al., 2015).

More recently, the terms overactive bladder (OAB) and detrusor overactivity
Incontinence have been introduced to describe urinary urgency, frequency, and nocturia, with or without UI, or leakage due to an involuntary detrusor contraction (Aoki et al., 2017; Bradway, 2004). OAB is defined by subjective symptoms, rather than objective measures, so the patient’s perspective is important in its management (Hung et al., 2013). Although some systemic neurological disorders result in urge incontinence, most UUI is regarded as idiopathic. Relevant clinical conditions include spinal cord injury, where damage toward the head at the sacral level results in bladder overactivity. Diseases such as Parkinson’s could be mediated by alterations in dopamine receptors that increase excitation and lower the threshold for micturition. Stroke causes a loss of inhibitory neurons, resulting in detrusor overactivity (Norton & Brubacker, 2006; Thomas et al., 2019).

When considering factors that predispose one to the occurrence of UI, genetics stands out. It appears that UI is higher in women whose ancestors suffered from UI. Age is also an important factor, as UI increases in direct proportion to age. In postmenopausal women, the incidence of UI is doubled. A very important factor is the number of pregnancies and births, particularly those induced with oxytocin. It is suggested that cesarean deliveries are safer in terms of the development of UI. The probability of UI also increases when the weight of the fetus exceeds 4 kg. Another important factor is obesity, with the most dangerous being abdominal obesity. Studies show that obese women are four to five times more likely to suffer from UI than those of normal weight. Among other factors that may affect the occurrence of UI but are ignored or improperly treated are urinary tract infections; chronic constipation; diabetic neuropathy; Parkinson’s disease; multiple sclerosis; polyradiculopathy; and drugs or medications such as diuretics, anti-hypertensives, and anxiolytics. Another risk factor is chronic respiratory disease, particularly those extending from a cough, which results in an increase in abdominal
pressure (Kolodynska et al., 2019). Other causes that contribute to UI are:

- **Constipation**: Individuals with long-term or chronic constipation are prone to developing UI.

- **Medicines**: Certain medications can cause UI as a side effect such as diuretics, used to treat congestive heart failure, hypertension, and kidney disease. Hormone replacement also contributes to worsening UI symptoms.

- **Caffeine and alcohol**: Beverages such as coffee, tea, or sodas cause the bladder to fill quickly and occasionally leak.

- **Obesity**: Being excessively overweight places pressure on the bladder, resulting in an increase in incontinence.

- **Infection**: Infections of the urinary tract and bladder may cause short-term incontinence, usually abating when the illness subsides (U.S. Department of Health and Human Services, 2010).

It is thought that UI is the result of environmental influences such as pelvic floor damage during childbirth and aging, but may also be attributed to genetic influence. Altman et al. (2008) studied 3,376 monozygotic and 5,067 dizygotic same-sex female twin pairs and suggested a genetic influence on SUI.

The etiology of UI is not fully understood but is thought to be the result of bodily changes. Treatment should be initiated conservatively, which should include pharmacology, physiotherapy, and behavioral therapy.

**How UI Impacts QOL**

Despite the high prevalence rate of UI, the majority of women approach UI as more of a social problem and a taboo than a medical problem. They hesitate to talk about the problem, and
most only consult a doctor at least a year after the problem begins. Although UI is not life threatening, it affects the QOL for women, making the individual feel uncomfortable, distressed, and inadequate due to continuous wetness and irritation. In addition, UI causes negative psychosocial effects such as continuous leakage of urine and fear of smelling bad, as well as feeling unclean. It can also result in decreased self-esteem, deterioration of body image, stigmatization, embarrassment, and decreased sexual desire. It has been reported that affected women withdraw from social activities such as exercising, shopping, and visiting friends, due to the bad smell and the possibility of being discovered. They see themselves as lacking and insufficient, and they lose their sense of attractiveness and sexual desirability, thus experiencing loneliness, isolation, depression, and distress (Gummossoy et al., 2019). Overall QOL declines as their preoccupation with bladder control worsens. Women with UUI have a lower QOL than women with heart disease, cancer, and depression (Kaveler, 2006).

UI occurs in about 20% to 30% of young women, 30% to 40% in middle age, and up to 50% of older women (Kolodynska et al., 2016). The most current epidemiologic data suggest an overall prevalence of 17% in women older than 20 years and 38% in women over the age of 60. It is estimated that 200 million women worldwide live with this dysfunction, which results in limitations in daily activities and impairs QOL. Only 25% of affected women seek care, and of those, only half receive treatment. Untreated incontinence is associated with falls and fractures, sleep disturbances, depression, and urinary tract infections (Aoki et al., 2019; Schreiner et al., 2010).

UI is not only the problem of the older woman, as 34% of post-partum women experience UI at 3 months and 20.7% at 6 months. Maternal emotional well-being and physical health during recovery in the postnatal period has important implications for clinical practice, as UI is
associated with the significant likelihood of depression at 6 to 7 months following childbirth (Tyrala-Seweryn et al., 2017). It has been shown that women who suffer urinary leakage three months postpartum will continue to do so five years later (Lipschuetz et al., 2015).

**Body Image**

Body image is an important component in examining one’s QOL. It is made up of the perceptions, thoughts, and feelings a person has about his or her own body. Conversely, negative body image has been described as negative thoughts about one’s own body and the discrepancy between a person’s ideal and current body image. Body image research has primarily focused on young adult females, but more recent research has expanded to include other age groups. More similarities than differences have been identified between younger and older women. Body image is influenced by interactions with other people and the media. These interactions help to shape a person’s understanding of how society helps him or her to act and look. A link exists between body image and self-esteem, a person’s sense of value, and physical health (Avants, 2014).

**Depression**

UI cannot be mentioned without discussing associated effects such as depression (Avery et al., 2015). Major depression and UI are prevalent distressing disorders that disproportionately affect women, with one fifth having major depression and nearly one-half reporting incontinence during their lifetimes. These illnesses are a major public health concern because of the many affected, adverse effects on functioning, and QOL decrements. This cross-sectional relationship between depression and UI could be explained by common neurologic or biochemical pathways underlying both conditions. The increased activity of the hypothalamic-pituitary axis seen in depression could also result in physiologic changes that contribute to involuntary urine loss.
Alternatively, the chronic embarrassment, social isolation, and symptom burden associated with UI could lead to depression over time (Luo et al., 2016; Melville et al., 2009).

Because of recent pharmacological research demonstrating the efficacy of serotonin-norepinephrine reuptake inhibitors in SUI, there has been an impetus for increased attention to the tendency for these disorders to co-occur and their combined impact on patients’ QOL. New studies suggest that OAB and depression may be linked through the serotonergic pathway (Lai et al., 2016), since antidepressant medications such as duloxetine is known to manage both symptoms (Mishra et al., 2015).

Depression is one of the significant factors determining female sexual dysfunction, linked to UI. Young females, averaging 38.3 years of age, experiencing sexual dysfunction had much higher Beck Depression score (24%) compared to those without the dysfunction (Tyrala-Seweryn et al., 2017).

**Impact of Incontinence on Sexual Function**

According to the World Health Organization, female sexual dysfunction is defined as an inability to derive satisfaction from the sexual act (Karbage et al., 2016). UI not only adversely affects QOL in terms of embarrassment and social isolation, but it is also linked with sexual dysfunction. Sexuality is an essential aspect of a woman’s life, and the quality of sexual life inevitably affects the general well-being of people (Caruso, 2017). Sexual health is a state of physical, emotional, mental and social well-being associated with sexuality; it is not only the absence of disease, dysfunction, or infirmity (Mestre et al., 2015).

It was found that over 50% of sexually active incontinent women suffer from sexual dysfunction as a result of their urinary symptoms and 1 in 4 are incontinent during sexual intercourse (Beji & Nalcin, 2004; Mota, 2017). In Beji’s study, the key finding was the existence
of an association between sexual satisfaction and urine leakage during coitus, leading to low sexual desire and deferring intercourse altogether (Beji & Nalcin, 2004; Mota, 2017).

There are several reasons for the association between UI and sexual dysfunction. Lack of libido and self-esteem due to fear of leakage are major factors, and urinary leakage during penetration or at orgasm plays a role.

**Financial Considerations**

UI places a significant financial burden on individuals, their families, and healthcare organizations. The current estimate on taxpayer dollars for UI is 66 billion dollars per year on routine care associated with incontinence, including diapers, pads, breakdown care, and sequelae associated with living with UI such as treatment from a fall as the result of UI. Patients pay out of pocket for 70% of conservative management, such as diapers and pads, amounting to a significant individual financial burden (Chong et al., 2011).

**Care-Seeking Barriers**

Despite the significant burden that UI places upon women, only about 3% of health care providers inquire about UI, 25% to 50% of women with UI seek care, and 23% to 38% receive treatment. A number of studies have examined the reasons that women suffering from UI are not seeking help. Women often consider their symptoms to be too trivial or not problematic enough, irrespective of objective severity. Women are less likely than men to seek help for UI symptoms, despite reporting more bother. Women also experience symptoms for years prior to seeking treatment. When women are driven to seek help for pelvic floor dysfunction, increased symptom severity—especially when linked with declining physical and psychosocial well-being—is usually the driving force (Tinetti et al., 2018).

Women’s search for medical help is influenced by several factors, including the general
understanding and interpretation of the disease itself, type and severity of the medical condition, available information regarding treatment opportunities, economic reasons, and the type of health care financing system that operates in such health care settings. Furthermore, the prevailing socio-cultural views of a particular medical condition could either be enabling or inhibiting to seeking help by the one suffering (Adedokun et al., 2018).

Explanations for delays in treatment are unclear, although lack of awareness or expertise by PCPs may play a role. Often, PCPs are the gatekeepers of women’s healthcare, and unfamiliarity with these conditions could influence the rate at which treatment is obtained. In women with UI symptoms, 75% did not have the proper diagnosis documented in their medical records, which might indicate a lack of diagnostic confidence reported by general practitioners. When women did report symptoms to a provider, the majority were not referred to an appropriate specialist (Mazloomdoost et al., 2018).

Other often-quoted reasons for not seeking help are belief that UI is a natural result of childbirth or a normal part of aging. These beliefs are accompanied by a lack of knowledge of treatment options, embarrassment, and fear of invasive procedures. People who do seek help can be unsuccessful in acquiring treatment for their condition if communication between the provider and the patient fails (Shaw et al., 2001). Many PCPs are uncomfortable diagnosing and treating possible UI, so they often refer to specialties such as gynecology. Weirs and Keilman (2017) documented a woman who sought UI help from her PCP. She was then referred to gynecology, where she was offered surgery for her problem. This was not an acceptable solution for the patient, so she decided to live with her problem, dramatically changing her lifestyle to avoid public embarrassment. This lack of information on the part of the PCP seems all too common. The National Association of Nurse Practitioners in Women’s Health surveyed 300 nurse
practitioners to ascertain their own level of recognition and treatment of OAB in their practice and found that most respondents could identify common symptoms of OAB and its adverse effects on QOL. However, more than half reported that they lacked confidence in their ability to accurately identify OAB, and more than half reported lacking sufficient knowledge to effectively treat OAB. Barriers to changing practice may have included a lack of provider confidence in discussing UI, lack of training in clinical examination, and lack of diagnosis and treatment of OAB. Advanced practice nurses who reported a higher level of education regarding UI had more accurate perceptions, more positive attitudes, and more knowledge regarding older adult women with UI than those who reported lesser levels of education on UI (Ngigi, 2017).

Nonpharmacological approaches and nonsurgical interventions can be offered in primary care and have been shown to be effective at improving or achieving continence and improved QOL (Wiers & Keilman, 2017). PCPs should be familiar with UI risk factors and be on the front lines of prevention, diagnosis, and treatment, starting with vigilant screening of adult women and other at-risk populations.

With PCPs often being women’s first contact with the healthcare system, it would likely be a public health benefit to encourage providers to screen for and recognize pelvic floor disorders. However, there is little information about the extent of knowledge of or comfort with the diagnosis of pelvic floor disorder among PCPs (Mazloomdoost et al., 2017).

All women over the age of 18 can be systematically screened for urine leakage. PCPs can screen women by asking them, “Do you ever accidentally leak urine?” To open up the discussion. Modifiable risk factors for UI should be determined early on with the patient and, as with all risk factors, the more a patient has, the more he or she is likely to develop the condition. Clinicians can differentiate the type of UI by asking patients under what conditions does leakage
occur such as coughing, lifting, laughing, bending, sneezing, straining, and/or with a sudden uncontrollable urge to void without being able to make it to the toilet in time. Screening for urine leakage should be done by the clinical support staff and PCPs. Once urine leakage is identified, the PCP should conduct a systematic evaluation and develop a holistic plan of care. A thorough investigation at the time of urine leakage is unlikely feasible, as most patients do not present with this issue as the primary reason for scheduling the office visit (Wiers & Keilman, 2017). Once diagnosed, patients should be educated that UI is never considered normal and that effective non-surgical interventions are available. These women should be encouraged to schedule a dedicated incontinence visit.

After performing a complete physical exam to unearth any health problems that might cause incontinence, the provider may perform several tests that will show how efficiently the bladder works and its capacity to hold urine. These include:

- **Bladder Stress test**: The patient will bear down or cough as the provider watches for the loss of urine.
- **Urinalysis**: A urinalysis will test the urine for signs of infection that might be causing the incontinence.
- **Ultrasound**: Sound waves visualize the kidneys, bladder, and urethra.
- **Cystoscopy**: A thin tube is inserted into the urethra, connected to a camera, to visualize the inside of the urethra and bladder.
- **Urodynamics**: A thin tube is placed into the bladder and the bladder is filled with water. This enables the provider to measure the pressure inside the bladder (Aoki et al., 2017, U.S. Department of Health and Human Services, 2010).

In a dissertation by Ngigi in 2017, it was found that clinic providers in Walgreens, where
the majority of patients are between 18 and 49, did not screen for OAB. However, the patients were screened for urinary tract infections. Often, the patients may have had a normal urinalysis but complained of urgency and nocturia. These women were not likely to divulge this information unless the providers asked them pointedly, “When you get up at night to void, do you pass a lot of urine each time or just a small amount?” Based on the literature, many women believe that some amount of incontinence is inevitable with aging and the majority of women with these symptoms do not talk with their health care providers about their concerns with bladder function. As a result, many women with OAB experience delays in treatment (Ngigi et al., 2017).

Patients with UI tend to hide their symptoms and avoid this discussion with their PCP. All providers should ask their patients about urinary symptoms, including UI, during regular check-ups, even when patients do not broach the subject. Patients will thank PCPs for asking them and for the opportunity to improve their QOL (Park, 2013).

**Misconceptions and Myths**

Women are reluctant to seek help for UI because they believe these myths:

- **I’m too young to be incontinent:** The reality is that young women can also be incontinent secondary to over-exercise, childbirth, or injury. One-third of female athletes are incontinent while participating in their sport.

- **It’s too late for me:** The reality is that incontinence is highly treatable.

- **Leaking does not make me incontinent:** Actually, any leaking—no matter how scant—is a symptom of incontinence and needs to be addressed.

- **Incontinence comes with age:** This is untrue, as most older women remain continent.

- **All I need is a pill or a diaper:** In reality, these treatments have terrible side effects and
do not address the real problem.

- **Incontinence is untreatable:** Actually, there are many options today for UI (Rabin, 2008).

**Treatment**

The treatment of UI involves a stepwise plan that starts with behavioral recommendations. First-line treatment includes lifestyle modifications such as weight loss, exercise, smoking cessation, constipation management, prompted voiding, avoidance of bladder irritants such as carbonated/caffeinated beverages and artificial sweeteners, pelvic floor muscle therapy, bladder training, habit training, behavioral training such as Kegel exercises, and topical vaginal estrogen. Women should take their time voiding and follow these steps: Void, take a break, stand up, then try again to void to make sure you are completely empty; always wipe from front to back to avoid urinary tract infections; avoid bubble baths and shower instead; drink enough fluids a day—half your weight in ounces of water. PCPs should familiarize themselves with first-line treatments and incorporate them into their practice. Pharmacologic treatment in SUI is not advised, and pharmacologic treatment in UI and MUI is only advised after pelvic floor muscle therapy fails to achieve therapeutic goals. Women who do not achieve their goals require a referral to a specialist. The PCP should cultivate collaborative relationships, with specialty providers sharing the goal of improving continence for women utilizing evidence-based guidelines, thereby improving the lives of women and reducing health care expenditures (Wiers & Keilman, 2017).

Various drugs are available to treat UI, depending on the underlying etiology. In the United States, there are currently no drugs that have been approved for SUI. Surgery is the go-to option providing the highest treatment cure, though it is suggested to be done only after the
woman opts to have no more children, as pregnancy and childbirth can potentially cause damage and more leakage to recur (Lukasz et al., 2020). Unfortunately, few pharmacologic treatments have been studied for SUI (Park, 2013).

For many individuals, UUI is so severe that they must rely on medications to manage their condition. If UI is caused by detrusor overactivity or low bladder compliance, the therapy is to eliminate or suppress involuntary detrusor contraction medically or surgically. An initial approach is the prescription of an antimuscarinic drug, used most often to treat UI or MUI, which targets the bladder smooth muscle and leads to relaxation. If UI is caused by sphincteric dysfunction, the therapy is to strengthen the pelvic floor muscle or sphincter medically or surgically. Examples of anticholinergic or antimuscarinic medications include Enablex, Toviaz, Ditropan, Oxytol, Vesicare, Detrol, and Sinctura. There is only one beta adrenergic medication—namely Myrbetriq. All of these medications, however, cause uncomfortable side effects such as constipation and dry mouth. They may even cause urinary retention, rapid heart rate, drowsiness, and confusion, so they must be used with caution by the elderly (Lukasz et al., 2020).

There are several drugs available, with new drugs on the horizon that will specifically target lower urinary tract receptors (Aoki et al., 2017; Cipullo et al., 2013). Advances in pharmacological options have dramatically improved the QOL of patients suffering from UI. Of interest is the presence of estrogen receptors throughout the lower urinary tract, which indicates that hormones may have a role in the mechanism of continence. Estrogens seem to increase urethral blood flow and maturation of urethral and bladder cells.

Besides lifestyle changes, there are other treatment modalities that have been found to be helpful.

- Acupuncture is used as a treatment option.
• Percutaneous Tibial Nerve Stimulation. A small needle is inserted into the tibial nerve above the ankle and connected to a battery source that provides impulses to the nerve that innervate the muscles in the bladder. After 12 weeks, many patients see a reduction in their urgency.

• Botox. Botulinum toxin A is injected into the bladder via a cystoscope, often providing up to six months of relief from urgency. This treatment is usually performed after an individual has failed alternate treatments. It has to be repeated, as the results fade over time.

• Sacral neuromodulation. This modality involves a stimulator that is surgically implanted into the sacral nerve in the lower back. Impulses are electrically sent to the sacral nerve, which helps with urge incontinence, as well as frequency and urinary retention (Lukacz et al., 2020).

Role of the Nurse

According to Stewart, continence care is a significant aspect of healthcare, and an assessment should be the responsibility of the nurse. They should be proactive in asking patients about their continence status. Prompt treatment can prevent deterioration that could result in surgical management other than conservative management. A literature review by Morishita et al. (1994) identified that little is known about the theoretical frameworks and teaching strategies used for promoting UI education for nursing students.

Summary

UI is highly prevalent and associated with significant impairment to QOL, including embarrassment, shame, isolation, and depression. It places a significant economic burden on the patient, including impaired work productivity and activity. Based on the literature, many women
feel that UI is an inevitable part of aging and do not mention it to their healthcare providers for years (Hartman et al., 2016), although it is highly treatable. Healthcare providers and nurses are key players in the recognition of this condition who must be better informed in the diagnosis and treatment of UI and be willing to question women and engage in a conversation on this sensitive topic, bringing it to the forefront. The forthcoming interviews aim to shed light on the individual through shared experiences of what it is like living as a young woman with the condition of UI and how it impacts QOL.
CHAPTER 2: LITERATURE REVIEW

UI is a common condition in women that is under-reported and under-treated (Luo et al., 2016; Norton & Brubaker, 2006). The literature is rich in studies on the deleterious effects of menopause on UI, but there is very little research on UI in the premenopausal woman, who are at a time in their lives when they are involved in family, careers, and intimate relationships. This chapter summarizes what is known about UI in all women, to serve as an understanding of this condition and how it affects their QOL. The definitions and concepts found in the literature do not necessarily apply to the participants in this study but can act as a guide to inquiry. The development of a close and trusting relationship between the researcher and each of the interviewees can ultimately unfold the true meaning that UI has for them.

Literature Search

The literature search began with a search of titles, abstracts, and keywords through the Molloy library resources. Peer-reviewed journals and books were researched using these keywords: urinary incontinence, barriers to care, urinary incontinence and sexuality, quality of life and urinary incontinence, providers knowledge on urinary incontinence, depression and urinary incontinence, and UI and premenopausal women.

Databases that were assessed included Google Scholar, PubMed, CINAHL, EBSCOhost, and OVID. Some articles were obtained via interlibrary loan. Articles were all peer-reviewed and preferably less than 10 years old, although some concepts related to UI are timeless and were therefore cited.

Urinary Incontinence

UI is globally recognized as a public health problem that causes a great deal of personal distress. It is considered a significant disease of morbidity worldwide, contributing to personal
economic burden that extends to the workplace. The literature reveals that women are often too embarrassed to report UI and may not disclose bothersome symptoms for years (Jopling & Meier, 2020).

UI is a condition that plagues women worldwide and affects all races and ethnic groups. A 2006 quantitative study by Thom compared the prevalence of UI by type among White, Black, Hispanic, and Asian-American women in a cohort of middle-aged and older women. The prevalence of weekly incontinence was highest among Hispanic women, followed by White, Black, and Asian-American women. This study was of interest, in that most studies to date have been limited to White women. The limitations to studies comparing groups are problematic since any differences could be due to differences in incontinence definition, population selection, or study design (Thom, 2006).

UI affects younger women as well as middle-aged and older women. A study by O’Halloran et al. (2012) examined UI in young Australian nulligravid women in a sample of women aged 16 to 30 years, with the mean age of 22.5 years. This was a cross-sectional, self-administered, questionnaire-based study with 1,002 participants. The researchers concluded the rate of UI in this population was 12.6% and more common in students than non-students. Women with UI reported significantly lower overall well-being than women without UI (O’Halloran et al., 2012).

Perimenopause

Perimenopause is the time in a woman’s life when the ovaries gradually begin to make less estrogen. It usually starts in a woman’s 40s but can start in her 30s or even earlier. Perimenopause lasts up until menopause, the point when the ovaries stop releasing eggs. In an article by Cipullo et al. (2014), estrogen hormones may have a role in the mechanism of
continence. Estrogens increase urethral blood flow and induce the maturation of urethral and bladder cells. This group of women often have children at home, are enjoying quality work and careers, enjoy being active, and enjoy satisfying intimate relationships. Additionally, according to an article by Karbage et al. (2016), 68% of pre-menopausal women were sexually active.

A 2002 study by Peyrat et al., looked into the prevalence of risk factors for UI in young and middle-aged women in a French academic hospital using anonymous questionnaires. In their quantitative study with 1,700 women, with a mean age of 40 years, it was found that UI increased with age > 40, with pregnancy, previous vaginal delivery, postpartum incontinence, and hysterectomy, especially for SUI. There was no relationship between obesity or previous Cesarean delivery (Peyrat et al., 2002).

In 2000, Moller, Lose, and Jorgensen studied the prevalence and bothersomeness of lower urinary tract symptoms in women 40 to 60 years of age. Four thousand women in a randomized longitudinal cohort study were recruited in Denmark and were asked to fill out a questionnaire. The prevalence of lower urinary tract symptoms was 27.8% for occurring more than weekly and 16.1% for UI. The prevalence of SUI increased from 40 years up to 55 years of age. Irritative symptoms such as urge incontinence and urgency steadily increased in a linear fashion with increasing age. Incontinence symptoms were stated to be the most bothersome. The significant increase in irritative symptoms of urge and urge incontinence during the perimenopausal period agrees with findings in other studies. Although the increase is followed by a decrease in estrogen production, any causal relationship has yet to be confirmed (Moller et al., 2000).

Urinary Incontinence and Menopause

There are many studies in the literature that focus on post-menopausal women with UI. In
fact, menopause itself is a risk factor in the development of UI due to the rapid decline in estrogen levels during menopause. With menopause, muscles and tissues in the pelvis lose strength and support due to the lower levels of collagen, and organs prolapse, which for many causes incontinence (Rabin, 2008).

**Impact of UI on QOL**

UI greatly affects QOL. Women suffering from this medical condition often experience poor self-esteem secondary to feeling ashamed and fearing that they are unclean and smell bad. It affects their social life, as they often fear being discovered, therefore curtailing activities that they previously enjoyed. Incontinent women also avoid sexual activities, fearing leaking during intercourse and feeling offensive to their partner (Saiki & Meizer-Grochowski, 2019).

In a 2016 Brazilian study by Keles et al., two groups of sexually active women over the age of 18 with UI were investigated to determine if erectile dysfunction of the partner was attributed to their UI. They were able to conclude that erectile dysfunction in the partners of women with UI may be adversely affected by the UI of their partners and that these partners should also have treatments planned for them as well. Seventy-five women participated in this study and were asked to have their partners fill out a validated 5-item International Index of Erectile Function questionnaire. This study used a small sample size, which is a limitation to this study.

Suffering from UI affects the way women feel about themselves. Significant psychosocial sequelae of UI have been well documented in the literature. Researchers who investigated midlife women’s perceptions of the effects of managing symptoms of chronic UI found recurrent themes of lowered self-esteem, feeling unfeminine, and feeling unattractive. Women reported that one of the biggest reasons they sought surgery for their incontinence was to improve their
body image and their confidence. They wanted to regain a positive view of themselves as being feminine and sexually desirable (Saiki et al., 2019).

QOL theory is an overall theory or meta-theory measuring global QOL. In essence, QOL means a good life composed of the subjective (how an individual perceives his or her life), the existential QOL (a deeper level of meaning such as spiritual or religious), and objective QOL (how one’s life is perceived by the outside world and influenced by the culture in which people live). It reveals individuals’ ability to adapt to the values of the culture that they live in.

In reviewing QOL literature, Vigod and Stewart (2006) explored the relationship between UI and major depression through data from the Canadian Community Health Survey. In this Level 1 study, the prevalence of depression was 15.5% in women with UI (30% in women ages 18 to 44) and only 9% in women without UI. Regardless of how the two disorders are related, the combined impact of UI and major depression exceeds the impact of either condition alone.

A 2015 Australian study by Mishra et al. sought to examine the association of depressive symptoms with subsequent UI symptoms among young women in a Level 1 study. Data were obtained from a cohort of 5,391 young women born between 1973 and 1978. Twenty-four percent of women reported the incidence of UI over the 9-year study period with the prevalence rising over time, suggesting significant public health implications for the prevention and treatment of UI (Mishra et al., 2015).

Mary Stewart (2001) explored the concept of self-esteem in a quantitative study using the Rosenberg Self-Esteem scale. Five positively worded statements and five negatively worded statements comprised the 10-item Likert-type scale. The Rosenberg Self-Esteem scale has been identified as the most appropriate measure for self-esteem in older adults. Self-esteem was measured at baseline in this Level 1 study and after receiving biofeedback in 15 women. No
significant correlation was found in scores before and after the intervention, concluding that self-esteem is not a function of urinary continence in this small study. Limitations to the study were the small sample size and only studying post-menopausal women (Stewart, 2001).

The subtypes of UI are associated with different risk factors, mechanisms, symptoms, and concomitant diseases. Previous studies, however, do not make clear how UI subtypes affect psychological state and QOL, including sexual life. According to the literature, MUI decreases the QOL most, followed by pure UUI and then pure SUI (Asoglu et al., 2013).

To assess a comparison in QOL in women with UUI versus SUI, Schimpf et al. (2009) studied 465 women in a Level 1 study, using validated questionnaires. All domains on the Pelvic Floor Distress Inventory revealed lower QOL scores among women with UUI compared to other women. Patients with UUI also reported a significantly lower frequency of sexual activity. In addition, UI has been correlated with depression in multiple studies, with incontinent women two to three times more likely to suffer from depression.

UI causes negative psychological effects such as continuous leakage of urine and fear of smelling bad, feeling unclean, decreased self-esteem, deterioration of body image, stigmatization, embarrassment, and decreased sexual desire. In 2019, Gumussoy et al. performed a descriptive study on 218 patients to investigate the effect of UI on body image, self-esteem, and QOL. The study used the Socio-Demographic Characteristics Questionnaire, Body Cathexis Scale, Rosenberg Self-Esteem Scale, and Incontinence Quality of Life Questionnaire for this Level 11 study. The results of the study found that the majority of women with UI had negative body image, moderate to low self-esteem, and a moderate QOL. Limitations to the study were that it was a convenience sample using a cross-sectional design. The participants were voluntary, posing a bias, and only 1 hospital was sampled, which limited generalizability.
A population-based study by Hagglund et al. (2004) studied changes in UI and QOL after four years in a Level 1 study. The follow-up questionnaire, which was the same as four years prior, used the SF-36 Health Survey, the Detrusor Instability Score, and three complementary questions about UI. The objectives of the study were to investigate the incidence and remission rates of UI, changes in types of UI and QOL, and whether professional help had been consulted regarding UI. The participants included 118 incontinent and 130 continent women between the ages of 22 and 50. The mean annual incidence and remission rates remained the same along with unchanged UI after 4 years. The QOL scores decreased in five dimensions among women with UI compared to women without incontinence. However, three out of four women with UI had not sought professional help.

Further development of the Incontinence Quality of Life Instrument was conducted on 288 incontinent women by Patrick et al. in 1999. Factor analysis confirmed an overall score and three subscale scores (avoidance and limiting behaviors, psychosocial impacts, and social embarrassment). The instrument showed good internal consistency, reproducibility, and validity. This Level 1 study confirmed the significant impact that UI has on the QOL of women, particularly those with moderate to severe UI. This study shows the relevance of QOL to this condition and an important outcome measure used to assess UI and its treatment (Patrick et al., 1999).

OAB is a constellation of symptoms consisting of urinary urgency, frequency, nocturia, and incontinence that has considerable detrimental effect on multiple domains of patient QOL. A Level 111 review by Jayarajan and Radomski (2014) searched for randomized controlled drug trials in adults with OAB and QOL. Trials have shown a significant QOL improvement in patients with OAB compared with placebo patients, following the use of anticholinergics,
Mirabegron, and botulinum toxin. The QOL burden of OAB patients is reflected in health utility scores, which are among the lowest when compared with other chronic conditions, such as asthma, diabetes, heart disease, malignancy, and migraine headaches.

The Body Image Quality of Life Inventory has been used to compare QOL related to body image among different populations, under different conditions and cultures. The inventory assesses the impact of body image on various aspects of life: emotions, social contact, food, sexuality, emotional well-being, exercise, and relations among friends, family, work, and school. Assuncao and Dantos (2013) studied the use of this tool on 77 Brazilian burn victims. The tool was found in this population to have statistically acceptable levels of reliability and validity in this Level 1 study.

**Impact of QOL on Sexual Function**

The debilitating consequence of UI interferes with a woman’s social well-being; psychological, occupational, and domestic aspects; and contributes to sexual function. Incontinence during sexual activity affects up to one-third of patients, and fear of UI during intercourse contributes to sexual dysfunction. Al-Shaikh et al., (2006) in a Level III study, highlights the use of pessaries as a good option for the treatment of UI. Prospective studies have found that their use with successful fitting yielded improvement in patient satisfaction levels.

Karbage et al. (2015) sought to assess the impact of UI on sexual function on 251 Brazilian women in a quantitative Level 1 study. Their findings were that women with sexual activity tend to be younger and premenopausal, have a steady partner, and were not hypertensive. Premenopausal women in this study with MUI had worse sexual function than those with SUI.

Kammerer-Doak (2009) reviewed sexual function questionnaires, a Level III study, with a focus on the experience and publications of validated sexual function questionnaires in the uro-
gynecologic literature. Most of the questionnaires included only a few questions on sexuality and focused primarily on QOL issues. There are surveys on sexual function alone but few condition specific. The use of validated questionnaires showed that Pelvic Floor Dysfunction, which includes pelvic organ prolapse and urinary and fecal incontinence, was associated with a negative impact on sexual function.

A study by Jha (2016), Level 111, studied the impact of treatment of OAB with anticholinergics and its impact on sexual function. This was a prospective observational questionnaire study with 34 women followed up to six months. Only 8% of the women had an improvement in sexual function, compared to 66% who experienced an improvement in OAB symptoms. Treatment in OAB symptoms does not, therefore, ensure an improvement in sexual function. Premenopausal women were analyzed separately, as menopause can impact on sexual function as an independent variable. Limitations were small sample size and that women were on a range of anticholinergics that may affect sexual function in different ways.

Caruso (2017) studied the effects of UI subtypes: SUI, UUI, and MUI on women’s sexual function and QOL, in a Level 1 study. Ninety-three women participated in this observational study using the short-form 36 questionnaire, Female Sexual Function Index, and Female Sexual Distress Scale. Women with MUI showed a significantly higher impairment of sexual function compared with the other groups. Women with MUI and UUI had more orgasmic disorder than the SUI group, and women with MUI and SUI had lower sexual desire than those with UUI. Women with SUI or MUI reported having mainly urine leakage during vaginal penetration, causing embarrassment, and UI reduced the desire to have sex. Women with UUI or MUI reported having embarrassing urine leakage during orgasm, so while they had vaginal intercourse, they were mainly anorgasmic.
In 2017, Saiki and Meize-Grochowski, studied 57 women between the ages of 45 and 65 in a quantitative study to explore associations among symptoms of UI, severity of symptoms, and measures of psychosocial health that may be assessed during a wellness screening exam and the possible contribution of these variables to the relationship satisfaction of partnered midlife women living with UI. Using the Sexual Quality of Life–Female scale among other scales, it was noted that the participants scored low on sexual function, but no consistent association between UI symptom severity and sexual function was identified. Limitations were the small sample size, underrepresentation from African American and Asian groups, and English fluency, rendering it a Level 111 study. Of note, though, 46% of respondents have not discussed their symptoms with their health care provider, which is consistent with findings from other studies.

