URINARY INCONTINENCE AND SEXUAL INTIMACY:
OLDER WOMEN’S PERCEPTIONS

by

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(ABSTRACT)

The purpose of this study was to examine factors that influence the experience of urinary incontinence (UI) as it relates to sexual intimacy for older women. Additionally, I wanted to identify perceived areas of intervention that might positively influence the experience of UI as it relates to sexual intimacy for participants. The sample consisted of 10 women who ranged in age from 65 to 81.

The theoretical framework guiding this study was a systemic perspective in which how participants make meaning is given prominence. Symbolic interactionism, social constructionism, and systems perspective are interwoven to provide the foundation for this study. Data were collected utilizing in-depth interviews. Self-portraits were introduced to enrich conversation during the second interview.

Three conclusions were drawn from this study. First, feelings of secrecy that permeated this project were manifested in the lack of willing participants as well as brevity of responses during interactions with participants. Second, participants indicated a tendency to minimize their incontinence and to manage their symptoms without formal medical intervention. Third, participants offered perceived potential interventions that might positively influence the experience of UI. These included the provision information related to UI in a way that does not require individuals to request the information, such as brochures at physicians’ offices, post-surgical follow-up, and individuals from whom participants would be most comfortable receiving such information.
Dedicated with love

to my daughter Kate
ACKNOWLEDGMENTS

Through interaction with others, an experience is created. Many people have influenced my life journey and therefore, this project.

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CHAPTER ONE

INTRODUCTION

Background of the Problem

Urinary incontinence (UI), a frequently occurring medical condition, affects approximately 13 million adults in the United States (Agency for Health Care Policy and Research [AHCPR], 1996). Nearly 30% of community based and 50% of institutionalized older adults experience some form of UI (Gallagher, 1998). Common among older women, affecting as many as 11 million (Fourcroy, 1998), UI is a major contributor to institutionalization. Loss of bladder function may result in decreased self-esteem, social isolation, and feelings of shame (Grimby, Milson, Molander, Wiklund, & Ekelund, 1993), potentially influencing overall life quality. Social and psychological well-being, which includes intimacy, is an area particularly affected in women with UI (Norton, 1982). Although sexual interest and activity may continue well into later life (Pfeiffer & Davis, 1972), little research exists that examines the effects of UI on intimate relationships, specifically sexual intimacy (Brown, Posner, & Stewart, 1999; E. Dugan, personal communication, October 23, 2000; Mooradian & Grieff, 1990; Roe & May, 1999).

Although not all individuals are sexually active, each person has core beliefs, values, and feelings regarding sexuality that are developed in childhood and may change throughout the lifespan. For example, early in life, one may believe that older adults are asexual (Cross, 1993); however, this perception may change as a result of age, experiences, and observations.

Similarly, there are core beliefs, values, and feelings held in regard to continence. For example, some individuals believe that UI is an unavoidable aspect of aging and that involuntary loss of urine is socially unacceptable (Morris, 1999; Umlauf, Goode, & Burgio, 1996). Conversely, one may have had a grandmother who coped well with UI, providing a more positive perspective. The experience of the intersection of UI and sexual intimacy for older women may therefore be different, depending on the woman involved or her personal beliefs and experiences. For example, a woman whose physician comfortably addresses issues with her related to UI and sexual intimacy may get the message that it is acceptable to discuss such issues and may therefore be more likely to communicate problems or concerns with her physician in the future.

Selecting a dissertation topic that merged my education and professional and personal experience related to sexuality and health concerns took me along several roads of exploration. The decision was guided by extensive literature review as well as professional interactions and observations (Creswell, 1994). I include my personal narrative in order to locate myself in my work (Allen, 2000). I entered the doctoral program with 12 years of nursing experience that included extensive training in rehabilitation and home health settings. At that time, I observed that sexuality was rarely if ever addressed with patients and partners by healthcare professionals. Feedback from other professionals regarding the need to address issues related to sexuality, as well as interactions with patients and their partners, prompted my entrance into the doctoral program with an interest in sexuality and older adults. My interest took on a new
dimension following a job change to a medical-surgical setting. I observed a similar phenomenon regarding UI. I met “Mr. Smith,” a 72-year-old gentleman, on the morning of his discharge from the hospital following a prostatectomy, excision of the prostate gland. While I was providing teaching related to management of his temporary indwelling catheter, he mentioned that his physician had told him that he might experience UI for several months post-operatively. He also mentioned that he was going to try to cut one of his grandson’s diapers and place it in his underwear so that he would be able to attend church briefly, something very important to him. I told him about several products (e.g., a small pouch designed to cover the penis and catch small amounts of urine and a pad that is held in place by a cotton brief) that are available to manage varying degrees of UI. I put him in touch with a supplier. He was immensely grateful, thanking me numerous times for providing what I considered to be basic information. Several co-workers stated that they were unaware of the products that I recommended. When working with patients experiencing involuntary loss of bladder function, staff focused on prevention of skin breakdown and management of indwelling catheters. This biomedical perspective (Engel, 1977) prohibited addressing psychological (e.g., anxiety and depression) and social issues (e.g., isolation) related to incontinence. Recognizing this and acknowledging the intersection of subjective experiences and human inquiry (Allen, 2000; Gergen, 1999), I began to investigate the interrelationship of older women’s UI and sexuality.

Statement of the Problem

As the population of older adults continues to increase, the number of older women experiencing UI will rise. Many women will face issues related to UI and sexual intimacy and may require assistance from health professionals to do so successfully. The current lack of research related to this topic area compounded by the taboo nature of discussing both sexual intimacy and UI make adequate handling of these issues difficult even for healthcare professionals, thereby reinforcing related myths, such as older adults are asexual or UI is an unavoidable aspect of aging (Cotton, 1990).

Women experiencing UI have reported significantly higher levels of social isolation (e.g., perceived inability to connect with others or lack of connection) and emotional disturbance (Grimby et al., 1993). The result of such findings may be far reaching. Lack of social support, which includes partners, is a risk factor for alteration in health status (Rowe & Kahn, 1998). As part of a marital status and happiness study involving participants of 17 nations, Stack and Eshleman (1998) reported a relationship between marriage and a more positive perception of health status. Therefore, in order to promote life quality, we must begin to explore issues related to the intersection of UI and sexual intimacy for older women.

Theoretical Framework

The theoretical framework guiding this study is a systemic perspective in which how participants make meaning is given prominence. Three theoretical ideas are interwoven -- symbolic interactionism, social constructionism, and systems perspective -- in order to provide the foundation for this study. To begin, symbolic interactionism is a leading theory of the social and behavioral sciences (LaRossa & Reitzes, 1993). According to Blumer (1969):
Human beings act toward things on the basis of the meanings that the things have for them and the meaning of such things is derived from or arises out of, the social interaction that one has with one’s fellows … These meanings are handled in, and modified through, an interpretative process used by the person in dealing with the things he encounters. (p. 2)

A thing, in the case of this study, urinary incontinence and sexual intimacy, is defined through the response of others and interaction with others. Sexual behavior and the experience of being sexual are defined by symbolic meanings or shared meanings. For example, a mother may avoid discussion related to “personal issues” with her daughter, instilling the belief that issues related to sexual intimacy are not to be discussed.

The meaning ascribed to an experience, such as UI as it relates to sexual intimacy, occurs through social construction (Longmore, 1998). Social construction theory asserts that reality is created from social interchange between people in a shared world (Hoffman, 1992). For example, two women who have the same physical manifestations of UI may have completely different sexual experiences. One may have a loving and supportive partner, willing to make adjustments such as incorporating a shower into foreplay. Alternatively, another woman’s partner may be repulsed and withdrawn from intimacy. Thus, these two women may have different experiences of the same physical manifestations of incontinence.

Additional influences of experiences include continuous interchange, verbal and nonverbal within and between system components (von Bertalanffy, 1968). These include responses and attitudes of friends and family members as well as broader societal messages such as legislative decisions that affect treatment/management option availability. In turn, women with UI influence the experiences of partners as well as factors at family, relationship, and societal levels (see Appendix A). For example, a woman who talks openly about her incontinence with her partner and shares concerns related to how her partner might respond to uncontrolled urine loss during intimacy may place her partner at ease and open communication. Through continuous transaction with multiple system components, individual interpretation, and assignment of meaning, one’s perceptions of life experiences are defined. This process, which takes place throughout the life-span, encompasses information and experiences related to UI and sexuality encountered during childhood (e.g., anger demonstrated by a parent in response to bed wetting or observed masturbation), during teen years (e.g., respect demonstrated by peers as a result of one’s decision to abstain from early sexual activity), during early to mid adulthood (e.g., comedians making jokes related to UI or Viagra and the aging population or advertisements that fail to portray older adults as active life participants), and during later years (e.g., a friend is able to cope successfully with UI or a physician fails to provide basic information in response to questions related sexual functioning, such as lack of vaginal lubrication).

A major application area evident in the healthcare setting is the multiple system components in established nursing theory. Neuman’s (1972) total system approach to addressing patient problems, such as issues related to sexual intimacy, includes elements at the internal individual level such as state of adaptation and response pattern as well as multiple contributors to overall health (e.g., stressors, interventions). Health of the
individual is viewed on a continuum of wellness to illness. When needs within the individual system are met, the individual is in a state of wellness.

According to Neuman’s perspective, the individual system is a “dynamic composite of interrelationships among physiological, psychological, sociocultural, developmental, and spiritual factors” (cited in Freese et al., 1998, p. 271). Continuous reciprocal interaction also occurs between the individual and the environment. External as well as internal factors can influence health status. For example, a nurse provides an intervention such as education related to physical changes that often occur as a result of menopause. Increased knowledge decreases the effects of external stressors on the individual, thereby altering the woman’s experience. In summary, these three perspectives are combined to provide a systemic and interpretive lens from which to understand how older women perceive and make meaning of their experience and to suggest appropriate societal interventions on their behalf.

Purpose of the Study

The purpose of this study is to examine factors that influence the experience of UI as it relates to sexual intimacy for older women. Lack of research and decreased comfort related to this topic necessitate further investigation in order to assist professionals in meeting the needs of older adults experiencing UI. Gaining insight into factors that influence successful adjustment related to UI and sexual intimacy will set the groundwork for future studies that include partners’ perceptions of the experience of UI. Results of such studies may provide an opportunity to normalize the experience of UI which could facilitate a positive interchange between individuals experiencing UI and partners, as well as those within the broader system such as family members, health care professionals, and society.

Research Questions

The following major research questions guided this study:

1) What does urinary incontinence mean to older women and by what process was that meaning acquired?
2) In what ways have messages from system components such as partners, family members, and society influenced that meaning?
3) What are perceived areas of intervention that might positively influence the experience of urinary incontinence as it relates to sexual intimacy for older women?

Overview of the Medical Aspects of Urinary Incontinence

There are several types of UI, which manifest in a variety of symptoms and influence individuals’ lives at personal and functional levels. Stress incontinence is demonstrated by frequent urge to void and urinary leakage with sneezing, laughing, coughing, exercise, and/or position changes. Urge incontinence is typically manifested by nocturia or excessive night voiding, bed wetting, urgency, and/or weak bladder. Symptoms of overflow incontinence include inadequate bladder emptying, urgency with hesitancy, nocturia, weak stream, and/or dribbling (Ignatavicius, Workman, & Mishler,
Loss of bladder function may also be aggravated by alteration in physical mobility, which results in delayed toilet transfers and clothing removal (Umlauf et al., 1996).

Researchers have operationalized UI in a variety of ways depending on the type of incontinence being examined. DuBeau, Kiely, and Resnick (1999) specified incontinence as urine leakage experienced at least twice weekly. DuBeau, Levy, Mangione, and Resnick’s (1998) inclusion criteria included “precipitant urgency with associated leakage of urine” (p. 684). Brown et al. (1999) limited participants to those experiencing urge incontinence manifested by “a minimum of six incontinent episodes per week and at least 10 voids per day” (p. 981). According to Grimby et al. (1993), UI is “involuntary urinary leakage confirmed by the use of a 48-hour pad test, micturition lists, and a cough provocation test” (p. 82). Cotton (1990) identified “leakage when coughing, laughing, and exercising” and urge incontinence as “an urgent desire to void which occurs before loss of control” (p. 2361) as criteria for stress incontinence. Fonda, Woodward, D’Astoli, and Chin (1995) stipulated loss of bladder function for at least two months.

As a qualitative researcher, I am attempting to limit imposition of my meaning of UI on participants, which has developed as a result of professional experiences, and thereby avoid altering their interpretation of their own experience. For the purpose of this study, UI is operationalized simply as “involuntary loss of urine” allowing participants to generate their own specific definition.