Among women, the lower urinary and genital tracts are in close approximation to each other, so it is no surprise that sexual activity may cause urinary symptoms and that lower urinary tract dysfunction may lead to sexual problems. Beji et al. (2005) studied 92 women in a Level 1 study—32 with UI and 60 without UI in Istanbul using the Sexual History Form, which includes 27 questions arranged into five stages of sexual activity: sexual desire, arousal, intercourse, orgasm, and satisfaction. Statistically meaningful differences were found between the control and study group in regard to sexual activities. The group with urinary leakage during intercourse felt more embarrassed, guilty, and anxious. They were less receptive to sexual arousal and had a very high percentage of dyspareunia.

Asoglu et al. (2014) sought to evaluate the associations between UI subtypes and women’s QOL, including sexual function in a Level 1 study. This retrospective cohort study was composed of 111 women with UI using the Beck anxiety inventory, pelvic organ prolapse/urinary incontinence sexual questionnaire 12, urogenital distress inventory 6, and
incontinence impact questionnaire 7. Each subtype of UI had different effects on sexual function, anxiety, and QOL. This study suggests that SUI is associated with greater sexual dysfunction than UUI or MUI.

**Barriers to Help Seeking**

Although UI is a common problem composed of significant clinical and embarrassing symptoms, as few as 20% of women suffering seek help.

Despite the significant burden of UI, only about 3% of health care providers inquire about UI, 25% to 50% of women with UI seek care, and 23% to 38% receive treatment. UI is largely undertreated in part because health care workers fail to inquire about involuntary urine leakage and are uncomfortable with UI diagnosis and treatment. Modifiable risk factors for UI should be determined early on with the patient. Raising provider and support staff awareness of the problem of UI and its treatment with educational modules and pertinent articles may improve staff cooperation with incorporating consistent screening into their practice (Wiers & Keilman, 2017). New findings from the National Poll on Healthy Aging suggest that more physicians should routinely ask their older female patients about incontinence issues they might be experiencing. From the poll of 1,027 women between the ages of 50 and 80, 43% of women in their 50s and early 60s said they had experienced UI, as had 51% age 65 and older. Yet two thirds of these women have never talked to their provider about this issue. The poll showed that women were finding their own ways of coping, from using pads or special underwear, to limiting fluid intake. Among women who did not talk to their provider about their UI, 22% said they did not think of urine leakage as a health problem, so they never brought it up for discussion (Malani et al., 2018).

Shaw et al. (2001) conducted a qualitative interview study on 31 individuals in a Level 1
study. The most common theme to emerge was a lack of knowledge on the condition and availability of treatments. Some individuals did not want to bother their provider, thinking their condition was too trivial. Some patients “just mentioned” their symptoms, and if the provider did not respond, the patient did not mention their UI again due to embarrassment or fear of invasive procedures. Some interpreted the doctor’s lack of addressing the issue as an indication that no treatment was available. Patients with UI tend to hide their symptoms. Therefore, all providers should ask their patients about urinary symptoms including UI in regular check-ups, even when the patients complain of other symptoms (Park, 2013). A common theme that emerged from the qualitative study was a lack of awareness about the condition, its causes, and its treatments. These help-seeking barriers are not unique to help seeking for UI; for example, help seeking for breast cancer also found lack of awareness of the significance of symptoms and 27.6% of men identified as impotent were aware of the availability of treatment. The research unearthed in this study suggests that sensitive conditions such as incontinence are not discussed frequently in social situations, reducing opportunities for informal acquisition of information. People are also less likely to discuss stigmatizing conditions with their PCP. Shame and embarrassment have been reported as barriers to help seeking in other conditions such as alcohol abuse, impotence, hearing impairment, and depression. Health promotion and education should be directed to these taboo areas to allay fears and misconceptions and to promote awareness of symptoms and treatments (Shaw et al., 2001).

UI tends to be ignored by the patient, with the misguided belief that it is an inevitable consequence of ageing (Stewart, 2018). Stewart’s article, a Level 111 study, intends to enhance nurses’ understanding of UI, the associated risk factors, continence assessment, and initial treatments that can be instigated by nurses.
A master’s thesis by Zeznock (2003) looked at the experiences of women living with UI in a Level 1 qualitative study of 17 women. It was found that women are hiding their incontinence due to embarrassment. They are also experiencing shame and isolation and deal with this problem for years before seeking help. Often, help is postponed due to inadequate expertise or education on the part of the healthcare provider. Nurses at all levels of practice should be able to detect this condition in women and refer appropriately.

A 2016 study by Jones et al. analyzed 158 women from a prospective Level 1 cohort study of midlife women (mean age 48) in northern California who were in late reproductive stage or menopause transition. Their findings were nocturia, or urinating at least once per night, and UI at least once per week. Incontinence was less prevalent in African American women compared to European Americans and Latinas and more prevalent in the late reproductive stage than in menopause transition (Jones et al., 2016).

A study by Adedokun et al. (2012) showed that very few women (approximately 1 in 10) in Nigeria seek medical care for UI. Logistic regression analysis showed that the odds of seeking medical care was higher among less educated women in this Level 1 study. Reasons for not seeking care include lack of funds, feeling too shy, a belief that the condition is not life threatening, fear of complications, and a belief that there is no treatment. The study revealed that the prevailing sociocultural views of a particular medical condition could either be enabling or inhibiting to seeking help by the patient.

Mallett et al, (2018) studied barriers to seeking care for UI in 209 Mexican American women, utilizing the Barriers to Incontinence Care Seeking Questionnaire, a 14-item Likert-type scale. It was uncovered, in this Level 1 study, that lack of interest expressed by the health care practitioner and staff was a barrier to help seeking.
This scale was used again in a Level 1 study by Svihra et al. in 2012, as they sought to compare barriers, gender, and health care disparities in incontinence sufferers. The sample was 567 adults: 147 males and 420 females. The results showed that the barriers to seeking care were gender specific. Obese females with urge incontinence and males with SUI were least likely to seek treatment.

A descriptive cross-sectional Level 1 study on prevalence, perceptions, predisposing factors, and health-seeking behavior of women with SUI was done on 400 women in Sri Lanka by Perera et al (2014). They used an interviewer-administered questionnaire. Twenty-three percent had SUI, and only 12.9% sought treatment. SUI was significantly associated with pregnancy, parity, vaginal delivery, complicated labor, diabetes mellitus, chronic cough, constipation, and fecal incontinence. Main reasons for not seeking help were being embarrassed, not knowing that it is remediable, perceiving SUI as being a normal sequela of childbirth, and having to attend to family needs.

Reymert and Hunskaar (1994) sought to investigate the reasons why only few perimenopausal women with UI consult a doctor in their Level 11 study. This was a telephone study in Norway with 78 women aged 40 to 50. Of the 67 interviewed, 58% of these women stated that they had UI, 32 thought incontinence was normal at their age, 33 claimed to have no social or practical inconveniences, and only 9 consulted a doctor, of whom 3 had been referred to a gynecologist (GYN). The most common reason for not consulting a doctor was that the incontinence problem was regarded as being too small.

Chen et al. (2019) performed a cross-sectional Level 1 study surveying 346 women to assess their knowledge of pelvic floor disorders, which includes UI. Knowledge non-proficiency was a common theme, signaling a need for health care workers to assess patients’ understanding
of UI, especially those with lower education, to eliminate any possible misconceptions.

Albers-Heitner et al. (2008) performed a Level 111 study and analyzed 264 questionnaires administered to GPs to determine adherence levels to the Guideline on Urinary Incontinence of the Dutch College of General practitioners. This questionnaire is used in the Netherlands when diagnosing UI. It was found from the study that Dutch GPs follow the guideline only partially, citing lack of time, lack of staff, and lack of competences to give this care.

Diokno et al. (2004) performed a two-stage nationwide cross-sectional Level 1 survey on 2,310 incontinent women. Almost half of incontinent women considered their incontinence moderately to extremely bothersome, yet only 56% of the moderately to extremely bothered women had ever talked to a physician about incontinence. In 85% of all cases, the incontinent woman, rather than the physician, raised the issue of incontinence.

Ngigi (2017), in her Level 1 study, explored providers’ perception and knowledge of overactive bladder in women. A pre- and post-screening tool was administered, an educational model, and the ABSST tool. Findings indicated that providers’ knowledge and awareness of OAB symptoms and screening in adult women were increased following an educational online module, suggesting that this tool is likely to improve patient outcomes for patients who are screened and that treatment should be initiated early if the criteria are met.

Nguyen et al. (2013) performed a Level 1 study investigating family physicians’ knowledge and understanding of UI as well as their perceptions of barriers to continence care in Alberta, Canada. In a survey of 158 providers, 58% of the physician respondents reported that they proactively discussed UI with most of their patients, 29% indicated that they discussed UI with some of their patients, and 15% reported not discussing this topic unless brought up by the
In 2017 and 2018, Mazloomdoost et al. sought to understand barriers to seeking care for pelvic floor disorders as well as identifying screening and referral patterns among PCPs in their Level 1 study. One hundred eight PCPs were invited to participate in a 14-question survey regarding the prevalence, diagnosis, and treatment of UI, OAB, and pelvic organ prolapse. The providers in this study reported comfort with the diagnosis or treatment of urinary symptoms, though they found female providers to be more proactive with UI care. Their 2018 study surveyed 391 physicians, with similar findings.

Jang et al. (2015), in a Level 1 study, explored the management status of patients with urological issues and examined the level of knowledge and practice behaviors regarding UI among Korean healthcare providers in 11 long-term care hospitals. The overall UI knowledge score among the providers was upper intermediate, but a knowledge deficit was found for risk factors of UI.

To fully understand an individual’s illness experience, health care providers must examine life and illness within a cultural context. Christine Bradway (2004) did a narrative Level 1 dissertation studying women with long-term UI within an anthropological framework. Her study used women’s narratives to identify a cultural model that provides a framework for the meanings that women assign to UI, based on the assumption that culture is learned and transmitted by individuals and groups. Findings suggest that self-esteem and individual UI experiences were dependent on women’s basic view of themselves, strategies for controlling UI, and how their UI was “handled”. For example, if UI was “handled in a bad way” (by nursing staff or the women themselves), feelings of shame, guilt, dependency, insecurity, and discomfort occurred. Ethnic women were interviewed to examine the effect of religious and cultural
practices on ideas and experiences associated with UI. Most felt some degree of taboo associated
with an “unclean” condition such as UI; some modified prayer routines to allow for their UI, and
others identified decreased libido associated with “feeling unclean”. Conclusions from this
narrative study suggest that sensitivity to the emotional, cultural, and social aspects of UI is
essential to understanding the experience of UI on women’s lives (Bradway, 2004).

Summary

A review of the literature yields a comprehensive understanding of urinary incontinence in women in general. Various measures have been used to evaluate the effect it has on quality of life, financial burden, sexual satisfaction, and depression. However, little is mentioned on the link between urinary incontinence and the younger premenopausal woman, nor the meaning that living with urinary incontinence has for this age group. This study attempted to gain an understanding of their perspective and shed light on their lived experience. While the literature review yields compelling findings, they may not in fact hold true for this researcher’s participants and merely serve as an information base. Rather, prolonged engagement with each participant will yield thick descriptions of how the participant sees her own unique experience as she lives in the world with urinary incontinence.
CHAPTER 3: RESEARCH DESIGN AND METHODS

Introduction

In order to gain a sense of experiencing life as a young woman with urinary incontinence, a deep dive into the lived essence of experiencing this phenomenon was performed through a qualitative phenomenological design, where the researcher attempted to extract the very essence of this phenomenon and how it affected the woman’s quality of life. This chapter will map out the research design that was used for this study along with research procedures and approaches. Hopefully, the participants benefited by sharing their stories that may potentially increase awareness of their plight to the medical community and impact change.

Analytic Framework

Phenomenology is the study of the lifeworld—the world as we immediately experience it pre-reflectively rather than as we conceptualize, categorize, or reflect on it (vanManen, 2016). Phenomenological human science is the study of lived or existential meanings, attempting to describe and interpret these meanings to a degree of depth and richness as we live them in our everyday existence, our lifeworld (vanManen, 2016, p. 19). A phenomenological method was selected for this particular study to enable the reader to be able to see, hear, and feel what the participants have truly experienced and the meaning the experience has had for them.

With the interpretive or hermeneutic approach espoused by Heidegger, presuppositions or expert knowledge on the part of the researcher are valuable guides to inquiry and make it more meaningful (Creswell, 2013). In interpretive phenomenological analysis, the researcher brings their preconceptions such as prior experiences, and assumptions, to the encounter, and cannot help but look at any new stimulus in the light of their own prior experience (Smith et al., 2009). Reflexivity plays a key role in the researcher’s attempts to keep their preconceptions in
Phenomenological inquiry involves decentering oneself from all presuppositions, beliefs, values, knowledge, thoughts, and ideas about the experience that is being studied, and attempting to understand without the overlay of prior knowledge (Munhall, 2012).

**Purpose of Study**

The purpose of this study was to investigate the lived experience of premenopausal women with urinary incontinence, gaining a better understanding of their perceptions of quality of life as they navigate through the healthcare system. This population has not been, heretofore, studied extensively.

**Research Design**

An interpretive phenomenological qualitative study was employed in this dissertation study, which centers on the common meaning of the lived experience of a phenomenon or what the participants share in common as they experience a phenomenon. Responses in a phenomenological study may be similar or common, but may also prove to be dissimilar. By collecting and examining the data, the researcher can see the essence of the phenomena and the what and how of an experience. The epistemological perspective of a qualitative study involves the researcher getting as close as possible to the participants being studied and meeting them where they live and work. The phenomenological approach that was used in this study was interpretive or hermeneutic, where the focus was on what humans experience rather than what they know, and that their realities are influenced by the world in which they live and their daily experiences.

A phenomenological design was chosen for this study to gain a description of a human experience that is felt and seen through the eyes of the participant that cannot be measured in
quantitative terms (Creswell, 2013). This design was chosen to explore the lived experience of the premenopausal woman living with UI and how it impacts her quality of life.

This interpretation of experience is one of the central tenets of Heidegger’s philosophy, which acknowledges existence as embeddedness and inseparability from the world (Horrigan-Kelly et al., 2016). One of the key goals within Heidegger’s philosophy is to expose the meaning of everyday ordinary human existence (Heidegger, 1927/2011). This philosophical analytic focuses on the human being’s existence in their world as an individual and within their social context.

This research study employed the philosophical underpinnings of Merleau-Ponty, which focuses on the human in their lived experience, embodiment, and meshing of the individual and the world. The philosophical underpinnings provide a framework for researchers to seek understanding of the content of experiences in the abstract way individuals experience living in the world. Perception of the human experience is not just a mental state but how individuals ascribe meaning to tangible things (Merleau-Ponty, 2014). Merleau-Ponty is an advocate for phenomenological reduction in order to reach an original awareness and to help us view our experience in a new light, not relying on the categories of our reflective experience; a pre-reflective experience (Dowling, 2005).

**Population/Sample**

In qualitative studies, a purposive approach is generally employed, by seeking participants that meet a predetermined criterion of importance (Polit & Beck, 2012). In this study, qualitative interviews were held with 13 participants who have experienced or are presently experiencing urinary incontinence. In phenomenological studies, the number of participants is between 10-12 in number. The primary requirement is that participants must have
experienced the phenomenon and be willing and able to talk about what it is like to live or have lived through the experience of interest (Polit & Beck, 2012). Because the participants must be able to articulate the lived experience, participants were chosen that have actually experienced the phenomenon of living with urinary incontinence. The interviews proceeded until no new themes emerged. The opening question was broadly related to the research topic: “What was your experience like living with urinary incontinence?” A self-developed topic list guided this research through the rest of the interview and probes were implemented based on quality of life specific to living with UI surveys and concepts found in the literature. Clarifying probes helped guide the interviews. The researcher served as the primary instrument, and therefore, was an active participant. The researcher interviewed participants until additional sampling or analysis no longer contributed to the discovery of new patterns and themes in the data.

**Recruitment Strategies**

This researcher recruited study participants through her place of employment, which actively treats premenopausal women with urinary incontinence, a criterion sampling technique. One participant was obtained through word of mouth, or through snowball sampling. To investigate the diversity in individual experiences, phenomenological researchers strive to recruit participants with demographic or other differences (Polit and Beck, 2012). This researcher attempted to interview women with different cultural backgrounds to see if premenopausal women from different cultures view incontinence through a different lens. Since the researcher is employed in Women’s Urology, permission was sought and granted through the corporate research board, to recruit participants experiencing this phenomenon. After reviewing the study, their research board determined that their corporate IRB board did not need to grant permission for this study. The physician that is a champion or gatekeeper for this researcher wrote a letter
indicating that she could provide participants and assist with the study (Appendix A). The
researcher planned on recruiting potential subjects through distributing flyers in medical offices,
gyms, and spas. However, a robust interest by premenopausal office patients proved to be very
fruitful. Potential subjects were asked to contact the researcher by phone or email to set up a
Zoom or telephone meeting at a time of their convenience, assuring them of complete
confidentiality.

**Human Subjects Considerations**

All participants were provided with informed consent, after having been informed about
the study, both orally and in writing, and being assured of complete confidentiality. The
researcher explained to each participant how all data will be encrypted and kept in a secure
locked location. Participants were made aware that they could discontinue the interview at any
time and withdraw from this study at any time without penalty. All participants were given a
pseudonym for the duration of the study and assured that no one other than the participant and
the researcher would have access to the interviews or data. Additionally, all data was de-
identified, using codes. The Molloy College IRB board approved the study protocol and ensured
that it was in compliance with its ethical research regulations.(See Appendix B). Because of
Covid 19 restrictions, Molloy’s IRB would not permit any face-to-face interviews. In accord
with the principle of Respect for Persons, informed consent was obtained from the research
subjects and they were fully apprised about what their participation in the research entailed, the
nature of the research and purpose, any discomforts or risks they might experience, and how
their privacy and confidentiality of personal information would be protected. They were made
aware that they were free to refuse to participate in the research or withdraw from the research
for any reason at any time. Risks to the participants was minimalized, in accord with the
principle of beneficence.

All participants were interviewed by phone for an average of 30 minutes, where they were assured of complete privacy and confidentiality. The participants opted for this option due to their convenience and for safety reasons, as per Covid 19 restrictions. All participants were requested to provide verbal consent, then written consent prior to the interview. The participants were asked to complete a brief demographic form, which was also held confidential, prior to the interview. The participants were assured that all data obtained will be kept in a locked secure location in the researcher’s home and was to be de-identified and coded. Electronic devices were locked and stowed away in a secure location in the researcher’s home. Due to potential emotional distress on the part of the participant recounting their experiences, a list of psychological support was offered, however, none of the participants sought this.

Data Collection

Data collection involves interviewing individuals that have experienced the phenomenon, as will be the case with my participants sharing their experiences living with urinary incontinence (Creswell, 2013).

All participants were called or emailed in advance to set up a convenient time for a zoom or telephone call. No in person face-to-face interview occurred at this time, due to the Covid 19 pandemic. This researcher used a digital voice recorder with an additional backup recorder, and field notes were taken throughout. Each participant was given a $25 amazon gift card as compensation for their participation in the study.

The researcher encouraged the sharing of the participants' stories using clarifying questions to help guide the interviews.
Proposed Data Analysis

Data analysis focuses on the “what” of the experience and the “how” they experienced it, leading to the ultimate essence of the experience (Creswell, 2013). VanManen provides 6 steps which help to guide the collection and analysis of the data.

1. The identification of the phenomenon, with reflections by the participants to understand the experience. The phenomenon should truly hold the researcher’s interest, which for this researcher, centers on living with UI as a premenopausal woman.

2- Conducting an investigation of the lived experience of a phenomenon allowing the participant to describe their unique perceptions. Investigating experiences as we live them, rather than how we conceptualize them.

3- The illumination of essential themes, which was revealed as the data unfolded.

4- Utilizing coding, memos, and diagramming to write and rewrite a description of the phenomenon allowing the emergence of themes transcribing the texts.

5- Maintaining a strong relation to the phenomenon to provide research rigor.

6- Stepping back and evaluating the whole in relation to its parts to balance the context (vanManen, 2016, p.30).

Data analysis began with the first interview using vanManen’s strategy as a guide. While reviewing the interview transcripts, meanings began to emerge from the participants dialog and continued to evolve as new concepts emerged. These meanings and concepts were organized into codes, until common themes began to emerge. Field notes and information obtained from memos were also analyzed and stored in NVivo software. Memos enhance the credibility of the research by aiding the researcher to derive meaning from the data and identify themes. This researcher also entered ideas, thoughts, and observations into a separate journal to help enhance the enhancement of theme development. This helped the researcher recall thoughts that came to
mind that may enhance the development of themes. Each transcript was analyzed for significant statements. Significant statements were highlighted through NVivo software, categorized into meanings, then into codes, which further developed into common themes. Meanings were derived from the statements and organized into codes. These codes were developed to evolve the formation of themes. This iterative process continued until no further themes emerged.

All digitally recorded interviews were transcribed through Rev.com, an internet transcription service, and, on their return, were organized using NVivo software. NVivo enables the researcher to markup text, make notes electronically and code and recode as often as needed (Rubin & Rubin, 2012). This allows for easy retrieval of memos associated with codes, themes, and transcribed interviews (Creswell, 2013).

**Inclusion Criteria**

Inclusion criteria for the study was that all participants must be premenopausal, have experienced UI for at least 1 year, and speak English. Participants must have been willing to participate in 1-2 interviews lasting between 30 and 60 minutes. The subtypes of UI were not a factor, as all types of UI have the potential to cause distress.

**Exclusion Criteria**

Exclusion Criteria included participants that have had cessation of menses for more than 1 year and experienced urinary incontinence for less than 1 year. Exclusion criteria also included women with renal disease and neurological disorders.

**Potential Study Benefits**

There were no benefits to the participants, per se, other than the knowledge that their stories have the potential to influence change in practice, so that others may benefit from the knowledge gleaned in this study.
Potential Study Limitations

Due to living during a time of an unprecedented worldwide pandemic, all interviews were conducted by telephone. This lack of person-to-person interaction might have lent itself to a less interpersonal interaction between the participants and the researcher. Technology offers many benefits, but it does not allow for the subtle nuances of expression that may translate less organically and more mechanically. This researcher had to be cognizant of this and really listen and engage with the participants for subtleties and nuances to gain the essence of the experience for these women.

Trustworthiness

In an attempt to ensure rigor, vanManen’s assertion comes to mind that rigor is less about adherence to the letter of rules and procedures than it is about fidelity to the spirit of qualitative work (vanManen, 1990). All during the data collection process, the qualitative inquirer must be concerned with rigor. Appropriate activities must be conducted to ensure that rigor has been attended to in the research process rather than only adhering to set criteria for rigor after the completion of the study. Trustworthiness is used as the central concept in Lincoln and Guba’s to appraisal of the rigor of a qualitative study. It refers to quality, authenticity, and truthfulness of findings of qualitative research. They proposed 4 terms within the naturalistic paradigm: credibility, transferability, dependability, and confirmability (Lincoln & Guba, 1985). An additional term, Authenticity, describes the feeling tone of the participants' lives as their stories are being told, so one is almost able to live vicariously through the participants stories (Polit & Beck, 2012).

Credibility

Credibility, the accurate and truthful depiction of a participant’s lived experience
(Cypress, 2017) was achieved in this study through engagement and observation to learn the context of the phenomenon in which it is embedded and to minimize distortions that might permeate the data. Lincoln and Guba point out that credibility involves two aspects: carrying out the study in a way that enhances the believability of the findings, and being able to demonstrate credibility (Lincoln & Guba, 1985). Leininger (1994) notes the importance of identifying and documenting recurrent features such as themes, patterns, and values in the research. To be able to implement this, the researcher must spend sufficient time with the participants to be able to submerge themselves in the research through intimate familiarity (prolonged engagement).

Member checks, by the participants were employed by checking the data and interpretations with the participants from which the data is collected. Participants were asked to review a transcribed interview and examine themes to assess if they agree with the researcher that the analysis best described their experience with the phenomenon of interest. The researcher asked her peers to review transcribed materials to validate the themes to ensure dependability, and to achieve confirmability by maintaining notes and memos to document reflections that would be beneficial and pertinent.

In qualitative research, the validity of the findings is related to the careful recording and continual verification of the data that the researcher undertakes during the investigative practice. If the validity or trustworthiness can be maximized or tested, then more credible and defensible results may lead to generalizability as the structure for both doing and documenting high-quality qualitative research (Cypress, 2017).

**Dependability**

Dependability or consistency refers to the reliability of the data over time and conditions. the question that requires answering is: Would the findings of the inquiry be repeated if it were
replicated with the same or similar participants in the same or similar context? (Polit & Beck, 2012). To enhance dependability, this researcher described the exact methods of data gathering, analysis, and interpretation. The researcher also conducted a code-recode procedure during the analysis phase, where, after coding a segment of the data, the researcher waited another two weeks to recode the same data, while comparing the results. Triangulation was also used, requesting colleagues and methodological experts to review the research plan and implementation (Krefting, 1991). The researcher’s dissertation committee, who are research experts, reviewed the data, transcription notes, and NVivo-aggregated codes. They were consulted regularly throughout the theoretical coding of the data.

**Confirmability**

Confirmability is concerned with objectivity that two or more independent people will concur about the accuracy, relevance, and meaning of the data. Confirmability is concerned with portraying the data as presented as the participants intended rather than how the researcher intended to portray it. The participants’ voice must be heard, rather than the researcher’s biases or preconceived notions (Polit & Beck, 2012). To achieve this, this researcher asked an external auditor to review the findings and to see if comparable conclusions can be obtained, given the same data and research context. The researcher asked the dissertation committee of expert researchers to initially review the raw data, field notes, audio recordings, field memos, and theoretical thematic categories. Reflective analysis was also used to ensure that this researcher was aware of her influence on the data through reflective journaling throughout the research process. Reflective journaling helped reduce personal bias and bracket the researcher’s personal opinion out of the findings.
Transferability

Transferability is the ability of findings to be transferred to or have applicability in other settings or groups. In qualitative research, transferring the results of the study is ultimately the responsibility of the reader. According to Lincoln and Guba (1985), it is the researcher’s responsibility to provide sufficient rich data so that potential researchers can apply the data to other contexts. The researcher has the challenging task of providing thick descriptions of the settings, subjects, and other persons involved, quotes, and other data-compelling interpretation and synthesis to position readers to transfer the findings to their own context. This researcher considered the data rather than the subjects and determined whether the content of the interviews, the behaviors, and observed events are typical or atypical of the lives of the informants. Thick descriptions were used as a result of persistent observation and prolonged engagement, advancing knowledge on the topic of interest. Member checking was also useful to see whether the data are typical.

Authenticity

Authenticity refers to the extent that researchers portray a range of realities and the tones of feelings that the participants convey as their experience is being unfolded. The reader will be better able to understand the participant’s mood, feelings, and experience living with the phenomenon vicariously (Polit & Beck, 2012). The researcher took care to assure that the participants were fully informed of consent; caring and trusting relationships were nurtured; inquiry procedures were rendered transparent to all participants and audiences; and participant-inquirer collaboration was built into every step, with full agreement on the rules to govern the inquiry and with information fully shared. The inquiry report was made available to all respondents and audiences.
Guba and Lincoln argued that perhaps the most significant accomplishment to date related to the authenticity criteria is simply its existence, a demonstration of the fact that it is possible to think outside in more creative and suitable ways about quality assessments (Amin et al., 2020).

**Researcher Bias**

One potential threat to validity is researcher bias, resulting from selective observation and selective recording of information and allowing one’s personal views and perspectives to affect how data are interpreted and how the research is conducted. In an attempt to develop a closeness with the participant, the researcher can become so enmeshed with the participants that they may have difficulty separating their own experience from that of the participant. To help ensure that over-involvement does not occur, a process called reflexivity was used. This refers to an assessment of the influence of the researchers’ own background, interests, and perceptions (Krefting, 1991). This researcher brought all past experiences and knowledge into the study but tried to set aside her own strongly held perceptions, preconceptions, and opinions and truly listened to the participant to learn their stories, experiences, and meanings.

As the researcher’s background as a provider is in primary care and women’s health treating women with UI, the questions to the participants were tailored based on personal experience treating these women. In this case the researcher’s knowledge base lead to specific ideas about how the inquiry needed to proceed to produce useful knowledge. As this researcher is a research instrument, a disclosure of bias and assumptions was made up front with each participant.

**Summary**

This chapter highlighted the analytic framework, study purpose, research design, ethical
considerations, sample and recruitment strategies, data collection and analysis, and
trustworthiness. The researcher’s assumptions were that participants experiencing urinary
incontinence would be interested in exploring their stories and be willing to answer the questions
to the best of their abilities so that both the researcher and the participant could grow in
knowledge and understanding of this important phenomenon, and hopefully, impact positive
change in the therapeutic management of this condition as well as an improved provider
awareness and knowledge.
CHAPTER 4: FINDINGS

This chapter provides a detailed description of the participants that were interviewed along with their demographic characteristics. Each participant was introduced to the reader to portray not only their verbalized individual stories, but also their tone and subtleties as perceived by this researcher in an attempt to better understand the essence of living with urinary incontinence as a premenopausal woman. The data collection and analysis process was discussed leading up to the development of emergent themes derived from significant participant statements culminating in the development of essential themes and findings.

Study Sample

Permission to conduct this study was granted by one of the lead urologists and Chief Medical Officer of a large multiservice medical facility in Long Island, NY, after Institutional Review Board (IRB) approval was granted from Molloy College in May, 2021. The medical facility was supportive of this study and eager to better understand the phenomenon of experiencing urinary incontinence as a premenopausal woman.

Participants were recruited primarily through the researcher’s place of business, using a criterion sampling technique. One participant was recruited via snowball sampling. Participants that met the inclusion criteria for this study were referred to this researcher by a urologist who has a professional rapport with each participant. Permission to interview each participant was accomplished by phone, ensuring complete confidentiality. Participants were then emailed a consent form to complete (Appendix A) and returned to this researcher prior to the interview.

Fourteen subjects in all were interviewed for this study, however during the interview stage, one subject was excluded, a 25-year-old African American single woman, as it was discovered that she fell into the exclusion category due to a neurological disorder, that was
previously undisclosed. A total of 13 subjects were ultimately included in this study. Due to the Covid 19 Pandemic, all interviews were conducted over the phone as per participant preference and safety concerns. No face-to-face interviews took place as per Molloy IRB stipulations.

**Data Collection**

Interviewing is a hermeneutic phenomenological research approach espoused by Husserl, 1913/1962, to collect information with the purpose of collecting a deep understanding of the phenomenon of interest. All research participants were contacted by phone prior to interviews. All interviews were conducted from late May 2021 to late July 2021. The interviews ranged in length from 25-40 minutes, with a mean length of 30 minutes. Each interview commenced with a re-introduction and description of the study, providing time to answer any participant questions. Verbal permission was obtained at least 1 week prior to each interview and written consents were in place. All queries were answered with verbalized understanding including the right to opt out of the study at any time without penalty. A copy of the signed consent was provided for the participants via email and US Postal Service in the event they may have future queries or concerns. Demographic data was collected on all participants following the interviews, which enhanced the understanding of their lived experiences by providing a more in-depth illustration of each participant. These 13 women shared their stories allowing the researcher to gain an insight into their lived experiences.

All recordings were digitally recorded using an Olympus WS-700M digital recorder with an EVISTR digital reorder as backup. All digital recordings and transcripts were then locked in a secure location in the researcher’s home. Each interview commenced with the prominent research open-ended questions: “What has your experience been like living with urinary incontinence and how has it impacted your quality of life?” Hermeneutic phenomenological
research relies on memory and the critical reflection of the participants to interpret and understand their experience rather than to simply explain. Follow up probe questions were inserted into the interview when the participant exhausted their responses to the primary question and the participant led the interviewer into a new topic to explore. Probe questions lended a more thorough understanding of what the participants were experiencing and added richness to the data. The participants were eager to participate and spoke freely discussing their experience.

This researcher took careful field notes during and after the interview process and recorded personal observations following each interview as to the timbre and intonation of each participants voice, as per recommendations suggested by Rubin and Rubin (2012). Field notes were included as part of the data collected. All field notes were kept in a dedicated notebook that was also kept in a secure locked location to be retained for the time frame stipulated by Molloy’s IRB regulations. This researcher also kept memos, which were thoughts and reactions to what transpired in the interviews.

Interviews concluded when the participants verbalized they had completed sharing their stories and had nothing further to add. Participants were encouraged to contact this researcher if they felt they had anything additional that they would like to share. None of the participants were interested in a follow up interview as they felt that they were thorough in sharing their stories with no need for a further interview, though several participants were seen several weeks later for various appointments with the urologist and were able to validate findings. At the end of the interviews, the participants were thanked for their time and willingness to participate.

**Characteristics of Research Participants**

Demographic data was compiled from the Demographic questionnaire (Appendix C). All of the 13 research participants were young premenopausal women who have or had experienced
urinary incontinence for more than a year, ranging in age from 24- to 49 years of age with a mean age of 38. Nine of the 13 women were White, with the remainder from a Latino background including Puerto Rican, Salvadorian, and Columbian. Nine of the women were married. The remaining 4 were single or divorced. Nine of the participants stated they had incontinence daily. The other 4 participants stated they had incontinence 3x per week. Nine of the participants cited having incontinence for more than 3 years, with the remaining 4 having it at least a year. Six of the participants stated their degree of bother was very or severe in intensity, 2 stated it was moderate, the remaining women described it as a slight bother. Seven of the participants had advanced Graduate degrees, 3 were college graduates, and 3 were high school graduates. All of the participants, with the exception of one, worked at least part time. Seven of the participants were mothers with at least one vaginal birth. The remaining women either delivered by caesarian section or have never given birth.