Treatment options or management techniques are available for all forms of incontinence. Mild stress incontinence may be successfully treated with Kegel exercises that strengthen pelvic floor muscles, electrical stimulation, or biofeedback. In more severe cases, implants are used to eliminate leakage or surgical intervention may be needed. Treatment utilized for overflow incontinence depends on the cause (Ignatavicius et al., 1999; Krames Communication, 1999). Ditropan, a medication that promotes relaxation of the bladder and provides a mild analgesia and local anesthesia may also be effective. Potential side effects of Ditropan include palpitations, tachycardia, nausea and vomiting, urinary hesitancy, and urgency (McPhee et al., 2000). Additionally, bladder distention, which results in overflow incontinence, may be managed utilizing clean intermittent self-catheterization to regularly drain the bladder. Surgical intervention may also be needed.

Urge incontinence may be treated with medication intervention such as Detrol, which acts to block muscle receptors and minimize involuntary bladder spasms. Potential side effects of Detrol include urinary retention, alteration in liver and kidney function, hypertension, dry mouth, abdominal pain, and nausea and vomiting (McPhee et al., 2000). Additionally, sphincter tone, which controls an individual’s ability to manage urine flow, may be improved through hormone replacement therapy. Other treatment options include Kegel exercises, electrical stimulation, and biofeedback (Ignatavicius et al., 1999; Krames Communication, 1999). The most difficult cases may be managed with various pads, diapers, and possibly an indwelling catheter.

Summary

In this chapter, I have presented the background of the issue examined in this study as well as the theoretical framework that guides this project. An overview of the
medical aspects of UI was also provided. In the following chapter, I will provide a review of current literature related to UI and sexual intimacy for older women.
CHAPTER TWO

REVIEW OF LITERATURE

The need for a study that examines urinary incontinence and sexual intimacy in older women is well-supported by literature review (Brown et al., 1999; Mooradian & Grieff, 1990; Walker, 1997). As I review available literature related to UI and sexual intimacy for older women, I will identify gaps that include reluctance to discuss UI, issues related to sexuality and older women, and the taboo nature of discussing the intersection of UI and sexual intimacy. I will also discuss how my study will contribute to existing research.

Reluctance to Discuss Urinary Incontinence

Urinary incontinence is both underreported and undertreated. Less than half of individuals experiencing loss of bladder function report symptoms to health care professionals (Cohen et al., 1999; “Urinary Incontinence,” 1989). At least four factors contribute to a reluctance to report UI. First, achieving continence at an early age is an expected task of the developmental process. Once continence is established, “accidents” are not well-tolerated by others and are most likely to result in negative responses and social distancing (Umlauf et al., 1996).

Second, individuals experiencing involuntary urine loss may think that incontinence is a normal part of the aging process. The normalization of incontinence and its gradual onset may result in women hiding and managing the symptoms themselves rather than seeking medical treatment (Morris, 1999; Umlauf et al., 1996).

Goldstein, Hawthorne, Engeberg, McDowell, and Burgio (1992) examined attitudes of older adults toward UI and the reasons reported for not seeking treatment. Participants included 119 women and 17 men, ranging in age from 55 to 99, who were involved with a senior center or assisted living facility. Forty-seven (39%) female participants and 2 (12%) male participants reported experiencing UI. Forty-nine percent of participants experiencing incontinence reported that they had not sought medical treatment. The majority (62%) of incontinent participants indicated that UI was a natural part of growing older. Fifty-five percent of participants experiencing loss of bladder function did not view UI as a problem.

Dugan et al. (2001) examined why older community dwelling adults with UI, who were not screened by their primary care provider, did not initiate discussion regarding incontinence with their physician. Participants in the telephone survey included 149 adults 60 and older who had visited their primary care physician within the last 60 days. Sixty-nine percent indicated that they had not initiated conversation related to their incontinence while 31% had initiated discussion. Results indicated that individuals who view UI as normal (19%) and those who do not perceive UI to be a big problem (45%) are less likely to broach the topic with their primary care provider.

Third, individuals may be unaware of availability and involvement of treatment options. According to Goldstein et al. (1992), 38% of participants 60 and older who had visited their primary care physician within the last 60 days reported that they were unaware of treatment availability. According to Lagace, Hansen, and Hickner (1993) who
examined prevalence and severity of UI in ambulatory adults, 79% of respondents who had not informed their physician regarding their incontinence indicated that they “might” or “would” seek treatment if they were aware of treatment availability.

Finally, due to a lack of knowledge regarding current research findings related to UI or time limitations in today’s health care environment, physicians interacting with patients may avoid questions related to incontinence. Individuals who could be successfully treated may not have treatment options made available to them, reinforcing beliefs that UI is an unavoidable aspect of aging (cited in Cohen et al., 1999; “Urinary Incontinence,” 1989).

Removing the Stigma

The issue of UI has reached nationwide prominence as celebrities promote products for incontinence on television and in printed advertisements. Adult diapers and various pads are no longer kept out of sight in retail establishments. In an attempt to facilitate this movement, the American Urological Association recently founded an educational campaign that attempts to de-stigmatize UI by utilizing the slogan “you are not alone” (Morris, 1999, p. 128); however, UI continues to be a difficult issue to address due to longstanding myths and the taboo nature of the subject matter.

Psychosocial Issues and Urinary Incontinence

Though researchers have examined the psychosocial impact of UI, they have not studied the effects of UI on sexual intimacy. DuBeau et al. (1999) developed an instrument to assess the impact of UI on quality of life (QoL). Though the instrument was determined to be a reliable and valid measurement tool regarding QoL, sexual intimacy, an important element of life quality, was not included. Wyman, Harkins, Choi, Taylor, and Fantl (1987) explored the psychosocial impact of UI and its relationship to urodynamic diagnosis and degree of urine loss among 69 community-based women age 55 and older. A correlation was identified between psychosocial scores, as measured by the Incontinent Impact Questionnaire, and frequency and amount of urine loss. Sexual intimacy was not specifically addressed, potentially adding to the belief that sexuality is not an important aspect for life quality for older adults. Lagro-Janssen, Debrutne, and Van Weel (1992) examined the psychological impact of UI on women. Participants included 110 women, ranging in age from 35 to 54, who reported UI to their general practitioner. Results indicated no reported psychological differences, as measured by standardized psychological tests, among participants experiencing urge incontinence, stress incontinence, and mixed incontinence. Data related to marital status were collected, but issues related to spousal support were not included.

The Absence of Research Related to Older Woman

Research related to UI and older women is limited. Much existing research related to UI includes younger women and males. DuBeau et al. (1998) examined patient-defined impact of UI on life quality in order to make a comparison with perceived provider/expert-defined impact from previous research. Participants consisted of 30 Caucasian men and women over 60. Results indicated that participants focused more on
the effects of UI on emotional well-being while experts focused on emotional well-being as well as functional aspects of UI. Sexual intimacy was not specifically addressed.

Dugan et al. (2000) identified a relationship between UI and depression among older adults. The sample included 668 males and females over 60. A relationship between depressive symptoms and UI was identified. The researchers did not collect information related to the specific medical diagnosis of incontinence nor did they examine participants’ current medications, both of which could affect the experience of UI. Ouslander and Abelson (1990) examined perceptions of UI among elderly outpatients. The sample consisted of 199 men and women. An association was reported between larger volumes of urine loss and more negative perceptions of UI. The majority of participants indicated UI as embarrassing, inconvenient, or distressing, potentially affecting life quality.

Sexuality and Older Women

Ageism, which is systematic discrimination against older adults, and sexism, which is systematic discrimination on the basis of gender, influence attitudes related to sexuality and aging women (Masters, Johnson, & Kolodny, 1988). It is often assumed that older adults are asexual and that with age, there is a concomitant decline in sexual desire (Read, 1999). Though sexual desire may not diminish as a result of aging itself, frequency of sexual activity often decreases, influenced in part by health, cultural norms, and partner availability (Rowe & Kahn, 1999). Wiley and Bortz (1996) surveyed 158 older adults (47% female, 53% male) before and after attending sexuality and aging lectures at a senior center. Data related to past, current, and desired sexual activity were collected. The purpose of the study included evaluation of attitudinal shifts related to sexuality (e.g., importance of kissing, intercourse, loving and caring, orgasm) as well as frequency of sexual behavior as compared to prior to the initial lecture. Males ranged in age from 56 to 85 and females from 42 to 82. Ninety-two percent of participants indicated a desire for sexual activity at least weekly, a frequency that did not change for participants over 70. Both males and females indicated sexual activity below the desired frequency. Relationship difficulties were identified by males and females as the most significant contributor to decreased sexual activity. Forty-three percent of females over 70 indicated illness as a significant contributor to diminished sexual activity; however, UI was not specifically addressed.

Age related changes can affect intimacy. For example, as a result of menopause, once thought to be predictive of decreased sexual activity (Mooradian & Greiff, 1990), a drop in estrogen levels can result in physical changes such as vaginal dryness and thinning of the vaginal wall, however, recently researchers report no significant relationship between these and desire or sexual function (Morrell, Dixon, & Carter, 1984; Roughan, Kaiser, & Morley, 1993). There are, however, chronic conditions that do affect sexual functioning.

Medical conditions that may affect older women’s sexuality include vaginal atrophy, cancer, diabetes, arthritis, renal disease, cardiovascular accidents, and incontinence (e.g., leakage during intercourse) (Roughan et al., 1993). Additional factors affecting the degree of decline in sexual activity include psychological health, level of sexual desire throughout the lifespan, changes in income, and loss of a long-term intimate partner (Cross, 1993; Read, 1999).
Like UI, definitions of sexual intimacy vary from person to person and do not necessarily include sexual intercourse. Physical changes such as musculoskeletal alterations that occur with aging may result in position limitations and position-related pain (Read, 1999). As alternatives, partners may turn to oral sex, masturbation, cuddling, and holding. According to Masters and Johnson, for sexual fulfillment in later life, persons need a “reasonably good state of general health” and “an interested and interesting partner” (cited in Schlesinger, 1996, p. 120). However, various factors influence individual experiences of sexual intimacy in later life, one of which is UI.

Conway-Turner (1992) reports a connection between sexual intimacy and self-esteem for a sample of 26 married older African American women. The women reported an interest in sexual intimacy; however, they were dissatisfied with frequency of sexual intercourse in their sexual relationships. Though the author acknowledged the possible influence of health problems, such as UI, they were not addressed in this study.

Researchers have also addressed comfort level related to one’s ability to discuss sexuality. Loehr, Verma, and Seguin (1997) used focus groups to investigate attitudes of women over 60 towards sexuality and intimacy, to elicit which issues concerning sexuality and intimacy are important to them, and to gather their perceptions of how issues of sexuality and intimacy are addressed by the medical profession. The sample consists of 14 women ranging in age from 60 to 85. Participants freely shared information related to early sexual maturity issues such as menstruation. Feelings of secrecy and general lack of information related to intimacy issues, including the act of intercourse, were common themes identified. Most of the women, however, indicated a good attitude related to sex that did not change throughout the aging process. Male sexual dysfunction was identified as the major contributor to relationship changes. Sexuality and physical intimacy were identified as important aspects of life quality. Responses also indicated that issues related to sexuality were rarely addressed by their physicians; however, feelings were mixed regarding the appropriateness of physicians addressing such issues.

Attitudes and misconceptions related to sexuality and women are hardly new. Until the sexual revolution of the 1960s, sexuality was viewed as an entitlement for men with little or no acknowledgement of the sexual needs or desires of women. The women’s movement, availability of oral contraception, and an increase in the number of women in the workforce, increased women’s sexual liberation (Roughan et al., 1993).

The Intersection of Urinary Incontinence and Sexual Intimacy

Problems related to the intersection of UI and sexual intimacy are frequently underreported, due in part to the joining of two taboo issues, UI and sexuality. Disinclination of older women to discuss issues related to sexuality and post-menopausal urogenital problems has been demonstrated in varying cultures. Results from three studies that examined attitudes of older women in Denmark, Sweden, and Norway (cited in Holte et al., 1994; H. Wright, personal communication, March 5, 2002), countries known to have more open attitudes regarding sexuality, identified a reticence to discuss such issues. First, in Denmark, women participating in focus groups tended to avoid using correct terminology, such as vulva and clitoris, when discussing “private parts” and avoided answering questions related to menopause and sexuality. Second, researchers in Sweden interviewed women 70 to 80 years old to learn about women’s knowledge and
awareness of urogenital aging. Respondents indicated that urinary incontinence was reported as embarrassing and contributed to low self-esteem. Participants were not comfortable discussing the issues and felt that their doctors should have initiated conversations related to these issues. Third, researchers involved in Norway interviewed women over 60 to evaluate attitudes regarding menopause. Participants were reluctant to discuss personal issues related to menopause and alteration in urological function with partners, physicians, and family members.

Limited research related to UI and sexual intimacy focuses on middle-aged women and men. Berglund, Eisemann, Lalos, and Lalos (1996) examined social adjustment and spousal relationships among 45 women with stress incontinence and their partners before and after surgical intervention and compared results of abdominal and vaginal surgical interventions. A reference group of 50 women was also utilized. No significant difference was reported in surgical outcomes. Areas of investigation include leisure activities, social network, working ability and job satisfaction, and spouse relationship and sexual life. Forty of the women were married or living jointly, three were divorced, and one was widowed. The women ranged in age from 34 to 62. Interviews were conducted three months before surgery and one year post-operatively. Thirty-eight husbands, ranging in age from 38 to 70, participated in the pre-surgery interviews, and 22 participated in the post-surgery questioning. At the time of the second interview, 34 women (Group A) were classified as cured of incontinence and 11 (Group B) indicated an improvement in continence status. Approximately 75% of participants in both groups indicated good relations pre- and post-operatively and the majority indicated that they were at least partially able to discuss related matters. No significant change in ability to demonstrate warmth, understanding, and attachment was noted and no change in frequency of intercourse was reported by either group. Slight decrease in orgasmic ability was reported by husbands of women in group B and increased sexual dysfunction (e.g., decreased vaginal lubrication) was reported by women of the same group. Nine of 11 of the women in group B were postmenopausal.

Although this study addresses psychosocial issues related to UI and advances research by addressing partner relations and sexuality, limitations are noted. First, women participants were initially diagnosed with the same type of UI, stress incontinence. Second, women in group B tended to be older than those in group A and the majority were post-menopausal, increasing the likelihood of alteration in sexual functioning such as discomfort with intercourse, potentially affecting sexual satisfaction. Additionally, women in group A, generally the younger group, reported no UI at the time of post-operative interviews with the remainder of participants reporting improved continence limiting the influence of UI on sexual intimacy at the time of the second interviews.

Sutherst (1979) examined UI and sexual dysfunction in 103 women, ranging in age from 20 to 68, who were attending a urodynamic clinic. Forty-eight participants indicated that alteration in urinary function had negatively affected their sex life with a decrease in frequency of intercourse reported by 36 of the women. Explanations for reduction in frequency included wetness at night, urine leakage during sexual activity, dyspareunia or pain during intercourse, decreased libido, and marital discord.

Roe and May (1999) utilized a qualitative approach to examine the impact of incontinence on an individual’s sexuality and to identify the impact of health interventions for the management of incontinence on sexuality. The sample consisted of
14 individuals who were managing their incontinence successfully, 12 who were not managing successfully and one who was not classified. It was not specified why this participant was unclassified. Participants included 19 women and 8 men ranging in age from 28 to 98 (mean age = 61). Identified themes include clothing and appearance, intimacy and caring, management techniques and relationships, and life trajectory. Experiences of incontinence ranged from 5 months to 46 years; four participants reported fecal incontinence as well as UI. Seventeen participants had diagnoses of one or more chronic conditions such as cardiovascular accident, diabetes, multiple sclerosis, and cancer.

Research related to UI and intimate relationships is limited, yet researchers have examined issues related to couples and other chronic conditions. For example, Lichtman, Taylor, and Wood (1987) assessed the perceptions of 78 breast cancer patients and their significant others regarding social support following diagnosis. Associations were identified between positive patient adjustment and perceived close supportive relationships during as well as post diagnosis and positive husband support after cancer and pre-illness satisfaction and successful marital adjustment. Manne and Zautra (1989) examined the influence of husband support and criticism on psychological adjustment of women with rheumatoid arthritis. A relationship was identified between poor psychological adjustment and maladaptive coping behaviors and spouse criticisms of the individual with arthritis. These studies inform this project by supporting the influence of partner support on the experience of chronic illness.

Significance of Proposed Study to Existing Work

Lack of current research related to UI and sexual intimacy for older women, as well as my professional experience, substantiate the need for the current study. As a nurse, I have seen how open individuals will be regarding the most taboo topics when given the opportunity to share in a nonjudgmental atmosphere. For example, “Jane,” a 65-year-old paraplegic with UI, and her husband were well known in the hospital system when we met. They made frequent sexual comments that were perceived by staff to be inappropriate. Neither had mentioned her incontinence or their intimate relationship. Within minutes of our meeting, I responded to a comment by providing an opportunity for elaboration. Given the chance, both freely voiced concerns regarding the influence of the patient’s UI on their intimate relationship and both indicated appreciation for the opportunity to do so. Through opening conversation and examining perceptions of the experience of UI as it relates to sexual intimacy for older women, we can begin to understand influencing factors such as multiple components of the family and societal system. This is a necessary aspect of meeting the needs of older adults and the promotion of successful aging.

Summary

In this chapter, I have presented a review of literature that supports the need for research related to urinary incontinence and sexual intimacy in older women. I have identified gaps in current research that include reluctance to discuss UI, issues related to sexuality and older women, and the taboo nature of discussing the intersection of UI and
sexual intimacy. In the following chapter, I will present the process of participant selection, data collection, and data analysis.
CHAPTER THREE

METHODOLOGY

Overview of Qualitative Methods

Several factors influenced my decision to utilize a qualitative research approach. My research questions aim at understanding the experience of urinary incontinence as it relates to sexual intimacy from the participant’s frame of reference. I wanted to know how the individual assigns meaning to this experience. Because limited research exists related to UI and sexual intimacy, specifically in older women, this emergent methodology allowed participants to provide a level of richness that could be difficult to obtain using a more structured approach. This advantage is due in part to the opportunity for rewording as well as the ongoing development of additional questions when needed for clarification (Bogdan & Biklen, 1998). This methodology afforded the opportunity for rapport building that facilitated increased willingness to discuss taboo topics (Bogdan & Biklen, 1998; Creswell, 1994). For example, during an informal pre-interview exchange with one participant, she realized that I had presented a program locally related to UI. This appeared to give me a level of credibility with her that opened the discussion regarding incontinence. Face-to-face interviews also allowed me to observe nonverbal data such as body positioning and expressions as well as overall appearance. One participant teared, and then recovered quickly, when she discussed the lack of intimacy in her marriage. Such impromptu displays of emotions would have been missed utilizing a quantitative approach.

My Role as Researcher

As the primary instrument for data collection and analysis, it is important to consider how my background and training as a nurse and counselor might influence findings (Merriam, 1998). As a nurse, I have well-developed rapport building and communication skills, an important element of conducting a qualitative interview. In the patient care setting, it is typically necessary for me to meet a stranger, place that individual as well as family members at ease, conduct a complete assessment, and provide treatment and teaching as needed within a brief period of time. These skills, as well as high levels of empathy and unconditional positive regard for others (Kirschenbaum & Henderson, 1989), that initially brought me into the field of nursing and were reinforced during counselor training, make qualitative research a good match for me. Additionally, in order to be effective as a nurse and as a counselor, one must be able to appear unaffected when confronted with situations that could be potentially uncomfortable such as addressing issues related to sexuality (Potter & Perry, 1997). For example, if a patient attempts to ask a question related to oral sex and the nurse responds with lack of eye contact or an expression that could be perceived as disapproval, the patient may change the subject and avoid the issue in the future.

I am acknowledging, however, that the same nursing experience may place me at greater risk for researcher bias due to increased awareness of the challenges sometimes faced by those experiencing UI. These challenges include the potential for skin
breakdown, decreased life quality, depression, anxiety, low self-esteem, and social isolation (Lagro-Janssen et al., 1992; Umlauf et al., 1996). Additionally, as a nurse, I have had the opportunity to see first hand the less than ideal circumstances of many older adults including inaccessible bathroom facilities, lack of needed assistance, and caregiving responsibilities. For example, as a home health nurse, I met a woman who lived in a recliner in her small cluttered trailer. Her chair was surrounded by food wrappers and cans of partially eaten food. She had no family members, and friends came in daily to change her soiled diapers. Until they arrived, usually late in the evening, she sat in a wet diaper, something she was willing to tolerate to hang on to her last thread of independence.

These observations have influenced how I interpret my patients’ experiences of UI. For example, during a community reentry activity, a patient who had been wheelchair bound for months ambulated proudly into a restaurant using a walker. Because of an inaccessible bathroom facility and impaired physical mobility, she soiled her clothing and had to exit the restaurant in full view of other patrons. Her whole demeanor changed. Eyes that were previously making contact with others were downcast, her head was bowed, and pride had been replaced with embarrassment and devastation. She became withdrawn and lost ground in every aspect of her rehabilitation. Sensitivity to the experience of participants, an attribute that is needed in qualitative research, as well as awareness of potential for biases helped sensitize me to be careful in collection and interpretation of data (Merriam, 1992).

Ethics

The study was approved by the Institutional Review Board at Virginia Polytechnic Institute and State University (see Appendix B). Prior to the initial interview, I read through the consent form (see Appendix C) with the participant and offered an opportunity for the participant to ask questions. After questions had been answered and the participant indicated clear understanding of the process, the consent form was signed. A copy of the consent form was provided to each participant. A list of local mental health resources was also provided, at the recommendation of the review board, as some participants may experience embarrassment, anxiety, or discomfort related to discussing such personal issues.

Sample Selection Procedure

Sample Selection Criteria

Initially, the criteria for participation in this study included women over age 65 who were experiencing involuntary loss of urine. The age requirement was lowered to over 64 at first and after two months to age 58 and older in an attempt to obtain an adequate sample size. I elected not to include women age 57 and below as they are in a different life stage and therefore, various age-related factors might influence outcomes. For example, younger women are more likely to be working outside the home, making managing UI more challenging in the confines of an office or work environment. Additionally, it is older women who have been virtually overlooked in previous research related to UI. Women without current partners were included because I felt that they
might be able to provide valuable insight into relationship avoidance and previous partner attitudes. For example, they may have avoided an intimate relationship due to fear of perceived rejection.

**Participant Recruitment**

Participant recruitment was challenging and ever-evolving. Initially, displays containing flyers (see Appendix D) were placed at two locally owned central Virginia drug stores and on the information board at a local health club. I had hoped that individuals who “manage” or hide their incontinence would be recruited utilizing this approach. Flyers were distributed to two large medical groups, urologists and internists. Prior to distribution, I discussed the current project with several physicians in each practice who agreed to assist with participant recruitment. It was my intention to limit the number of participants selected from urologist’s referral to fewer than 50% because it is estimated that 50% of individuals experiencing UI do not seek medical treatment (Cohen et al, 1999). Additionally, flyers were given to an ostomy appliance consultant at a local medical supply company, well-known in the community for assisting with needs related to alteration in bladder function. Flyers contained limited information regarding the study as well as contact information. “Respond by” dates on the flyers were restricted to two weeks and extended during the process to encourage quick response. Half way through the process, I changed the color of the flyers from pink to neon green in an attempt to attract more attention.

My quest for project participants was broadened when none were forthcoming after two weeks. I solicited the assistance of a nurse educator in the urology office, numerous additional physicians, and nurse practitioners. I also started mentioning the study at every opportunity. While attending a holiday dinner, one month after beginning the recruitment process, I discussed the project and was put in contact with my first participant, a relative of the hostess. I then added a snowball sampling technique, the process by which contact with potential participants is made through current participants (Merriam, 1998) in an attempt to access additional participants, with which I had limited success. I continued to utilize this technique throughout the project and eventually gained two additional participants.

I continued to inform as many people as possible regarding my search for participants and to follow-up on every lead. I told numerous friends and family members about the study. I gained two additional participants through friends. I also contacted two old friends of my deceased grandmother, one in her upper-eighties and one in her mid-nineties. Information related to the study was met with silence by both women.

Additionally, I discussed the project at every opportunity as I moved throughout my daily routine. I informed men and women who work-out with me each morning at the local gym regarding the importance of such a study and my search for participants. Through this effort, I made contact with one participant. I solicited the assistance of co-workers in the recruitment process and obtained an additional participant. Bikers, who frequently share a morning ride, were also recruited to assist in my mission to obtain an adequate sample. I mentioned the project when asked about my schooling as I moved through the check-out line at a local grocery store. I even mentioned the project to a clerk in a department store 50 miles from my home who talked openly regarding her incontinence, but in her early 50s, was too young to participate in this project. I discussed
my search with women who attend my church and was put in contact with one participant.

Many individuals, including a local business woman in her eighties, known to be very open regarding sexuality issues, appeared eager to assist me in my search for participants; however, she stated that she did not experience incontinence herself. I made numerous attempts both by phone and in person to reconnect with her without success.

I talked with a group of women at a local apartment complex for older adults and left a flyer with each, many whom openly denied experiencing incontinence or gave no indication that it was a problem for them. I talked with a neighbor who put me in touch with another woman, not age appropriate for this study, who was featured in a local newspaper article on incontinence. I solicited her assistance in obtaining participants. I also made contact with the director of the local gerontology center and made her aware of my search.