The following table illustrates the demographic characteristics of the 13 premenopausal women with UI that have participated in this study.
Demographic Data

<table>
<thead>
<tr>
<th>Age</th>
<th>Race</th>
<th>Marital Status</th>
<th>Length of time with leakage</th>
<th>Severity of leakage</th>
<th>Degree of bother</th>
<th># Vaginal deliveries</th>
<th>Exerci-sion</th>
<th>Over-weight</th>
<th>Level of Educa-tion</th>
<th>Diabe-tes</th>
<th>Depre-sion</th>
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<td>Daily</td>
<td>Very</td>
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<td>No</td>
<td>HS</td>
<td>No</td>
<td>No</td>
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<tr>
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<td>M</td>
<td>&gt;1 year</td>
<td>Daily</td>
<td>Very</td>
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<td>HS</td>
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<td>No</td>
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<tr>
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<td>&gt;3 years</td>
<td>Daily</td>
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<td>Bachelor's</td>
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<td>Daily</td>
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<td>Bachelor's</td>
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</table>

Descriptive Summaries of the Participants and their Stories

Botanical names were given as pseudonyms to all of the participants, because they all displayed such beauty and grace, not unlike the most splendid flowers in a garden with their stems riddled with thorns. They are perfect despite their challenges. This researcher chose the pseudonyms following the completion of the interviews in keeping with the participants’ strong, beautiful, and resilient natures.

Pseudonyms were given to protect confidentiality. The following descriptive summaries briefly reconstructed the participant’s stories and their lived experience with this phenomenon.

Iris

Iris is a 42-year-old Latina woman with 2 children, all by Caesarian Section. She is divorced and works a rigorous schedule of more than 40 hours per week as a nurse’s aide. Iris is a very busy single working mom that was very open about her journey with urinary incontinence. Although Iris could not be visualized in person, her persona was very strong. She presented
herself as very frank and honest and one could detect bitterness and frustration in her voice. She definitely projected emotions of feeling out of control, alone and not heard. Iris lamented that living with urinary incontinence is “terrible and uncomfortable” and exhausting. “Waking up in the middle of the night 6-7 times is terrible, especially since I’m only just 42 years old and I think I’m too young to experience this.” She explained that she often has to stop whatever she’s doing and run to the bathroom because she wasn’t able to hold her urine anymore. Iris admitted that she has been suffering from urinary incontinence for more than 3 years, following the birth of her 2 children that she describes as “big babies.” After reporting her symptoms to her gynecologist (GYN), she was told “Oh, that’s normal, that’s nothing, blah, blah, blah…” She reported that she felt disappointed at that point because she felt she wasn’t taken seriously or even heard. Her primary care provider sent her to see a urologist, who gave her Botox injections into her bladder. …” but it didn’t help, it made me worse. I had the urge to go but I couldn’t go.” Iris also tried an array of medications but “I just want to feel like I don’t have to be on medications all the time, just to feel like a normal person…” Her GYN also gave her exercises which she reports did not help at all.” So, she didn’t listen to me, but I always looked for more help. It took 5 years to get the correct person to realize what was wrong with me.” Iris also reported with an air of frustration, that she had a bad smell to her and that she felt she was offensive to others to the point where “I was afraid to date someone because what would happen if he can see that? If he feels like, Oh, she smells like pee? It was no fun at all.”

Living with urinary incontinence not only negatively impacted her socially, but also impacted her work, specifically travelling to and from work, when she reported “I live half an hour from work and sometimes I leak, because I couldn’t make it to the bathroom because of the distance from the parking lot to the apartment where I live. So, it was terrible. It was a fear that
you don’t want to drive so far.” Iris shared that wherever she travelled, she would always carry a pad, new underwear, and pants for fear of leaking through the clothes she was wearing. Any kind of exercise, such as walking, was curtailed. She reported she could walk 10-15 minutes before she’d have to stop and use the bathroom. “You didn’t feel like a normal person. That’s what I felt.” Though this researcher could not see Iris’ facial expressions, her frustration and desperation came across quite clearly. Iris related that living with urinary incontinence negatively impacted her marriage. “I didn’t want to have sex with him. I was afraid that when we were having sex, what would happen if I just leak and everything? It damaged the relationship a lot.” She confided that her husband was not very supportive and that her fears were “all in her head.” Iris described her sexual encounters as being “pretty scary.” She is now divorced and proclaimed that since her recent sling procedure she is 85% better but continues to have uncomfortable urgency. Note: (In the sling procedure, a piece of supporting material is placed directly under the urethra and is attached to the connective tissue of the abdominal muscles, working like a hammock. When the patient sneezes or coughs, then, the urethra is forced against the sling, closing it off, thus preventing leakage).

When asked to describe a dominant emotion, Iris averred that it would be feeling depressed. She often asked herself “why me? I’m so young to have this problem. Sometimes I feel depressed because I say Wow, this is not quality of life.” Iris often laughed during the interview to perhaps lighten the mood for the researcher. She is very honest and kind hearted, but despite her vulnerability, one can detect a sense of resilience and strength about her, motivating her to improve her quality of life.

Rose

Rose is a 39-year-old white married woman with a baby girl born via Vaginal delivery. She
noted that during the latter part of her pregnancy she started to notice UI and recalled “complete incontinence for 3 weeks…” She stated that it is now slowly improving, but it did take a while. “I was devastated because, you know, I know it’s normal, but I didn’t expect it.” Rose is a very busy young woman with a master’s degree, working full-time as a teacher. Due to time constraints expressed by Rose, she opted to have a telephone interview. This interview was planned one week prior with all questions answered. Rose is enthusiastic and bubbly and was eager to answer any and all questions related to her experience, stating, “I hope this is helpful.” Although subtleties such as body language were not identified due to the nature of the interview, one could detect Rose’s frankness, honesty, and eagerness to contribute knowledge in her voice. She laughed at times, showing her vulnerability, particularly when describing her feelings of being out of control and feeling old. Rose is presently working with a pelvic floor physical therapist, doing exercises to strengthen her pelvic floor. Initially, though, she reported what she felt when she first started to experience UI:

I felt like a different person. I felt very strange. I felt like what has happened to my body? I was able to just do this amazing thing and give birth. Is my body destroyed? I mean, I’m 39 years old. I was 38. I felt like I was 85 years old, like an old lady. I hate to say that, but yeah.

Since Rose was on maternity leave and there were Covid restrictions, she was home more frequently but confessed she would have been embarrassed if she had to be at work and could not make it to the bathroom. She recalled feeling very anxious and worried concerning car travel. She voiced that she couldn’t be in the car for too long and invested in a commode for the car: “I still have it in the car with me because I always get nervous, you know, if I couldn’t stop or if I had to go. I had a lot more anxiety about it than embarrassment.” This hampered Rose’s
spontaneity, making her feel increasingly out of control. When leaving her home, Rose reported she would plan her day around bathroom stops: “I’d have to really have to time it…maybe try not to drink as much liquid. I would alter my lifestyle, manipulate my day around it.” For Rose, anxiety was a big issue: “It kind of causes more issues with the bladder. It’s like all connected, right? I think you get a nervous bladder, then you get anxiety, and then you’re like, oh no, I have to go!” To gain a sense of control when she traveled by car, Rose recalled that she would make “a plan of action,” where she mapped out planned bathroom stops in addition to relying on her commode. She stated that because of Covid-19, socializing was, for her, restricted anyway, but admitted that during normal circumstances, she would have pushed off some social situations for fear of leaking. When she began walking outside, “I wouldn’t go too far. I’d be nervous to go too far because if I have to go, I want to be close to home.” She explained that exercising at home felt safer to her than going to a gym situation because “at home, I can have more control over that variable.” In addition to UI, Rose also developed a vaginal prolapse, where the vagina literally bulges out of the vaginal opening. Rose confided that now that she is feeling more control over her incontinence, this has become a bigger source of embarrassment for her. When she was experiencing these issues, she reportedly did confide in her girlfriends who were also having babies around the same time. “So, I said, I didn’t know that this happens. And they were like, oh yeah, that happens, you know, like this is normal.” Rose described a loving happy marriage with a supportive husband and shared she felt that she can be open with him. She recounted that he had a father in a wheelchair and had to do a lot for him in terms of personal care. “So he’s kind of used to things like this.” She did, however, say she felt very self-conscious about the urinous odor:

I felt like I smell like urine. That was the only thing that was very embarrassing to me
because it was something that you couldn’t really hide. You can wear a pad if you pee your pants. No one can see sometimes, but the smell really embarrassed me.

Her journey getting help began with her obstetrician (OB), when she felt that something “wasn’t right.” According to Rose, the OB was very dismissive: “It’s part of childbirth. It’s okay. It’s okay.” She reports that the OB was even dismissive concerning the prolapse and kept insisting that it’s completely normal.

Rose recently embarked on a pelvic floor rehab program to treat her incontinence and is reportedly enjoying success. “It’s been unbelievable. Like I can’t even tell you. I didn’t know it existed for pelvic floor dysfunction and urinary incontinence. It has been amazing.” She relayed her feelings that everything “is medical to the providers and they really don’t care.” She claimed that she is now more confident now that she has more knowledge and the tools to deal with her incontinence. She did, however, express being fearful that the incontinence might get worse should she ever have another baby. Since she is a bit older, she would like to try for another baby but disclosed that she is nervous about it.

Rose asserted she felt comfortable sharing her story with her friends and family. When she mentioned it to her mother, her mother told her that she wasn’t really able to relate to her experience since it never happened to her. She was very open to discussion and very motivated to find a solution for women with UI: “Why not talk to people to get their ideas…and prevention. I didn’t know half of the stuff that happens after birth; no one’s ever mentioned that to me and I know a lot of people that have kids.” Rose professed that she is so passionate about helping other women with UI. “I even want to become an advocate for it, because you know, insurance doesn’t cover it. In Europe, it’s normal for people to talk about it and get help and it’s covered in post-partum care, but here, it’s taboo and still very American.”
Flora

Flora is a 49-year-old White married woman who had three deliveries via caesarian section and no vaginal deliveries. Flora was identified through snowball sampling and was eager to participate. Flora has a very busy schedule and personal life and scheduled this interview a week earlier. She preferred to speak over the phone, to accommodate her busy schedule and to maintain safety. In fact, she was driving while we had our conversation. Flora has a very effervescent and carefree personality and spoke very rapidly with clipped answers. This researcher utilized a good number of probes during the interview, as Flora tended to respond with yes or no answers and didn’t tend to elaborate. Flora works for a large police department as a crossing guard 25 hours a week and responded often with “Yes, Ma’am” or “No, Ma’am.” Her demeanor was somewhat regimented and fast paced. Often during the interview, she spoke so rapidly that it was often difficult to understand her. Additionally, since she was driving in the car, there was a lot of background noise. When initially asked to participate in the study and asked whether she has ever experienced urinary leakage, her response was “Who doesn’t?”

Flora reported that she has had mild leakage for more than 7 years. She started noticing it after the birth of her last child when she was 44 years old. She admitted that having UI is more of a “nuisance” than anything else. She stated that her leakage “doesn’t affect anything,” including her QOL but said that it’s “just very annoying. I’m so used to it. I never thought anything of it.” Although Flora didn’t report her UI to be a bother, she admitted that she will prepare before she goes out socially with friends or work by always wearing a panty liner, stating that “If I’m out for the whole night, that’s a different story.” From her description, it appeared that she has learned how to cope with and adapt to her incontinence very well and has integrated it into her life as a normal condition. Flora is an insulin-dependent diabetic that takes Novolog and
Humulin and admitted to being “pretty on top of” her diabetes, including her medications and diet, but appeared to be completely unaware that incontinence should not be considered a normal occurrence. From Flora’s description of symptoms, it appeared to occur more when she laughed, sneezed, or coughed, and it often woke her up during the night. She recounted that during the end of her shift at work, she would need to use the bathroom: “I can hold it for a few hours but will lose it at times.” Flora reported that she mentioned it once to her primary doctor, who told her, “I mean, who doesn’t pee when you laugh? Yeah, it’s so normal.” According to Flora, the leakage is “just a few drops” but enough to make her aware: “I’m just so used to it. I never thought anything of it as a problem. I’ve lived with it for so long now.” Although Flora doesn’t detect any odor on herself, she admitted she is concerned that she might smell bad. “I know I can smell when I’m sweaty and hot. I know I can smell.”

Flora appeared very comfortable talking about her incontinence and denied feeling embarrassed or frustrated. She verbalized that her husband is aware and that she felt no embarrassment sharing it with him:

We’ve talked about it and he’s okay about it. It is what it is; I mean I never went to the doctor to inquire about it. I assumed that it was something that was part of my life, that was, well, normal for someone with three children.

Toward the conclusion of this interview, when asked if she would now choose to broach the subject with her PCP or GYN, she stated that now she would choose to bring up the subject and talk about it more: “You know, I just thought I’d have to live with this and there is nothing to be done for it.” Flora was truly unaware that UI does not have to be a requisite to having children; nor is it something that should be a normal part of one’s life.
Poppy

Poppy is a 42-year-old Iranian woman who has been living in the United States for more than 20 years. She is happily married with two teenage sons and a 3-year-old daughter. Poppy speaks English well, but her speech is heavily accented. She came across as reserved but was very open and frank with her assessment of her UI. Because of Poppy’s busy schedule, she opted to be interviewed by phone. This interview was scheduled a week prior, with all questions regarding participation in the study answered.

Poppy works as a receptionist in a local doctor’s office a few days a week. She reported that she likes to keep busy and enjoys interacting with people. Poppy has a large extended family and a wide circle of friends. She admitted to having UI for several years and averred that it has truly negatively impacted her lifestyle and QOL. Poppy mused that living with her condition has been very embarrassing for her and revealed that she felt that the subject of UI is a “sensitive conversation”:

It’s not easy to tell people that you can’t hold your urine and you’re going to pee all over yourself if there is no bathroom available, which happened a lot to me. I had to wear a diaper. Who do I want to talk to about wearing a diaper?

Other than her immediate family, Poppy told no one about her UI. Her family was aware and “they would complain how many times I have to use the bathroom, saying it’s not normal and shouldn’t be like this...” Poppy stated that over time her incontinence “got worse and worse,” to the point where she would avoid activities she previously enjoyed. “I would only go to places that I was sure there were bathrooms.” This curtailed travel plans and social activities. “I wouldn’t go for a walk with my friends. I never know when it’s going to happen.” Even if she deliberately dehydrated herself and didn’t drink much, “it would just happen, a patch of water
right in front of me, meaning I would just get wet.” Poppy shared she would try to cope with her situation and try to gain control by severely restricting her fluids to the point where she would get dizzy and suffer headaches from being dehydrated. “There is no control over this, this is controlling me.” Although this researcher was unable to visually see this participant, Poppy’s tone of voice and auditory intonations painted a picture of a woman that was very frustrated and in despair. One could hear the pain in her voice along with felling out of control. Poppy is a woman who enjoys her family, and her life, and is desperate to have it back again.

Poppy shared a scenario, which exemplified her extreme embarrassment and lack of control. She recalled a situation where she lost her urine all over her pants and on the floor in front of her 15-year-old son. She said he was so embarrassed by this that he couldn’t talk to her for months, as though his whole impression of her, how he perceived her, was altered. “It was not easy to understand that the day that this happened. It’s not easy for me to understand. He’s only a child. Who wants to see their mom do that?” This was very upsetting for Poppy to relate and this researcher could sense from her tone of voice, how very ashamed she was. Poppy also conveyed her fear of smelling bad and not feeling pretty. “If I’m going to wet my pants, obviously it’s going to smell bad, so it can’t be good.” Poppy did say that her husband was supportive, but said that she found it difficult to be out in public with him because she never knew when she’d have an accident. Although she disclosed that it didn’t affect relations with him, she did admit that when they were out together in public, he saw her having an accident. “I couldn’t hold it and he had to walk with me and that was so embarrassing. He tried to be understanding, but there’s not much understanding towards things like this.”

In addition to limiting fluids, in an attempt to gain some semblance of control, Poppy also recalled she avoided being out in public. Poppy stated she had something in the car to sit on, so
I wouldn’t get my car wet because I didn’t want urine in my car.”

Embarrassment was one of the dominant feelings expressed by Poppy along with her air of despair and lack of control. “It’s very, very upsetting. I had to walk in a diaper. I walked in a diaper for about 2 months or maybe longer. I walked with a diaper.”

Because of the Covid 19 restrictions, Poppy admitted she felt more comfortable being at home with her UI with less fear of discovery. “It was Covid times, and we didn’t leave. We didn’t go anywhere.” When asked about her journey getting care for her UI, Poppy said that her primary care doctor was “aware but he didn’t have a solution.” Poppy did her own research and opted to begin treatment with PTNS (percutaneous tibial nerve stimulation), which is a treatment modality used for urge incontinence. Poppy is presently feeling more in control with less accidents. She asserted she is so much happier and so much more relaxed knowing that “I can now leave the house and be ok with it, knowing that I can control my urine.”

In addition to feeling such an array of emotions, Poppy expressed bewilderment that this could happen to a young person. “I would think that this doesn’t happen to 30 and 40 year olds. Maybe when you’re 90.”

Daisy: Daisy is a 37-year-old white married woman working full time with 2 small children. Daisy is a high energy person and very busy, scheduling her interview with this researcher after her children were asleep in bed. She was somewhat distracted at first, but eased right into the interview seamlessly exuding an air of optimism and self-reliance. Daisy was very frank and not embarrassed in the least to have a conversation about her urinary incontinence. She exuded an aura of confidence and came across as being very upbeat. She admitted to having a history of depression but stopped taking medications for it more than 16 years ago. Daisy reported that she started to experience incontinence as far back as high school and stated it got progressively
worse after her children were born. In high school, she recounted, “I would like literally pee in my pants, like holding myself, like literally, and I was like, oh my God, I gotta go, or just cut the line....my friends made fun of me, you know what I mean?” If the bathroom was far away from where she was,” I would just go off to the side and pee, like on the floor or behind a car.” As an adult, “I would pull up to my house and pull my pants down in my driveway, because I can’t make it to the bathroom. I can’t even open my garage.” Daisy revealed she believed that “oh, I just had a baby,” was the reason it got worse and wasn’t sure if it was pregnancy related, but, as her youngest was turning 4, it still continued. When she attempted to exercise, she would get on the treadmill to run and “it would just come out of me. Like I would be soaking wet or like, I would start to buy workout clothes that were more like patterns or dark colors.” Daisy eventually stopped running, dancing and jumping on the trampoline for fear of leaking. She disclosed she felt such a lack of control exemplified by recalling how she loved to jump on the trampoline in her backyard with her daughters. She stated she couldn’t even jump on the trampoline. “As soon as I would do like 2-3 jumps, I would pee... I would have just gone to the bathroom and peed. And if they had to pee (children), 2 minutes later, if I heard them pee, I had to pee.” Daisy admitted it got so difficult for her that just hearing the shower run would make her have to urinate. “and like, I couldn’t make it to the bathroom. Like I would pee on the floor...I would have a change of underwear for my 3-year-old, you know, just in case, and a change of underwear for me.” Daisy is very level headed and states that while she was unable to control her situation, she was able to control her reaction to her situation. While Daisy was describing her experiences with urinary incontinence, she often laughed and tried to interject some levity into the conversation, but one can detect from her tone that she recognized that she had “a problem.”
Daisy reported that she never felt ashamed or embarrassed at all by her urinary incontinence. She said she was not embarrassed but was “more prepared for it. I laughed it off and don’t even care. But my husband wanted it fixed for me. He was just like, you need to get this fixed, this isn’t normal.” Daisy said that as she got older, she prepared more for it and stopped doing things that she knew would make it happen.

Daisy eventually got the vaginal sling procedure, which helped with urinary leaking, but admitted that the urge to urinate is still very strong. She was recently started on a medication, but had to stop it, as it caused her to gain weight from it and made her feel “swollen.” She disclosed that since she has a history of an eating disorder that is under control, she did not want to take anything that would contribute to a weight gain. Daisy continues to have some leakage, but not to the extent that she had before the sling procedure. The urge continues to be strong, “it’s like that sensory part. If I hear the water running, I still have to go.” In terms of quality of life, “I could definitely see how it can make someone like embarrassed or depressed, I just have a different personality like that…I wish I kind of got it taken care of sooner than later.”

Daisy asserted she always believed that urinary incontinence was something that everyone experiences after having children, so she never mentioned it to her obstetrician/gynecologist (OBGYN). “I would talk to my friends and then they’d say, oh, we have that too, but it was never to the extreme that I was having it.” Daisy eventually was directed for urological treatment on the advice of her mother-in-law, putting Daisy on the initial road to improving her situation. It was clear to this researcher that Daisy never felt like a victim, but was a forward thinker, always looking ahead.

**Hyacinth**

Hyacinth is a 25-year-old single white American woman, that has never had any children.
She came across in the interview as being very young and naive, with her voice tremulous at times. Hyacinth scheduled this interview around her busy schedule. She works a night shift 5 nights a week, so scheduled the interview after her gym workout with her mother on a day that she could sleep. Hyacinth opted to conduct this interview over the phone, as it was the most convenient for her.

Hyacinth reported noticing symptoms of urinary incontinence a little over a year ago. Prior to that time, she verbalized she didn’t have to be concerned about it and came across as being truly baffled and bewildered as to its origins. “I didn’t have to worry about this. I went to concerts, but I didn’t have to worry about planning bathroom…. and having a sudden urge to go.” She described her UI as “I’ll have the urge to go and I have nowhere to go. Like, I cannot just bang on someone’s door and ask to use their bathroom.” When recounting her experiences with urinary incontinence, Hyacinth often inserted laughter towards the end of her sentences, to perhaps lighten the conversation. One could physically hear the frustration and worry that she projected in her voice. “So, the whole day and every time I have to hold it, I feel, you know, like leakage coming out a little bit. It’s super uncomfortable.”

Hyacinth reported she experienced a wide array of emotions associated with having to live with UI, from embarrassment to anger to bafflement. “I was trying to understand it more because I always thought this is what happens to older people, you know, people in their seventies, eighties, nineties, you know.” Hyacinth mentioned her bewilderment of being too young to be incontinent several times during this interview. Hyacinth stated that having UI has negatively impacted the way she feels about herself as a young woman, including her sense of attractiveness. She is not in a relationship at present but admitted that she would most likely not share this with anyone she was casually dating. She confessed that she would only share her
problem with someone that she was in a long-term relationship with: “If I wasn’t with them too long, I wouldn’t tell them.” Hyacinth related that she wouldn’t be inclined to share this with her friends. In fact, she did not tell her mother for a long time, because it made her too embarrassed.

When Hyacinth’s UI first began, she went to her primary doctor who “didn’t recommend anything really.” She found her present urologist that she is now working with through one of her mother’s friends: “You know, I didn’t think it was normal, but I—you know—I’m not sure.” Hyacinth admitted she is baffled as to why her primary doctor told her that it is common.

Hyacinth appeared bewildered by her condition and even asked this researcher if it is common and normal in 20-year-olds to have UI. She projected an aura of innocence and naiveté when she asked this question, almost looking to be reassured that everything was okay and she was normal. She seemed hungry for answers, yet projected a keen determination for a solution.

Hyacinth reported that having UI negatively impacted her QOL and that there are many things that she probably would have done normally but now chooses to avoid because she is afraid of putting herself into a potentially embarrassing situation. She cited an example of feeling frustrated this very day: “I was working out and I was like, I couldn’t even finish working out because I had to go to the bathroom.” She reported that her UI greatly limited her participation in activities that she enjoys:

For example, I like to take my dog on a walk, and it’s like, every time I leave the house, like if I’m in the middle of a walk, I’ll have the urge to go to the bathroom and have nowhere to go.

Her UI also reportedly caused her a great deal of anxiety and stress: “I guess I get stressed very easily and I think the stress makes it worse.”

Having UI definitely was a hindrance to Hyacinth’s life, but although she appeared to be
frustrated and worried, there was a resilience and strength that she also portrayed as she attempted to make sense of her situation. To date, Hyacinth has not found a solution, but she is indomitable and not likely to let it bring her down for too long.

**Lily**

Lily is a 44-year-old married Latino woman with three children born via vaginal delivery. Lily has lived with UI for several years and describes it as “the worst thing that can happen to you.” Lily’s English is heavily accented, but she is eager to understand, and when she had trouble describing something or couldn’t find the words, she would point that out, to make herself understood. Lily described herself as being a “real chatterbox” and was frank and forthcoming in sharing her story. Since Lily was unable to be visualized due to Covid-19 restrictions, this researcher listened carefully for any auditory cues that might augment her verbalized story and give insight into her emotional state.

During the interview, Lily conveyed a wide range of emotions such as sadness, embarrassment, and frustration: “It took a lot from me.” One could also detect a level of frustration and hopelessness in the tone of her voice at times. Lily was very eager to share her story and feels that women need to be taken seriously and need to “go to the root of the problem and what is really going on.” She gave honest and thoughtful answers and expressed how grateful she felt after ultimately receiving a vaginal sling procedure, which helped her enormously.

Lily has tried many treatment modalities for her MUI, such as medications and percutaneous tibial nerve stimulation, with minimal success. Since Lily is a patient in the practice where this researcher is employed, some of her responses were validated in subsequent appointments in this office (with the urologist). This member checking was not taped, but Lily
validated her experiences by validating several significant statements.

Lily expressed a range of emotions when asked about her journey with UI:

It’s really not good. I mean, as a woman, it steals a lot of stuff—your confidence and even with intimacy…it kinda drains you, too, because you never know when you want to feel the urge to go to the bathroom again.

Lily further elaborated that it takes over your life and robs one of simple pleasures such as taking a walk or shopping. She disclosed she felt she had to plan her day around going to the bathroom. She was often reportedly embarrassed in front of her friends and family, saying they would make fun of her always having to go to the bathroom. “But, I mean, it’s something that you can’t control, even though you try your best.” She explained she felt that her friends, family, and children couldn’t understand what she was going through “because they are not in your shoes.”

Lily got to the point where she admitted she felt like she lost all hope regarding her condition:

Most young women, sometimes they don’t want to speak about what’s going on with this situation...they feel embarrassed to talk about it because they feel shame. They don’t feel comfortable opening up to the doctors because you lose hope when you can’t find the help.

Lily averred that her husband was supportive but she felt embarrassed nonetheless leaking urine during intimacy. I had to say to my husband, “I’m sorry; stop, stop. I need to go to the bathroom.” She recalled that this contributed to her libido becoming “non-existent.”

Lily reported always being exhausted, waking up five to six times during the night to urinate. She complained of having headaches from depriving herself of fluids and fearing that she smelled offensive to people: “I was feeling myself that I smelled bad, even though I wash my clothes, and when I take a shower, I wash myself with a special soap that I use for my down
there.” Lily shared that this fear of smelling bad worried her to the point where she would avoid getting too close to people. As the full-time housekeeper of a large estate on the North Shore, Lily has many responsibilities, which include shopping, cleaning, and overseeing the day-to-day running of the household. Living with UI proved to be difficult for Lily. She voiced how she avoided being out in public, but since it was part of her job, “I have to do it.” When traveling to the grocery store by car, she would “put like a lot of toilet paper inside me,” in case of an accident, with a towel for the seat and change of clothes.

Lily recalled it took her many, many years to find help for her UI. She was directed by her family physician to see two different urologists. One of them gave her a medicine but its side effect was “turning me like pink, my whole skin.” The second urologist wanted to instill an implantable device into her lower back and add more medications. Ultimately, Lily had a vaginal sling procedure, which helped her UI, though she revealed that she continues to suffer from urgency. She declared that she feels strongly that most providers, including women providers, don’t really listen or get to the root of the problem, but try to mask the problem by prescribing medications or procedures that are not even covered by insurance. She also verbalized that she felt that most providers, in her experience, were very dismissive. One female GYN told her, “Our grandmothers and our mothers suffer from this, so this is not something new. All women suffer.” Lily was then directed to do exercises but unable to attend exercise therapy due to the cost: “I don’t make that much money.” Lily asserted she felt strongly that this should never be something that women have to deal with: “I know science advances more and more, and I know they are not gods, but they are there to help us.” Lily verbalized that she felt that, unfortunately, many women doctors don’t really care about women patients.

Lily always has to wear pads, which she finds to be extremely irritating to her skin.
Before the sling surgery, and even now, to a lesser extent, she would only go to places where she knew where the bathroom was. In fact, when traveling by plane, Lily would book a seat in the rear of the plane adjacent to the bathroom. When traveling by car, “My husband had to stop the car on the side of the road and I’d get out—somebody can see me do my business…it’s something that you can’t control.” While walking around her property, Lily would have to run into the bushes to urinate. She would do the same at parks or in the water at the beach. When at the beach for a two-hour trip, she reported she would have to urinate three to four times, even though she drank the least bit of water. While relaying these incidents, Lily would often laugh at the end of each thought, to perhaps diffuse some of the frustration that she was feeling, but for the most part, she was brutally honest with her emotions when describing how this was “taking over her life.”

Lily is a very open and passionate person who is very easy to talk to and was more than willing to participate in this study and share her story. She is very level headed and strong and intent on not only helping herself find a solution but to help other women as well.

**Jasmine**

Jasmine is a 24-year-old single Latina-American woman who has never given birth. She has a very busy work schedule as a nanny, while pursuing a master’s degree in clinical mental health counseling. Jasmine is a very bright young woman who was eager to participate in this study. Jasmine opted for a telephone interview between her busy work schedule, as it was the most convenient method for her. She was in the car as the interview unfolded, between a physician’s appointment and getting a coffee at Starbucks. While describing the study to Jasmine, she told this researcher that she was very familiar with qualitative studies and that she actually authored a qualitative research paper on breast cancer and fertility last semester. She
expounded that in her experience with qualitative studies, “When it comes to issues like this, qualitative studies are much more effective than just getting statistics.”

Jasmine has been having issues with UI for almost six years:

It definitely takes a toll emotionally and physically because getting up six times throughout the night, it’s not efficient for a good night’s sleep, and it kind of makes you depressed because you try to enjoy certain things with your friends and you have to make sure when you go places that there’s a bathroom.

Jasmine explained that she would always map out rest stops for road trips. On plane trips, she admitted to always booking an aisle seat so she could get to the bathroom easily: “As far as travel, I always like need a method of transportation where there is a bathroom.” She said she would always carry tissues in the car and a change of underwear. Since she works as a nanny, she stated she plans to invest in a porta-potty for the car, since it works so well for the children she cares for. Jasmine related how she has experienced times when she was unable to hold her urine and had to urinate on the side of the road. She disclosed she felt fearful of holding her urine at all, as she feared she would get a urinary tract infection, which she reported, for her, are very difficult to eradicate. This was very embarrassing for Jasmine, as she is “afraid I will get in trouble for public urination…God forbid, someone caught you and you got into trouble. But, like, you really can’t hold it in.” Jasmine also recounted being uncomfortable while being intimate with her boyfriend: “Sometimes it’s really hard to have to stop in the middle like to go to the bathroom.” Jasmine is in a long-term relationship with her boyfriend and stated that he is very supportive. He always checks up on her regarding her medical appointments “just because he obviously wants to increase my quality of life.”

Although facial expressions and body language were not able to be visualized, Jasmine
was very expressive verbally, conveying how she was feeling emotionally. She would often sigh beginning a difficult explanation and often inject a laugh at the end of a difficult statement. One could feel the frustration and fatigue coming across over the telephone. Jasmine often made a reference to the fact that she is young and is bewildered as to why this is happening to her: “I’m young, you know; it just sucks.”

Jasmine recalled an instance where she was “severely worried and anxious.” She was preparing to take a 5-hour competency exam for school and requested to be in a special group that would permit her to take bathroom breaks:

The fact that I cannot go to the bathroom for four hours…I won’t be able to finish the test because I will literally have a panic attack if I feel like I have to pee and can’t get up to go to the bathroom. I literally thought about buying myself Depends just to sit and take the test.

Fortunately, Jasmine was accommodated and allowed to use the bathroom, but for Jasmine, “It was extreme anxiety.”

Living with UI, for Jasmine, has “definitely taken a toll on how I feel about myself.” She reported restricting her fluids, especially toward the end of the day:

Typically, if I know, like I had that test, I would not drink. I honestly restrict my water towards the end of the night as well. I try not to drink any water or very minimal water because I don’t want to be going to the bathroom four times during the night.

She worries about what her QOL will be like in the future after she has children: “I definitely want to have children, but it definitely puts like a fear that I have a weaker bladder than some women that already have three kids.”

Despite having UI, Jasmine related,
My quality of life is pretty good, but urinary issues definitely put a damper on it. I’m really tired if I’m up during the night. I’m really irritable. It’s like sometimes it can make you feel depressed because you just want to feel normal. Like some people hold their pee for hours and I’m like amazed by it.

Jasmine’s journey of seeking care began during her sophomore year of college, when she first realized it was becoming an issue, shortly after she began suffering from urinary tract infections. When she mentioned her incontinence to her providers, their excuse was always, “You’re young. Give it a few more months. Give it six more months. You’re young, you’re young, you’re young.” Shortly after that, she went to a urologist who put her on anti-depressants to relax the bladder. According to Jasmine, she was never examined, nor did she feel that they believed her:

My doctor didn’t so much as touch on the conversation with me. They kind of were, just like, you know, it would be better if you saw a urologist because we’re not really sure what’s going on with you. You know, even some urologists, I just feel like, don’t feel like it’s an issue if you’re young, you know? Like my old urologist was like, sometimes this happens with people your age and it’ll subside in 6 months. I’m like, but I’ve dealt with this for 2 and ½ years.

Jasmine felt unheard, not believed, and completely “brushed off.”

To date, Jasmine is feeling more optimistic and is actively exploring treatment options for her UI. She does report having anxiety and “I feel like when my anxiety is really bad, I pee a lot more.” Jasmine is caught up in a cycle of anxiety causing more incontinence and incontinence causing more anxiety for her. One gets a sense of how alone Jasmine feels during this journey and how out of control and embarrassed she is regarding her situation. She disclosed that she is
also worried about what her future holds for her with this condition but is adamant that she will move forward and continue to pursue her personal goals and aspirations.

**Marigold**

Marigold is a 44-year-old White American married woman with two small children, both born via cesarean section. She is a busy wife and mother who also works part-time in her own sales business, where she dedicates approximately 30 hours per week. Marigold is lively and vivacious, and eager to share her story of UI: “I mean, I wish more women would come forward and seek help for it, because it’s out there.” Marigold spoke rapidly and her responses were deliberate and well thought out. She often injected laughter into the end of sentences and described herself as a “jokey type” of person, although her tone of voice portrayed a very intelligent, confident, and optimistic young woman. Marigold opted to do a phone interview due to personal time constraints and safety, scheduling this interview immediately after work.

Marigold suffered from SUI for more than three years. She sought help from a urologist she was seeing for her frequent urinary tract infections and mentioned to him that

I’m like, I can’t hold my urine. My quality of life was horrible, and he said it could be due to age. It could be due to having children. I was like, well, I had C-sections, so I don’t know if that had anything to do with it. I didn’t give birth vaginally to either one. So, I just went about my daily life, but it was horrific. I would get up in the morning, put a panty liner on, and sometimes I would forget and I would be, you know, getting my kids ready for school and I would pee. I would literally just pee myself.

Marigold also reported limiting her fluids drastically, but without success. She was ultimately referred by a friend to her present urologist, who performed a vaginal sling procedure, which according to Marigold, greatly improved her QOL.
Marigold has a very friendly and upbeat personality and was very frank in her responses. She reported that “I’m not one of those embarrassed types.” She stated that she feels very free discussing this with her friends but admitted that she only shared this with her husband for a long time at first. She reported that her husband is very supportive and she feels very comfortable sharing this with him: “He was so supportive because he just knew that this was like crippling my life. He was like, ‘I’m so glad that you’re doing this.’ He felt bad for me essentially. He was like, this sucks.”

Marigold disclosed that even more damaging than embarrassment, she felt her UI was a big disruption in her life, as it caused her to be late for everything. “I’d have to turn around and go home and shower and change,” calling her clients to let them know that she’d be late again:

I would always have extra underwear in my work bag because if it happened at work, I’d be horrified. I would make sure that I had a panty liner on, and you know, I always had a change of underwear, always. I still do.

Marigold was always prepared and literally pre-planned her day around trips to the bathroom: “It just became part of my daily life.” Marigold expressed that she was never embarrassed in front of her children either. “They think it’s hilarious.” When Marigold first started to notice her UI: “Me and my husband would laugh. I would sneeze, and he’d go, did you pee? But it just became more problematic.” In fact, Marigold sees having UI at her age as a normal phenomenon: “I would say that it’s probably really prevalent among just, I would say anywhere from age 35 on. If there’s women that are embarrassed to talk about it, they shouldn’t.”

Since Marigold had the vaginal sling procedure this past November, she admitted feeling much improved but could recall having accidents prior to the surgery, where she would lose her urine on the floor: “I peed the floor. I didn’t pee the bed, but I did get it getting out of bed. Oh,
my God, I didn’t make it.” Since her procedure was scheduled during the pandemic, Marigold expressed she was very worried that it would be canceled. This was a great source of anxiety for her, since she wanted some form of hope to hold on to.

Despite Marigold’s happy affect, downplaying her situation with joviality, this researcher was able to discern the importance that getting help and finding a solution had for her. Although she verbalized that there are “tons” of women with this condition and that “it’s common; it’s so common,” one could feel her anxiety and need for a solution. Marigold is very pragmatic and a determined problem solver, and one gets the sense that she will stop at nothing to get a solution.

**Violet**

Violet is a 44-year-old White Latino American married woman with two young daughters. One of the daughters was born via vaginal delivery and the other was born via caesarian section. At the time of this interview, which occurred in the late afternoon, one daughter was doing homework at the kitchen table, while the other daughter was playing in the backyard. Violet is a very bright woman, a law school graduate who practiced law for several years but is now working as a teacher. Her schedule, coupled with work and family, is very demanding, with appointments carefully scheduled into her day. Violet was very receptive to being interviewed for this study and verbalized that the topic of UI in premenopausal women is an important topic to address:

There’s not a lot of information out there. I don’t even think some women have the words to describe what they’re really feeling. I feel like society in general is going through this phase where everyone’s trying to pay more attention to things that weren’t necessarily paid attention to, right? Like, you don’t have to push through pain. Self-care is important. Violet was very expressive and eager to share her experiences in an honest and
forthcoming manner. She verbalized gratitude for the opportunity to share her story, and her enthusiasm was palpable. Violet had been experiencing UI for more than four years following the birth of her daughters: “But, it just kept getting worse and worse to the point where I was like…there were some times I couldn’t hold it in. Sometimes I just totally peed myself.” Violet sought help from her GYN, who instructed her to do kegals. However, nothing seemed to help. Violet was seeing a therapist at that time for anxiety, and it was actually her therapist who recommended she see a urologist:

It kept coming up in therapy as a part of like…It was really wrecking my confidence and self-esteem. It made me not want to go out places, because you never knew what was going to happen. It all just did a number on my psyche. 

Violet ultimately had a urethral sling procedure done, which yielded a good outcome.

Violet recounted how fearful she was being any distance from her house. She always had to plan everything around the bathroom, bringing extra clothes for herself, which were dark and patterned to hide any wetness stains. She recalled how she wouldn’t wear any form-fitting clothing and was worried that she smelled like urine: “I just felt like everything smelled.” She would always travel with towels on the seat of her car and even used a cup to urinate in, in the car. It interfered with her work as a teacher. “The minute I even think it’s happening, I’m going to go, because to wet my pants in front of the class would have been horrible.” Violet recollected being in many uncomfortable situations, where she had to stop the car, open the door, and “pee in the middle of the street.”

Violet’s husband, though supportive, would ask her over and over, “Are you sure this is normal? He felt there was something wrong, but I don’t think he felt comfortable enough to tell me.” She shared that she did feel comfortable confiding in her girlfriends and family members.
They would tell her,

Welcome, this is what happens. It isn’t that, though. It became a focal point of my therapy sessions because it was just so defeating and was affecting my self-esteem and confidence and my wanting to go out and always having to prepare and anticipate the parade of horribles that might occur if you didn’t blah, blah, blah.

Her UI negatively impacted her sense of femininity, attractiveness, and sensuality: “You don’t feel like being touched in a sexy way when you’re not feeling fresh. Ever.” Violet’s daughter became aware of her UI, which she tried unsuccessfully to hide from her. She disclosed that having her children know was a big source of embarrassment for her. Violet would often laugh after recounting an embarrassing experience and sounded genuinely baffled as to what was happening to her body. She reported that her sleep was constantly interrupted, negatively impacting her QOL. She claimed she was always thirsty from depriving herself fluids and was always exhausted.

Violet shared her long journey to diagnosis from her GYN, who told her to tilt when urinating and do kegals. Violet said she tried so many things to self-correct, which she admitted was horrible. She recommends that all GYNs pose all post-partum mothers the questions: “By the way, has your urinary incontinence gotten better? Has it gotten worse? With emoji faces on a scale of 1 to whatever.” Violet was told by others for so long: “Alright. This is how it is. This is our lot in life.”

The interview concluded with Violet sharing a newfound self-knowledge and confidence:

I do realize that sometimes I don’t take as good care of myself as I should. After spending so much time with myself in quarantine, I made conscious choices that I’m going to pay attention to these things. So, if I have to go, I’ll go. I’m not going to wait. Everything else
Willow

Willow is a 31-year-old single White American woman who works full-time as a teacher. She is very organized and structured and scheduled this researcher 30 minutes in total on her calendar for this interview. Since Willow has a very full professional schedule, she opted to schedule a phone interview based on her convenience. Willow offered very clipped responses and was guarded in her demeanor. She tended to reply with a lot of “yes” or “no” answers without much elaboration. Many probes were used during this interview, as the researcher sensed that the interview was not flowing that easily.

Willow shared that during the past year, she was unable to hold her urine in the middle of the night. It woke her up at least two to three nights a week: “I’m assuming when I’m in a deep sleep, that’s when it happens.” Willow was defensive when asked to elaborate more on her symptoms, reinforcing that “It’s not every night…and that it’s very subtle, it doesn’t go through my pants or anything,” giving one the impression that she’s convincing herself that there is nothing wrong. She explained that even if she is really thirsty before bedtime, she would limit her fluids: “If I drink a whole water bottle, I will pee probably like 20 times.” During the daytime hours, she admitted to limiting her fluids as well, especially if she’s at work. Willow denied having this condition as a child and states she felt that it has worsened this past year. She was unable to offer an opinion as to how this incontinence began: “Maybe my body changed.” When asked how it affected her QOL, she responded, “How do I feel about it? I mean I’m not into it, but what I mean, nothing’s wrong. It is what it is.” Willow asserted that having incontinence does not affect her femininity or sense of attractiveness at all. “It’s more of just a nuisance.” She shared that when she first noticed it at night, she thought it was normal discharge and didn’t
really know what it was. When asked if she was ever embarrassed by her incontinence, Willow responded,

   Embarrassed of what, though? I don’t think it’s embarrassing. It’s not that odd either. I feel like a lot of women pee often, which is true. I mean, most people don’t as often in the middle of the night. I don’t think it’s anything to feel strange about.

Although Willow was almost defensive in her responses and tried to convince herself and this researcher that this is not an unusual phenomenon, in the next pause, though, she actually asked this researcher about any theories that might be had regarding UI based on speaking with other young women. Although denying the severity of its meaning for her, she was nonetheless eager for knowledge, to make sense out of what she is experiencing, and did seek help for it from her physicians.

   Willow’s journey to seeking care began when she saw her GYN, who did a urine sample, and was told that everything looked fine: “She didn’t really have a solution.” She recommended a urologist and told her to practice kegals to strengthen her pelvic floor. Although Willow vehemently denied its impact on her QOL, she did seek help from a urologist: “It’s uncomfortable to hold it in while I’m at work and such.” Willow does not want to take any medications at this time and is very cautious regarding treatments, stating she wants to do her own research before agreeing to do anything.

   Although Willow denied any negative impact on her QOL, she voiced she is very conscious of how much water she is consuming before traveling by plane or by car, deliberately restricting her fluids. She related that she has a long-term boyfriend who is very supportive of her. She recounted that she would often get the sensation to urinate but would not be able to urinate, particularly after having sexual relations: “I would push really hard on my bladder. I feel
like I messed my bladder up. I don’t know if that’s possible. You probably shouldn’t be pressing on your organs like that.” Willow admitted to a history of depression but doesn’t take any medications for it. She believes that her UI does not make her depression worse: “I don’t think they’re related.” She denied any leakage with exercise, “I guess I can’t hold it in the middle of the night.”

This researcher was able to see Willow several weeks after this interview, after Willow had completed several weeks of percutaneous tibial nerve stimulation therapy. Willow validated her responses and reported that she was very pleased that her symptoms are beginning to improve with these sessions. She is preparing to return to her teaching job in the fall and verbalized that she is strategically planning her therapy sessions around her work schedule so she doesn’t have to miss any work days. She continues to refer to her symptoms as more of a “nuisance” than anything else, but her demeanor is much more positive now that her symptoms are responding to treatment. She appeared much more confident and whispered to this researcher, “You know, I feel that now something is helping me.” Her relief was palpable, as she appeared more encouraged. She is now looking ahead to her job and her life with less UI.

Holly

Holly is a 40-year-old White American woman with three young children born via caesarian section. She works full-time as a therapist, with a very full professional and personal schedule. Holly was able to schedule this interview on a day off from work but had her children in the background. She was restricted in her time and scheduled a very tight 30 minutes to share her experience. Holly opted for a phone interview out of safety and her convenience.

Holly was very matter of fact, guarded, and tended to offer clipped “yes” or “no” answers in the beginning of the interview. One could sense that she may have been wary of being asked
personal questions, though she was fully briefed by phone before the interview. As the interview progressed, she tended to relax and often would interject laughter when describing her experiences. Throughout the interview, one could hear the chatter of her children, sometimes louder than she wanted, and one could sense that her eyes were on them and she was multi-tasking while interviewing.

Although she was not one to elaborate on her responses, she was able to convey a sense that UI, for her, was more of an annoyance than anything else and emphasized that it doesn’t occur daily: “It just happens. It’s nothing anybody else would know is happening.” She asserted that she never felt ashamed or embarrassed to talk about it with her friends, family, or spouse:

Yeah, I mean, I feel like most women my age are experiencing the same thing. When I speak to most of my friends, they seem to be experiencing similar, maybe not as bad, or I think some women just think you need to accept it?

Holly explained that she copes with her UI by always being prepared for the potential possibility of an accident. She said that especially when she’s running home or if she’s stopping someplace, “I’m pretty trained in the idea of being able to hold it. It’s more when I get up, I need to beeline for the restroom.” She admitted feeling most comfortable in her own home, where she could easily make it to the bathroom. Holly shared that she worries when she’s running late at work during her therapy sessions, which last 45 to 60 minutes. When she’s running over or late, “those couple of minutes count,” where she had to literally run to make it to the bathroom. She said that so far, she hasn’t had an accident at work, but it is a worry for her. The sound of water in the shower is also a big trigger for Holly that gives her the strong urge to urinate. She reported having to wake up every night anywhere from two to four times to use the bathroom. She explained that she always experienced a sudden urge since she was younger “and if I don’t get
there quick enough, you know.” When recounting her experiences working out, “There’s some
women at my gym that use Poise pads when they’re working out, just because…”

Holly disclosed that her journey getting help was relatively simple. She was seen by her
GYN, who then referred her to a urologist. Holly has been taking oral medications for several
years with good results but has recently stopped due to gastrointestinal side effects. She is
anxious to get off the medications entirely and “just retrain my bladder.” What she reportedly
finds most annoying is the reality of going to the bathroom and then having the strong urge to go
to the bathroom again five minutes later. She confessed that she has no control over the urge and
cannot leave her house until she performs the ritual of going to the bathroom again and again.

Although the interview with Holly was one of the shorter participant interviews, Holly
contributed an awareness of the spectral range of perceived QOL and how everyone has a unique
story to tell.

**Fleur**

Fleur is an open and friendly 44-year-old White American married woman with three
young children all born vaginally. She was very open and often injected laughter into her
comments. She spoke very rapidly with a Midwestern accent, so the researcher had to listen
carefully to understand everything she said. Fleur was very pleased to participate in this study
and felt that it was an important topic to explore. Her children were in school at the time, so the
interview was scheduled to take place before they came home. She is presently not employed and
is a full-time mom but is contemplating returning to work next year.

Fleur admitted to some occasional leaking, but for the most part, she could make it to the
bathroom on time. She reported that her incontinence improved shortly after having a
transvaginal sling procedure but that her main concern was an overwhelming urge to urinate,
which can be triggered easily by hearing running water or just walking by the bathroom door.

She shared that prior to having children, she had a “bladder of steel.” Her oldest child is now 11. She explained that her leaking began around that time and was always under the impression that it was a normal phenomenon throughout pregnancy, particularly in the 3rd trimester. She often heard, “It was just because you had a baby. You won’t have this issue anymore, but then it just got worse…It got a bit worse with baby number 2, and then I probably broke the bank with baby number 3.”

Fleur began to seek help more than three years ago. She started on oral medications but relayed that “didn’t really put much of a dent in it.” When she asked her pharmacist if there was a higher dosage she could take, she was told there wasn’t a higher dosage than that. Fleur began her journey with her PCP and was subsequently referred to a urologist at New York Presbyterian Hospital. The urologist performed a transvaginal sling, which addressed the leaking problem but not the urge. Fleur admitted that she was confused by her doctor’s approach when they recommended the sling procedure and divulged that she felt she was misinformed regarding the procedure but went ahead with it on the doctors’ advice, feeling she needed to find a solution: “It’s going to address something. I guess I had to learn the hard way. I didn’t know. The more I looked into it, the more I realized I should have talked to the doctor more.” Fleur voiced that she continues to suffer from a strong urge, feeling she has to urinate all the time: “I feel like I have to go really bad and I’ve just gone like an hour ago. I don’t have that much urine. I can’t have to go that bad, because I just went. I know that’s quality of life.” She also averred that she felt that most of her doctors gave her misinformation: “It has to do with having babies or it has nothing to do with having babies.” She shared it did occur to her that having another baby might make her situation worse: “I probably wouldn’t have done it to my body. I wouldn’t say that would have
been a deciding factor though. Three is enough.”

Fleur confessed that she is baffled as to how this all started and had to give up activities that she enjoyed, such as her daily run. She used to wake up in the morning and do a 3-mile run. She concluded that the pounding of the pavement, to tramp up and down “doesn’t work with a full bladder.” She admitted that she copes by severely restricting her fluids:

Like I used to hydrate myself. I don’t hydrate myself much anymore. I’ll be thirsty going out the door, but I don’t want to drink it. I can’t drink a bottle of water because I’ll have to go to the bathroom.

Fleur also dehydrates herself on purpose before any travel by car or air. During social events, she admitted that it’s always on her mind that she may have to get up and use the bathroom. She doesn’t seem embarrassed or bothered by it in a group or social situation: “If I go out with four or five girls, there’s always someone that has to use the bathroom.” It’s the deliberate dehydrating that seemed to be the most bothersome for Fleur:

Like when I’m taking the kids to Lacrosse or basketball practice, I’m like thirsty and I’m gonna grab a bottle of water, but nope, I don’t want to drink it cause then I’ll have to go to the bathroom. I’ll just be thirsty. That’s how I solve it by just not drinking a lot. That’s probably the wrong way to go.

Fleur confided that her husband is supportive of her but admitted that he wonders, “Why do you have to go to the bathroom all the time?” When asked if she ever felt self-conscious about her leaking or urge, she responded, “Like why me? Going to the bathroom all the time. Why doesn’t Cindy have this or whatever. She could drink a bottle of water and not have to go—that’s not cool. That’s not fair.” Fleur didn’t come across as angry or bitter but more bewildered as to why this was happening to her.
This researcher was able to speak with Fleur again, as she was seen in the office where the researcher is employed. She validated her earlier responses and is feeling optimistic regarding her current situation. She is going for percutaneous tibial nerve stimulation treatments that she reports are working nicely. She is very hopeful and looking forward to finding a solution. This second encounter was about 15 minutes in length and was not recorded. Notes were taken by this researcher after the encounter for validity. Fleur thanked this researcher and reinforced that she was happy that such a study is being conducted and was grateful to be included.

**Summary of Participants’ Stories**

A total of 13 premenopausal women shared their lived experiences living with UI and its effect on their QOL. Although each woman had a different story to tell, with a different range of emotions, all agreed that living with UI negatively impacted their QOL, from being “annoying” or just “a nuisance” to being the “worst thing that can happen to a woman.” They were all bewildered by what was happening to them and tried to cope with it in their own way. Their stories illuminated how strong and resilient they were in the face of adversity and how indomitable their spirits were in their quest to find a solution.

**Data Analysis**

The data analysis involved the researcher thoroughly immersing herself into all of the collected information obtained from the participants, including transcribed interviews, field notes, and memos. All interviews were read simultaneously while listening to the audio recordings of the participants stories within hours of the interview to assist with recall. Thoughts and perceptions by the researcher were also written shortly after each interview, which enhanced subtleties in tone and expression, lending a better understanding of the lived experiences of these
young women. The transcribed interviews through an online service, Rev.com, were edited for unrelated conversation, such as interruptions from children and words such as “uh” and “um.” After re-listening and re-reading the transcripts several times, the data were systematically categorized and organized using the NVIVO software program, which managed the data for coding and development of themes. Sentences of the transcripts were read line by line, and the sentences that pertained to the phenomenon were highlighted and imported into nodes in NVIVO. This process was also repeated two weeks later to ensure that nothing was overlooked. Each sentence was read to interpret what the phenomenon revealed. Codes were then generated from significant words and sentences used by the participants. All units with similar meanings were then categorized into themes and subthemes. After re-examining and revising the codes, the researcher determined the final themes and subthemes. The interviews spanned from the end of May to the end of July, 2021. Entry into NVIVO commenced when the last interview was installed into the program. All transcripts, audio files, and NVIVO nodes and themes were mailed to the dissertation chair for review, serving as the content expert. Many sessions took place with the chair to validate the findings and exchange thoughts.

The six methodological activities by van Manen (2016) were used to guide this study of premenopausal women living with UI and its effect on their QOL.

- Turning to the nature of lived experience: Thinking and focusing on premenopausal women who have UI, formulating the phenomenological question: What has your experience been like living with UI, and how has it impacted your QOL?
- Investigating experience as we live it: Prolonged engagement with premenopausal women with UI, conducting in-depth interviews, to capture the phenomenon.
• Reflecting on essential themes: Listening to audio recordings, immersing oneself in data, conducting thematic analysis (using holistic, selective, and line-by-line approaches) to understand the overall meaning that the experience had for the participants by reflecting on themes.

• Hermeneutic phenomenological writing: Writing transcripts, writing about themes, writing to create a phenomenological text. Through the process of writing, the intention is to make visible the feelings, thoughts, and attitudes of the participants.

• Maintaining a strong and oriented relation to the phenomenon: Striving to remain focused on the research question.

• Balancing the research context by considering the parts and the whole:

The next section presents the emerging themes that were uncovered by using the process of data collection described. According to van Manen (2016, p. 79), phenomenological themes can be understood as the structures of experience, the experiential structures that make up that experience. The emergent themes that evolved include:

• Disruptive Realities

• Beliefs

  Belief that I’m Too Young

  What I was Told

• Willingness to Share

• Coping Strategies

• Infringement on QOL

  Effect on Intimacy

  Restrictions to One’s Way of Life
• Reported Feelings
  
  Fear of Embarrassment
  Fear of Smelling Bad
  Feeling Like a Child
  Feeling Out of Control
  Negative Self-Image

• Journey to Care

Expense

The Way It Should Be

These emerging themes will be further elucidated through interview excerpts from the young women as they share their lived experience living with UI.

Emerging Themes

Theme 1: Disruptive Realities

I am in awe of flowers. Not because of their colors, but because even though they have dirt in their roots, they still grow. They still bloom.

– D. Antoinette Foy

The data analysis yielded 7 emerging themes and 10 subthemes. Theme number one, Disruptive Realities, was a dominant theme in many of the interviews, as these participants shared their stories. Disruptive Realities speaks to some of the many uncomfortable situations that the participants found themselves in. In terms of UI impacting work and career, Violet recalled being afraid of embarrassing herself in front of her students:

   Working was horrible because I’m a teacher, and at that time, we were in the building, right. As teachers, the ongoing joke is that we never drink or eat. But I definitely had to
leave my class in the classroom…that’s the thing about incontinence; sometimes it’s a lot, and other times it’s just nothing. Right. And then leave them and then run back, literally run. But often, I’ve left my kids in the class just doing like work, ‘I’ll be right back. I can hear you.

When Iris was asked about situations that she was uncomfortable in, she recollected, “Because I’m at work and sometimes you don’t realize that you have to go and then, when you want to go, it was too late and you don’t have the bathroom right there.” Holly agreed that the work situation can make her uneasy and felt that she has to try and stay on top of her urges to urinate:

Work is a little more difficult for what I do for a living. I’m a therapist, so I sit with people for 45 minutes to 60 minutes. Yeah. And the way I schedule myself is back to back with no breaks. So, you know, typically a lot of times, you’re running late with appointments—you know, a couple of minutes—but those couple of minutes count. So, if I feel like I’m already late with someone, I might not run to the bathroom and then, by the time the 45 minutes is up, I have to run to the bathroom.

Jasmine, a 24-year-old graduate student, remembered a particular occasion where she became extremely anxious and became fearful that she would not be able to hold her urine:

I’m in graduate school for clinical mental health counseling. In my program, we have a competency exam at the end of the semester that you sit for—it’s kind of like a mock licensing exam that you have to pass, but it’s five hours. I had to go into the special requests group. I asked my teacher, you know, it’s Zoom and we have cameras set up behind us…Am I allowed to go to the bathroom? Like it’s causing me severe anxiety. The fact that I cannot go to the bathroom for four hours, I will not be able to finish the
test because I will literally have a panic attack if I feel like I have to pee and can’t get up
to go to the bathroom. I literally thought about buying myself Depends, just to sit and
take the test.
Fortunately, Jasmine was accommodated and she was placed in a special group where she
actually got up three times: “That was rough, but if they would not have let me go, I would have
bought myself Depends.”
Travel also proved to be a source of anxiety and frustration for the participants as they tried
to navigate their daily lives. Iris remembered:
It was very bad because most of the time, I live a half an hour from work to the house,
and in that half an hour, I want to go, but have to wait. Sometimes I just run to the house,
and sometimes I leak because I couldn’t make it to the bathroom because of the distance
from the parking lot to the apartment where I live. So, it was terrible. It was a fear that
you don’t want to drive so far. When I went to the doctors, I was afraid, because since I
got there, I have to ask at the desk. I have to go to the bathroom; I can’t wait anymore. It
was bad.
Lily admitted being unable to have any control over her urination: “I mean, to be honest
with you, sometimes I had my husband stop the car to the side of the road, and I’d get out there
in the middle of... somebody can see me doing my business.”
Marigold shared a time when her UI became very disruptive to her life:
It became disruptive as far as me being late to everything because I’d have to turn around
and go home and change and shower. So, I would literally soak my pants driving to
work… It was literally like, it would be a puddle in my car, like driving. I’d look down,
and I’m like, oh my God! I’d have to call my client and say I’m sorry, I’m going to be 15
minutes late. I’d have to turn around, go home, shower really quick, and change my pants and sometimes my shoes. Cause it would beat down all the way down to my shoes. Jasmine recalled traveling with friends and finding herself in an impossible situation: The rest stops are good…I’ll go to the bathroom in there. Then with Covid and stuff, some places didn’t even let you. So, I would have to pee outside. Like, I mean, there’s no way that I could hold it, and then you know, ’cause holding it can also produce urinary tract infections. I don’t get urinary tract infections often, but when I do, they’re really hard to eradicate…so that’s another; in your mind, you’re holding it way too long or peeing on the side of the road and having to shake it out and pull my pants up and you’re not wiping.

Marigold remembered a beach vacation with her family, where she wasn’t able to control her urination. She recalled this memory in a light-hearted way, but one could tell that she was worried about being thrust into an embarrassing situation:

I would limit my liquid intake wherever we would go. But last June, we were at the beach and I couldn’t hold it and I just peed right walking to the ocean. I’m like, I can’t hold it! My sister-in-law was with me and they knew and were like, don’t worry about it. No one knows. Okay, I’m like sort of walking closely with my legs shut. Lily is less lighthearted when she recounted how frustrated she has been at times:

You see, in the property where I live, we have a huge property and we have the chance to go walk around. But if I had to go to the bathroom, I had to use like a very thick pad in case I had to go to the bathroom, and if I can’t hold it, I’d have to run into the bushes to go to the bathroom.

Daisy talked candidly about her reality:
It got to the point where, like in the morning, I would wake up and…my shower doesn’t get hot right away—it takes a couple of minutes. So I would wake up, turn on the shower and would have to pee, but I couldn’t make it to the bathroom.

There were many recollections from the participants as they candidly shared their lived experience on how living with UI became a cruel reality. Like Daisy, Marigold remembered, “I did; I peed on the floor, but I got out of bed. I didn’t pee the bed, but I did getting out of bed. Oh my God, I didn’t make it!” She also recollected, “I would get up in the morning, put a panty liner on, and sometimes I would forget and I would be—you know, getting my kids ready for school and I would pee—I would literally just pee myself.”

**Theme 2: Beliefs**

*She might look like a fragile flower but her stem is made of steel*  
— *Jonny Ox*

A reoccurring theme during the interview process was the participants’ beliefs and what they thought about living with UI, particularly as it relates to their age. Most of the participants were baffled and bewildered, though some accepted it as part of their lifestyle. The theme of beliefs was categorized into two subthemes:

1. What I was told

2. A belief that I’m too young

Flora, when questioned about her thoughts on UI, replied, “I mean, who doesn’t pee when you laugh? Yeah. It’s so normal. You know, I just thought that I’d have to live with this and there’s nothing to be done for it.” Later in the interview, she shared, “I mean, I never went to the doctor to inquire about it. I assumed it was something that was part of my life, that was, well, normal for someone with three children.”
In a similar vein, Willow, who was seeking help for nocturnal enuresis, defensively responded, “It’s not that odd either. I feel like a lot of women pee often. Yeah, like most people don’t as often in the middle of the night, but I don’t know. I don’t think it’s anything to feel strange about.”

Holly pensively agreed:

Yeah, I mean, I feel that most women my age are experiencing the same thing. I’m not embarrassed by it. When I speak to most of my friends, they seem to be experiencing similar, maybe not as bad, or I think some women they’ll just think, you need to accept it.

Marigold views UI as a phenomenon that is age related:

I would say that it’s really prevalent among, I would say from 35 on. If there’s women that are embarrassed to talk about it, they shouldn’t. There’s definitely women out there, like in my circle of friends, who are over 40, in the mid-range 40-45; there’s tons. It’s mostly women who, you know, have had kids, but also women who have not have kids. My sister-in-law, she’s 47. It happened to her, too. So, I think it’s also just age. I don’t know what the cause is.

She laughingly remembered a family beach trip she went on two years ago when she had a sudden uncontrollable urge to urinate while walking the beach with her sister-in-law: “I was walking tightly and I’m thinking, ‘Nobody knows; nobody knows.’ I think she peed in the beach chair ’cause she laughed so hard. It happened to her, too. It’s common. It’s so common.”

Rose did not really know what to believe but expressed bewilderment: “I didn’t know half of the stuff that happened after birth. I was like ‘oh, no’ no one’s ever mentioned that to me.”

Daisy recalled in a more somber tone:
I always thought it was more like after kids, and I feel like I would talk to my friends and then like ‘Oh, we have that, too,’ but it was never to the extreme that I was having it. You expect it to get better, to go away, but it got worse. I didn’t realize until it got so bad, like in the morning when I wasn’t making it to the bathroom and like peeing on the floor and my kids were with me, like, alright, this isn’t normal.

She was under the impression that “Oh, I just had a baby,” but was soaking through her clothes when she would run on the treadmill.

Hyacinth believed her UI was stress related: “It’s usually during the day. Like for me, I guess I get stressed very easily and I think the stress makes it worse. When I’m not stressed, it’s better.”

Violet recalled what she believed about UI:

I hadn’t even turned 40. By the time I got the surgery, which was only last summer, it had gotten super worse and I had let it go on for many years because, what am I, 44? I guess I had the surgery when I was 43. I let it go on for a very long time, because I thought it would just fix itself, because that’s another thing that’s out there. It fixes itself. It’s aggravated by stress.

What I Was Told

Several of the participants shared things that they were told by people who mattered to them and had a strong influence on what they believed to be true, regarding living with UI.

Violet recollected:

But even close girlfriends and especially my mother and the older women in my family are like ‘See, welcome. This is what happens. Oh, it happens as you get older, after you have a baby; all this stuff gets weak down there and blah, blah, blah.
Violet also recalled later in the interview, adding,

And by the way, my mother growing up was like, ‘Oh, do you know why this is happening? Because you used to hold your pee for too long, and now this is what’s happened. Now your bladder is weak. It’s like a fait accompli.’ It’s like, alright, this is how it is. This is what happens. This is our lot in life.

Violet reported that instead of getting better though, “It kept getting worse and worse to the point where I was like…there were sometimes I couldn’t hold it in. Sometimes I just totally peed myself.”

Fleur genuinely believed that her incontinence was triggered by childbirth and then expected it to improve after that: “I guess all through pregnancy…and then I remembered something, oh, it was just because you had a baby. You won’t have this issue anymore.” However, Fleur shared that her incontinence never went away but “just got worse.”

Willow, who claimed that she is experiencing more symptoms of annoyance, due to her nocturnal eneuris, related:

My boyfriend told me I should tell the doctor this, but I forgot…Sometimes I guess, there was like a period of time where I felt I had to pee and it wouldn’t come out and I would push really hard on my bladder, and I feel I messed my bladder up. I don’t know if that’s possible. You probably shouldn’t be pressing on your organs like that. I don’t know if that did anything harmful to me.

Although Willow didn’t appear to be overly concerned with her incontinence, she nevertheless gave it enough thought that she believed that she may have caused her situation to occur.

Violet expressed that many of the prior firmly held beliefs are often not valid, however:
“Between the old wives’ tales, it was just a massive amount of misinformation.”

**Belief that I’m Too Young**

A belief that emerged on numerous occasions was the idea that the participants believed that they were too young to be faced with this problem and that they always thought and believed that it was something that happens to much older people. Poppy verbalized confusion as to why this was happening to her: “Also, I’m young aged. I would think that things like this don’t happen in your 30s and 40s. It would happen at a later time.”

Rose expressed a similar sentiment, “You know, I felt, and to be honest, I mean I’m 38. I was 38 and now I’m 39. I felt like I was like 85 years old. I was like an old lady. I hate to say that, but yeah.”

Violet recalled with frustration:

And, plus I was on two kinds of medications for it. It was helping me, but not that much. And I feel bad because I’m just 42 years old and I think that I’m too young to be experiencing that. And I’m the first one in the family who has this, too.

Iris, who works as a nurse’s aide, also believed that she is too young to experience UI:

“My job is an aide, so you can see that in older people, not people in your age.

Hyacinth appeared equally baffled by her reality:

At first, I was embarrassed and then I was trying to understand it more because I always thought this is what happens to older people, you know, people in their 70s, 80s, 90s, you know. That’s how I first thought about it because you hear, you know, people in nursing homes, you know, people in their 90s and 80s. I guess this would make anyone depressed, especially at my age, you know.
Theme 3: Willingness to Share

*Flowers grow out of dark moments*

– Corita Kent, “Moments of 1984”

As the participants’ stories began to unfold, the theme of being open to share their stories also began to emerge. Many of the participants felt very comfortable discussing their incontinence, and some didn’t find it to be much of a problem at all. Some of the participants felt that sharing their stories would help other women with UI, yet others were very reticent about sharing their stories and were embarrassed and guarded. Rose, for example, felt very comfortable telling her friends:

You know, it’s funny. I’ve told a couple of friends who were also having babies around the same time as me and so I said, you know, I didn’t know that this happens. And they were like, oh yeah, that happens. You know, like it’s normal.