During the entire three month recruitment course, I reconnected with potential participant sources as often as possible. I frequently checked displays and updated physicians, nurse practitioners, and the ostomy appliance consultant.

Two prospective participants, who had agreed to participate in the project, eventually withdrew during the project. The first woman, a friend of another participant, delayed the interview several times and later cancelled altogether. The second met with me, but appeared to become uncomfortable as we read through the consent form. I reinforced that participation was voluntary and she decided to withdraw from the project without explanation. I sensed at the time that it was the “sexual intimacy” piece that influenced both participants’ decision to withdraw. It was at the mention of sexual intimacy that they appeared to become uncomfortable. Reticence to discuss sexual intimacy has been noted in literature regarding older women (Loehr et al., 1997) and my experience and participant recruitment confirms this.

At this point, I began to speculate regarding my limited success in obtaining willing participants. While many women in my own age range, mid-forties, appeared to freely admit that they have experienced some degree of UI (i.e., occasional leakage with a sneeze or exercise), there appeared to be reluctance on the part of older women to admit that UI was an issue for them.

After realizing that participant recruitment was going to be more challenging than I had anticipated, I began to open the interview process by assuring participants that questions were designed to gain general knowledge regarding their experience and not intimate details regarding their sex lives. This appeared to put participants at ease. In retrospect, I became a bit more guarded, while still attempting to get at the same information, fearing that additional participants would withdraw from the study. I felt that gaining limited information was better than gaining none.

Sample Description

The sample consisted of 10 women ranging in age from 65 to 81 who were experiencing involuntary urinary loss. Three of the participants were widows and seven had been married for 43 to 56 years. One participant was assisted by her spouse due to alteration in communication skills resulting from a debilitating cardiovascular accident several years ago. I decided to include this participant in the study because I felt that she had an important perspective on UI and a valuable contribution to make to this study.
Table 3.1 contains pseudonyms, age, ethnicity, and marital status. Table 3.2 contains highest level of education completed and annual income range. Level of education ranged from “completed the eleventh grade” to completion of a master’s degree. A Likert-type scale was utilized to determine annual income range. All participants identified themselves as being in the middle-income range, with the exception of one participant who was unsure, but from my assessment of her home and appearance, she seemed to also be in the middle income range. Table 3.3 contains partner’s general state of health and general relationship satisfaction. Participants were asked to use their own words to describe their partner’s current health status as well as perceived relationship satisfaction with their spouses. Responses regarding partner’s health status ranged from “poor” to “very good” and relationship satisfaction ranged from “fair” to “very good.”

Next, I will describe each participant according to three marital status groups: married, married with caregiving issues, and widowed.

Married Participants

There were four married participants: Bea, Eve, Gaye, and Jenna. Sixty-nine year old Bea is a ball of energy. She is talkative and articulate. A striking woman with soft gray hair, high cheek bones, and flawless skin, she strives toward a healthy diet and regular exercise. She appears knowledgeable regarding medical issues and is proactive in her approach to life. She and her husband of 51 years appear to have a genuine fondness for each other and enjoy multiple activities together.

Eve was pleasant, but somewhat intimidating. At 65, she is slim and attractive, looking younger than her age. Her responses were brief, frequently consisting of only a nod and requiring clarification. She demonstrated closed body language, her arms folded and legs crossed. She was a homemaker, on her own turf. She elected not to complete the portrait. At one point, I wondered why she had agreed to be interviewed.

Gaye is slim and attractive and looks younger than her 65 years. She is a proud mother and grandmother. In spite of several health problems, she is active and participates in exercise. She and her husband are both retired and appear to enjoy spending time together.

Seventy-one year old Jenna is energetic and outgoing. She faces life with a sense of humor. A problem solver, she approaches challenges head-on. She and her retired spouse enjoy many activities together. They appear to have a playfulness to their relationship that is refreshing.

Married with Caregiving Issues

The three women in this group were Anna, Hazel, and Freda. Anna, age 74, is a soft spoken woman with a welcoming manner. She wears her hair pulled back loosely and appears well-kept. Her general state of health is good. She is a mother and grandmother. As the primary care provider for her husband of 56 years, she seldom leaves her home other than to shop or run errands. She focuses mainly on the needs of her husband and another family member whom she assists. This is quite a change from her pre-retirement years, when she describes herself as being “selfish” because she took time to attend to her own needs as well and “dressed to the nines.”
Hazel is an attractive woman with a soft smile. She is talkative. Her roles in the family include mother, grandmother, and caregiver for her spouse of 50 years. While he can move about the home freely in an electric wheelchair and get out for short periods of time, he has required assistance with activities of daily living such as bathing and dressing since an injury many years ago. She faces daily challenges with courage and resolve, “just glad I have him.”

Freda is a beautiful woman with soft white hair. She appears to be someone who has cared for herself throughout her lifetime. Her spouse, who has been her constant companion since a debilitating illness several years ago, was at her side. She requires the use of a walker for ambulation and has expressive aphasia. Receptively, she appears intact. Her husband seems to handle their situation with humor and when describing his roles stated, “she needs transport and sometimes translation.” The family demonstrates a pattern of resiliency in a challenging situation. They have one child who is a cancer survivor.

**Widows**

These include Clara, Dora, and Ilsa. Clara, 72 years old, is a small busty woman, as she depicted herself in her self-portrait, who is attractive with little or no makeup. She appears close with her children and grandchildren. She exercises regularly and seeks information related to improving her health. She gets out frequently with friends and is involved in numerous activities. A widow for over 20 years, she was the first to bring up the intimacy issue and to say that she had been alone for a “long time” and that she had no desire for such a relationship. I got the feeling that an intimate relationship would be an inconvenience for her at this point. She appears to be happy with her life. As a retired educator, she indicated an awareness of the effort required to pursue a Ph.D., and was therefore eager to help with this project.

Dora, a recent widow, is an attractive woman, appearing younger than her 81 years. Prior to the death of her partner of 54 years, she devoted herself to provision of his care within their home. She remains his devoted wife and is proud of the children that they raised together and her grandchildren who live outside the area. Currently, she visits a family member daily who is in an extended care facility.

Seventy-three year-old Ilsa describes herself as a mother and grandmother. She is petite and attractive with beautiful white hair. She is soft spoken and quick to smile, but reserved. Ilsa is an active participant in life, enjoying what life has to offer with friends and family.
### Table 3.1
**Participant Description**

<table>
<thead>
<tr>
<th>Participant #</th>
<th>Pseudonym</th>
<th>Age</th>
<th>Ethnicity</th>
<th>Marital Status</th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
<td>Anna</td>
<td>74</td>
<td>Caucasian</td>
<td>Married</td>
</tr>
<tr>
<td>2</td>
<td>Bea</td>
<td>69</td>
<td>Caucasian</td>
<td>Married</td>
</tr>
<tr>
<td>3</td>
<td>Clara</td>
<td>72</td>
<td>Caucasian</td>
<td>Widowed</td>
</tr>
<tr>
<td>4</td>
<td>Dora</td>
<td>81</td>
<td>Caucasian</td>
<td>Widowed</td>
</tr>
<tr>
<td>5</td>
<td>Eve</td>
<td>65</td>
<td>Caucasian</td>
<td>Married</td>
</tr>
<tr>
<td>6</td>
<td>Freda</td>
<td>73</td>
<td>Caucasian</td>
<td>Married</td>
</tr>
<tr>
<td>7</td>
<td>Gaye</td>
<td>65</td>
<td>Caucasian</td>
<td>Married</td>
</tr>
<tr>
<td>8</td>
<td>Hazel</td>
<td>70</td>
<td>Caucasian</td>
<td>Married</td>
</tr>
<tr>
<td>9</td>
<td>Ilsa</td>
<td>73</td>
<td>Caucasian</td>
<td>Widowed</td>
</tr>
<tr>
<td>10</td>
<td>Jenna</td>
<td>71</td>
<td>Caucasian</td>
<td>Married</td>
</tr>
</tbody>
</table>

### Table 3.2
**Educational Background and Annual Income Range**

<table>
<thead>
<tr>
<th>Participant #</th>
<th>Highest Level of Education Completed by Participant</th>
<th>Annual Income Range</th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
<td>Eleventh Grade</td>
<td>15,000-25,000</td>
</tr>
<tr>
<td>2</td>
<td>Master’s</td>
<td>25,000-50,000</td>
</tr>
<tr>
<td>3</td>
<td>Bachelor’s</td>
<td>15,000-25,000</td>
</tr>
<tr>
<td>4</td>
<td>Some College</td>
<td>15,000-25,000</td>
</tr>
<tr>
<td>5</td>
<td>Bachelor’s</td>
<td>25,000-50,000</td>
</tr>
<tr>
<td>6</td>
<td>Master’s</td>
<td>15,000-25,000</td>
</tr>
<tr>
<td>7</td>
<td>High School</td>
<td>25,000-50,000</td>
</tr>
<tr>
<td>8</td>
<td>High School</td>
<td>25,000-50,000</td>
</tr>
<tr>
<td>9</td>
<td>Bachelor’s</td>
<td>25,000-50,000</td>
</tr>
<tr>
<td>10</td>
<td>Some College</td>
<td>Unsure</td>
</tr>
</tbody>
</table>

### Table 3.3
**Partners’ Health and Relationship Satisfaction**

<table>
<thead>
<tr>
<th>Participant #</th>
<th>Partner’s General State of Health</th>
<th>General Relationship Satisfaction With Spouse</th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
<td>Poor</td>
<td>Fair</td>
</tr>
<tr>
<td>2</td>
<td>Very Good</td>
<td>Very Good</td>
</tr>
<tr>
<td>3</td>
<td>N/A</td>
<td>N/A</td>
</tr>
<tr>
<td>4</td>
<td>N/A</td>
<td>N/A</td>
</tr>
<tr>
<td>5</td>
<td>Fair</td>
<td>Great</td>
</tr>
<tr>
<td>6</td>
<td>Good</td>
<td>Good</td>
</tr>
<tr>
<td>7</td>
<td>Good</td>
<td>Good</td>
</tr>
<tr>
<td>8</td>
<td>Fair</td>
<td>Good</td>
</tr>
<tr>
<td>9</td>
<td>N/A</td>
<td>N/A</td>
</tr>
<tr>
<td>10</td>
<td>Good</td>
<td>Good</td>
</tr>
</tbody>
</table>
Confidentiality of Participants

Care was taken to assure anonymity and confidentiality. Participants were initially asked to select a pseudonym; however, in an attempt to protect participants during the reporting process, I reassigned pseudonyms. I transcribed the tape recordings and actual names were replaced during this process. For example the name of the participant’s partner was replaced by the word “partner.” Tape recordings were stored in a locked container in my home and will be destroyed when the study is complete. Review of the transcripts has been restricted to me and my advisor.

Data Collection

Face-to-face interviews were conducted utilizing structured and open-ended questions (see Appendix E) which were piloted during three interviews prior to this study. This avenue provided an opportunity to refine the interview tools and process. Initial questions (see Appendix F) were related to demographic data that included age, ethnicity, general income range, overall medical condition, and current relationship status. Questions regarding general knowledge related to UI as well as perceived partners’, family members’, and societal attitudes and influence on UI and sexual intimacy provided a basic framework for less structured questioning. Participants were offered an opportunity to elaborate and explore topics in their own words. Just as all older adults are unique, so are their ways of defining their experience of UI, which are dependent on factors to which they are exposed and individual interpretation (Blumer, 1969).

In order to facilitate increased comfort and privacy, participants were invited to select the interview locations. All interviews took place in the participants’ homes. Initial interviews lasted from 60 to 90 minutes. Thirty minute follow-up interviews were scheduled upon completion of the first interview. At that time, participants were provided with paper and instructions to complete a self-portrait prior to the second interview. Participants were also asked to keep a list of any additional thoughts they might have regarding the initial interview questions so they could be shared at the time of the second interview, if desired. Eight participants completed a self-portrait (see Appendix G). One participant was unable to complete the drawing due to physical limitations and one participant, the most restrained; matter-of-factly stated up front that she would not do it.

Self-portraits were utilized to initiate additional conversation at the time of the second meeting, which were generally 30 to 45 minutes. Participants were asked to describe the self-portrait and to offer explanations of perceived influences related to UI. I also asked if the portrait would be different if they were not experiencing UI. Utilizing this variation of portraiture, an alternative method of inquiry, provided participants with an additional way to communicate their particular interpretation of their experience of UI. Portraitists utilize portrait development to gain understanding of the complexities of the experience of the subject. It is through dialogue between the two that the portrait is co-created (Lawrence-Lightfoot & Davis, 1997).