On reflecting on telling her husband, Rose explained that he used to care for his father, who was wheelchair bound and was one of his primary caregivers. “So, he was kind of used to things like this, like incontinence, yeah.” Rose had a more pragmatic attitude toward sharing her story: “I’m pretty open because I like, you know, I want to find out what, like I want a solution, right? So, it’s like, why not talk to people to see like ideas and all.”

Fleur did not have any reservations sharing with her friends, family, or her husband: “He understands, like, oh yeah, these big babies. I didn’t have this when I met him; now I have this issue.”

Flora felt similarly: “I never felt it made me feel bad or depressed, and my husband knows. We’ve talked about it, and he’s okay about it.”

Daisy averred that she felt free to share with her husband but also gave the impression
that he was a bit frustrated by her condition:

He was fine with it, but he was also like, you know, when it got kind of worse, like over the last couple of months… and now last year, he’s like, “you need to see a doctor and you need to get this fixed.”

Violet recalled sharing with her husband:

He was very supportive. He didn’t tell me to go see the doctor. He was just saying over and over, “Are you sure this is normal?” He felt there was something wrong, but I don’t think he felt comfortable enough to tell me. But I think when my therapist told me to go get this addressed, he was like, “Thank God somebody told her.”

Violet also confessed that her husband felt sorry for her and told her “This is a shame.”

Daisy relayed that she felt free to share her issue with her friends over many, many years:

Like I said, I definitely noticed that like, looking back, like, oh my God, I feel like I had this when I was younger. Even my high school friends are like, oh my God, I remember you always peeing your pants.

Poppy also voiced being comfortable sharing her story with her family members and friends, but it wasn’t always met with compassion:

It was often that they would complain to me how many times I have to use the bathroom.

They would complain to me that I had to use the bathroom so many times and it’s not normal and it shouldn’t be like this and why is it like this?

Lily admitted to feeling comfortable sharing as well but didn’t feel that she was really understood:

So, like everyone knows that I have my situation, like going into the bathroom a lot and peeing, so they don’t understand. They don’t really understand how messed up you are in
that part of your body. Most women—sometimes they don’t want to speak on what’s going on with the situation. I mean, they are not in my shoes. When people don’t suffer from what you have been suffering, they don’t understand. My daughter understands a little bit.

Jasmine was very lighthearted and appeared not to be concerned with sharing her story: “My friends will make jokes—cheeky jokes—like obviously not meant to intentionally hurt my feelings but like, ‘Oh, we gotta make sure there’s a bathroom.’ ‘Like there she goes again to the bathroom.’” Jasmine’s family was also very supportive and she never felt embarrassed sharing with them:

I have a great support system when it comes to medical issues and whatnot. So that’s been something my parents and friends have been aware of for years. Even if I didn’t want them to know, it’s really hard to hide it when we go out. I mean, I’m running to the bathroom every five seconds. But yeah, my parents know about it and they definitely don’t shame me.

When reflecting on her vulnerability around her husband, Jasmine was very trusting and appreciative of her relationship: “He always checks up on me and how my doctor’s appointments have gone. Just because he obviously wants to increase my quality of life and just be supportive. So, I’ve been lucky with that.” Jasmine, on further reflection, shared:

It does a number on you quite quickly, but I also didn’t enjoy people who were around me often could now tell when something was happening, because my foot would tap. I’d try to pretend like it’s not happening because you don’t want to be that person.

When Iris was asked how comfortable she was in sharing her story, she replied, “Yeah. I spoke about it with them and everything. They don’t have the same problem, but they
understand.” Conversely, not all of the participants were as comfortable sharing their story with friends, family, or significant others.

When Poppy was asked how comfortable she was, she confided,

That’s very embarrassing. My family knew about it. I told my family and my sister-in-law, but other than that, no. I didn’t want anyone to know, because this is a sensitive conversation. It’s not easy for you to tell people that you can’t hold your urine and you are going to pee all over yourself if there is no bathroom available, which happened a lot to me. I had to wear a diaper. Who do I want to talk to about wearing diapers?

Hyacinth was also reticent about sharing, “And I didn’t tell my mom, ’cause I was like, ‘What is going on here?’ I guess I was embarrassed to tell her.” She did eventually tell her, “I guess I wasn’t sure what I had. I told her, like, I’m not sure if I’m leaking. I didn’t know what it was.” When Hyacinth was asked if she would share this with a boyfriend, she instantly replied “no,” not taking a second to think about her answer. She then added,

Well, it depends how long. I think it depends how long I’ve been with the person. If I’d been with the person for years, I would probably tell them, but if I wasn’t with them too long, I wouldn’t tell them, if that makes sense.

**Theme 4: Coping Strategies**

*The flower that blooms in adversity is the rarest and most beautiful of all*

– *Walt Disney*

Coping with UI elicited many responses, because whether their incontinence was mild or severe, each participant appeared to have a battle plan or ways to attempt to compensate for it and adapt to her situation. As Rose explained, “I would kind of alter my lifestyle, manipulate my day around it.” By compensating for it, many of the participants were actually adapting to their
situation to effectively function.

Poppy shared in a frustrated tone of voice:

The problem is, as I got older and as time went by, it just got harder and harder and more problems and more accidents. It’s very hard not to drink water, not to leave the house, not to go anywhere because of this problem and because I don’t want to get embarrassed in front of people and my children and my husband.

Rose explained that she has a portable commode in the car when she travels:

I still have it in the car with me because I always get nervous, you know, if I couldn’t stop or if I had to go. I have to go like now—I would have to and I’d have a lot of anxiety about it.

Poppy has had UI for many years and admitted that she continues to have little control over her situation:

But anyway, I couldn’t go to a lot of places because I had to make sure there are bathrooms available and I could only drink water the times that I’m home. The times that I wanted to leave the house, I wouldn’t drink water. If I was out for a few hours, I would just sip the water because these things would come like a sharp pain and then my pee would just release and that’s it. There’s nothing I can do. I couldn’t hold. It was very hard. It was very hard. I was trying my best not to drink a lot of water. I was dehydrated all the time. I used to have headaches. I used to get dizzy.

Poppy explained that she would never drink after 6 o’clock at night and would always go to sleep thirsty. She also lamented about having to wear a diaper: “I had to walk with a diaper. I walked with a diaper for about two months or maybe longer.” Poppy would also have to prepare for traveling by car: “I had to have something in the car to sit on. Plastic, so I wouldn’t get my
car wet because I didn’t want urine in my car.”

Rose remembered,

Even traveling, we didn’t go in the car too long. I was nervous. I brought with me—they had these things—I bought it, like I could go to the bathroom in the car if I had to. You know, it was a thing that you can hold under you.

Rose also recalled restricting her fluids: “I had to really kind of try not to drink as much liquid then. I would kind of like alter my lifestyle, manipulate my day around it.”

Lily confessed that she had to resort to using sanitary pads but found them to be very irritating to her skin: “I really hated using the pads because it was…but I mean it was my only option.” Lily shared that she, when traveling by air, would book a seat in the plane closest to the bathroom and would look at the plane configuration as she was purchasing her ticket to see where the bathrooms were situated. When traveling by car, Lily would also be prepared. She would have a towel on the seat of the car “in case something happened and I put like a lot of toilet paper. I use a lot of pieces of thick paper inside me.”

Violet remembered that she had an event that occurred at her gym many years ago, which prompted her to “only buy workout clothes in certain colors. I’m not going to drink. That’s when all the weird coping mechanisms started occurring.” Violet would always have an extra outfit in the car and an outfit that was “splatter proof” that she could wash. She never wore anything form-fitting, only loose-fitting attire. She recollected that there would always be towels on the seats of her car:

And I would get so mad because I wouldn’t always remember, because it didn’t happen all the time. And so, sometimes it was just kind of wishful thinking and I was feeling good, so, ‘This isn’t going to happen, right?’ And then maybe it’s getting better. It’s this
false narrative that you tell yourself and then something happens and you have to go right back home because you were not prepared enough.

She did admit that many times she had to urinate in her car. “I have peed in things in the car. I’ve peed in a cup if it’s gotten too bad.” Violet ultimately confided,

I think probably the worst thing that I ever did in the name of just trying to avoid what came with incontinence was just restricting my liquids, such that it’d be the least amount of liquids possible, but that was not healthy. So, as time goes on, I feel like it became like listen to the whispers of your body before it becomes a scream.

Fleur was a big runner years ago and would plan daily 3-mile runs:

I don’t run anymore. I walk after that. I used to hydrate myself. I don’t hydrate myself much anymore. I mean, if I’m going to sit by the bathroom all the time, but like, gee, I’m thirsty on the way out the door, but I don’t want to go and drink it, ’cause like, I can’t drink a bottle of water because I’ll have to go to the bathroom. I just don’t drink a lot because that’s how I solve it by just not drinking a lot. That’s probably the wrong way to go. I’ll just be thirsty.

Jasmine reflected on how she prepares and copes to prevent any unforeseen situations:

I wear panty liners sometimes, but it really just depends. I sometimes think I don’t wear it because I’m in denial that I don’t need that. That’s why I bring my underwear out with me…and I always make sure I have tissues in my car, but not everyone, you know, carries tissues with them in their car, and um, I would have to, you just shake and pull your pants up ’cause you gotta let it out.

Jasmine also admitted to restricting her water intake:

I honestly restrict my water towards the end of the night as well. So, once the clock
comes around, I try not to drink any water or minimal water because I don’t want to be
going to the bathroom four times a night. You know what I mean? Kind of restrict my
water in different ways on a daily basis, depending on the situation.

When queried about making any adaptations around traveling, Jasmine thoughtfully replied,
“Yeah, I plan, I…we plan out the routes anytime we take a long drive, and I plan and make sure
we take the route with the most rest stops. I look along the way.” She also admitted “investing in
a porta potty,” as she found that, since working as a nanny, this works efficiently for her and the
children she cares for. In regards to travel by plane or train,

Yeah, so traveling, um, I used to love sitting in the window seat of the plane, that was
like…I no longer can stay in that seat anymore. I always have to make sure I get an aisle
seat… meeting up social wise like with my friends, if I take…I live in Long Island—the
LIRR goes straight to Penn for 40 minutes and some of the cars don’t have bathrooms, so
I have to hold it either until we get there or go to a bathroom in the train station and it just
causes panic. It really does. It causes panic. So as far as travel, I always need a method of
transportation where there is a bathroom.

Daisy recalled that cardio and exercise activities such as dancing, running, and jumping
would trigger her to have an accident:

I would go to the bathroom before the class. It wasn’t, it was just like it would just come
out. It was really like, during like, kind of exercising. I never truly enjoyed it, so I didn’t
miss it too much, but yeah, it did impact me that way that I did stop doing that. I just got
to the point where like, I’m not doing cardio anymore. As I got older, I stopped doing the
things that I knew would make it happen. I mean, there were times where my underwear
would get wet.
Daisy coped with her incontinence in her own way: “I would be soaking wet. I would start to buy workout clothes that were more like patterns or dark colors, because I’m not going off the treadmill. I’m just going to go even wearing pads and everything.” Holly recalled,

I mean, I just try to prepare for it. And so, you know, I’m pretty trained in the idea of being able to hold it. It’s more when I get up, I need to make a beeline for the restroom and if I’m stopping someplace.

Iris shared, “Yes, I always carry pants, underwear, and a pad, too.” Willow prepared by limiting her fluids as well:

I’ll be really thirsty before I go to bed, but I limit how much I drink because I know if I drink a whole water bottle, I will pee probably like 20 times. If I’m going on a plane or somewhere where I don’t want to use a public restroom, I’m like very conscious of how much water I’m drinking beforehand.

Marigold is very pragmatic when discussing planning for the eventuality of incontinence:

I would always have extra underwear in my work bag because if it happened at work, I’d be horrified. Once, I went home and changed. I would make sure that I would have a panty liner on. And, you know, I always had underwear, always. I still do.

**Theme 5: Infringement on QOL**

_The lotus is the most beautiful flower, whose petals open one by one. But it will only grow in the mud. In order to grow and gain wisdom, first you must have the mud—the obstacles of life and its suffering…_

– Goldie Hawn

Every participant, for the most part, could say that their QOL was affected by living with UI to some degree. Some found that it had a minimal effect, whereas others felt it had a severe
negative impact on their lives. The theme of infringement on QOL was further broken down into two subthemes: (1) Restrictions to One’s Way of Life and (2) Effects on Intimacy.

Flora is one of the participants on the end of the spectrum where she averred that her incontinence did not negatively affect her life quality:

It’s just very annoying, I will say that much. But you know what? I think if I’m out with my girlfriends or whatnot, I know it’s going to be an issue. I’ll put on a panty liner so I’m prepared. But if I’m out the whole night with my friends and we’re constantly laughing, that’s a different story. Then it can be a lot more leaking and very annoying. I’m just so used to it, I never thought anything of it. I never thought of it as a problem. I’ve lived with it for so long now.

Fleur related, “I feel like I have to go really bad and I’ve just gone like an hour ago and not much urine comes out. I can’t have to go that bad, because I just went. I know, that’s quality of life.” Fleur admitted that her incontinence is not as bad as it was at the end of her pregnancy and got better once she delivered but then got bad again.

Willow, who could be defensive regarding her nighttime incontinence, replied:

I mean, it’s like very subtle. It doesn’t go through my pants or anything. At first, I thought it was discharge because it’s so subtle. How do I feel about it? I mean, I’m not into it, but what I mean is nothing’s wrong. It is what it is.

Although Willow insisted that her life has not been affected by her incontinence, she still sought help from medical providers and continues to seek a solution: “I mean, yeah. It’s uncomfortable to hold it in while I’m at work and such.”

Holly also shared that her UI is more of an annoyance than anything else. When asked if her incontinence has had any impact on her QOL, she responded, “It really has not affected it
greatly at all. It’s not like a daily occurrence. It just happens. It’s not, you know, it’s nothing anybody else would know is happening.” She described her incontinence as more of an urge and something she’s had since she was younger: “If I don’t get there quick enough, you know…it might be just a little leaking. I never have full emptying of my bladder or anything like that and you know—also in the shower…”

Daisy described her incontinence as “It wasn’t just leakage—like I’m talking full pee coming out.” Daisy is very warm and light hearted and stated, “It didn’t bother me at all. I laughed it off and I joked it off and I don’t even care, but my husband wanted it fixed for me. He was just like, ‘you need to get this fixed. This isn’t normal.’” Although Daisy sought treatment and a solution, it didn’t seem to bother her at all: “I would be like, oh my God, where’s the bathroom? And, if it was far, I thought I would just go off to the side and pee, like on the floor or behind the car and pee.” Daisy recalled that most mornings she wouldn’t be able to make it out of bed:

I would literally pee in my pants, like holding myself literally. I was like, oh my God, I gotta go. The moment I got out of bed, like I had to just go and like sometimes, I wouldn’t even make it. I would pee on the floor. It started getting bad. And then it started getting to the point where like in the morning, I would wake up and, like, my shower in my bedroom, it doesn’t get hot right away. It takes a couple of minutes. So, you know, I would wake up, turn on the shower, and then go pee. And like, I couldn’t make it to the bathroom.

On the flip side of the coin, there were a number of participants who found that living with UI negatively impacted their QOL in a large way. When Jasmine was asked if her QOL was affected, she replied:
A hundred percent, like a hundred percent socially, physically, emotionally. Like, if I’m out with my friends, and you know, drinking obviously makes it worse, like we’re mid-sentence and I have to get up four times to go to the bathroom. It’s ridiculous. I can hold it, but even if I’m not, if I were to sneeze right now, I’d probably pee on myself a little bit, but if I’m holding it and it’s bad…I definitely keep underwear with me because it can definitely be a bad situation. I mean, in general, my quality of life is pretty good, but the urinary issues definitely put a damper on it. I’m really tired. If I’m up during the night, I’m really tired. I’m really irritable. It’s like sometimes it can make you feel depressed because you just want to feel normal. Like some of them hold their pee in for hours and I’m amazed by it. I haven’t experienced that since I was a kid, you know?

When the question was posed to Iris, she responded,

Oh, it’s terrible. Waking up in the middle of the night for six, seven times is just terrible. Sometimes you want to go out or something or you are at work and you couldn’t make it on time to the bathroom, so you wet yourself and then in your mind, you smell like pee. It was very uncomfortable.

Iris is recently divorced and shared that she would like to date again, but was afraid: “…because what would happen if he can see that? If he feels like, oh, she smells like pee or something like that? It was not fun at all.” In terms of exercising, she would have to quit after 10 to 15 minutes, because the urge would come over her so strongly: “You didn’t feel like a normal person. Sometimes I feel depressed because I said Wow, this is not a quality of life.”

Marigold found that her QOL greatly suffered as well:

I literally soaked my pants or I would be getting into the shower and just running the shower. It would just drip out of me, like hearing or seeing water, I would just start
peeing. I couldn’t even hold it. I was telling one of my girlfriends, I just can’t live with this anymore. It’s just horrible… I was literally like, it would be a puddle in my car. I’ll be driving and look down and I’m like, oh my God. And I’d have to call my client and say “Sorry, I’ll be 15 minutes late.” I had to turn around and go home, shower really quick and change my pants and sometimes have to change my shoes, ’cause it would beat all the way down to my shoes. I mean, it interrupts everything, you know. It’s just like anything you want to do. It’s like, you know, if you want to take a walk or whatever, you always have to be aware that there could be a problem.

Hyacinth’s words and tone suggested that she is equally as frustrated and disappointed in her reality:

I don’t think I’m using the right words. It’s just super uncomfortable anywhere I have to go. For example, I like to take my dog on a walk and it’s like, every time I leave the house, in the middle of the walk, I’ll have the urge to go to the bathroom and have nowhere to go. I just can’t bang on someone’s door and ask to use their bathroom. So, the whole day and every time I have to hold it, I feel leakage coming out.

She reported that she can’t even finish working out because she had the urge to go to the bathroom, but, “There’s already been leakage and wet underwear. So, I try to hold it. Hopefully it doesn’t fully come out. It’s just worrying. So, it really interrupts your quality of life.” Hyacinth recalled going to the bathroom constantly: “I used to sit on the toilet like for 20, 30, 40 minutes because it was constantly leaking. Because I didn’t want to leak, you know—it would be just coming out and it was horrible.”

Jasmine also lamented that her incontinence affected her QOL:

So, definitely when I cough and sneeze, I pee on myself, typically when I’m running. I do
drink a lot of water, but even if I cut back on my water intake, which I’ve tried, I go to
the bathroom probably every 45 minutes to an hour. It gets really bad at night before I go
to bed and try to fall asleep, I’ll go to the bathroom at least four or five times. So, it
definitely takes a toll emotionally and physically because getting up six times throughout
the night is not efficient for a good night’s sleep. And it makes you depressed kind of,
because you try to enjoy certain things with your friends and you have to make sure when
you go places that there’s a bathroom.
Violet agreed that living with UI negatively affected her QOL:
It all just did a number on my psyche… I was afraid of where I could go, how far I could
be from the house. Always having to plan everything around the bathroom and try to get
there, having to have extra clothes for myself. Then never mind the physicality of when
you feel it coming and then you’re trying to tighten up yourself and still walk like a
normal person…it became a focal point of my therapy sessions because it was so
defeating and was affecting my self-esteem and my confidence and my wanting to go out
and always having to prepare and anticipate the parade of horribles that might occur if
you didn’t do blah, blah, blah.
Rose was bewildered by her incontinence:
I felt like a different person. I felt very strange. I felt like what is happening to my body?
I was able to do this amazing thing and give birth, but I’m like, my body can do this, like,
is it destroyed?
Poppy is very discouraged and verbalized that her UI has been very difficult:
I think living with this problem is very, very hard living like this. I’m not getting enough
water, as much as I want to, and I know to drink water. It’s the not knowing when I’ll
have to use the bathroom and not making it soon enough to the bathroom. This is not a good thing. You can’t live with this. This is not an easy thing to live with. Nobody wants to live with this. Nobody wants this.

Lily concurred the feeling that her life has been stolen from her:

I mean, living with that is the most embarrassing thing. It’s really not good. I mean, as a woman, it steals a lot of stuff—your confidence, and even with intimacy, seriously. It’s the worst thing that can happen to you. It steals from you like really enjoyable things, simple things that you can really enjoy. Sometimes you cannot do it because there is no bathroom around. It has been tough. It drains you a lot.

**Restrictions to One’s Way of Life**

The subtheme of Restrictions to One’s Way of Life is a compilation of experiences some of the participants expressed concerning how UI placed restrictions on their QOL. Poppy found travel to be very challenging and restricting:

Very hard, very hard. Traveling, actually, we had this time in late August that we went away, and on the way back, we had to stop two to four times for me to use the bathroom. I thought that was a lot. I would only go to places that I was sure there were bathrooms. If I wasn’t sure that there were bathrooms, I would not go.

Rose recalled restricting her activities as well: “I know when I started walking outside, I wouldn’t go too far. I’d be nervous to go too far because if I have to go, you know, I want to be close to home.”

Fleur shared that there were many triggers that would interrupt her life: “If I hear water running, I’m like, oh, I have to go to the bathroom. It’ll just make me feel like I have to go.” Fleur admitted that anywhere she would want to go, such as concerts or movies, she’d have the
urge to go and not always be able to hold it.

**Effects on Intimacy**

Many of the participants verbalized that their UI negatively impacted their QOL with regards to intimacy with their significant other. Not every participant felt comfortable discussing intimacy issues and deflected probe questions. Poppy reflected, “He tried to be understanding, but there’s not much understanding towards things like this.” Even going out socially with her husband impacted her relationship with him: “It was hard to go places with him because I didn’t know when this was going to happen.”

Lily was very frank and comfortable discussing intimacy issues and was eager to share her experience:

In that situation—like having intimacy—it’s terrible because you feel embarrassed. You avoid not having intimacy because it’s uncomfortable. It’s not satisfying you as a person. I was so embarrassed. Then in the middle of my situation, I had to say to my husband, “I’m sorry; stop, stop. I need to go to the bathroom.” Sometimes he will say, “No, you can hold it.” And I said I can’t. Between you and me, no matter what position it was, it was the same thing.

Lily stated that it she got to the point where she avoided intimacy altogether and felt her libido was "like zero.” Lily stated that her husband was not put off by her incontinence though:

He really doesn’t care. I think, I mean, as long as he’s satisfied, he’s okay. He’s not the type of man that will complain, even though I feel like I always said I feel embarrassed and I’m not okay. I said I’d rather not do it than to do it. He says it’s okay. It’s okay. You know men are different from us as women, but I mean, that’s true dealing with this situation for so many years. It took a lot from me.
Violet was also very open and honest as she described how she felt about intimacy while experiencing incontinence. “So, I was lucky he was very supportive and he swore there was no smell and he was willing to push through any kind of sexual encounter. And I was like, no, let’s not.” Violet recalled,

Here’s the thing. I didn’t want him even approaching that area because I felt no matter what I did, it already smelled. So, there were certain things that he does, that he enjoys doing. I was like, “Can you please not do it?” Because I didn’t feel comfortable with him being down there. And it didn’t matter. I’m a waxer. I wax all my hair off down there, but it still felt like there was just a dampness. I can’t even describe it. So, it definitely…and you don’t feel like being touched in a sexy way when you’re not feeling fresh. Ever.

Jasmine also reported that UI had a negative impact on intimacy for her:

Sometimes it’s like really hard to have to stop in the middle like to go to the bathroom. Like it’s around the bladder, yeah. I’ve been dating him since I was 16, so it’s really not that bad, but like, there’s been times where like we’ve had sex and I peed. It just involuntarily came out. It was definitely pee and it was extremely full. It was something I just couldn’t help. I couldn’t hold it in, but you know, if I was in a situation like that with a random person, I think I’d be mortified.

Iris is newly divorced and is considering dating again. She shared that her husband was not at all supportive of her and her situation. Iris admitted that she was actually afraid to have sexual relations with her husband, as she feared leaking. She confessed that it has happened to her and it was enough to turn her off from sex. When asked how it impacted her relationship with her husband, Iris responded,

It damaged the relationship a lot…because I didn’t want to have sex with him. I just was
afraid that when we were having sex, it was like, what happened if I just leak and
everything? It affects a lot from the woman: “Just leave me alone. I will deal with this,
but leave me alone.”

Her husband didn’t believe Iris though and thought she was making up excuses: “He thought it
was just in my head. It wasn’t like that. He believed it one time, but then he was like, ‘Oh, you’re
just making excuses.’ I said I’m not. I don’t want to have sex.” Now that Iris is newly single, she
is still fearful of intimacy: “Yes, I was afraid to date someone because what would happen if he
can see that? If he feels like, oh, she smells like pee or something like that? Yeah. It was not fun
at all.”

**Theme 6: Reported Feelings**

*Where flowers bloom, so does hope*  
— *Lady Bird Johnson*

During each participant interview, a myriad of feelings was expressed and a wide range
of emotions. The researcher listened carefully for intonations in voice that revealed subtleties in
feelings. One could detect a great deal of information not only in the spoken word but also in the
way it was expressed. Some laughed when they were embarrassed and others were
straightforward and brutally honest with their answers. In fact, some participants spoke in a very
upbeat tone when describing uncomfortable situations, almost in an effort to protect the
researcher and to convey an attitude that all is well. Reported feelings are compartmentalized
into several sub-themes: fear of embarrassment, fear of odor, feeling like a child, feeling out of
control, feeling attractive, and feeling frustrated.

Rose admitted she was feeling a strong sense of anxiety more than anything else, which
she felt was causing her incontinence to actually worsen. She shared that she really felt
“disappointed” that it was happening, and “devastated…just because, I know it’s normal, but I
guess I didn’t expect it.” Lily voiced she felt drained by her incontinence, felt out of control,
embarrassed, and especially tired: “The next day you wake up and you’re still really tired
because you didn’t get a good night’s sleep and if I don’t drink enough water, I’m getting
headaches because I’m dehydrated.” She also verbalized that she was always worried after she
wet herself: “I was worried that I had to go back into the car and then I didn’t have extra clothes
and I don’t want to leave the car seat wet and later having it stink inside.”

Violet confessed that her incontinence “really did a number on my psyche” and one
could hear and feel the frustration in her voice.

Jasmine concurred that for her, the dominant feeling was “extreme anxiety.” She also
confided that she felt very “sad and just wanted to feel normal.”

Iris shared that her incontinence made her feel “depressed” and asked herself, “Why
me?” She said, “You always ask that question. Why me? I’m so young to have this problem.”

Hyacinth voiced,

It’s super uncomfortable. I guess I’m embarrassed and a little bit angry. I guess there
could be worse things, you know, a worse diagnosis. I think it does make me feel
depressed. It makes me feel embarrassed, depressed—everything you could think of.

Feeling Embarrassed

Most of the participants verbalized embarrassment or fear of being embarrassed, which
really hampered their QOL. Poppy confided, “It’s very hard not to drink water, not to leave the
house, not to go anywhere because of this problem and because I don’t want to get embarrassed
in front of people and my children and my husband.” Poppy recalled a time that she became very
embarrassed in front of her husband: “I had an accident when we were out and I couldn’t hold it
and he had to walk with me and that was so embarrassing.” She was unquestionably devastated as she tremulously recounted a time when she had an accident in front of her 15-year-old son:

With my older son, he saw me when the urine was coming out. It was the beginning of COVID and the bathroom, he didn’t want to use the bathroom or the bathroom was closed, whatever the reason was. I just went in front of him and just peed all over the floor in my pants right in front of him. I was very embarrassed in front of my son for a long time, and he was embarrassed by me for a long time.

Rose felt bewildered and baffled: “It was a little embarrassing. Like I was like, oh my gosh, I can’t, you know. I feel like I can’t make it to the bathroom. Like what’s happening?”

For Lily, as she thinks back on going out with friends, she expressed,

It was really terrible. It was really embarrassing because, like sometimes they made fun of me because they said all the time you want to go to the bathroom. But, I mean, it’s something that you can’t control, even though you try your best.

Violet conveyed a sense of worry and concern over what could happen while at work. “The minute I even think that it’s happening, I’m going to go, because to wet my pants in front of the class would have been...” Violet was so emotional verbalizing this concern that she couldn’t even finish the sentence.

Hyacinth recounted being so embarrassed, she didn’t want to tell her mother. “And I didn’t tell my mom ’cause I was like, ‘What’s going on here?’ I guess I was embarrassed to tell her.”

Although most of the participants shared that they were embarrassed in some capacity, not all were. In fact, Willow, who has a history of nocturnal enuresis, maintained that she was not embarrassed in the least:
Embarrassed of what though? I don’t think it’s embarrassing. It’s not that odd either. I feel like a lot of women pee often. I mean, most people don’t as often in the middle of the night, but I don’t know. I don’t think it’s anything to feel strange about.

Willow continues to seek help, though she defensively avers that she doesn’t have a problem.

**Fear of Smelling Bad**

Many of the participants shared they were fearful that they smelled like urine, and some admitted to avoiding social situations, fearing that they had a strong odor to them. Poppy shared, “If I’m going to make my pants wet, obviously it’s going to smell bad, so it can’t be good.”

Rose was very self-conscious and embarrassed about odor:

So, I will tell you what I did feel self-conscious about was I felt I smell like urine. I would’ve dripped and would leak and I feel like…I feel that I smelled like urine, like I had to change my underwear often. And even my husband mentioned—I said, you know, all of a sudden, about a month ago, I said, I don’t feel like I smell anymore. And he goes, “No, I haven’t really smelled any like old—like urine odor.” And I said, “Wow. I said, I must be really, you know, improving.” That was the only thing that was very embarrassing to me because it was something that you couldn’t really like hide. Right. You know, you can wear a pad if you pee your pants. No one can see that, but the smell, that embarrassed me.

Lily was very straightforward with her experience:

Like I was feeling myself that I smell bad, even though I wash my clothes. And when I take a shower, I wash myself with a special soap that I use for, for my down there. And I dry myself with the dryer, but sometimes, I mean it’s hard, you know?

Violet was also very frank and honest in her responses:
I thought that I felt that I always smelled. And my husband assured me that I didn’t, but of course I didn’t believe him. I was like, “No, there is a smell.” It was just always in my nostrils just because I just felt like I was dealing with it all the time. I washed an abundance of clothes because you could never wear something more than once. I think the range is from a little squirt, which will do you in, to full on losing control, which has happened to me. I’ve had to kind of open up a couple of car doors and pee in the middle of the street. I’ve been in so many uncomfortable situations. I really was sensitive to smell. I just felt like everything smelled.

Flora, who maintained that this is a normal occurrence for anyone who has had three children, did share an awareness of having an odor: “I mean, I know I can smell.”

Hyacinth declared, “Yeah. I mean, I smell bad. You know, it’s not like so strong, but you know, you can smell; you smell it in your underwear, yeah.”

**Feeling Like a Child**

Several of the participants lamented that their UI actually made them feel that their roles were reversed with their children and that their children were looking after their parents, instead of the other way around, experiencing life as a child. Violet recalled, “But your own daughter was like, ‘Mom, you have to go to the bathroom, don’t you?’” Violet tried to hide it from her children, but they knew that she had to go to the bathroom when her foot would tap:

My older daughter started sniffing out figuratively, not literally, when I needed to go to the bathroom and I was trying to hide it. So, for me, I felt that was really embarrassing, because your daughter is seeing that you’re in trouble and sometimes there’d be nowhere to go, and most of the time, it’d be during an activity for her.

Fleur remembered, “But we’re talking about potty training kids, so I’d turn on the water
for them to get it. So, those kinds of things. If I hear water running, I’m like, ‘oh yeah.’” The running water was also a trigger for Daisy:

What was happening with my daughter is, if they had to pee, I would have just have gone to the bathroom and peed. And if they had to pee, two minutes later, if I heard them pee, I had to pee. Like if my kids were peeing, I’d be like, ‘Oh my God, I need to pee.’ Or, like literally, they would be peeing and then all of a sudden, I’d be holding myself, you know? I have a problem here. I guess it started getting…it got to the point where like, okay, change of underpants for my 3-year-old, you know, just in case, and a change of underpants for me.

Poppy reported that her son was so mortified that his mother lost her urine in front of him, that it took months for him to be able to face her again, and she was equally embarrassed in front of him.

**Feeling Out of Control**

Many of the participants shared feeling out of control when discussing their UI and that there was really nothing any of them could do to stop it, despite all of the coping mechanisms they participated in. Poppy lamented,

Yeah, it’s so hard. Everything was hard not knowing when this is going to happen. It’s not like I’m going to know when it’s going to happen so I can schedule bathroom appointments. I couldn’t do such a thing. It would just happen out of nowhere. It doesn’t really matter how much water I’m drinking or not…There is no control over this. This is controlling me.

Rose admitted she felt equally out of control and chose to stay close to home as a way to minimize the risk of an accident in public: “Oh, well, you know, at home, I can have more
control over that variable.”

Lily agreed with Poppy’s assessment: “But I mean, it’s something that you can’t control, even though you try your best.”

Violet had a similar strategy to Rose, by limiting her distance from her house:

I think it was because I was afraid of where I could go, how far I could be from the house. Always having to plan everything around the bathroom and trying to get there, having to have extra clothes for myself. Then never mind the physicality of when you feel it coming and then you’re trying to tighten up yourself and still walk like a normal person.

Hyacinth confessed that she had no sense of control either: “So, it just started coming out of the blue, like you were just walking and then you couldn’t hold it kind of thing.”

Daisy was very open and willing to share all of her experiences with UI. In terms of control, her urge to void became so uncontrollable that quite often she would not make it to the bathroom at all:

I guess, like the moment I got out of bed, I had to just go, and like sometimes, I wouldn’t even make it, like I would pee on the floor. Sometimes I would pull up to my house and would just pull my pants down in the driveway ’cause I can’t make it to the bathroom. I can’t even open up my garage… You could definitely see how it can make someone embarrassed or depressed. I just have a different personality than that. I guess I was always able to control, not control it, but control my reaction to my situation. But, I wish I kind of like got it taken care of sooner than later.

**Negative Self-Image**

Some of the participants offered insight into how they perceived their sense of
attractiveness. While speaking to Poppy regarding her experience, the topic of feeling attractive came up organically. When Poppy was asked if having UI made her feel less pretty, she responded “Yes, yes, a lot less pretty, a lot less pretty.”

Hyacinth, on reflection, lamented,

I guess unattractive because it’s like, if you can’t hold your urine, you know, in my mind, I don’t have any kids, I’m not married. You expect these things from older people, like in their 80s and 90s, you know? And I’m still wondering why the doctor told me that it’s common, which I didn’t know… It’s horrible to have to wear pads all the time. It’s like I forever have my period.

Violet thoughtfully responded, “And whereas I appreciate all the clever marketing and the bringing in of older celebrities to, and the way they’ve upgraded the undergarments that people wear for incontinence, I still don’t want to wear those.”

Poppy confessed to feeling desperately out of control and unattractive, having to resort to wearing bulky loose-fitting clothes and diapers for months on end.

**Feeling Frustrated**

Although most of the participants conveyed some degree of frustration, Fleur literally verbalized how unfair it is to live with UI and asked,

Why me? Going to the bathroom all the time. That’s annoying. Why me? I can’t drink a bottle of water because it’s healthy, but why me? Because I have to go to the bathroom all the time. I ask, why doesn’t Cindy have this or whatever? She could drink a bottle of water and not have to go. That’s not cool. That’s not fair.

**Theme 7: Journey to Care**

*The sunflower climbs to its majestic height despite its physical constraints.*
All of the participants shared their own unique journey to obtaining the care that they needed. Some were helped promptly, while others took years to come close to finding a solution. Some participants didn’t in fact feel that they needed therapeutic intervention and thought of their UI as something that they had to live with, while others felt that it was something that no one should have to live with. Two subthemes of Expense and How It Should Be are discussed in this overarching theme of Journey to Care.

Poppy originally sought help from her primary doctor: “He was aware, but he didn’t have any solution. He told me that the only thing I can do is see a urologist to see if they can fix this.” Poppy ultimately sought help from a urologist and is presently being treated.

Rose expressed that her doctors were dismissive of her problem: “They were dismissive. They would say it’s normal, and I would say really? They were definitely dismissive about the leakage. They said normal, normal, normal.” The OB told her, “Oh, it’s part of childbirth; it’s okay.”

Lily was very passionate about how she was treated and freely voiced her opinion without reservation:

So, I mean, it’s important to have people around that can hear us and guide us and be that right person to help us in our situation. Yes, I’m always open to explain to people, especially to women what’s going on and what I’ve always heard. The complaint that I always heard was that the doctors, sometimes they don’t care. The first thing they want to do is send you for some kind of therapy because that’s how insurance works. Then they kick in some medicine to contract your bladder, to help you hold the urine. Medicine doesn’t cure you. It helps you, but it masks the real cause. Medicine can help you on one thing and then can destroy you 10 more. Like I always said, I respect good doctors, but I
mean, I find that for so many women, they feel embarrassed talking about this situation because they feel shame. They don’t feel comfortable opening up to doctors, because you lose hope when you can’t find the help. So, then I went to see two different urologists who prescribed me medicine that turned my skin pink and made me feel swollen, I felt like I lost hope and was a little afraid. Yeah, so it scared me a little knowing I have something in my body. I think my body will react that it would not like it, so I didn’t say anything. My feeling is that some of these doctors—these primary care doctors—they don’t want to really deal with this situation. They do what they have to do, sending you to a specialist. But, like I’ve heard from other women, I feel that they don’t really care about their situation. The first thing that doctors want to do is treat you with medicine, which to me is really bad because we need to go to the root of the problem. The root—that is really going on. They don’t tell you anything. When I went to my gynecologist and I explained to her what was happening, she discouraged me from continuing to see her. I don’t want to see her anymore. She said, “Our grandmothers and mothers suffer from this. So, this is not something new. All women suffer.” I mean, I understand that all women suffer. She’s a woman. She’s a doctor. She’s a specialist doctor, and she told me those words.

Violet described her interaction with her doctors on her journey to care:

So, this is going back to…this happened after my first, and my first is nine. So, there was just a whole bunch of things I was telling myself and I guess inaccurate information and even my gynecologist was like, just do kegals. That’ll be fine. It always happens. Blah, blah, blah. Here’s the other thing my gynecologist told me. Maybe I wasn’t emptying my bladder enough. So, then my gynecologist told me a better way to sit on the toilet so that I
would empty my bladder more completely. That was another thing I remember being told.

Flora remembered, “When I went to the doctor and mentioned it, they said it was a normal thing.”

Fleur averred that she received a lot of misinformation regarding her incontinence. “Well, one doctor said it had nothing to do with having babies, and the other doctor was like, oh yeah, it has everything to do with having babies.” When Fleur originally scheduled her sling procedure, she received a lot of mixed messages and didn’t really understand what she was getting into. She recalled she also didn’t feel heard by her doctors and felt that they only treated one facet of her incontinence: “There’s too much of a gray line. I was like, it’s going to address something. I didn’t know. The more I looked into it, the more I realized I should have talked to the doctor more.”

Jasmine spoke of her journey to obtaining care with an air of disappointment. She divulged that she was slighted because of her young age:

I feel not many people or doctors pay attention to younger women that have urinary issues. I went to a urologist for a couple of years throughout college and he was like, you’re young, you know, let it pass. He didn’t really take into consideration that it was a real issue because I was young and it would eventually go away. But obviously it has become a permanent issue now. A lot of types of medications just make me have really bad dry mouth to the point where I can’t, like I have cotton balls in my mouth. So, I try not to take the medications, but go back, I’d go back every six months to a year, and their thing, their excuse was always, “You’re young. Give it a few more months. Give it six more months. You’re young, you’re young, you’re young.” Up until now I had the same
doctor. I’m like, he’s not really doing anything for me. The last time I was there, he tried to put me on another medicine. They tried to put me on anti-depressants or anti-anxiety medicine because they say that relaxes the bladder muscle, but I refused. They didn’t even like, even so much as do an exam. They didn’t even so much touch the conversation with me. They kind of were just like, you know, it would be better if you saw a urologist because we’re not really sure what’s going on with you. You know, even some urologists, I just feel like they don’t feel like it’s an issue if you’re young, you know? My old urologist was like, “Sometimes this happens with people your age and it’ll subside in six months,” and I’m like, “But I’ve dealt with this for two and a half years.” It’s like I was brushed off, you know?

When Willow broached the subject with her provider, she was told, “to see a urologist and practice Kegel’s and strengthen the pelvic floor.” Her GYN tested her urine and told her that her urine sample looked fine, “but she really didn’t have a solution.”

Hyacinth remembered her provider with frustration, “No. She didn’t really recommend anything really.” Iris experienced a similar response from her doctors:

I have a new OBGYN, another person that I keep telling, and she’s like, “Oh, that’s normal; that’s nothing, blah, blah, blah.” It’s not a comfortable feeling, feeling like you’re peeing yourself all the time. She never paid attention to me. It’s not normal. Just exercise is not going to help me. And I knew that it didn’t. So, she didn’t listen to me, but I was always looking for more help. Then I went to my primary doctor, who told me that you have to see a urologist. Yes, it took me five years to get the correct person to realize what was wrong with me.

Marigold also reported that her journey to care took some time:
So, I don’t know the exact timeframe, but I was telling one of my girlfriends about it, and I’m like, I just can’t live with this anymore. It’s just horrible. I wasn’t feeling comfortable with the urologist that I saw. He was a male. Not that he wasn’t professional. I just didn’t feel the comfort level was there.

**Expense**

The subtheme of expense did not come up that much during the interviews, as most of the participants were working professional women with insurance. However, a few women did mention expense as a reason that they were unable to avail themselves to all of the treatments that might have been available to them.

Lily mentioned that she was often referred by her doctors for pelvic floor rehab exercises to strengthen her pelvic floor: “I mean, I can’t go get exercise therapies because I don’t make that much money. It’s a lot of money for me and so she wasn’t willing to help me.” Lily further lamented, “I mean, it’s sad at the time because I know they have more stuff out there that can help us, but insurance won’t pay for it.”

Rose concurred, “Insurance doesn’t cover it as much.” She further elaborated, “And it’s funny—in Europe, it’s like the norm for people to talk about it and they get help and it’s covered by postpartum care and everything, and I feel like here, it’s taboo and it’s still very American.”

**How it Should Be**

Some of the participants appeared to think that living with UI is something that one just has to live with, though others were frustrated with the care they received and the length of time it took to have their needs recognized. Hyacinth reported that it took her five years before she began to get care. Also, many participants felt that their doctors were dismissive and that their situation was not taken seriously, telling them they were “young” or that “it’s normal” and will
get better.

Violet, on thoughtful reflection, stated,

You know, they’re all into…I don’t know about the primaries, but like for the gynecologists, they’re so into those postpartum checkups and check-ins, I think they just need to add one of those questions. It could be as simple as that. And then when they come back, they should say, “By the way, has this gotten better? Has this gotten worse?” And again, the only thing that stands out to me is those faces, right? On a scale of 1 point to whatever. [Violet was referring to the emoji faces similar to those in the pain scale.] I feel like the education needs to sound like, “Yes, this does happen after you give birth, but it shouldn’t last longer than this, it shouldn’t be like this, but instead…” The timeline of when you should go get this checked out and when you shouldn’t. And hopefully, I feel like society in general is going through this phase where everyone’s trying to pay more attention to things that weren’t necessarily paid attention to, right? Like you don’t have to push through pain. Self-care is important and just because it happened to your mother, it doesn’t mean it will happen to you. So, maybe you’ll seize upon all this kind of awareness.”

**Essential Themes**

Five essential themes were identified in the final iteration of this study, where the evolving meanings and essences of the women living with UI were revealed through phenomenological reflection. The aim of phenomenology is to transform lived experience into a textual expression of its essence in such a way that the text is at once reflexive re-living and a reflective appropriation of something meaningful: a notion by which a reader is powerfully animated in his or her own lived experience. Phenomenological research, unlike any other kind
of research, makes a distinction between appearance and essence, between things of our experience, and that which grounds the things of our experience (van Manen, 1997).

By repeated reflection and immersion in the transcripts, field notes, audiotapes, journal entries, and emerging themes, this researcher was better able to identify similarities and differences in the participants’ stories and was able to categorize and build essential themes, all while keeping the research question in mind. Phenomenological themes may be understood as the structures of experience as opposed to conceptual abstractions. Five essential themes emerged from this process: Fictitious Dialogue, Strategic Planning, A Walk in My Shoes, Sailing on a Sea of Emotions, and Barricades and Barriers to Care.

Figure 1 illustrates the development of subthemes into the formation of essential themes, or structures of experience, with a summative description of the higher formulated meaning for each of the five themes.
Figure 1: Development of Themes

Essential Theme 1: Fictitious Dialogue

Each one of the participants shared what they believed to be true about their UI, particularly what they were told by others and their belief that they were all too young to experience this. Many of the participants believed that their incontinence was the direct result of having children and were told by their mothers, family members, friends, and even their providers that UI after having a baby is “normal, normal, normal.” Some participants believed
that they actually caused their incontinence themselves by things that they did when they were younger, such as “holding your pee for too long, and now your bladder is weak,” which Violet’s mother admonished her for, and Willow’s belief that pressing down on her bladder to get all of her urine out after sex damaged her bladder. Many of the participants, when speaking to their friends, agreed that this phenomenon is par for the course after having kids, when they would say, according to Daisy, “Oh, we have that too” and as per Violet, “This is what happens. This is our lot in life.” Some participants, like Marigold, believed that UI is prevalent in the ages 35 and on and that “It’s common. It’s so common.” Participants such as Daisy and Marigold believed that it was something that was “just part of my life” and something “I’d have to live with and there’s nothing that can be done for it.” Willow actually believed that it wasn’t odd at all to lose urine in the middle of the night. Many of the participants convinced themselves that their incontinence was stress related and actually believed their providers when they were told that if they gave it enough time, their incontinence would go away. Most participants believed that depriving themselves of liquids would help them. Many participants also were told by their GYN that if they just did Kegel exercises or try to train their bladders and time their voiding, they would be able to control their urination better. However, most of the participants found that their beliefs and what they were told did not serve them well and they soon realized, as Daisy did, “This is not normal.”

Most of the participants were baffled and bewildered by experiencing UI at such a young age and truly believed that this is a phenomenon that only older people experience. Hyacinth believed, “I always thought this is what happens to older people, in their 70s, 80s, 90s, you know; that’s how I first thought about it because you hear, you know, people in nursing homes…”
Violet realized, as did many of the participants, that much of what they believed and what they were told was inaccurate: “Between the old wives’ tales, it was just a massive amount of misinformation.”

The original theme of Willingness to Share was merged under this essential theme, as it featured a reluctance to share information of their incontinence with others due to the embarrassment they felt.

Sharing the reality of living with UI with others had a wide spectrum of responses. Some participants admitted they thought nothing of it and were willing to speak freely to anyone, while other participants kept their incontinence close to the vest and were reluctant to let anyone know that they were experiencing this. Rose reported that she told a few of her friends who were having babies around the same time as her and was somewhat reassured that they also shared her situation. Most of the participants shared with their long-term boyfriends and husbands, but some participants like Hyacinth stated, “If I wasn’t with them too long, I wouldn’t tell them.” In fact, Hyacinth neglected to tell her own mother about her incontinence because she was “too embarrassed.” Some participants, such as Poppy, vehemently replied that “That’s very embarrassing. My family knew about it. I told my family and my sister-in-law knew, but other than that, I didn’t want anyone to know.” Lily came to her own understanding: “Most young women, sometimes they don’t want to speak about what’s going on with this situation.”

**Essential Theme 2: Strategic Planning**

All of the participants in this study verbalized a strategy or means of attempting to cope with their UI to gain some semblance of control over their situation. The meticulous review of the audio and written transcripts, journals, and memos showed that the recurring theme of Coping continued to emerge among the participants. The most common strategy used universally
was to restrict fluid consumption, often to the point of dehydration, to avoid the urge to urinate. Most participants believed that if they restricted their fluids dramatically, they would have more control and fewer accidents. Most of the participants were aware that restricting fluids wasn’t healthy for them, and some even experienced headaches and dizziness. Poppy recalled that when she felt the urge to urinate, “There’s nothing I can do. I couldn’t hold it. I was trying my best not to drink a lot of water. I was dehydrated all the time. I used to have headaches. I used to get dizzy.” Other participants employed strategies such as wearing dark, patterned, loose-fitting clothing to hide any wetness stains. Violet recalled, “Okay, I’m only going to buy workout clothes in certain colors. I’m not going to drink. That’s when all the weird coping mechanisms started occurring.” All of the participants, though, were aware that if they ventured too far from home, they might be in danger of experiencing an accident and would avoid, as Poppy did, drinking water while out. They would only drink fluids when they were home, and most curtailed their fluids after dinner. They admitted that they would only go to places where they knew there were available bathrooms. As Rose explained, “I would kind of alter my lifestyle, manipulate my day around it.” Many of the participants restricted activities that they enjoyed to avoid leakage or wetting themselves. Daisy remembered she had to stop running and jumping on the trampoline in her backyard with her daughters. Fleur admitted that she stopped running, as the pounding of the pavement prompted her leaking. Violet became frustrated with her coping strategies:

It didn’t happen all the time and sometimes it was just kind of wishful thinking and I was feeling good, so ‘This isn’t going to happen,’ right? And maybe it’s getting better. It’s this false narrative that you tell yourself. Then something happens and you have to go right back home because you were not prepared enough. I felt like it became, ‘Listen to
the whispers of your body before it becomes a scream.’

**Essential Theme 3: A Walk in My Shoes**

Most of the participants in this study did indeed feel that living with UI did in some capacity affect their QOL. There was a wide range of perceptions in this theme. Some participants were not that bothered by it at all, while others felt that their lives had become “horrible” and that “no one should live like this.” As Lily had stated, it is hard to describe what it’s like living with UI because “They are not in my shoes. When people don’t suffer from what you’ve been suffering, they don’t understand and they don’t care.” The review of the transcripts, field notes, and memos showed that the theme of Perceived QOL was identified with two identified subthemes: (1) Intimacy and Urinary Incontinence and (2) Restrictions to One’s Way of Life. These were further developed and molded into A Walk in My Shoes.

Many of the participants felt that living with their situation hampered their life socially, physically, and emotionally. As Iris pointed out, you have to always stop everything in the middle of what you’re doing because you just can’t hold it anymore. She reported that sometimes it would make her depressed: “Wow, this is not a quality of life.” She declared that she just wanted to feel like a normal person. The participants conveyed the notion that there was never any spontaneity and that everything in life had to be planned around trips to the bathroom. There was also the anxiety and worry associated with being unable to make it to the bathroom in time, despite all of the planning associated with their incontinence. Violet recalled, “I was afraid of where I could go, how far I could be from the house, and always having to plan everything around the bathroom.” Some participants readily admitted that they often would have to urinate on the side of the road or in their driveway because they knew they couldn’t make it to the bathroom and actually worried about getting in trouble for public urination. Some participants
often felt like children themselves at times. Poppy admitted, “This is not a good thing. You can’t live with this. This is not an easy thing to live with.” Even the participants who did not seem particularly bothered by it preplanned any outings by wearing a pad before they went out. Lily voiced that UI is “the worst thing that can happen to you” as a woman, as it “steals a lot of stuff—your confidence and even with intimacy.” The participants stated they were tired from interrupted sleep and, as Violet pointed out, “always having to prepare and anticipate the parade of horribles that might occur…” The participants shared that this placed so many restrictions on their lives. Rose stated she wouldn’t walk too far from her house, wouldn’t walk with friends, or go to concerts or movies, lest she would have an accident. Poppy verbalized she was fearful of traveling and some participants would not travel anywhere unless they knew for certain there would be a bathroom.

Many of the participants voiced that they felt that their QOL was also negatively impacted in terms of intimacy. Lily explained,

It’s terrible because you feel embarrassed, you avoid not having intimacy because it’s not comfortable. It’s not satisfying you as a person…in the middle of my situation, I had to say to my husband, “I’m sorry; stop, stop. I need to go to the bathroom.”

Iris explained that having UI “damaged the relationship a lot.” She was always worried that she would leak urine while she was having sex, because that did in fact happen.

Violet also admitted to feeling self-conscious and did not feel comfortable having relations with her husband and avoided it, fearing she smelled. Most of the men were supportive of their partners and “were willing to push through any kind of sexual encounter” as Violet’s husband was, but most of the participants actually avoided intimacy for fear of leakage and odor.

**Essential Theme 4: Sailing on a Sea of Emotions**
All of the participants were able to share a myriad of emotions concerning their UI and displayed a wide range of feelings. Although this researcher was unable to read facial nuances and body language, vocal intonations and the timbre of their voices opened a clear window into the essence of what they were experiencing. The original theme of Reported Feelings had several subthemes: Fear of Embarrassment, Fear of Smelling Bad, Feeling Like a Child, Feeling Out of Control, Negative Self-Image, and Feeling Frustration.

Many of the participants openly shared some of their most embarrassing situations with this researcher and cited embarrassment as being a prominent feature in living with UI.

Fear of odor or fear of discovery due to the odor was a paralyzing fear experienced by most of the participants. Most of these women, despite frequent bathing and fastidious attention to their hygiene, stated that they felt that they smelled and were afraid that others would be able to detect their odor.

A few of the participants voiced that they were often not perceived in a normal adult role as parent but were more like children, as they attempted to unsuccessfully hide their incontinence from their children.

Most of the participants shared that they had no control over their incontinence, despite their attempts to “plan their day around trips to the bathroom.” For most of these young women, a strong urge would be the preview to a situation that they would not be able to control.

A few of the participants admitted that life with UI had a negative effect on their sense of attractiveness and femininity and their self-image. Many lamented that always wearing dark, patterned, loose fitting clothes over pads or diapers influenced how they perceived themselves in terms of attractiveness.

Many of the participants also expressed an overall frustration associated with their
situation, asking “Why me?” They wondered why they cannot live their lives and feel “normal” instead of always having to prepare for “the parade of horribles” that might occur.

These are young active women who enjoy going out socially and engaging in physical activity, and to be faced with many of these emotions all at the same time contributes to a feeling, voiced by Poppy, as “losing hope.” Considering all of the stress that comes with being a parent, spouse, and a working professional, one can understand the emotional burden that living with UI can pose.

**Essential Theme 5: Barricades and Barriers to Care**

Barricades and barriers evolved from the theme of *Journey to Care*, which included the subthemes of *Expense* and *How It Should Be*.

While reading and re-reading the written transcripts, field notes, and memos, and listening and re-listening to the audio interviews, this researcher was struck by the quagmire that was encountered by many of these women as they pursued care. Iris stated, “It took me five years to find the correct person.” Many participants were met with misinformation or lack of information by their providers, “You’re young; it will go away,” when in most cases, their UI actually got worse. Some of the barriers to care were actually from the participants themselves. Some did not pursue care because of their own beliefs and their own misinformation, whereas others felt they were “dismissed” by their primary providers and female specialists, such as their OBGYNs. Some of the participants cited expense as a barrier to obtaining the care that they required. As Lily explained, the specialists recommended physical therapy exercises, but since she didn’t have insurance, she was not able to afford it. Many of the medications and procedures, if not covered by insurance, are often out of reach for the patient. Violet felt that providers such as OBGYNs should ask their patients during their postpartum checkups if their incontinence has
gotten better or worse. She suggested smiley faces or an emoji-type scale to determine the severity of their incontinence. She opined that the American healthcare system would be better served if they identified more with the European care models, where patients are followed up more closely for a longer time and the topic of female UI is not as “taboo.”

**Summary**

Through the process of continued reading and re-reading and writing and re-writing, the five essential themes of Fictitious Dialogue, Strategic Planning, A Walk in My Shoes, Sailing on a Sea of Emotions, and Barricades and Barriers to Care emerged, which captured the essence and lived experience of living as a premenopausal woman with UI and answered the posed research question. According to van Manen (2006, pp.713-722), it is in the act of reading and writing that insights emerge. It is precisely in the process of writing that the data of the research are gained and interpreted and the fundamental nature of the research questions are perceived. In a phenomenological sense, the research produces knowledge in the form of texts that not only describe and analyze phenomena of the lifeworld but also evoke understandings that otherwise lie beyond their reach (van Manen, 2006).

This chapter detailed the experiences of the participants living with UI, the development of emerging themes, culminating in the development of essential themes.

Figure 2 illustrates factors showing the influence that living with UI has on QOL.
Figure 2: Impact of UI on Quality of Life

The tiny seed knew that in order to grow, it needed to be dropped in dirt, covered in darkness, and struggle to reach the light

– Sandra King
CHAPTER 5: DISCUSSION

The night blooming Jasmin unfurls its beautiful petals in the darkest hours of the night

This phenomenological study sought to gain a better understanding of the lived experience of the premenopausal woman living with UI and its effect on her QOL. Uncovered themes were summarized and woven into findings found in the literature. This researcher attempted to set her own biases and preconceived notions aside and, with an open and curious mind, discovered several interesting attributes unique to this group of women that were integrated into five final themes. Each theme and its integration with the literature was examined individually, but as this process unfolded, this researcher was struck by how each subtheme and theme were like a painter’s palette, where the edges blurred and the colors melded to create the essence and substance of a portrait of this unique group of women.

This chapter concluded with a discussion on limitations to the study, implications for nursing and health care provider practice, education, policy, and future research. Many findings in the literature applied to all women who suffer with UI, but this study has successfully yielded other findings that were barely touched upon in the literature. These findings may serve as a starting point for these women to ultimately receive the care that they so desperately need.

The literature search began with Molloy’s library resources for literature related to premenopausal women with UI, including impact on QOL. Databases that were assessed included Pubmed, CINAHL, EBSCOhost, and Ovid. Several books on this topic were also consulted, while attempting to filter the literature to peer-reviewed works less than 10 years of age. Since UI affects women in many domains, literature outside of the nursing realm was additionally consulted, including articles pertaining to the fields of psychology, sociology, anthropology, medicine, business, and economics.
The focus of this study was on the phenomenon of living with UI as a premenopausal woman and its impact on her QOL. Thirteen young women were participants in this study and graciously offered and shared their unique stories. All participants resided in the Long Island area, though a few were born and raised outside of the United States, which may have influenced their experiences living with UI. The participants ranged in age from 24 to 49. All interviews were conducted over the telephone due to Molloy College’s stipulation of no in-person interviews due to the Covid-19 pandemic and as per request from the participants. The current literature search highlighted information that was already elucidated but also revealed literature gaps in the lived experience of living as a premenopausal woman with UI. The five themes that emerged and evolved from the data are the following: Fictitious Dialogue, Strategic Planning, A Walk in My Shoes, Sailing on a Sea of Emotions, and Barricades and Barriers to Care.

**Essential Theme 1: Fictitious Dialogue**

This theme developed from the emerging themes of Beliefs, Disruptive Realities and Willingness to Share, with subthemes of What I was Told and I’m Too Young. Essentially, Fictitious Dialogue comprises the firmly held beliefs that these women have or have had regarding their UI. These include many things they were told from the people in their lives, including their health care providers, family, and friends. Some of the participants, though, suffered in silence as they didn’t want to speak to others about their incontinence. As Lily pointed out, “Most young women, they don’t want to speak what’s going on with this situation.”

The theme of Fictitious Dialogue includes many of the widely held myths and misconceptions that have actually hampered and prevented these women from seeking the care they need. A 2018 study by Stewart revealed that urinary incontinence tended to be ignored by the patient with the misguided belief that it is an inevitable consequence of aging, which was
found to ring true for many of the premenopausal participants. As Violet pointed out, “But, even close girlfriends and especially my mother and the older women in my family are like ‘See, welcome. This is what happens.’” On further reflection, “It’s like a fait accompli. This is our lot in life.” Many women blamed their incontinence on having children. “Oh, it happens as you get older, after you have a baby, all this stuff down there gets weak.” One of the participants believed she brought her incontinence upon herself by holding her urine for too long. Another believed that pressing down on her bladder contributed to her incontinence. Participants like Flora, held the belief that it’s a normal part of life. “I mean, who doesn’t pee when you laugh? It’s so normal.” Holly pensively agreed. “I feel that most women my age are experiencing the same thing. I’m not embarrassed by it. When I speak to most of my friends, they seem to be experiencing similar, maybe not as bad…I think some women, you need to accept it.”

It is a general belief that UI is associated almost exclusively with the elderly and women who have given birth. However, epidemiological studies report that younger women who are nulliparous, also experience UI episodes, with the risk factors unknown (Almousa, 2017).

The current literature supports findings that the participants shared. A 2019 qualitative study by Pintos-Diaz et al., composed of 18 women with a mean age of 47 years of age, found that most of their knowledge on the subject of UI was based upon a series of beliefs or myths. For example, there was a belief that urinary leakage was a normal occurrence that would eventually affect all women. Another belief is that it worsened with age and that women should resign themselves to living with this condition. Another common myth was that UI was the direct result of childbirth, therefore relating urinary leakage to the process of reproduction (pregnancy, giving birth, and maternity). Most participants in the Pintos-Diaz study confirmed how this idea was reinforced by their close friends and family and even by some health professionals. Other
participants believed that UI was something that they had inherited, as there were previous cases in the family. Finally, all the participants expressed how the lack of credible information caused them to have doubts, until they eventually decided to seek help in order to receive trustworthy information.

Violet confirmed this lack of credible information. “I let it go on for a very long time, just because I also thought it would just fix itself, because that’s another thing that’s out there. It fixes itself, it’s aggravated by stress.”

Media and advertising campaigns have further added salt to the wound by normalizing urinary incontinence in women, essentially telling them that it’s ok to laugh- you’re wearing a pad. Though these campaigns have raised awareness of the problem that UI has for women, they are also making it seem more acceptable (BBC News, 2019). Urinary Incontinence is also an expensive proposition for the woman. In the United States, the average cost per year for “routine care”, such as absorbent pads, diapers, protection and laundry is $900 (Almousa & vanLoon, 2018).

Since there is a paucity on studies that focus on the younger woman with urinary incontinence, the concept that “I’m too young” to be incontinent was a new finding, but a finding that appeared over and over among the participants. As Hyacinth shared “At first, I was embarrassed and then I was trying to understand it more because I always thought this is what happens to older people, you know, people in their seventies, eighties, nineties, you know, that’s how I first thought about it because you hear, you know, people in nursing homes, people like in their eighties and nineties.”

The participant stories have illuminated many of the findings in the current literature and have added additional areas to explore in terms of beliefs. You are never too old or too young to
seek the care that you need to correct this troubling problem. It is not the result of bad manners, poor hygiene or behavior, or faulty upbringing and, more importantly, it is not something that any woman should simply endure.

**Essential Theme 2: Strategic Planning**

Strategic Planning evolved from the emerging theme of Coping Strategies, as each one of the participants was found to plan interventions around their incontinence as a means to better cope. Strategic planning centers on the myriad of coping mechanisms that women of all ages employ to maintain some semblance of normalcy as they go about their daily lives. The literature has long cited some of the coping styles used by the older adult woman. These coping mechanisms or planning may not necessarily prove to be beneficial to the participant in the long-term, and therefore, warrant examination.

A 2015 study by Xu et al. explored coping styles through an 18 question Likert type coping scale in a qualitative study, which included 592 Chinese women 18 years of age and older. They found that these women employed avoidant and palliative coping styles that were aimed at avoiding or concealing urine leakage. To avoid urine leakage, for example, they restricted fluid intake and made frequent bathroom visits. They also made extra efforts to conceal the problem from others; for example, they restricted physical activities that could provoke leakage, avoided places where toilet facilities were inaccessible, and restricted social contact that required them to leave their home. Other strategies included using absorbent pads and taking frequent showers to hide the visible signs of leakage or the smell of urine. These behavior patterns indicate the maladaptive character of avoidant and palliative coping styles, as they resulted in self-imposed isolation, limited social interactions, and psychological distress. Failure to conceal the problem, and the embarrassment of wetting themselves, seriously affected
participants self-esteem, leading to social isolation.

Race/ethnicity, culture, and beliefs may be factors that determine the strategies adopted by women. A 2019 qualitative study by Pintos-Diaz et al. described how Black, White, and Latino women shared experiences of embarrassment and isolation because of UI, plus communication barriers with doctors, as well as reporting the longest delays in seeking care. They seek help ultimately, because of the failure of previous strategies, and also because women hope to be able to learn and develop strategies that are helpful and which may be effective for the control of UI in the long term. Unfortunately, although these strategies may work for a certain time, they fail to offer a long-term solution for their incontinence and may even result in restrictions to their lifestyles.

Many of the thirteen participants used some forms of coping strategies to enable them to feel normal and in control. Most of the participants admitted to purposely dehydrating themselves. Poppy shared “I was trying my best not to drink a lot of water. I was dehydrated all the time. I used to have headaches. I used to get dizzy.” Rose added “I have to really kind of time it, maybe try not to drink as much liquid then. I would kind of alter my lifestyle, manipulate my day around it.”

Other coping mechanisms employed the use of wearing diapers or pads and lining their cars with towels. Some even resorted to urinating in cups or porta potties if they were unable to hold their urine. Lily reported lining the seats of her car with towels and “I put a lot of pieces of thick toilet paper inside me. I really hate to use the pads, but, it was my only option.” Poppy also reported that she had to line her car seats with plastic so she wouldn’t get her car wet. She also wore a diaper. “I walked with a diaper for about two months or maybe longer.” Many of the participants preplanned their travel routes by car, train, or plane in order to be assured of a
nearby rest stop or bathroom availability. Many participants would avoid socializing altogether. Poppy feared leaving her house, while others feared walking too far from home.

A finding that emerged from many of the participants was how they coped in a work situation. Since most studies focus on the older woman with urinary incontinence, there is virtually nothing written on the impact that UI has on work and careers. Many of the participants feared discovery at work, so they brought extra pads and a change of clothes with them to work. Marigold shared, “I would always have extra underwear in my work bag because if it happened at work, I’d be horrified. I would make sure that I would have a panty liner on. And you know, I always had underwear, always. I still do.” Jasmine, who works as a nanny, is considering buying a porta potty for herself and for her charges.

In a 2014 paper by Gervais and Miller, it was noted that women who work are more likely to be healthier and cope better with life than those who are not active in the workforce. Ill health, as experienced through stress and other forms of mental distress, increases sickness absence levels, incurring cost to the individual and organization.

Another finding barely touched upon in the literature is that many of these young women engage in exercise as a regular part of their lives. Some walked a few miles, while others engaged in cardio. Unfortunately, many of these women curtailed or quit engaging in exercise altogether for fear of leakage. Daisy shared that she stopped jumping on the trampoline with her daughters: “I stopped doing the things that I knew would make it happen.” Other participants stopped their daily run, because the pounding of the pavement encouraged leakage. Some of the participants would only wear loose-fitting, splatter-proof, dark clothes. Violet explained, “Okay, I’m only going to buy workout clothes in certain colors. I’m not going to drink. That’s when all the weird coping mechanisms started occurring.”
A small 2020 qualitative study by Dobbertin Gram and Bo touched on the impact that UI has on exercise and sports. In their research, 133 Norwegian gymnasts with a mean age of 21 were studied to investigate the prevalence and risk factors for UI and the impact on performance. Of the 133 gymnasts, 34 or 31.8% reported urinary leakage. Systematic reviews cited in their study have found that the prevalence rates ranged between 0% and 80% in different sports, with higher prevalences in sports involving high-impact activities. Although some athletes reported that UI may negatively affect sport performance, many have quit sports participation entirely. This particular Norwegian study stated that athletes seldom report the condition to coaches and health personnel and have scant knowledge about the pelvic floor and pelvic floor dysfunctions. It was found that 70% of the participants felt UI had some influence on their sport performance. A number of the premenopausal participants similarly curtailed their sports and activities because they couldn’t risk being embarrassed through discovery (Dobbertin Gram & Bo, 2020).