While I do not have formal training related to portrait analysis, the portraits provided interesting insight into self-concept and for one participant, perceived influences related to UI. Several participants depicted negative physical aspects of aging
such as “sagging necks” and “bulging abdomens,” which led to conversation regarding their perceptions of their aging bodies. Additional insight gained during this process will be discussed in the Chapter Four.

Interviews were tape recorded with permission of participants. I transcribed the recordings. Process notes, which include descriptive and reflective information, were completed following each interview and reviewed throughout this project. For example, after interviewing the participant whom I perceived as being the most challenging, I made note of her closed body language and responses that were limited at times to simply a nod. I also documented my own frustration with the process. It was at that time that I began to see the value in what participants were not saying. This allowed me to approach the second meeting with this participant free of frustrations that I carried with me at the end of the initial interview. Field notes, which tracked the process of participant recruitment as well as my personal reactions, were also kept. These added forms of data collection provided a method of recording information not obtained through tape-recorded interviews, such as pre- and post-interview conversations and smells (e.g., urine). For example, one participant, who cares lovingly for her disabled spouse, shared a glimpse of what the cost has been for her personally, once the recorder had been turned off, by tearing up over their lack of intimacy. Review of these notes and identification of themes provided an opportunity for me to track how I was influenced as a researcher by the process as well as how I might have influenced the study (Bogdan & Biklen, 1998). I shared all of this information with my advisor, who read the process notes, commented, and offered guidance along the way.

Data Analysis

Qualitative analysis that includes theme identification, coding, and interpretation was utilized. The process was guided by techniques outlined in Allen (1989) and Bogdan and Biklen (1998), and was influenced by established theory, existing literature, current research questions, hunches, and personal experiences.

While process notes and field notes provided an opportunity for ongoing reflection, formal analysis was delayed until data collection was complete to allow me to focus on the interview process. Once data collection was complete, I read and reread all transcripts, process notes, and field notes three times, making a list of potential emerging themes as well as my reflexive interpretations and hunches. The initial list contained 118 items. I read and reread the list combining like items. At that point, the list narrowed to 70. I formed loose categories such as “ways of managing incontinence.” I then reread the data and reviewed the list of emerging themes and developed a list of potential coding categories. For example, “proactive behavior,” “accepting life’s challenges,” and “minimization” became “It’s a little thing and I can handle it.” I then read and reread my advisor’s comments on transcripts and process notes. At that time, I identified 19 coding categories and nine coding families. I also made a list of criteria for each category to help me stay clear and consistent regarding the content of each. For example, phrases such as “I just can’t hold it” or “How it hits,” are physical manifestations of participants’ actual experience of UI. I then reread transcripts and process notes, marking the appropriate codes in the margins, and further condensed the coding scheme to 18 coding categories and six coding families (see Appendix H). At that time, “What they know and don’t know” became part of “Perceptions of UI” and communication-related items were pulled
into a single category. I reread the data one additional time to be sure that the coding scheme could not be further collapsed. This entire process took place over a two week period. I then electronically transferred coded data to the appropriate coding categories and printed the 58 page document for review. This document consisted of an exhaustive list of quotes and other data that were representative of established coding categories. Additionally, I periodically reviewed my research questions to assure that I stayed focused on the purpose of this project. During revision, there was an ongoing exchange of ideas between my advisor and myself and we met frequently to discuss my progress.

Summary

In this chapter, I have presented the process by which I collected and analyzed data as well as how my background might have influenced that process. In spite of the challenges encountered during my search for participants as well as the reluctance of participants to provide expanded responses, rich data were obtained from women who were willing to share their experiences of UI. Findings will be presented in the next chapter.
CHAPTER FOUR

FINDINGS

This study was conducted in an attempt to gain insight into the experience of urinary incontinence as it relates to sexual intimacy in older women and to examine factors that influence that experience. Additionally, I wanted to identify perceived areas of intervention that might positively influence the experience of UI as it relates to sexual intimacy for participants. For example, what can partners and physicians do to make the experience better for participants?

Findings are based on interviews with 10 women. Data were gathered utilizing structured and open-ended questions during an initial interview and a follow-up interview. Through this process, I began to understand how these women define their personal experience as well as factors that might influence the construction of that experience. It is perhaps the absence of verbal communication, demonstrated as brevity by willing participants and by the absence of those unwilling to come forward and openly discuss this taboo issue that is most telling.

The analysis is presented in six sections that refer to the six coding families. In the first five sections, data are presented in the form of participant quotes in order to best convey their experience as presented to me during the interviews. Section six was compiled using field note and process note entries collected throughout this study.

In the first section, “Perceptions of Urinary Incontinence,” I present information related to participants’ level of knowledge regarding UI, prior to having the experience of incontinence themselves. Additionally, I address participants’ interpretations of the physical manifestations, the actual physical experience (i.e., “leaking,” “gushing”) of incontinence, as well as how urine loss is managed. This section also includes participants’ attitudes regarding incontinence, such as the degree to which they perceive UI to be a problem for them.

In section two, “We Just Don’t Talk About It,” I present information related to spoken and unspoken intergenerational communication between mothers and daughters regarding UI as well as verbal and nonverbal transference of communication between sisters. Communication among friends is also included. Additionally, in this section, I address interactions as well as comfort levels related to doctor-patient communication regarding UI and “personal issues.” Finally, verbal and nonverbal messages regarding sexuality and the reluctance to address such issues are also included.

The third section, “What Do Others Think?” addresses participants’ perceptions regarding what might be offensive to others about their incontinence. This includes participants’ feelings regarding urine-related body odors. Additionally, partners’ perceived responses are also included in this section.

Section four, “My Aging Body,” contains participants’ perceptions regarding the influence of UI on how they feel about themselves as women as well as perceived influences on self-esteem. This section also includes participants’ descriptions and interpretations of their self-portraits as they relate UI.

In section five, “What Would Make It Better?” I present participants’ perceptions regarding interventions that could potentially improve the experience of UI. This section
also includes the sources from which participants would like to see such interventions come.

In the final section, “The Process of Conducting Research,” I discuss the participant recruitment process as well as the meaning of the absence of data regarding this taboo topic. I will also discuss my impact as a researcher on this project as well as how I was influenced by this project.

Perceptions of Urinary Incontinence

Participants bring to this study a perception of UI, which includes their knowledge related to UI, both prior to experiencing incontinence and currently. This perception also includes interpretations of actual physical manifestations of UI as well as how involuntary urine loss is managed or not managed (e.g., wearing pad, voiding frequently). Additionally, participants’ perceptions related to UI are influenced by the degree to which they perceive UI to be a problem for them.

What Do You Know?

As I began to interview participants, I was struck by the number of participants who had little or no basic knowledge regarding incontinence prior to experiencing involuntary urine loss themselves. Responses to the question, “Before you experienced urinary incontinence, how much did you know about it?” were varied, and in spite of extensive effort on my part to get more expansive responses, brief. Responses included:

Nothing. (Ilia)
I didn’t know anything about it. I just thought, you know, it wasn’t nothing much said about it. (Hazel)
Anna, who appeared appropriate in her responses during the initial interview phase, later confessed that she had no idea what incontinence meant and indicated that the information provided on the consent form was the first information that she has received:

I didn’t know anything. I would never have known because, I was reading that paper you left me, I had no idea what the word (incontinence) meant. I don’t reckon if I heard it before. I didn’t know what it meant.

When asked if she knew anything about incontinence prior to her experience, Freda, whose incontinence came on suddenly as a result of illness, responded simply:

No.

Several participants had limited information related to UI and when asked to share that knowledge responded:

Not much. Just what you see on TV or every now and then, you might read something about it. (Gaye)
I guess I had heard of it and was aware that it sometimes came. (Eve)
In response to the questions, “Where did you hear about it?” or “Where did that information come from?” Eve simply responded:

Just on the street, I guess.

Clara, someone interested in gaining information related to her health responded:

Well, I hadn’t thought that much about it, other than you hear these people saying
when you have babies, that it affects your control of urine and so forth and how they would say, “try to do these little exercises. Kegels?”

Similar responses were evoked when participants were asked about current knowledge regarding Kegel exercises, which are used to strengthen pelvic floor muscles:

I don’t even know what that is. (Dora)

After an explanation, Dora responded:

I did, I just didn’t know the name of it.

Several participants indicated knowledge of Kegel exercises, but provided only brief responses:

Yes, which I’ve used. (Jenna)

I think I probably read something about that in Prevention magazine or something like that… (Gaye)

Two participants had vivid childhood memories regarding UI:

Well, I knew from childhood, because we had a neighbor lady that was very old and the cat ran between her legs one day. She was out watching us in our backyard doing something and a cat, a neighbor’s cat ran right through her legs and she said, “Oh my God”, and the water just poured from her and she said “well I have wet my pants.” Ms. (neighbor) just laughed it off because it was something. And I had heard from my mother there was some. It is easy to have leakage…” (Bea)

Anna’s aunt, who she describes as being somewhat of a free spirit, experienced temporary incontinence prior to having a “brace put in,” which is likely a pessary, sometimes inserted in the vagina to support the uterus. She is unclear regarding further details related to her aunt’s “condition” other than her memory of the actual urine loss:

She weeweed down her leg…

Two participants indicated that they grew up in families where communication was open regarding their bodies. When referring to her mother’s openness regarding addressing such issues, Jenna stated:

Well, my grandfather was a doctor and she grew up in an atmosphere of open communication regarding the human body.

When asked about her apparent comfort level when discussing her incontinence as well as intimacy issues, Bea stated:

Well, I think that’s partly because our family valued the medical and thought that it was important to be educated in the medical. Call it by the right name and address issues at the time.

When participants were asked to define UI, responses included the following:

Inability to control your bladder. (Ilsa)

Involuntary loss of urine. Like I said, I think it’s just the loss of fluid when you can’t control it. (Gaye)

I would say, you leak a whole lot. That’s what I call it. (Dora)

I would say, it is like urine, just involuntarily just coming, when you hadn’t planned on it… (Clara)

Lack of bladder control. (Eve)

Bea, who has undergone a surgical intervention for UI, but continues to experience some leakage defined UI as:

It is when the bladder fails to be strong enough and the outlet for the bladder
becomes weakened and simply doesn’t have muscles to hold it up or to hold it in
its place and you no longer have the control of your bladder…it just leaks or it
could be a constant running or it could be agitated with such as a sneeze, body
jerking in such a way that it sloshes out.

Responses from several participants indicated a level of secrecy related to
incontinence within the family. In response to the question, “How did your mother handle
her incontinence?” participants responded:

- Just normal. In fact, I wasn’t really aware. (Bea)
- Of course, my mom had experienced that before she passed away and she had to
  wear protection all the time, but so far as I know, she was never treated for it.
  (Gaye)
- When asked if she had known anyone who had experienced UI prior to her
  experience, Ilsa responded by saying that her aunt had had UI. When asked for more
details she responded:
  - I don’t know. She has a real problem.
  Knowledge of her aunt’s UI was the result of her having to buy incontinent
  products and not as a result of her aunt openly sharing information regarding her
  condition.
- Hazel, whose mother experienced UI, was only aware of her mother’s
  incontinence because she wore a pad and had an odor. Still, she seemed unsure and
  stated:
  - My mom, I think she had it…
- When asked if her mother had experienced UI, Eve replied:
  - I think my mother did.
- Regarding her older sister’s surgical procedure for UI, Dora stated:
  - I really don’t know a lot about it, but there was a lot to be done…
- In response to the question, “Did your mother experience incontinence?” Dora
  replied:
  - Mother didn’t as far as I know. Mother died when she was 78. I don’t think she
did.
  - When asked about her mother who experienced UI during the last few years of
  her life:
  - I swear I don’t know. We had sitters around the clock. I just never dealt with it.
  (Ilsa)
- When participants were asked if they had any particular thought regarding why
  they were experiencing UI, responses included:
  - Age. I blame it on everything. (Ilsa)
  - I just thought it was my age. (Dora)
  - I just figure like everything else they say, well it goes along with your age. (Clara)
- Anna, who was aware that her sisters had experienced UI, responded:
  - We just figured it was old people.

I Just Can’t Hold It!