Incorrect beliefs about UI may be supported if health care providers are unresponsive to, or dismissive of, patients’ queries regarding urine loss. They may reinforce the myth of normalcy by saying, “Don’t worry; you’re young, you’re young.”

Many of the premenopausal participants—not unlike the participants featured in the literature—have used coping strategies to gain control for themselves. They socially isolated themselves, withdrew from physical activity, and severely limited their intake of fluids. The sobering bottom line for many of the premenopausal participants who decided to grin and bear incontinence soon discovered every aspect of their life diminished.

Many of the participants, as highlighted, have learned to adapt to their reality. Their adaptation or coping strategies have enabled them to gain some semblance of control over their situation through alterations in their lifestyles. While many coping or adaptation strategies used
by the participants proved to be maladaptive and harmful in the long run, several of the participants found adaptation measures that worked successfully for them. Rose recalled always having a porta potty in her car at all times in the event that she would be unable to stop and use a restroom. Lily adapted by lining her car seats with towels, and Violet adapted by purchasing dark-patterned clothes to work out in to camouflage any wetness or accidents. Jasmine described her way of adapting when traveling. She explained that she would always buy a seat on the aisle and map out all the rest stops along her car route. Marigold adapted to her reality by always carrying a change of underwear with her and a change of pads.

Adaptation, according to Roy (2009), is a dynamic and fluid process, not a static state. The Roy Adaptation model may explicate many of the coping mechanisms seen by the participants. According to this model, individuals are biological, psychological, and social organisms and communicate with their environment and use adaptation mechanisms to communicate in order to maintain balance. Individuals are in a continuous process of adaptation as they respond to environmental stimuli. Coping processes are the mechanisms by which humans respond to the changing environment and play a role in the person’s adaptation level. Behaviors are the observable manifestations of how individuals respond to environmental input stimuli and are observed in relation to four adaptive modes. The four dimensions of Roy’s (2009) model include the self-concept, interdependence, role function, and physiological mode. Since patients suffering from UI are exposed to many tensions, physical and social changes, and changes in personal and family life, they may suffer the consequences of reduced satisfaction with life, leading to disharmony and a reduction in their QOL (Babamohamadi et al., 2016).

The self-concept mode is defined as individuals’ feelings about themselves that is influenced by how others perceive and respond to them. Self-esteem, perceptual self-awareness,
and consciousness of meaning are attributes that comprise the self-concept mode (Roy, 2009). It consists of the physical self (or body image), body sense, and personal self—these are formed by their thoughts, moral ethics, and spirituality (Ursaves et al., 2014). This mode is of particular interest to the young woman that is concerned with feeling attractive and fit and “normal” as her peers. Fearing odor, constant leaking, and discovery by others is a frightening reality, so she often copes by restricting fluids, wearing loose dark clothes, and even stopping activities that she thinks will cause UI to occur.

The components of the interdependence mode include relationships with others that are meaningful to the person and support systems (Roy, 2009). The young women in this qualitative study might be open to their partner or spouse regarding their incontinence but are actually curtailing sexual relations for fear of leaking and being in an “uncomfortable situation.” They avoided social activities with friends and were always aware of the possibility of having an accident in front of their children and fearful of being in an uncomfortable situation at work.

The role-function mode focuses on the roles of the person in society and the roles within a group. The basic need underlying the role function mode is social integrity—that is, to know who one is in relation to others so that one will know how to act (Roy, 2009). Many of the participants in the study had young children and were aware that they were losing their urine in front of them. Poppy described that she was so embarrassed that she urinated in front of her son and that he couldn’t face her for a long time. Many of the participants expressed the sentiment that their role as adult had changed: “A change of underpants for my 3-year-old, and a change of underpants for me” Many of the participants verbalized that their role as an intimate partner was compromised, and many avoided intimacy altogether for fear of leaking.

The physiological mode is a response to stimuli from the environment to meet survival
needs. These are basic needs and regulatory functions that include oxygen, fluid and electrolytes, nutrition, elimination, rest and activity, neurosensory, and protection (Roy, 2009). A young woman suffering from UI that deliberately is dehydrating herself as a coping mechanism is in danger of negatively affecting her health. Furthermore, the woman who is getting up every hour during the night to urinate is not getting the rest that she requires.

Adaptation is a dynamic life process that is regulated by individuals’ coping processes as they respond to environmental stimuli. Coping processes are the mechanisms by which humans regulate environmental stimuli and play a role in a person’s adaptation level (Roy, 2009). Nurses are poised to use knowledge of these adaptation modes in their practice to assess the level of health and integration of the individual.

**Essential Theme 3: A Walk in My Shoes**

The theme *A Walk in My Shoes* evolved from the essential theme of *Infringement on Quality of Life*, which included the subthemes of *Restrictions to One’s way of Life* and *Urinary Incontinence and Intimacy*.

The literature is rich in studies on the postmenopausal woman with UI and how it impacts QOL, but very little could be found on the premenopausal woman and her unique needs.

Research on QOL issues is sometimes contradictory. Some studies suggest that UI leads to embarrassment, loss of self-esteem, and social isolation in the elderly. In younger women, a correlation was found between incontinence symptoms and their impact on travel as well as social, physical, and emotional activities. Still, other studies suggest that women are coping effectively with their incontinence in terms of self-esteem and depression and are experiencing a normal response of anger to an unexpected and uncomfortable problem (Bush et al., 2001).

In 2015, Xu et al. investigated the relationships among symptom severity, coping styles,
and QOL in 592 Chinese community-dwelling women with UI. In this study, the use of avoidant coping styles—which includes the efforts women make to reduce, minimize, or prevent urine leakage (such as limiting fluids, avoiding social situations); palliative coping styles; efforts taken to temporarily alleviate distress (wearing pads, taking frequent showers)—was found to be higher with more severe urine leakage, resulting in a lower QOL. This appears to be consistent with the findings in the 13 premenopausal women, where there was a wide spectrum of reactions to their perceived QOL. Participants like Holly described their incontinence as “It really hasn’t affected it greatly at all; it’s more of an annoyance,” whereas participants like Marigold viewed their incontinence as “It interrupts everything. It’s just like anything you want to do...you always have to be aware that there could be a problem.”

Abrams et al. (2015) evaluated the interference of UI in the QOL of a female population using an electronic question form applied to 1,203 women with UI who were 45 to 60 years old and living in the USA, France, Germany, and the UK. They found that incontinence grade (number of losses daily) correlated positively with interference in daily life (daily tasks, social activities, and perception of mental health and well-being) and emphasized the linkage between incontinence severity and impairment of social life, ability to visit friends, and impact in family. The results indicated that incontinence is associated with a profound sense of humiliation and stigma.

Every one of the 13 participants in this study had their QOL impacted to some degree. The spectrum ranged from it being a “nuisance” to “the most horrible thing you can think of.” What became clear, though, was that most of the participants looked at their UI as something they felt they had to endure, and some participants even showed signs that they were actually suffering the consequences of living with UI.
Morse’s (2017) praxis of suffering theory appears to tie in with how many of these young women responded to their incontinence. In Morse’s theory, there are several features that ring true for the participants in terms of impact on QOL.

Emotional suffering, according to Morse (2017), is where individuals recognize that they are suffering and respond with distress, such as crying, and recognize loss and change (Morse, 2017). This is evident with Violet, who actually sought help from a therapist: “It became a focal point of my therapy sessions, because it was just so defeating and it was affecting my self-esteem and my confidence and my wanting to go out and always having to prepare and anticipate the parade of horribles.”

Many of the participants exhibited *enduring* as they attempted to cope with their incontinence. They spent so much emotional energy and resources trying to conceal their incontinence. This is evident with Fleur, who recalled she would like to grab a bottle of water out the door on her way to driving to her son’s basketball practice: “I’m like, I’m thirsty, I’m going to grab a bottle of water, but nope. I don’t drink it because then I’ll have to go to the bathroom.” According to Morse, enduring is an instinctive behavior, whose function is to carry on in times where they must focus on the present. Most of the participants had careers, children, and families to tend to that required them to carry on and endure.

**Urinary Incontinence and Intimacy**

Living with UI not only restricted the participants in terms of travel and activities that they used to enjoy but also affected their QOL with regards to intimacy. Not every participant felt comfortable discussing intimacy issues, but the ones that felt comfortable recalled intimacy as being “uncomfortable” and “not satisfying.” The participants shared that they felt embarrassed by their incontinence. Violet recalled, “You don’t feel like being touched in a sexy way when
A 2019 study by Saiki and Meize-Grochowski sought to analyze both qualitative and quantitative data to explore the effect of UI on relationship satisfaction from the perspective of both midlife women with UI and their partners. They found that distress in the relationship was significantly associated with poor communication about UI, poor sexual QOL, and low perceived trust in the relationship. These factors were not significantly affected by the UI symptom profile or severity. Descriptions of emotional withdrawal and sexual avoidance were characteristic of distress in the relationship. The ability to see some humor in the situation may have provided some protective benefit. This is reminiscent of Iris’s story, where her husband thought that it was in her head and said, “Oh, you’re just making excuses.” Iris eventually divorced: “I didn’t want to have sex with him. I just was afraid that when we were having sex, what happened if I just leak there and everything. It affects a lot from the woman.”

Mota (2017) concluded that UI negatively affects female sexual life. Fear of intimacy associated to sexual activity is evident in view of the lower frequency of sexual activity and low sexual and global satisfaction indices among incontinent women. Lily shared her experience with intimacy: “It’s terrible because you feel embarrassed; you avoid intimacy because it’s uncomfortable. It’s not satisfying you as a person.”

A finding of note uncovered in this study was that despite the women feeling reluctant to engage in sexual activities, they were involved in nurturing and supportive relationships with their partners, which in itself helped increase their QOL. As Violet shared, “So I was lucky he was very supportive and he swore there was no smell and he was willing to push through any kind of sexual encounter.” When Marigold first started to notice her UI, “Me and my husband would laugh. I would sneeze, and he’d go, ‘Did you pee?’ But, it just became more problematic.”
Not only was her husband supportive, but the couple also shared a sense of humor regarding her UI, an attribute mentioned in Saiki and Meize-Grochowski’s 2019 study.

As the participants have shared and the literature has reinforced, it is not easy to take a walk in their shoes. The negative effect on overall QOL, including intimacy and self-imposed restrictions, is discouraging to endure and suffer through. What most silent, suffering women don’t realize though, is that there is a wide range of treatments for incontinence problems, many of which don’t involve surgery (Rabin & Stein. 2008). Hopefully, findings from this study will in some small way help to break the silence.

**Essential Theme 4: Sailing on a Sea of Emotions**

Sailing on a sea of emotions was developed as the emerging theme of *Reported Feelings*, which included the subthemes of *Feeling Embarrassment, Fear of Smelling Bad, Feeling Like a Child, Feeling Out of Control, Negative Self-Image, and Feeling Frustrated*. This theme centers on the myriad of emotions that are well known to women of all ages living with UI, with careful attention to feelings elicited by this particular subset of women (Rabin, 2008).

Incontinence is associated with adverse psychological, physical, social, and economic consequences. The National Association for Continence reported the psychosocial consequences of UI included depression, isolation, decreased self-esteem, and work-related difficulties. Anxiety and depression were the highest psychological problem in women with UI (Luo et al., 2016).

**Anxiety and Depression**

Anxiety was found among several of the study participants to be a greater problem than depression. As Rose explained, “I always get nervous, you know, if I couldn’t stop; or if I had to go, I’d have to go like now. I’ll have a lot of anxiety about it—I would say more than
embarrassment.” Jasmine recalled when confronted with a situation where she may not be able to use a bathroom, “Like it’s causing me severe anxiety…I will literally have a panic attack if I feel I have to pee and can’t get up to go to the bathroom.”

A 2015 quantitative study by Felde et al. examined anxiety and depression associated with UI in a 10-year Norwegian study composed of 16,263 women from 19 to 55 years of age. Prior studies have given conflicting answers on the question of whether it is anxiety or depression that give a higher incidence of UI or UI that gives a higher risk of developing anxiety and depression, as there are biological and neurological explanation models for both directions of the associations. Serotonergic pathways and the sympathetic nerve system are involved in UI, anxiety, and depression (Felde et al., 2015).

**Stigma**

A 2017 qualitative study by Pintos-Diaz et al., composed of 60 women over the age of 18 years of age, found that women’s UI experiences were accompanied by feelings of stress and shame, and moreover, related to the presence of perceived stigma, a label that associates a person to a set of unwanted characteristics that changes behavior and shapes their emotions and beliefs. Stigma enhances the formation of negative attitudes toward seeking professional help for UI through the effect of internalized shame. The results of the 2019 study illustrated how UI is experienced with feelings of unpleasantness, shame, insecurity, and guilt, to the extent that some participants described feeling “dirty.” UI triggers changes that force women to develop certain strategies in their daily life. Previous research has reported how urinary leakage and issues related to the smell of urine can lead to feelings of shame, loss of self-esteem, isolation, and delay in the search for help (Schimpf et al., 2009).
Self-Esteem and Urinary Incontinence

The feeling of shame is greater during sexual relationships and in the event of urinary leaks in public. Consequently, self-esteem can be hampered and women may reject their own body by avoiding personal hygiene habits and attempting to hide their situation. Furthermore, it was found that women suffering from UI are in vulnerable situations in that they feel they have no control over UI, living with a body over which they have lost control, and experiencing feelings of powerlessness. UI leads to a disruption of daily life, has negative effects on women’s intimacy, and leads to changes in the ways that women experience intimacy. As a result, women may self-impose a series of restrictions, as seen in this qualitative study, or the suppression of pleasures and needs and the avoidance of social interactions. In addition, feelings of despair are described by many of the participants regarding gloom about the future due to living with UI as well as a sense of ambiguity and hopelessness (Malani et al., 2018). As Lily described her ordeal, “Living with this is the most embarrassing thing. It steals a lot of stuff—your confidence, and even with intimacy. It’s the worst thing that can happen to you.” Violet described a similar sentiment: “It became a focal point of my therapy sessions because it was so defeating and it was affecting my self-esteem and my confidence and my wanting to go out and always having to prepare and anticipate the parade of horribles…”

In a 2021 qualitative study by Devendorf et al. on data collected from 26 interviews of male and female veterans with urinary and fecal incontinences, self-stigma among the participants emerged as shame, embarrassment, feelings of differentness, and a decreased self-esteem related to incontinence. The interviews disclosed that the fear of others’ discovery of their incontinence caused a withdrawal from social participation to hide evidence of the condition. Incontinence may also increase sexual anxiety, threats to self-esteem, and feelings of
Embarrassment and Shame

Many of the 13 premenopausal women who so graciously shared their lived experience living with UI paralleled the literature. The subtheme of embarrassment and self-imposed isolation came up repeatedly in the interviews. As Lily recalled, “It’s really embarrassing. It takes a lot of things from you. And that’s what I avoid not going out for real, because of that situation.” Hyacinth described her incontinence as, “I think it does make me feel depressed. It makes me feel embarrassed, depressed, everything you could think of.” Poppy recounted, “It’s very hard not to drink water, not to leave the house, not to go anywhere because of this problem and because I don’t want to get embarrassed in front of people and my children and my husband.”

Shame and embarrassment were big deterrents for many of the participants in sharing their condition with others. As Poppy confided,

That’s very embarrassing. My family knew about it. I told my family and my sister-in-law knew, but other than that, no. I didn’t want anyone to know…It’s not easy for you to tell people that you can’t hold your urine and you’re going to pee all over yourself if there’s no bathroom available, which happened a lot to me. I had to wear a diaper. Who do I want to talk to about wearing diapers?

Hyacinth was so embarrassed she didn’t tell her mother that she was experiencing incontinence: “I guess I was embarrassed to tell her.”

Feeling Out of Control

Many of the participants—not unlike the participants featured in the literature—lamented that they felt out of control in regard to their UI. Daisy remembered,
…like the moment I got out of bed, like I had to go and, sometimes, I wouldn’t even make it, like I would pee on the floor…you could, I could definitely see how it can make someone embarrassed or depressed…I guess I was always able to control, not control it, but control my reaction to my situation.

Poppy mused:

It’s hard not knowing when this is going to happen. It’s not like I’m going to know when it’s going to happen so I can schedule bathroom appointments. I couldn’t do such a thing. It would just happen out of nowhere. It doesn’t really matter how much water I’m drinking or not.

**Fear of Odor**

Fear of odor was a dominant concept in the literature as well as a dominant concern among the 13 participants (Schimpf et al., 2009). As Rose recalled, “So I will tell you what I felt self-conscious about; I felt like I smell like urine…” Violet expressed a similar emotion, “I just thought that I felt that I always smelled…it was always in my nostrils just because I felt like I was dealing with it all the time.”

**Frustration**

Feelings of despair and frustration are cited in the literature and found in many of the participants as expressed by their frustration (Schimpf et al., 2009). Fleur lamented, “Why me? Because I have to go to the bathroom all the time. Why doesn’t Cindy have it or whatever? She could drink a bottle of water and not have to…that’s not cool. That’s not fair.” Poppy also added in an exasperated tone, “Yeah, it’s so hard. Everything. It was very hard not knowing when this is going to happen.”
Feeling Like a Child

Feeling like a child was a finding that is likely unique to this subset of women and therefore a new finding. Because most of the literature centers on the older woman with UI, the younger woman raising children may be overlooked. Most of the participants had small children they were raising. A few of them were discovered experiencing incontinence by their children and were put in a position where their traditional roles became reversed. The participants made every effort to hide their incontinence from them and became very embarrassed when they were discovered. Violet recalled,

My older daughter started sniffing, figuratively, not literally, when I needed to go to the bathroom and I was trying to hide it. So, for me, I felt that was really embarrassing, because your daughter is seeing that you’re in trouble and sometimes there’d be nowhere to go and most of the times, it’d be during an activity for her.

Daisy added, “I guess it got to the point where like, okay, change of underwear for my 3-year-old, you know, just in case, and a change of underwear for me.”

Negative Self-Image

Feeling attractive, or rather, feeling unattractive was a new finding expressed by several of the participants and not widely discussed in the literature in regards to UI. When Poppy was queried if living with UI affected her self-image. She responded, “Yes, yes, a lot less pretty...a lot less pretty.” Violet clarified, “Whereas I appreciate all the clever marketing and the bringing in of older celebrities…and the way they’ve upgraded the undergarments that people wear for incontinence, I still don’t want to wear those.” Hyacinth admitted, “I guess unattractive, because it’s like, if you can’t hold your urine, you know…It’s horrible I have to wear pads all the time. It’s like forever I have my period.”
A 2012 qualitative study by Holmquist and Frison studied 30 adolescent girls and their body appreciation. In their study, it was found that body appreciation is associated with high self-esteem, high psychological well-being, and less body shame, body preoccupation, and eating disorder symptoms. It was also uncovered that the media, which includes magazines, ads, TV, and the internet, can be blamed for the instillation of unrealistic appearance ideals for young women to feel dissatisfied with their bodies as they internalize these images of appearance ideals.

Wearing bulky pads, diapers, and dark loose-fitting clothes paired with the knowledge of always smelling like urine is a challenge for these young women to feel stylish and attractive.

The participants were able to speak to a myriad of emotions, which include stigma, anxiety, depression, loss of self-esteem, fear of odor, embarrassment, shame, feeling out of control, frustration, feeling like a child, and desperately longing to feel normal. As Violet explained, “I don’t even think some women have the words to describe what they’re really feeling.”

**Essential Theme 5: Barricades and Barriers to Care**

Barriers and Barricades to Care evolved from the emergent theme of *Journey to Care*, with subthemes of *Expense* and *How It Should Be*. This theme summarizes many of the barriers found in the patients’ stories and the literature that prevents them from obtaining the care that they require. By recognizing and breaking down some of the barriers, young women with UI may be able to take back their rightful QOL.

UI is an increasingly prevalent but under-reported and under-diagnosed health problem. In the general population, surveys have found that UI is reported by 7% to 37% of women aged 20 to 39. Although the literature on the incidence of UI in women varies greatly, it has been
determined that up to 50% of women aged 15 to 39 have UI (Tremback-Ball et al., 2008).

Patients often do not seek treatment for UI due to feelings of embarrassment and taboos, cultural beliefs, and lack of health care providers’ knowledge regarding this issue (Hunter & Wagg, 2018). Prior studies have found that only about a quarter of women with UI symptoms have consulted doctors on this issue and nearly one third of older people perceived UI as shameful (Luo et al., 2016).

**Myths**

Women’s beliefs and attitudes toward UI vary based on race and culture, but the belief that UI is a normal part of aging, or a consequence of childbirth, is present regardless (Parker et al., 2002). Women’s beliefs that UI is a normal part of aging are inaccurate and may be partially responsible for the high incidence of the disorder among women (Tremback-Ball et al., 2008). Lack of knowledge about the causes of and treatments for UI may be partly to blame for women’s acceptance of this disorder and may influence their care-seeking behaviors.

Additionally, many women believe that their incontinence is only a trivial problem that they can self-manage. These beliefs are evident when Flora recalls, “I mean, I never went to the doctor to inquire about it. I assumed it was something that was part of my life, that was, well, normal for someone with three children.”

A qualitative study by Pintos-Diaz et al. (2017) concluded that a lack of information on UI and pelvic floor dysfunctions has led to many myths and misconceptions that have strengthened the taboo of UI. This is not a subject that women feel they should speak about and, therefore, women who suffer from UI may display apathy or even deny the problem altogether. As Poppy explained, “This is a sensitive conversation. It’s not easy for you to tell people that you can’t hold your urine and you’re going to pee all over yourself if there is no bathroom
available...Who do I want to talk to about wearing diapers?”

**An Anthropological Perspective on Barriers to Care**

A meta-ethnography conducted in 2020 by Toye and Barker concluded that a culture of secrecy and profound sense of shame is a barrier to seeking help. Women with UI feel stigmatized, ashamed, and guilty. They cite early but relevant and important anthropological texts that help to explain the profound sense of defilement associated with UI and to explain women’s feelings of ambivalence as to what normalcy is. In the seminal text, “Purity and Danger” by Douglas (1966), he describes how feelings of abhorrence, defilement, and dirt stem from a cultural reaction to ambiguity and anomaly: “Dirt offends against order.” Toye and Barker (2020) concluded that UI is indeed experienced as anomalous, as it defies social categorization: ‘I am ill and also not ill’; ‘urination is normal and also not normal’; ‘I am an adult and also not like an adult.’ Thus, women living with UI exist in a liminal social space in between normal and abnormal. The anomaly of UI can make it very difficult to talk about, explaining why only the rare few seek help. Toye and Barker further examined an even earlier text—Talcott-Parson’s (1951) *Sick Role*, which indicates that we are obliged to go to the doctor to access the privileges of the “Sick Role,” but people with ambiguous or stigmatized conditions are torn between the incentive to access these privileges and the cultural incentive to remain silent. These older texts speak to the triviality many women feel about their incontinence even though they may recognize it, or their family may recognize it as being a problem. Trivializing the experience of incontinence can be a barrier for many women, by not appreciating that UI is very treatable and is not something that has to be accepted and endured. They may feel that they are not really ill and their condition may not warrant seeking help and accessing the privileges of the Sick Role. This sentiment of acceptance and unawareness can be illustrated by Holly, who explained,
“When I speak to most of my friends, they seem to be experiencing similar…I think some women, you need to accept it.”

**Barriers to Discussing UI with Providers**

A qualitative study by Fakari et al. (2021) examined 34 women in Tehran, Iran, and found that many of the participants felt shame and discomfort with discussing their UI and the examination of the genital area, especially if done by a male doctor. Women with UI prefer to receive help from a female provider.

A quantitative study by Duralde et al. (2016) studied 969 women aged 40 and older who were examined through structured questionnaires. Their study showed that 55% of women reported discussing incontinence with a health care provider, with 40% discussing their symptoms with a specialist. Greater than 95% of women initiated the discussion of incontinence, with only 3% reporting that a provider initiated the discussion. Nearly two thirds waited for more than a year after the onset of symptoms before consulting a provider. Of the women who denied speaking with their provider, the most common reason for not discussing their symptoms was that they considered their incontinence to be small or an insufficiently bothersome problem. Other common reasons included a preference to manage the problem on their own, a belief that they should put up with their incontinence, or a view that incontinence was a normal part of aging. Women with only a high school education were less likely to report discussing incontinence within the first year, compared to women with professional or graduate school education. This is evident with Flora, a high school graduate, who stated “I’m just so used to it…I’ve lived with it for so long now.”

According to the same study, women with more severe symptoms were more likely to report having discussed their symptoms with a provider within the first symptomatic year. The
findings in the study also indicate that even among women with frequent incontinence and streamlined and affordable access to primary care and specialist services, the rates of patient–provider discussion of incontinence remain low and provider-initiated screening for incontinence are even lower (Duralde et al., 2016).

A finding in this qualitative study was that the participants’ beliefs or what they were told greatly influenced and reinforced their help-seeking behaviors. Violet recalled her therapist encouraging her to seek help for her incontinence who had said, “I think you should have this checked out.” When she explained that everyone says it happens after you give birth, he said, “No, that doesn’t sound like that’s what it is.”

Daisy accepted her incontinence as part of her life:

I always thought it was more like after kids, you know, and I felt like I would talk to my friends and they said, “Oh, we have that too...It didn’t bother me at all.” I laughed it off and joked it off and didn’t even care. But my husband wanted it fixed for me. He was just like, “You need to get this fixed. This isn’t normal.”

Rose similarly remembered sharing her incontinence situation with friends: “I’ve told a couple of friends, you know, I said to who I know had kids and this was my first child. So, I said, ‘I didn’t know that this happens’. And they were like, ‘oh yeah, that happens’. You know, like this is normal.”

Provider Barriers to Care

Many studies found that beliefs, values, and attitudes of health care professionals can contribute to how UI is diagnosed, managed, and treated (Luo et al., 2016). Incorrect beliefs about UI may be supported if health care providers are unresponsive to, or dismissive of, their patient’s questions regarding incontinence. They may reinforce the belief of normalcy by saying,
as in the case of Violet, “Just do kegals. That’ll be fine.” Health care providers may also add to the feelings of stigmatization that women experience through the lack of sensitivity and negative responses to their UI. These providers tended to prescribe palliative, rather than rehabilitative therapy, which may be attributed to the providers’ beliefs that incontinence was somehow the fault of the patient or a normal age phenomenon. This practice suggests that the behavior of health care providers may be affected by societal beliefs that are incongruent with a purely biomedical understanding of etiology and treatment alternatives (Bush et al., 2001).

Many of the premenopausal participants initiated the conversation of their incontinence with their providers, but most felt dismissed and unheard by them. When Marigold sought help from her urologist, he told her:

It could be due to age. It could be due to having children. I was like, well, I had C-sections, so I don’t know if that had anything to do with it. So, I just went about my daily life, but it was horrific. I would get up in the morning, put a panty liner on and sometimes I would forget and I would be, you know, getting my kids ready for school and I would literally just pee myself all over the floor.

Jasmine recalled a similar sentiment:

I think that not many people or doctors pay attention to younger women that have urinary issues. I went to a urologist for a couple of years throughout college and he was like ‘you’re young, you know; let it pass’. He didn’t take into consideration that it was a real issue just because I was young and it would eventually go away. But obviously, this has been a permanent issue now.

Rose remembered broaching the subject with her OB. “The OB kind of, you know, dismissed it like, ‘Oh, it’s part of childbirth. It’s ok.’” Lily was immediately dismissed by her
GYN when she sought help for her incontinence and was told, “Our grandmothers and mothers suffer from this, so this is not something new.” Providers who support that incontinence is a normal part of aging by providing inaccurate information, reinforces barriers and barricades to timely and thorough care.

How It Should Be

Despite the significant burden of UI, only about 3% of health care providers inquire about UI; 25% to 50% of women with UI seek care, with 23% to 38% receiving treatment. Despite the availability of effective interventions, UI is largely untreated due to a number of factors, including the failure of providers to inquire about urinary leakage. Guidelines and standards have been available for decades, yet urine leakage continues to go undiagnosed and untreated, leading to incredibly high health care costs. Therefore, it is essential that providers be familiar with UI risk factors while being on the frontlines of diagnosis and treatment. By consistently identifying and treating women with UI, providers can improve the lives of women and reduce health care expenditures. They can ask about UI during regular checkups, even when the focus is on other symptoms. All women over the age of 18 can be systematically screened for urine leakage with the simple question, “Do you ever accidentally leak urine?” (Wiers & Keilman, 2017).

Poor communication, lack of clear education, and the power of experiences were barriers to seeking help because they promote the normalization of suffering in silence and therefore disempower women. Participants who had erroneous beliefs, accepting UI as a result of childbirth or part of life, plus provider dismissiveness in recognizing UI as a QOL issue contribute to the erection of barricades and barriers to expeditious and thorough care.

Health care professionals should be encouraged to improve communication and
education, reducing barriers and enabling female patients to seek help. They should assist
women during their care journey by informing, guiding, and applying interventions based on
clear and realistic goals. Proactively asking patients about UI would help to reduce the taboo and
ensure that help is made available. A cultural environment that reduces shame and stigma of UI
may help women switch the focus to strategies that will improve continence. At the same time, it
would be useful for healthcare professionals to recognize a person’s need to conceal UI and to
collaborate in a treatment approach that not only facilitates this need but also aims to improve
continence.

**Economic Burden of UI**

Many participants cited the high costs of diagnostic and therapeutic procedures as one of
the factors delaying their pursuit of treatment and the insufficient coverage of diagnostic and
treatment costs by insurance companies, preferring not to refer for treatment or delay it as much
as possible. When instructed by her GYN to go for pelvic floor rehabilitation, Lily remembered
“I mean, I can’t go get exercise therapies because I don’t make that much money.”

A systematic review by Almousa and van Loon (2018) revealed that the economic cost of
UI is substantial. In the United States, each patient pays on average over $900 per year on
resources used for routine care such as absorbent pads, diapers, protection and laundry. Buckley
and Lapitan (2010) noted that the annual direct costs of UI are estimated to be higher than the
equivalent costs of breast cancer, pneumonia and influenza, and osteoporosis.

**Reconciling Findings with the Current Literature**

The five themes uncovered in this study were Fictitious Dialogue, Strategic Planning, A
Walk in My Shoes, Sailing on a Sea of Emotions, and Barricades and Barriers to Care. Fictitious
Dialogue comprises many of the beliefs that women have regarding their incontinence. The
literature cites various myths such as incontinence is an inevitability of aging. A finding unique to this population of women though, and not found in the literature, was that most of the participants were baffled by their incontinence and truly felt that they were “too young” to experience it, when in fact, age is not a factor for experiencing UI.

Strategic planning captured many of the coping mechanisms that women used to hide or better live with their incontinence. The literature cites many instances of fluid restriction and social avoidance, but with this unique subset of women, other coping means were used. Since these young women emphasized exercise and fitness, they talked about ways they would hide their incontinence by wearing loose, dark, and patterned clothing. This population of women were also involved in work and careers and planned very carefully to avoid being discovered while in a work situation.

A Walk in My Shoes highlighted the myriad of experiences that women have encountered living with UI. The literature cites instances where UI places restrictions on one’s life, but this study revealed how devastating living with UI can be for the younger woman, who is actively involved socially and with family. There are several quantitative studies in the literature that measure sexual function and UI, but this study is unique in that it explored what the participants are actually encountering and how they are experiencing intimacy with incontinence. Many of the participants were reluctant to engage in intimacy due to their overwhelming fear of revealing their secret. Yet, for the most part, the participants revealed that as much as their UI contributed to a decrement in their QOL, it appeared to be offset by the loving and supportive relationships they shared with their partners.

Sailing on a Sea of Emotions showcases the multitude of emotions experienced by women living with UI. Most of the emotions discovered in this study were noted in prior studies,
though several newer concepts were revealed. Many of the participants in this study were made to feel like a child again, by attempting to hide their incontinence from their children. When discovered by their children, they experienced a sense of role reversal. Many of the participants in this qualitative study verbalized that their incontinence made them feel “less pretty” and were concerned with how they appeared to others and to themselves. Most of the participants admitted to feelings of shame and embarrassment, but a big concern that emerged was their feelings of anxiety and depression. This is a major public health concern, and providers need to be aware of the correlation among UI and these symptoms.

Barricades and Barriers to Care discussed the many erected walls that have prevented women from getting expeditious care for their UI. The literature cites studies where it is clear that women trivialize their incontinence or are too ashamed to ask for help. It also has explored lack of provider information in several quantitative studies. However, this study revealed how rampant misinformation is for these young women. Many of the women in this study could have received therapeutic care years earlier had they been given more thoughtful care. Rather, many of these women were told their incontinence would “go away” if they just gave it more time. These negative beliefs on the part of the providers cost the participants valuable time that they had to endure and suffer through.

Many of the uncovered themes in this study were confirmed by the literature and were explored quantitatively. However, this study uncovered the essence and the true meaning that living with UI has for this group of resilient and adaptive young women.

**Influence of Nursing Theorists on Assisting Women with Urinary Incontinence**

Historically, nursing theorists have greatly contributed to and enhanced patient care by significantly enhancing nursing education, policy, and practice. Nursing theory is important to
the science of nursing, as it creates a setting to combine the organization of ideas, concepts, and beliefs relating a phenomenon of interest and philosophical conviction to professional practice. Theory gives reason to nursing and justifies its existence by providing the framework for practice, knowledge, and research. The use of theory in practice promotes a logical method for nurses to provide services by identifying the necessity of nursing interventions. Ultimately, theory and practice promote research encouraging practicing nurses to question and develop methodologies to enable change, growth, and progress (Bernier, 2002).