Descriptions of the physical manifestations of UI among participants varied.
Severity of the amount of urine leakage ranged from occasional urine loss to a continuous
“drip drip.” These included:
- It started off when I would sneeze or get tickled with something, then usually, I
would just a little bit. I didn’t wear a pad then, but now I can stomp my toe or sneeze, cough and particularly at night, it’s awful. Sometimes at night, I have to change my undies three times, cause I don’t wear a pad at night… I would say it’s been doing it a good three or four years. It seems to get worse all of the time…I usually go every two hours when I’m home… Before I lost my whatever it is that I can’t hold my water, I have to change my pants sometimes three times a night. Last night, I had to three times, because when I go to get out of bed, you know it’s an effort sort of, and when I make this effort to get up, that’s when it comes and I can’t hold it. (Anna)

Sometimes when I sneeze or cough. That’s about it… when you get to laughing and you have a full bladder, then you’re going to have to run to the bathroom because you feel like you’re going to go any minute and you just don’t want to have an accident… It started when we were doing a lot of hiking. I would be drinking a lot of water as you have to and all of a sudden I would stumble and think “oh dear, I might dribble”… If I’m going to go somewhere, I go to the bathroom first. If I’m going out for a long period of time, I think “well there could be a problem” and so I will go. I do wear a pad. I do wear a pad when I go out. (Jenna)

I just drip drip all night, but I don’t know it…I get up during the night and right much, and time I get up in the morning, I have to go…and then sometime like I be in here, standing in the kitchen, you can feel it dripping and when I cough, I have to cross my legs… sometimes it’s just like a water spigot. (Hazel)

Probably a couple of years ago when I started noticing that some days I would have to wear a pad because just all of a sudden it was there, and then I’d go and then I’d go for two or three months at a time and have no problem, but then again, I’d go before I could get to the bathroom, because I have no way of knowing when it’s going to hit. I have no warning ahead of time, because I don’t feel like I have to and it’s all of a sudden...(Gaye)

When asked to describe her incontinence, Eve, who has experienced symptoms of UI for three or four years, and was the most closed of the participants, responded:

It’s not major. I have to go frequently and I do wear a light pad which pretty much controls it… If I don’t get there quite in time, I have a little leakage.

When asked about the amount of urine lost Gaye responded:

Just, I’d say, just a small amount, but enough that you would be uncomfortable if you didn’t have some protection.

Dora, who has had collagen injections, a treatment sometimes used to manage incontinence, on a couple of occasions, talked about their temporary success:

At first they’re fine, and then it just started…I was out with my cousin that goes with me a lot of times in the car. I didn’t even know it. She walked up behind me and said, you’re wet all in back” and I said “will you stand behind me until I got in the car? I happened to have a plastic that I could sit on. So that just really made me so uncomfortable and I knew I had to see about it then.

Dora’s comments regarding the current status of her incontinence and future treatment plans included:

So this last time, I guess it’s better, but it’s not great because I just pass it. I dribble a lot. I do feel the urge to go to the bathroom now, but in-between that, I
dribble. Now I might mention that before I had the one in November (collagen treatment), that I didn’t feel any urge to go at all. I just never knew and so now when I told him (her urologist) I can handle it now, but he said that he can do it again (the treatment), but I have to wait at least four months. I don’t know, I’m going to see what happens.

None of the participants felt that their incontinence has kept them from activities outside the home; however, outings do not always go smoothly, as the following examples reveal:

No, I just go prepared and this last, you know I had it done (collagen injections) November 5 and just before Christmas, on the Saturday before Christmas, I went over to, my nephew had all of us over to eat, my nephew and his wife, and I drank two cups of coffee and when I was coming home, when I got out of the car, it was just running down and that’s the only two times I’ve had that happen. (Dora)

What caused me to have the operation was that no matter what I did, and so maybe the operation did help, no matter what I did, just the least little sneeze or cough, I was immediately dumping a lot of fluid. I went out; we had a snowfall two days before the operation. I was thinking “I have not had any leakage, nothing. I went out and took the shovel and dipped the snow off the front walk and I wasn’t out there two seconds, the second shovel full, I had to come in and change my clothes. It was, I know I had gone to the bathroom before I started the job, so it wasn’t like I had anything in my bladder. (Bea)

When discussing how she handles her UI when out, Clara responded:
They had a restroom there and when I’d get there, I’d go. After I’d finish reading to her and whatever, I’d go again.

When asked how she felt generally about her UI, Bea responded:
It’s a nag…just before I had the operation, I was really afraid to go almost anywhere for fear I would not be able to make it through an hour or two hours.

Several participants mentioned their urine stream, either the delay in initiating a stream or a decrease in the force of the stream once initiated:

And it’s not like you hear people over in the next one (bathroom stall) cause mine (referring to urine stream) is like a quieter, doesn’t seem like it gushes out like other people…I’d be in the stool and I’d hear somebody like just gushing. And mine see, is a stream, but it’s just slower and less I guess and it takes longer. You know, they’ve finished and gone. Now I wonder why that is. You know what I’m saying. I’m urinating, but it’s just not a forceful stream as some other people. (Clara)

I don’t know what it is, but when I urinate, I will urinate a goodly amount of liquid, but then I’ll stop and start again just briefly, and that’s it… (Jenna)

If I’m going to leave the house, I’ll go. I can’t do anything. I can sit until I turn blue and nothing will happen. I can get down the road a little bit and I will. It’s crazy….(Anna)

I think it’s not emptying right or something…I have the urge, usually about four o’clock. I have to get up and go, but sometimes I feel like it don’t empty all the way.(Hazel)

When asked about having to go to the bathroom while on outings:
Usually in the store I do. At Kroger, I have a terrible time! Usually, it’s busy and if I have to stand and wait, it’s just too bad. I can’t hold it! I just can’t hold it! (Anna)
If I’m going to go somewhere, I go to the bathroom first. If I’m going out for a long period of time, I think well there could be a problem and so I will go. I do wear a pad. I do wear a pad when I go out. (Jenna)

What’s in a Pad?

Responses varied to the question, “Do you wear a pad?” depending on the degree of incontinence being experienced. While one participant stated that she did not wear a pad at all, other responses ranged from occasional to continuous pad use:
I do wear a pad. I do wear a pad when I go out….just in case. (Jenna)
I do if I’m going out; just for fear that I’m going to sneeze. If I’m going to a concert or to church, I just don’t want the wetness. It’s not very much, but you know, it’s just a leak, a little bit. (Bea)
I don’t wear a pad at night. It’s bad enough when you have to go out….I use to use the thin ones. I can’t stand those big bulky ones…. I bought those pants (with the pad built in), they just don’t work at all. (Anna)
I take an extra pad with me in case I need it. (Dora)
I think I have wore more pads now than the whole time I had my period… (Hazel)

When asked if incontinence has kept her at home or caused her to curb activities, Hazel responded:
No, because I prepare for a pad and Depend underpants together.
Ilisa stated that she does not wear a pad at all.

It’s a Little Thing and I Can Handle It

Participants demonstrated an attitude of facing life’s challenges, including UI head-on. This is demonstrated by the self-management, which is opting to manage their incontinence without the assistance of a physician, of involuntary urine loss as well as minimization and acceptance that it is “something that just happens.” This is consistent with behavior that was modeled by Ilisa’s aunt. When asked how her aunt had handled her incontinence, Ilisa replied:
She handled it because she had to.
When asked about her concerns should her UI worsen in coming years, she responded:
I don’t worry about what can happen. I wait till it does. (Ilisa)
When asked about her UI, Eve the most reticent participant, in one of her longer responses said simply:
I can live with it.
Later in the interview, when asked how her husband has responded to her UI, Eve again responded:
I just live with it.
When asked if she had mentioned her UI to her physician, Jenna responded:
No, I haven’t mentioned it because I just sort of took care of it myself. If I needed it, if I had had a really bad problem, then I would have mentioned it, because I’m
not that shy about it, but otherwise, as you can see, I just figured out how much
intake and I watched my output, so.

As the interview started, Gaye stated that she was not sure that she could help
with this study, concerned that she was not “incontinent enough” to participate. She
wanted to make a difference for herself and for others regarding UI and for that reason,
she was willing to participate. Her perception at this point is that her UI is no big deal.

Freda described her family as demonstrating a pattern of resiliency in dealing with
life challenges. These include her daughter’s recovery from cancer and managing the
daily challenges related to her physical limitations. In the scheme of things, her
incontinence is “no big deal.” Her spouse, who was present during the interview and
offered input, summed up their attitude related to UI:

This came out of a horrendous stroke that had to do with being unable to swallow
for awhile and she still can’t use her leg and arm and speak. So all these things
occurred at once, so to isolate one of them...You have to take so much with the
stroke. This is just one other thing.

While Jenna has not mentioned her incontinence to her physician, she conducted
an experiment at home in an attempt to measure her bladder capacity. She uses what she
has determined to be her intake “limit” for outings in order to avoid accidents. When
asked what it would take for her to seek treatment, she responded:

I guess if I had to wear a pad and wasn’t able to make it through certain things, I
probably would check and see what is available. It’s just like when we have, when
we go to Sunday school and church, I know that there are people that every
Sunday morning, they are having coffee and I thought, no. I had it at home early
and I don’t want to have, you know.

When describing the influence that UI has on her life, Bea stated:
Incontinence is such a miniscule part. Our bodies fail us. There may be nothing
that can be done for certain things.

In response to, “How much would your incontinence change before you would go
in and ask your doctor?” Clara responded:
See, I guess the thing was I didn’t know exactly what was normal....

Feelings of acceptance were also evident when I asked about the lack of intimacy.
Anna, who focuses on caring for her husband and another family member, appeared to be
accepting of her lot in life, be it caring for others, lack of sexual intimacy, or UI. She
shared:

I’m use to it now.... I guess I just take it as everything else that comes along
(Anna)

As we discussed comfort levels related to discussing sexual intimacy issues, Jenna
shared with me that she had experienced some of the symptoms often associated with
menopause such as vaginal dryness. When I asked if she would feel comfortable
addressing the issue with her doctor, she responded:

I didn’t even mention it. (Jenna)

A level of disconnect was noted in some responses.
When asked about the amount of wetness that she experiences, Hazel responded:
I don’t pay that much attention, I just go (referring to the bathroom).
When asked about her mother’s incontinence, which was managed by caregivers,
Ilza replied:
I just never dealt with it.

We Just Don’t Talk About It.

Participants shared spoken and unspoken intergenerational messages that facilitated a cloak of secrecy even between mothers and daughters related to UI as well as “personal issues.” This pattern was also evident in communication between sisters, despite the closeness found in the literature between mothers and daughters and sisters (Baber & Allen, 1992). A hesitancy to openly discuss the same issues was demonstrated by participants in their interactions with their physicians.

What My Mother Taught Me.

When asked if her mother had experienced UI, Anna’s response included: I never heard mine say a word about it and she died when she was 65 so I guess she didn’t get to the point where she was having the problem. When I suggested that her mother may have opted not to share such information, Anna did not appear surprised and replied: Yea, that’s true.

When asked if her mother had experienced UI, Hazel replied: I hadn’t never heard mama say anything about it.

When discussing her mother’s incontinence, Gaye indicated that her mother never allowed her incontinence to curb her activity. She stated: She’d just protect herself and go ahead…

But when asked what her mother told her about her UI, Gaye responded: She didn’t…

She was aware of her mother’s incontinence only because her mother wore a pad. During the interview, as we talked about lack of communication regarding UI, Gaye stated:

It’s strange, because growing up; I don’t remember my grandmother or my great-grandmother having it (incontinence). I’m sure they must have because my great-grandmother was 104 when she died, but there again, that was something that you probably just didn’t talk about.

When asked if her mother had experienced incontinence, Eve responded: I think my mother did.

She was unable, however to provide additional details.

Perpetuation of the secrecy regarding UI was evident when I asked Ilsa if her grown daughters were aware of her incontinence. She replied: Well, I don’t know.

When asked what her daughter and grandchildren knew about her incontinence, Bea replied: They all knew grandma had her little operation.

Lack of open communication was also evident when I asked participants about their mothers’ comfort levels regarding issues related to sexual intimacy. According to Anna, her mother never told her about her menstrual cycle and she thought that she was dying when she started her first period.
Ilsa was given the message by her mother that it was not ok to discuss “personal issues.” This is something that she has carried over into her communication with her children. When asked if issues related to puberty were addressed by her mother, she replied:

No, I don’t think so. No, I got a book on the butterflies and the birds and I never got the next one.

I then asked if she was comfortable discussing issues related to sexual intimacy with her children, she replied:

I wasn’t comfortable either.

The question, “When you were growing up and going through puberty, was your mother comfortable addressing issues relate to your menstrual cycle?” evoked the following response from Hazel who got her information from friends:

She never did.

To the same question, Gaye responded:

No. most of what we learned then, we learned through health classes at school.

While Eve professed comfort and open communication regarding “intimate issues” with her mother, Eve’s responses to related questions were limited to an occasional few words, “uh huh” responses, and nods.

Jenna’s response to the same question was indicative of open communication and increased comfort regarding such issues. Her response included:

Yes…my grandfather was a doctor and she (her mother) grew up in that atmosphere.

This is an attitude that she passed down to her own children.