As themes uncovered in this study are multi-faceted, no one specific theorist guided this study. Rather, contributions from various theorists helped shape implications for nursing education, practice, policy, and future research. The three theorists consulted in this study were Morse (2017), Roy (2009), and Orem (2001), whose contributions are illustrated in the following section:

**Morse’s Praxis of Suffering Theory**

Many themes in this study intersected and intertwined with each other, but a prominent concept that emerged throughout was the idea that many of the participants endured their UI in silence and lived with a reduced QOL. Themes such as A Walk in my Shoes highlight how many of these women actually suffered with their reality and were desperate for a solution. As one of the participants described, “It became a focal point of my therapy sessions.”

Morse’s (2017) praxis of suffering theory is composed of two components: enduring and emotional suffering. When an individual is enduring, they are suppressing their emotions in response to whatever is being suffered. In this instance, the individual deliberately blocks any thoughts they may have regarding the event, thus blocking emotional responses. An immediate focus is maintained, blocking the past and future, thereby controlling any thoughts of what the
potential outcome might be. Instead, they focus on one step or task at a time. This cognitive suppression removes the emotional response and panic, allowing for daily functioning. However, this denying process requires much energy and vigilance, which may also suppress behavior, produce a flat affect, loss of spontaneous movement, and an unfocused gaze. They may feel that they are coping, but they are expending all of their energy suppressing their feelings (Morse, 2017).

As in Morse’s theory, some of the participants felt that UI is something they should “just live with” and endure, while others actually verbalized suffering: “This is the worst thing that can happen to you.”

The theme of strategic planning also exemplified how maladaptive coping behaviors was another avenue for the participants to endure in living with UI to normalize their reality. Severely limiting fluids and avoiding social situations may work in the short term but cannot be maintained in the long term.

Morse’s Praxis of Suffering can and should be used by nurses to better understand the psyche of these young women. Interventions and education should be directed not only on the physical manifestations of UI but also on their multitude of feelings and deep-seated beliefs that these young women carry with them on a daily basis. All education and counseling should integrate Morse’s theory by acknowledging the woman’s coping strategies as well as providing pragmatic instruction.

**Roy’s Adaptation Model**

A prominent concept that continually emerged throughout this study was the idea that all of these young women were able to adapt to living with UI. That is not to say, however, that their methods of adaptation were positive. This attempt at adaptation was particularly evident in the
The theme of strategic planning, where many of the participants severely limited their fluids to the point of dehydration, in an effort to avoid an accident. Others limited social interactions and leaving their house. Still, others participated in “weird coping mechanisms” such as stuffing themselves with toilet paper and using cups and commodes in their cars. Many of the participants, however, engaged in coping behaviors that were not maladaptive and worked positively for them. Some participants planned out bathroom routes while traveling, and others knew where all the bathrooms were located when they went shopping; others bought dark-patterned clothing so they could continue to exercise without discovery. All of these women, despite the severity of their incontinence or their perceived QOL, had a plan, which for some was not one that served them well, but for others, worked positively to improve their QOL.

The Roy Adaptation Model can serve as an important guide for nurses to use when encountering patients with UI. To use the model in practice, the nurse follows Roy’s six-step nursing process, which includes an assessment of the behaviors manifested from the four adaptive modes, assessing and categorizing the stimuli for those behaviors, making a nursing diagnosis based on the client’s adaptive state, setting goals to promote adaptation, and evaluating the achievement of adaptive goals (Philips, 2005). Roy pointed out that by manipulating the stimuli rather than the patient, the nurse enhances the interaction of the person with his or her environment, thereby promoting health (Roy, 2009).

The Roy Adaptation Model can be used by nurses to promote and support healthy behaviors as they relate to the incontinent young woman. By looking at the patient holistically from the framework of the four adaptive modes, the nurse can initiate interventions to support and educate these women through approaches such as physical care, anticipatory guidance, health teaching, and counseling.
The physiological mode is a response to stimuli from the environment to meet survival needs, which include elimination, fluid and electrolytes, rest, and activity (Roy, 2009). The nurse can educate the young woman on techniques, such as timed voiding, pelvic floor rehabilitation, and other treatment modalities, which can help with incontinence and educate the patient to all of the opportunities that exist that can potentially help the woman achieve more control. Nurses can eradicate many of the fallacies that many young women have regarding their incontinence and replace some of their negative coping mechanisms, such as limiting fluids.

The self-concept mode is defined as individuals’ feelings about themselves that are influenced by how others perceive and respond to them. It consists of the physical self, or body image and body sense, and personal self, which is formed by their thoughts, moral ethics, and spirituality (Ursaves et al., 2014). Since many young women develop a negative body image due to continued wetness and wearing bulky diapers and pads, they are in danger of integrating these negative feelings and becoming depressed or anxious. Nurses are in a good position to support these women through education and providing avenues of information.

The role function mode focuses on the roles of the person in society and within a group, with its underlying need of social integrity—to know who one is in relation to others so that one will know how to act (Roy, 2009). Nurses can assist the young women through educational interventions that create optimal conditions for patient learning. This could occur during the initial postpartum checkups by the nurse practitioner, who can identify women that are at risk for UI and offer positive support, education, and encouragement.

The interdependence mode includes relationships with others that are meaningful to the person and their support systems (Roy, 2009). The nurse, through education and counseling, can replace negative reinforcement, which stems from negative beliefs and values, through educating
both the spouse and her family.

Nurses can use knowledge of these adaptation modes in their practice to assess the level of health and integration of the individual as a whole person. Themes discovered through this research examined through the lens of the Roy Adaptation Model can generate important knowledge that is specific to the discipline of nursing.

It is essential that nurses, while providing education to women with UI, have an awareness of many of the adaptations that are made to help cope with this situation, so that many of these adaptive and maladaptive behaviors can be addressed, and myths and beliefs can be dispelled and replaced with positive and realistic education.

**Orem’s Self-Care Deficit Theory**

Self-care agency to manage UI represents a woman’s perceived ability to manage UI. Self-care agency, as described by Orem (Orem, 2001) represents one’s ability to regulate physical processes and meet the management needs of caring for oneself (Hines et al., 2007). Several of the themes in this study identified barriers to meeting these self-management needs adequately. Themes such as strategic planning demonstrate how negative coping measures such as fluid restriction and social avoidance may prove to be harmful in the long run. Inaccurate myths and beliefs are evident in the theme Barricades and Barriers to Care, by prolonging poor self-management.

Orem’s Self-Care Deficit Theory puts the emphasis on actions needed to support the patient in acting as their self-care agent for healthcare rather than assuming nursing responsibility (nurse agency) for healthcare needs, including those the patient can maintain for themselves. In Orem’s theory, the emphasis is on patient responsibility. Nurses do not cure the incontinence but instead provide the patient with the means to regain self-care agency (the
capabilities needed to assume control) over their bladder dysfunction.

With Orem’s theory, interventions include nursing diagnoses and specific nursing actions applicable to the patient situation. The nurse can provide purposeful therapeutic intervention, resulting in patient awareness of contributing factors, causes, and help for UI symptoms. Thus, with understanding, the client can understand and embrace necessary self-care requisites to make lifestyle changes.

**Implications of Findings**

**Implications for Nursing Education**

The national objective of Healthy People 2030 has its core goal of improving the health, function, and QOL of older adults, including addressing UI, which has a significant negative effect on QOL. The National Institutes of Health reports that the prevalence of UI is high but the recognition of this problem is low, contributing to its burgeoning cost. Decreased patient reporting and clinician assessment contribute significantly to the problem because undiagnosed UI exacerbates the scope of the problem. Educational competencies for student nurses focusing on UI treatment and prevention may help alleviate some of the financial burden (Hutchings & Sutherland, 2014).

To reduce UI-associated demands on the American public, the Agency for Health Care and Policy Research initial guidelines recommend that UI education be included in graduate and undergraduate training programs for all health care providers, but the current guidelines do not provide UI education recommendations for health care workers. It is recommended that nursing faculty incorporate incontinence education in both the classroom and clinical setting. Nurses have an opportunity to enhance a patient’s QOL through encouragement of health-promotion strategies related to UI and its resulting symptoms (Hutchings & Sutherland, 2014).
Nurses are in key positions to assist those affected by UI. They can identify people with incontinence, establish appropriate interventions, and provide valuable education to empower patients. UI may have a substantial negative impact on patients’ QOL. Many clinicians, however, are unaware of how UI affects individuals’ perception of themselves, relationships, and overall feelings related to QOL. Practicing nurses often lack accurate information and treatment strategies to deal with UI, with care focusing on containment. Multiple sources have identified nurses’ lack of sufficient knowledge as a barrier to appropriate interventions for patients who suffer from an inability to control their bladder. For nurses to apply evidence-based interventions, they must first have a working knowledge of incontinence causative etiologies, assessment techniques, and intervention models (Hutchings & Sutherland, 2014).

A contributing factor to this practice gap is the lack of standardized educational approaches for nursing curriculums in undergraduate nursing programs. One study surveyed nurses regarding their educational preparation, with only 40% identifying that they received education related to UI. The American Association of Colleges of Nursing 2006 guide for faculty does not provide any guidance related to UI management education. A search of the literature did not yield any recent information or guidance related to UI management education. The formal inclusion of UI education in the BSN (Bachelor of Science in Nursing) curriculum is needed with an emphasis on the patient’s feelings and experiences related to incontinence. Although professional schools of nursing may include information on UI in their teachings, there is no mention of the psycho-social sequela experienced by women, particularly young women suffering from UI. A lack of knowledge has been recognized as a barrier to the implementation of patient-centered UI nursing interventions, not just for baccalaureate students but other levels of nursing practice as well. Formal inclusion of urinary continence education into the BSN
curriculum, with an emphasis on the psycho-social impact, may help students implement incontinence interventions (Hutchings & Sutherland, 2014).

Some basic continence training is included in initial nurse education, but there is a need for each nursing specialty to have more in-depth knowledge appropriate for them, including clinical nurse specialists in continence care and urology nurse specialists. It is imperative that schools of nursing integrate incontinence care into OBGYN lectures and discussions on the female. It is also essential that nurses are aware of options for care and have the knowledge to give appropriate treatment and referral pathways for more specialist care from other disciplines, such as physical therapy.

**Implications for Nursing Practice**

Nurses can and should look to the many nursing theorists to provide a framework for practice, knowledge, and research. Although nursing theorists describe their individual philosophies and descriptions differently, the use of theory in nursing gives justification to the art and science of nursing practice (Bernier, 2002).

Many nursing theories can be used by nurses to promote and support healthy behaviors as they relate to the incontinent young woman. By looking at the patient holistically, the nurse can initiate interventions in their practice to support and educate these women through approaches such as physical care, anticipatory guidance, health teaching, and counseling.

Nurses can enhance their practice by integrating knowledge of the Adaptation Modes that Roy has posited, by assessing the level of health and integration of the individual as a whole person.

Utilizing Orem’s self-deficit model, which emphasizes patient responsibility, the nurse can provide purposeful therapeutic intervention, resulting in patient awareness of contributing
factors, causes, and help for UI symptoms. The patient can therefore, with new comprehension, make the necessary self-care requisites to make lifestyle changes.

Morse’s Praxis of Suffering can be used by nurses in their practice to obtain a better understanding of the psyche of these young women. Interventions and education should not only be directed on the physical manifestations of UI but also on their multitude of feelings and deep-seated beliefs that these young women carry with them on a daily basis.

Implications for Nursing Research

This study supports the potential value for conducting further nursing research based on the study findings. An essential need would be the research and development of educational programs to inform women about UI. Educational programs could help a woman’s self-care agency to manage UI in a number of ways.

These educational programs can be initiated by nurses, but before that can be accomplished, an in-depth assessment of the knowledge base of the interdisciplinary team has to take place, raising awareness levels to better serve these women with incontinence. With awareness and knowledge, screening tools can be developed to capture and treat UI earlier. More extensive research should be allocated for the development of screening tools that the nurse can administer to identify and treat incontinent women more expeditiously. The tool need not be complicated and should be included as an assessment tool along with other tools such as the Depression Screen Tool. This assessment tool can be also integrated into the EMR (Electronic Medical Record) and perhaps into the Hospital EMR on postpartum floors. When postpartum nurses are instructing their patients on breastfeeding, for example, they can also instruct on incontinence and what is and what is not normal. This information can become part of the EMR, so that each nurse signs off that he or she has instructed the patient on UI.
Accurate information about UI and treatment approaches would give women specific details and language to initiate discussions with their healthcare providers and provide a venue wherein women could be introduced to providers that specialize in UI treatment. Research and development of a public education program might encourage open discussion and sharing among friends and family about UI through the sharing of information in a non-threatening way, perhaps helping to dispel misconceptions and myths.

Research is also warranted to further understand the correlation among women with UI and depression/anxiety. This is a large public health concern that is important for nurses to be aware of and warrants further research. Social needs such as work and careers, health and exercise, and body image are also important to this subset of women and greatly influences their QOL. More research studying the impact that UI has on these QOL variables is therefore warranted. Future studies can explore the meaning that living with UI has for each of these women and how it affects their relationships. Focus groups can be conducted to further explore the experience of living with urinary incontinence to gain further knowledge of how it impacts the premenopausal woman’s QOL.

In 2018, O’Reilly et al. published screening recommendations for UI in women from the Women’s Preventive Services Initiative, targeting all clinicians providing preventive health care for women, particularly in primary settings. This initiative concluded that standardized screening in routine practice, particularly + has the potential to identify women and initiate diagnostic evaluations and treatment. To date, no clinical recommendations addressing routine screening for UI have been issued from guideline groups, although recommendations for diagnostic evaluations and treatment are available and regarded as standards of care.

Qualitative knowledge gleaned from the participants in this study, such as impact on UI
on sexual health, exercise, work and careers, self-esteem, parenting, and depression and anxiety, can be further studied qualitatively and quantitatively to facilitate the development of tools to capture with precision QOL attributes found in this unique subset of women, enabling their voices to be heard and important interventions to be made.

**Implications for Nursing Policy**

While there are various treatment modalities available to treat women with UI, there is a great need for an increase in nursing education that also addresses early identification of these women. Policies should be initiated at the university level to ramp up the curriculum and include topics such as UI assessment and treatment, including the psycho-social impact of UI. Time spent successfully educating future nurses has the potential to improve women’s QOL by reducing the personal burden of living with UI.

A clinical policy can be established where a UI assessment tool is incorporated into a well-woman examination in any primary care setting. A policy should be initiated wherein all OBGYN nurse practitioners ask postpartum mothers if they are experiencing any leakage at their 6-week checkups. If they are identified, they can and should be screened again at 3 months and again at 6 months, while continually providing information and guidance. Furthermore, in light of the strong correlation between UI and depression/anxiety, any woman suffering from UI should be screened for depression. This should be enacted as a policy in all clinical settings.

In lieu of the enormous cost of incontinence care to the patient, healthcare providers should utilize their policy development muscle to encourage the passage of legislature that would help defray the cost of UI products. There is some financial support through Medicaid, the U.S. Department of Veteran Affairs, and state or community-based programs, but for the most part, Medicare (Parts A and B) and Medigap (supplemental insurance) does not cover the cost of UI
supplies (Davis & Wyman, 2020). Nurses are in a key position to challenge legislation and make an impact.

**Limitations and Recommendations**

This study is unique in that it captures a specific subset of women in a particular age category living with UI. This small qualitative study was limited in that it was essentially ethnically homogeneous, with most of the participants well-educated professionals who were predominantly White or Latina. Because this group of women were all insured, it did not include women that did not have access to healthcare. Twelve out of the 13 women were also actively seeking treatment and in the process of seeking help, excluding women who have yet to be identified and treated.

The participants in this study also shared a similar socio-economic background and were involved in heterosexual relationships. Two of the participants were born and raised outside of the United States. It would have been interesting to see whether their culture impacted how they viewed their incontinence. It is recommended that future studies include women from varying economic and ethnic backgrounds to see if those variables influence their perceived QOL. Perhaps including family members in the study design would give insight into how living with UI affects family members and their significant others.

Despite limitations, findings from this study can hopefully impact clinical practice. Results will help nurse clinicians to understand the importance of assessing sexual concerns of young women and to educate female patients on how urinary symptoms might impact sexual intimacy. Additionally, the importance of work, exercise, and a positive body image are all factors that, if disrupted, can seriously alter QOL. Juggling life with young children, significant others, and careers are also important to these young women. Of greater concern, though, is the
link found between depression and anxiety and UI. Attention should be given to this public health concern, with timely recognition. Attention to the postpartum patient should also be looked at more closely with a less dismissive attitude on the part of the providers. Insights from this study revealed that many GYNs feel that incontinence following birth is a normal phenomenon. Patients need to be educated that, although some leakage may be normal at 6 weeks post-partum, it is not normal at 3-6 months post-partum. These women need to be better identified and treated more expeditiously. Perhaps this group of women, if answering affirmatively to UI at their 6-week checkup, should be followed at 3 months and 6 months out, as UI doesn’t always resolve on its own, despite being “young.” The nurse practitioner or registered nurse can query these young mothers to ensure that their incontinence needs are being addressed. Violet recommended that the providers use emoji faces to assess if the incontinence has gotten better or worse at the postpartum checkups:

You know, they’re all big into…I don’t know about the primaries but for the gynecologist; they’re so big into those postpartum checkups and check-ins. I think they just need to add one of those questions: “By the way, has this gotten better? Has this gotten worse?” On a scale from 1 to whatever.”

Nurses and providers appear to be lacking in awareness of the magnitude of the problem that living with UI has for women, especially younger women, contributing to a barrier to obtaining care. According to the literature, there is a significant lack in the education of physicians, nurses, and other health providers on the topic of UI. The academic curriculum needs to add information about this phenomenon so that it becomes normal to ask a woman if she is experiencing any leakage. Knowing the correlation between UI and depression/anxiety, women with UI should always be questioned about depression. Guidelines and questionnaires similar to
the depression screen (Maurer et al., 2018) can be adopted to query any woman that presents for primary care and especially for any woman presenting with a urinary concern, such as a urinary tract infection. Perhaps the EMR can include a check-the-box feature to address UI, to reinforce providers and nurses to address it, with an algorithm leading to a depression screen. Focus groups and surveys to providers and nursing staff can help to assess what is known about UI so that education can be provided and reinforced.

Nurses and health care workers need to be aware of the uniqueness of living life as a premenopausal woman and how to address her unique set of needs. Because younger women may have different concerns than older women with the same condition, more research is needed for a greater understanding of pre-menopausal women’s perceptions of UI. Developing a better understanding of the coping mechanisms that are specific to this subset of women may be key to providing care for this patient group.

Conclusion

It is important that premenopausal women come to realize that UI is not something that they have to live with and not something that is to be merely accepted after having a baby or getting older. It is very treatable, but there are still weeds to pull to appreciate the beauty. Hopefully, more young women will begin to, as Violet described, “listen to the whispers of your body” and go after the help that is available for the asking. Women should also be encouraged, most importantly, to always be advocates for themselves. If they feel that something isn’t quite right with their bodies, they should never remain quiet but keep up the pursuit and keep asking questions until they are ultimately heard. It is hoped that the findings from this study will be used as a springboard for further research with this unique, courageous, and resilient group of women and their significant others.
The tiny seed knew that in order to grow, it needed to be dropped in dirt, covered in darkness, and struggle to reach the light

– Sandra King
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University of Alaska Anchorage.
Appendix A Approval Letter from Integrated Medical Professionals

February 10, 2021

Molloy College Dept. of Nursing

1000 Hempstead Avenue

Rockville Centre, New York

Dear Dr. Girardi,

I am currently pursuing a PhD in Nursing at Molloy College in Rockville Centre, New York, and am employed as a nurse practitioner at AUC, Manhasset, New York. I am conducting a qualitative study on urinary incontinence in the pre-menopausal woman and its impact on their quality of life. I am hoping that you will be able to act as a champion or mentor and allow me the opportunity to conduct this research with a sample of your premenopausal patients suffering with urinary incontinence. Information gleaned from this study has the potential to positively impact practice. Inclusion criteria for this study include: Patients that are English speaking and are willing to commit to a 60-90-minute interview, available for interviews before June, 2021, pre-menopausal, and have experience urinary incontinence for at least 1 year. Exclusion criteria will include patients who have ceased menses for at least 1 year and experienced urinary incontinence for less than 1 year.

All interviews will be conducted via Zoom, phone, or Facetime for 60-90 minutes. Interviews will be audio recorded and notes will be taken by the researcher throughout, which
the participant will have full access to. All interviews, names, and data will be kept confidential. Informed consent will be obtained from each participant prior to the interview as well as IRB approval from Molloy College. Participation in this study is strictly voluntary and the participants are free to opt out of the study at any time.

Please complete the attached form to grant permission to conduct this research at the Manhasset AUC office. Please sign, date, and return this form to Jackiekirk1@verizon.net. Thank you in advance for this wonderful opportunity.

Respectfully yours,

Jacqueline Kirk, R.N., MBA, APN

I grant permission for Jacqueline Kirk, NP, to conduct research for her qualitative doctoral study with participants from the AUC, Manhasset Division, N.Y. office.

Name          Title          Date
SARAH K. GIRLES,[ M.D.  2/11/21

[Signature]
Appendix B IRB Approval Letter

DATE: May 6, 2021
TO: Jacqueline Kirk, MSN
FROM: Molloy College IRB
PROJECT TITLE: [1756888-1] Urinary incontinence in the premenopausal woman and impact on quality of life
REFERENCE #: New Project
SUBMISSION TYPE: New Project
ACTION: DETERMINATION OF EXEMPT STATUS
DECISION DATE: May 6, 2021
REVIEW CATEGORY: Exemption category # 2

Thank you for your submission of New Project materials for this project. The Molloy College IRB has determined this project is EXEMPT FROM IRB REVIEW according to federal regulations. However, exempt research activities are subject to the same human subject protections and ethical standards as outlined in the Belmont Report.

NOT APPROVED FOR FACE TO FACE INTERVIEWS DUE TO COVID 19.

This acknowledgment expires within three years- unless there is a change to the protocol.

Though this protocol does not require annual IRB review, the IRB requires an annual report of your exempt protocol (Expedited and Exempt Research Protocol Annual Report Form) which is available on the IRB webpage.

If there is a proposed change to the protocol, it is the responsibility of the Principal Investigator to inform the Molloy College IRB of any requested changes before implementation. A change in the research may change the project from EXEMPT status and requires prior communication with the IRB.

We will retain a copy of this correspondence within our records.

If you have any questions, please contact Patricia Eckardt at 516-323-3711 or peckardt@molloy.edu. Please include your project title and reference number in all correspondence with this committee.

Sincerely,

Patricia Eckardt, Ph.D., RN, FAAN
Appendix C Demographic Table

**Which category includes your age?**
- O 30-39
- O 40-49
- O 50-53

**What is your race?**
- O White
- O African American
- O Asian
- O Other

**Marital Status**
- O Never married
- O Married
- O Widowed
- O Divorced
- O Separated

**Highest level of school completed**
- O Less than High School degree
- O High School Degree
- O Some College but no degree
- O Associates Degree
- O Bachelor’s Degree
O Graduate Degree

**Employment**

O Employed working 1-30 hours per week

O Employed working more than 40 hours per week

O Not employed and looking for work

O Not employed and not looking for work

O Retired

O Disabled and unable to work

**Vaginal Deliveries**

O None

O 1-2 Deliveries

O More than 3 deliveries

**Are you overweight?**

O Yes

O No

**Length of time with urinary leakage**

O < 1 year

O >1 year

O > 3 years

**Severity of urinary leakage**

O Less than weekly

O 3 x per week

O Daily
Degree of symptom bother

O Slightly bothersome
O Moderately bothersome
O Very bothersome

Diabetes History

O Yes
O No

Depression History

O Yes
O No

Do you take any medications such as diuretics, or meds for blood pressure or depression/anxiety?

O Yes
O No

Do you engage in any exercise?

O Yes
O No
Appendix D Informed Consent

Molloy College
Barbara H. Hagan School of Nursing
1000 Hempstead Avenue
Rockville Centre, NY, 11571
516-323-3000

**Title of Study:** Urinary incontinence in the premenopausal woman and impact on quality of life: a phenomenological qualitative study.

**This study is being conducted by:** Jacqueline Skene Kirk, MBA, MSN, PhD candidate in the Barbara H. Hagan School of Nursing and Health Sciences.

**My email:** jackiekirk1@verizon.net

**Phone:** 917-359-8535

**My faculty advisor:** Dr. Margaret Whelan; mwhelan@molloy.edu or 516-323-3000.

**Key Information About This Study**
This consent form is designed to inform you about the study you are being asked to participate in. Here you will find a brief summary about the study; however, you can find more detailed information later on in the form.

- This is a research activity studying the lived experience of premenopausal women living with urinary incontinence and how it impacts their quality of life.
- There are no known or anticipated risks or benefits. Participating is voluntary and you can withdraw from the study at any time without penalty.
- The time commitment will consist of a recorded interview lasting approximately 60-90 minutes. A copy of the transcribed interview will be provided to you for accuracy and validation of your statements. A follow up interview of approximately 30 minutes may be conducted if feasible to validate the interview data.
- A $25.00 Amazon gift card will be provided for participation at the completion of your interviews.
- Interview data, investigator notes, and voice recordings will be kept confidential, and anonymity will be protected to the greatest extent possible. A pseudonym (not your real name) will be assigned, and pertinent information will be shared only with Molloy’s faculty dissertation committee.

Why am I being asked to take part in this study?

There is little known about the experience of premenopausal women with urinary incontinence. By participating in this study, your experience will provide insights that may be helpful in influencing changes in health care practices and policy. The long-term significance of this study is that knowledge of any impediments to quality of life may
ultimately improve quality of life for individuals suffering with urinary incontinence.

What will I be asked to do?

After signing the consent form, you will then be asked to schedule an interview (approximately 60-90 minutes) at your convenience with this investigator. This may be by telephone, Zoom, Face-time, or in-person if permitted by Molloy College regulations. The interview will be voice recorded and I will take written notes. I will begin by asking you some brief demographic questions including your age, marital status, education, how long you have had urinary incontinence, and number of vaginal deliveries. There are interview topics that have to do with your experience living with urinary incontinence and how it has affected your quality of life. An optional follow-up interview (approximately 30 minutes) can be scheduled for you to add information, as desired, and to clarify my understanding of your information. This may be done by telephone, Zoom, Facetime, or in-person if permitted by Molloy College.

Where is this study going to take place, and how long will it take?

You will choose a comfortable place to interview and at a time convenient to you. The interview will last around 60-90 minutes. An optional follow-up interview of approximately 30 minutes will be scheduled at your convenience about 1-4 weeks later.

What are the risks and discomforts?

It is not possible to identify all potential risks in research; however, reasonable safeguards have been taken to minimize known risks. If an uncomfortable memory triggers a physical or psychological response, the interview will stop. Time will be allotted for any necessary support and the decision to continue with the interview will be yours. If new findings develop during the course of research which may change your willingness to
participate, I will tell you about these findings and you may withdraw from the study at any time. Although every reasonable effort will be taken, breach of the protections in place to maintain confidentiality cannot be guaranteed. I will minimize any risks of confidentiality breach by coding written data on interviews and using pseudonyms. This way, while information will not be anonymous, it will be coded, decreasing risk to your data confidentiality.

**What are the expected benefits of this research?**

There is no direct benefit to you from the study, however, the findings may provide insights that may be helpful in influencing changes in healthcare practices such as removal of barriers to obtaining care and thereby, improving this population’s quality of life.

**Do I have to take part in this study?**

Participation in this study is your choice. If you decide to participate in the study, you may change your mind and stop participating at any time without penalty.

**Will it cost me anything to participate?** There are no costs to participating.

**What are the alternatives to being in this study?** Instead of being in this study, you may choose to not participate.

**Who will have access to my information?**

You will be identified only by a pseudonym. Your personal information and signed consent will be kept confidential. Your real name will not be reported in any publication or presentation of the study.

Only the group data obtained as a result of your participation in this study will be made public. Personal identifiers such as addresses, workplace, or healthcare providers will not
be used in any publication. Email communication will be kept confidential and deleted after read and transcribed to secure computer study files without any of your personal identifiers.

**How will my information be used?**

All the study participants’ information will be analyzed as a group and summarized into a written document for the purpose of sharing the research analysis with health professionals and the academic (college and university) community. Any future publications related to this research may then help to inform nurses of identified barriers to care, and needed knowledge to improve quality of life for individuals experiencing urinary incontinence. Your information collected as part of this research will not be used or distributed for future research studies.

**To ensure that this research activity is being conducted properly, Molloy College’s Institutional Review Board (IRB), whose members are responsible for the protection of human subjects’ rights for all Molloy-approved research protocols, have the right to review study records, but confidentiality will be maintained as allowed by law.**

**Can my participation in the study end early?**

Your decision to continue in this study is completely voluntary. At any time during the interview process, you have the right to withdraw from the study if you so choose. Any information you have contributed may also be excluded if you choose.

**Will I receive any compensation for participating in this study?**

You will receive a $25.00 Amazon gift card for participating in this study following your
What if I have a question?

Before you decide whether you would like to participate in this study, please ask any questions that come to mind now. Later, if you have questions about the study, you can contact Jacqueline Kirk @ jackiekirk1@verizon.net or my Doctoral Dissertation Chairperson, Dr. Margaret Whelan at mwhelan@molloy.edu.

What are my rights as a research participant?

You have rights as a research participant. All research with human participants is reviewed by a committee call the Institutional Review Board (IRB) which works to protect your rights and welfare. If you have any questions about your rights, an unresolved question, a concern, or complaint about this research, you may contact the Molloy IRB office at irb@molloy.edu or call 516-323-3000.

Documentation of informed consent:

You are freely making a decision whether to be in this research study. Signing this form means that

1. You have read and understood this consent form
2. You have had your questions answered, and,
3. After sufficient time to make your choice, you have decided to be in the study.
You will be given a copy of this consent form to keep.

____________________________________ __________________
Your Signature Date

____________________________________ __________________
Your printed name Date

I will also consent to audio tape recording of my interview(s) if conducted in person, by telephone, Facetime, or video/audio recording if conducted by Zoom.

____________________________________ __________________
Signature of researcher explaining study Date

____________________________________ __________________
Printed name of researcher explaining study Date
Appendix E Transcriptionist Confidentiality Form

This document is to verify that each transcriptionist hired for this study will agree to confidentiality prior to and throughout the transcription process.

I am aware that the following information contained in each study interview transcript belongs to the researcher of this study, Jacqueline Skene Kirk, and that the privacy and confidentiality will be maintained by me during and after my work in transcribing these interviews. I will destroy all data at the behest of the researcher at the end of the study.

Researcher signature: -----------------------------

Transcriptionist signature: -----------------------------

Transcriptionist (please print): -----------------------------

Date: -----------------------------
Appendix F Interview Guide

Thank you for agreeing to participate in this phenomenological study and answering questions developed to study “the lived experience of premenopausal women with urinary incontinence and how it impacts their quality of life”. As you probably know, I would like to ask you a few specific questions about your experience with urinary incontinence and a few more open-ended questions. The goal of these questions will be to allow the lived experience of the participants to reveal themselves and to identify any possible barriers to obtaining care. I will also ask you to fill out a form requesting some demographic information, such as your age, marital status, and how long you have been experiencing urinary incontinence. I will be recording this interview and will transcribe it, but your identity will not be shared when I compile responses from other participants that are in the study. In fact, all interviews will be de-identified and your responses will be encrypted and kept in a locked location. The transcriptionist will also sign a confidentiality agreement. Your participation and whatever you might disclose is voluntary and you may stop the interview at any time. You are more than welcome to read the transcripts and comment on any of the findings. This interview, and possibly a follow up interview, will require 30-60 minutes of your time. If you would like to receive a copy of your transcribed interview, I will ask you to provide me with your address, so that I can forward it to you. Do you have any questions thus far?

“Ok, here are a few specific questions”:

Can you tell me what it is like to live with urinary incontinence?

Can you tell me how living with urinary incontinence has affected your quality of life?
Probes:

Thank you. Can you reflect on feelings that come to mind when you think about urinary incontinence?

Can you tell me how living with urinary incontinence impacts how you feel about yourself?

Can you tell me how urinary incontinence has impacted your lifestyle in terms of travel, socializing with friends, work, physical activity, interactions with others?

Can you tell me if and how urinary incontinence has affected your sexual relationships with your significant other?

Can you share your medical journey getting treatment for your urinary incontinence?

Is there anything you would like to add or comment on that was not brought up before and think I should know about? I thank you for sharing your experience with me. Here is my contact information if you need to reach me. I will contact you after I have transcribed the interview so that you may read it, or I will read it to you to let me know if that the information has been accurately recorded.
Appendix G Statement to Potential Participants

Date __________

Dear __________,

Thank you for your interest in participating in this qualitative research study. The purpose of this study is to understand the experience of premenopausal women living with urinary incontinence and how it impacts their quality of life. It is hoped that knowledge gained from this research will help future nursing professionals understand how to assist individuals with urinary incontinence and to ensure they are treated more expeditiously.

Volunteers will participate in an individual recorded interview with the investigator lasting between 60-90 minutes. The interview will be scheduled at your convenience via Internet Technology such as Zoom or Skype, or via phone or Facetime.

An optional follow up interview may be scheduled for you to clarify and validate the interview that you participated in. This can be done via email, telephone, Zoom, or Facetime and would take less than 30 minutes.

You will be provided with a consent form that I will review with you over the telephone. After all of your questions are answered to your satisfaction, I will request that you sign the consent form and return it to me by email or postal mail in the stamped, self-addressed envelope I will provide. You will be given a signed copy to retain.

Please contact me with any questions you might have. Thank you for your consideration in participating in this study. Your perspective on this important topic is greatly appreciated.

Sincerely,
Jacqueline Skene Kirk, MBA, MSN, PhD candidate

Barbara H. Hagan School of Nursing and Health Sciences

Molloy College

1000 Hempstead Ave., Rockville Centre, NY 11571

jackiekirk1@verizon.net or 917 359 8535