Jenna’s mother also openly discussed issues related to menopause and offered adaptive techniques. Regarding coping with hot flashes that often accompany menopause:

My mother told me about it. She always did her own sewing and she would make these sleeveless dresses with jackets…And you could slip your jacket off and I learned to do that and then I passed it on to my daughter who is just getting to menopause stage now and I’ve mentioned to her that this is a way that you can casually have your hot flash and keep on with what you’re doing.

Sister to Sister

Although not as prevalent as mother/daughter communication, communication among sisters was also characterized by secrecy related to UI. When asked, “Has your sister experienced UI?” Jenna responded:

No she hadn’t had any problem either or else she’s not saying anything….That can happen too.

Again, the feel of secrecy was present. When asked about her sisters, Anna responded:

My sister has the same problem. The sister that’s two years younger than I am doesn’t have it that bad, but the other that’s two years younger, four years almost younger than I am, she has had it longer that I have…She didn’t have anything to say except she hated it.

Anna’s sister, however, did not seek treatment for her incontinence even though she “hated it.” This may have communicated to Anna attitudes regarding UI, such as it
must be endured, it is a normal part of aging, or that it is something not to be discussed, even with your physician.

Friend to Friend

Limited discussion between friends regarding UI appears to be in the form of generalizations rather than sharing of personal information. Participants indicated an awareness of a similar thought regarding the need to “hit the bathroom frequently” or take “group potty trips,” an understanding of sharing the experience without sharing details. Possibly depersonalizing the experience is a way of handling what is perceived by many as a difficult issue to address. When asked if she and her friends discuss incontinence Ilsa replied:

No, not really.
She was, however, aware that a friend had experienced it. When asked how she knew, she replied:

I think she had an operation.
When Eve was asked about communication with friends regarding UI, she replied:

We all just sort of laugh and say, “don’t make any sudden moves.”
When I asked Clara the same question, her response included:

We were friends enough to talk about it.
I then followed-up with “what did they tell you about it?,” to which she replied:

Well, they just said, they couldn’t leave home without them (referring to pads) and so I figured…mine must not be as bad, bothering me as much as theirs.
When asked about communication with her friends regarding UI, Ilsa responded:

Well, everybody I know practically when they cough and sneeze have you know, but no, it’s just not the thing you talk about a lot.
After our first interview, Gaye initiated a conversation about incontinence with an older friend. She indicated surprise at the friend’s response:

She said she didn’t have it, hadn’t had any problem, but whether she was truthful or not, I don’t know. She is older than I am, so I can’t imagine her not having some hint of it anyway.

Attitudes About Communicating with Doctors

While some participants indicated that they felt comfortable discussing issues related to UI and “personal issues” with their physician, responses indicate an overall lack of open communication.

When I asked Anna if she had discussed her UI with her primary care physician, she replied:

No. Not lately. No, he’s so busy anymore, he don’t have time to talk to you. It’s almost useless to go to him.
She then volunteered that her previous physician had retired and that she felt uncomfortable with her new physician performing her annual pap smear. She stated:

He’s kind of young and I just couldn’t do it with him. I told him that I was sorry, that it wasn’t anything against him, but he’s younger than my son…(Anna)
I then asked, “Would you have felt comfortable discussing issues related to your intimate relationship with your previous (older) doctor?” to which she replied:

I think so.

However, in conveying a conversation in which she talked with her husband about her incontinence and he encouraged her to see her physician, she responded to her husband with:

What’s he going to do about it?

While Jenna states that she perceives her physician as being approachable regarding issues related to incontinence or sexual intimacy such as vaginal dryness, she elected to self-treat with an over-the-counter lubricant and has not mentioned either issue to her physician.

Hazel, who did address her incontinence with her physician, appeared somewhat dissatisfied with her physician’s response:

I told my doctor about it (her incontinence). I told him “Sometimes, it’s just like a water spigot” and I told him other week that I didn’t see where it was getting no better with those pills, so he increased it three times a day…

I then asked, “Did he seem comfortable talking with you about it?” to which she replied:

He didn’t talk a whole lot about it. Sometimes you just wonder.

I then followed with, “So if you hadn’t brought the subject up, do you think he might have asked you ‘are you having any trouble holding your water?’” to which her reply was:

I don’t think so. They just so busy and he’s getting ready to retire…

Several participants indicated that they would be comfortable addressing issues related to UI or sexual intimacy with their physician. I then said, “As we go through menopause, sometimes women will experience things like vaginal dryness and those types of things. Were they issues that you would have felt comfortable bringing up with your doctor?,” to which she replied:

I would have brought it up…I got so now that I bring things up cause they doctors, like I told you, they don’t pay no attention to it so I just tell em. (Hazel)

While Gaye does not view her current UI as a problem, when asked, “If your incontinence became more severe, how would you feel about talking with your doctor about it?” she replied:

I definitely would feel free to go and ask for some help.

I then asked, “What type of information has your primary care physician given you regarding UI?”

Nothing really. I mean other than to ask if there has been any problem in the area…I’m sure if he knew it was a real problem he would, I feel like he would give me some information. (Gaye)

While Gaye indicated increased comfort related to discussing her incontinence with her physician, she had opted not to do so.

When asked if she would feel comfortable talking with her physician, Dora, who is currently under the care of a urologist and is received collagen injections to treat her incontinence, responded:
Oh yea. He asked me, “have you got any problems with this and this and this?” and he named off everything and I said “yes I am having some with that” when he said “incontinence” and so that’s when he told me about Dr. (urologist)…I feel comfortable talking with him about everything.

To which I replied “and he seemed comfortable having that conversation with you?”

Yea, he did. (Dora)

Dora describes her urologist as:
A nice person…easy to talk to…

I then asked, “Did regular doctor raise the issue?,” to which she replied:
No, cause I never said to him, I think I should be able to hold it longer.

In response to the question, “Is UI something that you are comfortable addressing with your doctor?” participants stated:

Oh yea. I would… Cause he even does my pap smear. So, yea I would. (Clara)
Yea, I had to bring it up…I really took care of it pretty quickly once it really got to be a true hassle. (Barb)

When asked if she would feel comfortable talking with her doctor about an issue related to sexual intimacy, Clara responded:
I would because like I said, I just think that people are more open with their doctors now…

S-E-X

Like UI, participants demonstrated varying levels of comfort regarding the discussion of issues related to sexual intimacy. Some participants were reticent to discuss sex as if it were a taboo issue. As I reviewed the consent form and discussed the project, Anna volunteered:
We haven’t, you know, in years.
When asked how UI has influenced her intimate relationship with her partner, she responded simply:
It hasn’t.

Two participants appeared comfortable as they shared their definition of sexual intimacy:

The male letting the female know that she’s still important, that, because if they put on a tremendous amount of weight, they couldn’t care less, but they want to see a woman stay slender as possible, to be interested in them. And the woman wants them to be interested in the woman and to say so, to touch. Touching is a big thing. They like to have somebody hug them and give them a kiss, a squeeze. And it doesn’t have to be intercourse. It can be just closeness. I don’t know how else to explain it. (Jenna)

Just being there for one another. I don’t know how you define that. (Gaye)
Ilse defined sexual intimacy as “intercourse.” When asked about the possible inclusion of cuddling and holding, she held fast to her definition of intercourse only.

When asked how her UI has influenced sexual intimacy in her relationship with her partner, Bea shared:
Oh, you don’t feel, if you think you are going to be flooding all over the world, you don’t feel very sexy at all….It’s not a sexy thing. It’s like going through a menstrual cycle every day. Not feeling quite clean and finding ways to be really clean….when we are in a sexual relationship, we really want to have pleasant odors about us…

In an attempt to obtain additional data related to sexual intimacy, I asked participants, “On a scale of 1 to 10 with 10 being “very important,” how important is sexual intimacy for women age 20 to age 30?” Responses included:

I believe I would put a 10 on it…because you’re just young, still young (Hazel)
Probably eight, maybe. At that time, I think it’s more so than later on. (Gaye)

When asked the same question regarding women in the 40 to 50 age range, responses included:

Eight to nine, but the men, they are preoccupied with their businesses, so the women are sort of left out…I know young people will say “you don’t have sex when you get older,” but that doesn’t go away…you still want it. You still enjoy it….when they go into menopause and they don’t have to worry about getting pregnant or having to take the pill or do any of those things. Well, it was a relief for me at 35 that I never had to worry. (Jenna)
It would lessen a little, maybe five….Lifestyle working and staying busy and being gone so much, so many different things going on in your life at that time. (Gaye)

I then asked the same question regarding women age 60 and older:
I don’t know, 50% maybe. (Ida)
I think probably it gets less even then because of just not being able to function like you want….probably at that age, that stage and time, it’s the togetherness and being comfort for one another, touching and that kind of thing. (Gaye)

What Do Others Think?

While participants tended to minimize the overall effects of their incontinence and to self-manage, there was indication of concern regarding the reaction of others to their incontinence. This includes partners as well as others with whom they come in contact.

Smell

When participants shared their experiences of incontinence, responses indicated concern regarding odor associated with involuntary urine loss and how others might respond to it. That concern is demonstrated by the following comments:

I don’t like it. I just don’t like it because it has an odor. I’m always afraid that people will you know, smell it….when I go out, I normally do (referring to “having an accident”) before I get home and it just worries me to death…Cause when I’m behind people in the store sometimes, particularly men, I can smell em. I can smell em and I always have a horror that somebody’s going to smell me. (Anna)
I can smell myself and I wash good and everything and still looks like sometimes I have an odor and then again I don’t. (Hazel)
Bea describes potential odor as one of the most disturbing things about UI: When we are in a sexual relationship, we really want to have pleasant odors about us. We want to feel relaxed and if we’re tense and having difficulties, it’s very difficult to sometimes maintain that odor free sweetness that a person can have…I recall going in restrooms after old women and thinking and realizing old people had an odor about them from a child on and I recognize that odor about me sometimes and it’s ghastly to me because I never ever want to feel that I’m a smelly person. I don’t smell that about people, but I feel that about me.

Perceptions of Husband’s Reaction

Responses indicated limited communication between participants and partners. When asked the question, “How has your husband responded to your incontinence?” Hazel stated:
Well, he don’t say nothing. I don’t guess he really knows….I mean, I just told him I had to go to the bathroom right quick.

In response to the same question, Eve responded:
He doesn’t pay any attention to it.

When I then asked, “Has he offered suggestions or support?” she added:
Well, I just deal with it….he just stops the car when I say stop.

When asked, “What kept you from mentioning it to him when it started to become a problem?” Anna replied:
Shoot, I didn’t not mention it. I just said, “I just weeed all over myself” No, I never kept anything from him. We have been married so long; it’s like your arm…He never said anything about it…he said I should talk to the doctor about it…he told me about that (referring to Kegel exercises) when I first started having the problem. It’n it funny, he had to tell me, but he did…he read about this exercise that you could do to strengthen your muscles.

According to Jenna, the only participant to include her partner in her self-portrait, she and her partner face UI with a sense of humor. She stated:
He kids me “you got to go again”?…he thinks I’m giving the city a hard time with the water supply. We are flushing constantly.

Gaye stated that UI has not affected her intimate relationship and added:
He just reminds me to go before we leave home. Like I tell him, we know where all the bathrooms are in all the stores. …

Dora, a recent widow, and her husband dealt successfully with his incontinence prior to his death. While her incontinence only began recently, she is confident that they could have openly discussed it. She said:
I could talk about anything with him. Well, when you are married to someone for 54 years, you should talk about everything.

Like Dora, Bea indicated that she and her husband have a supportive relationship. When describing his reaction to her incontinence, she stated:
Initially, he didn’t pay any attention to me, but when it got to be an everyday kind of thing and I would think I was not having very much and then I would just leak awful wearing extra protection, but when I started having to wear the regular Kotex, then I knew I was in bad shape….
When asked what her husband might have done differently regarding supporting her in dealing with incontinence Bea replied:

No, because he accepted all of that. No what he did was positive. He is such a believer himself of taking care of something if it can be medically done and you’re having a medical problem. He simply said “that’s not a good sign. You need to go have that checked out and you just really need to take care of that because we need to find out why you’re doing that.” He was concerned….he was always supportive and when somehow it didn’t seem to work right then because we care so much for each other, we chide each other on things we are concerned about…

My Aging Body

Participants indicated a lack of influence between their UI and how they feel about themselves as women as well as their self-esteem. They did, however, provide a glimpse of how they view themselves as aging women as well as how they perceive UI in relation to growing older. In response to the question, “In what ways has UI influenced how feel about yourself as a woman?” two respondents immediately responded:

None. (Ilsa)
No. (Freda)

In response to the same question, three participants indicated a level of acceptance related to their incontinence, stating:

I’m just aware, it’s an aging process….I don’t know that it has. (Eve)
I’m just, I’m realistic about things… (Dora)

Like Dora, Gaye has accepted her incontinence as part of the aging process:

I really haven’t thought about it. I have always just thought that that’s a part of aging and I know that I’m doing that, fast getting to that point and I just guess, just accept it as part of growing older.

Strong feelings were evoked for two participants when they were asked how UI might have influenced how they feel about themselves as women:

It’s been frustrating sometimes, when I’m say out to dinner, and I make the mistake of drinking too much water, then I have to get up and say ‘excuse me’, just like on TV. Just exactly like that only I try to do it gracefully. But otherwise, I have had no problems. (Jenna)

Well, it’s kind of embarrassing and yet I have to wear these pads and everything, but I don’t work in an office or nothing…sometimes, if I’m walking around all day, it’s not as bad, but then all at once. (Hazel)

Bea’s response reflected her positive life perspective:

Oh, I think we are different from men in the way that our body is constructed to have children. I think we are a great piece of work…

According to Anna, who stated that her UI has not influenced how she feels about herself as a women, it is the confines of caregiving responsibilities and financial changes that came about as a result of retirement been the greatest influence on how she feels about herself:

I have let myself go. I don’t dress like I use to. I’m gonna admit it, I was vain. I
bought clothes; I spent all my money nearly on clothes. I would buy 350.00 outfits and not blink an eye and now I have to go to Wal-Mart or Family Dollar to buy something because I can’t afford it. People always say, well when you retire oh you’re going to have so much money because you don’t have to pay for this and you don’t have to pay for that. That is the biggest fib that anybody ever told because it is not so. I bought a new car every two years and I dressed to the tenths, ninths, or whatever and now look at me…I don’t care, I just don’t care anymore and that’s not good. I know it’s not good. You can see from my picture. I’m just a washed-out turd.

Anna then pointed to a large portrait at the side of the room. The portrait was of a beautiful young woman who looked like Jane Russell during her early years with Howard Hughes. She was sitting on the floor with a peasant-type top and ample cleavage showing. Her face was young and flawless. Anna appeared disturbed by the physical changes that had taken place. I then asked her to name five things that she likes about herself now. She was unable to name one.

When asked, “In what ways has UI influenced your self-esteem?” seven participants denied any influence. Responses included:
- None. (Ilisa)
- No. (Jenna)
- No. (Eve)
- I don’t think so. (Anna)
- I don’t think it does. (Gaye)
- No. (Freda)
- No. I can’t think that it has. (Dora)

Hazel shared her perspective on the same question:
It ain’t bothered me too much. I’m more self-conscious of this (indicating her post-mastectomy breast).

When discussing societal pressures on women to look a certain way Bea stated:
To be this gorgeous, no matter how old you are, you’re suppose to be gorgeous, shapely and beautiful, and smell sweet. There is nothing about incontinence that sounds very very pleasant or beautiful.

Almost Picture Perfect

Discussion of the self-portraits between participants and myself provided an opportunity for me to gain insight into participants’ self-concepts as well as their perception of the influence of UI on self-esteem. Additionally, this interaction provided an opportunity to open further communication between participants and myself.

Of the eight women who completed the self-portraits, only one indicated that UI was reflected in the portrait. Jenna, the only participant to include her partner in her portrait (see Appendix G), drew a man and woman facing each other, making eye contact, and holding hands. In the lower corner, she wrote the word “partners.” She explained that she and her partner face life’s challenges together.

The remaining seven participants who completed a self-portrait stated that UI was not reflected in their portrait. Additionally, they stated that their portraits would not be different if they were not experiencing UI.
Ilsa, a widow of many years, depicted herself as a small figure in the upper left corner of the paper, holding a baby (see Appendix G). The rest of the page remained blank. She stated that she left the room in order to have space to practice her drawing. She proudly described herself as a mother and grandmother.  

When asked, “Is your incontinence reflected in any way in that picture?” she responded:  
No. Never thought about it.  
I then followed with, “How would your picture be different if you were not experiencing incontinence?” She responded:  
It wouldn’t.  

Dora presented herself clad in a pearl necklace and earrings (see Appendix G). She was smiling and her hair was neatly done. On her abdomen, she had written the word “big” and on her neck, next to squiggly marks, she had written “turkey neck.” When describing her picture, she stated:  
I love bangs and earrings and I always wear pearls or something like that, but then my neck gets in the way and I always think of myself as having a big stomach.  
When asked if UI was reflected in her picture, she stated:  
No. Not that I know of.  
I then asked, “So if you didn’t have the incontinence, would that picture look any different?” to which she replied:  
No, I’ve got this regardless (indicating her neck) and I’ve got my big stomach. I’ve always had a big stomach. With some people, it’s better than others, but I’ve been so conscious of this, (indicating her neck) but I can’t do nothing about it and I’m alive. I’ve got to be thankful for that...I look in the mirror and say, “well, you’re alive.”  

When asked to describe her self-portrait (see Appendix G), Clara pointed out the multiple lines under her chin and described the changes that have taken place in “that area” as she has aged. She appeared somewhat detached from her body as she described her picture:  
You can tell how she’s got rows (lines) on her, she’s got so many chins and big bosoms. Just kind of here I am person.  

Gaye, who depicted herself as a stick figure with a flared skirt and flowing hair, described herself as:  
Well, I just thought that it was a friendly, a happy type of thing and most of the time, that’s the way I am…  
She also stated that her UI was not reflected in her self-portrait.  

Bea appeared to put a lot of thought into her self-portrait (see Appendix G), which depicted a heart-shaped head at the top center of the page. She surrounded herself with thoughts related to her personal life journey. She described herself as someone who is evolving while interacting with those around her. She denied any reflection of incontinence and denied that her portrait would be changed if incontinence was not a part of her life.  

What Would Make it Better?  

While participants indicated little or no knowledge regarding UI prior to experiencing incontinence themselves, there was indication on the part of seven
participants that obtaining information related to incontinence would have been useful in facilitating successful management of UI. Additionally, participants shared their perceptions regarding who would be best suited to provide such an intervention.

A Dribble Here, a Dribble There

Participants were able to provide insight into possible interventions that might improve the experience of UI for older women. Two participants put a lot of thought into their responses:

In response to the question, “What might have made the experience of UI better for you?” Bea, who takes a proactive approach to life, voiced frustration at the lack of information made available related to UI:

Possibly, having a whole lot more information available to me in the very beginning. It seemed like I was the only one going through this for a few months before I could find anything. Nobody had anything on it.

It was clear that she had given thought to what might have made her experience better, however, her deepest concern was for improving the experience and surgical outcomes for other women who must go through bladder surgery for UI, something that she has experienced:

I really thought about what I would do to help others do a better job and one thing for certain would be to ask the doctors who do the surgery to have a follow-through. Much more than. I didn’t have any follow-through with the surgeon afterwards. I wasn’t invited back in a month or two months or six months or a year and I think all those stages would be very important to have a follow-up. To see if it was holding, to have that constant reminder what you should be doing in order to promote strength there. I was not given any exercises to do. I think there’s a lot you could do in exercise for strengthening the abdominal muscles which would naturally I think support the bladder better. And I feel like, because I didn’t follow-through nor have that push, that’s my own fault because we’re suppose to take care of our own selves, but the doctors can do a lot better. As they do, you know there’s a follow-up on so many other things. This is one that could have a good follow-up. And promote that that’s normal, that’s not uncommon, that’s you know, if you lift more than five pounds you’re going to pay for it. The doctor can hand you something to say at one month “Are you still doing this, at two months what’s happening, call me if this happens, do these things. Don’t do these things and make sure you call me on such and such and such and such.” I just think those would be awfully good. Or he can turn it over to a nurse or someone who would double check or do that. He doesn’t have to be there to do that. It would give the patient an opportunity to really look at what’s happening to them. I think that’s the major thing that I failed to do for myself and failed to really. It’s awfully hard to stop in the middle of doing something important to analyze how much you are lifting. Where are you lifting? What are you lifting? How are you lifting? I think you can lift 20 pounds, but how do you do that? What are you doing when you are doing that? Just going up stairs too soon, too fast. That’s wrong. And that’s what has happened to two or three people. Stairs are everywhere. How do you stop yourself? How do you click in, this is a no no? And doctors really need to come up with some way as well as the people, the patients
and really glue into hypnosis, “you shall not climb stairs until ten days have passed, you shall only climb them slowly, you cannot descend stairs, you must take elevators.” That sort of thing. When it’s safe to do this kind of exercise and I felt my doctor, very knowledgeable as he was, he was not knowledgeable on therapy. After surgery therapy.

Bea then shared her thoughts regarding why professional support is often not available for those experiencing UI:

That seems such a yucky part of our body. The elimination process. Yet, we’re yucky if we don’t eliminate properly.

Gaye’s response to the same question included:

Well, I guess any type of illness like that, if you know what to expect and know that there is help for you, I guess it makes it easier for you to handle it when it does happen to you. It’s not something that you’d be ashamed of, I don’t think, because it’s just a normal part of life so I guess that all the information that’s out there that if you want help you can find it. I think that would make it easier for us today than it use to.

She also indicated that she felt that brochures in doctors’ offices as well as community educational programs would be helpful. It was her feeling that these approaches might reach individuals who would be reluctant to broach the issue with their physicians.

Clara and Jenna, who had both attended a community education program on incontinence, felt that was a good way to make information available to those experiencing UI.

When asked if she could think of anything that might have made her experience of UI better, Anna replied:

Not having it.

While she stated that she did not know about UI, she later admitted to reading “little dribbles here and there.”

When asked, “If someone had given you information regarding available products for managing UI or given you samples to try, would that have been helpful?” Jenna replied:

That’s good, they don’t feel like they have to go and buy it.

Jenna also added that she had seen advertisements regarding incontinent products on television in which a well-known actress admitted to experiencing UI. She indicated that she felt that this type of endorsement helped to normalize the experience of UI for older women, something that she perceived as being positive.

When asked where she got her information related to product availability, Hazel responded:

TV and seen it on that.

When asked if she had considered television as an information source regarding UI, Eve indicated that she had seen ads for Detrol, a medication that is given for overactive bladder with symptoms of frequency or urge incontinence.

When asked if the media would be a useful source for information related to incontinence, responses included:

I have mixed feelings about how the media portrays anything medical. The pushing of prescription drugs, I have some problems with that. (Gaye)
I think it is not handled at all because nothing has come out and because there hasn’t been any true answer yet. There is no advertisement, ‘get your incontinence taken care of here’” (Barb)

When asked about perceptions of advertising related to UI, Anna refers to Detrol ads:
Well, it’s medicine. You’d die of the side effects. And the Pampers or whatever they call em. I’ve seen those ads….I don’t find it offensive. (Anna)

Other participants indicated frustration regarding what is shown on “personal product” ads:
I don’t think they should advertise some of the women’s products on TV. I really don’t. I mean women’s women. They know about it and they don’t think it should be televised, a lot of stuff. (Hazel)

I don’t know, I really don’t. I get aggravated with the media sometimes for the way they push things a little too much, but I don’t know. I just haven’t had much thought about that….It’s like everything else. It’s just out there. They don’t think about who sees it. Now you know children today, I guess know more about this type of thing than we did when we were growing up. It’s there fore everybody who wants to see it. I don’t agree with a lot of it. That’s television. (Gaye)

Who Could Make a Difference?

In response to the question, “If you had been given information (related to UI), where would you have been comfortable with that information coming from?” several participants indicated that they would expect the information to come from their physician:
My doctor. (Ilsa)
I would assume the doctor would be the first line. (Eve)
Well, the medical profession. I mean, because I think they really know what they are talking about. I don’t like this advertising garbage on television, not one bit. (Bea)
When asked where she thought such information should come from, Jenna, who has a nursing background, responded:
Well, I think AARP is terrific. And I hesitate to have too much on television, but sometimes when people can see other people, and it may not be their next door neighbor or family member, it make an impression on them. And so it might relieve them in some way but that’s the only thing I can think of.
She then indicated that she felt that information related to UI should be provided by a female.
I think that it should be given to an older woman by a nurse or the - what’s the assistant doctor called now? What’s it called now days? Yes, a nurse practitioner, because I think they would be more comfortable with someone like that telling them and would appreciate knowing.
Ilsa, whose physician is male, indicated that she would be comfortable with either a male or female providing such information related to UI.
When asked what form for such information should take, Ilsa indicated that she would have liked to received both verbal and written information.
If someone would take the time to just sit and say now this is how you do it. And
give a slight demonstration (referring to Kegel exercises) on tightening up and
firming up. That might help.
Several participants indicated alternative sources of information:
Well, I think something like this (showing booklet) would probable be interesting.
It gives a lot of information. I’ve given this to several people. (Dora)
I have gone to talks over at the Fine Arts center the urologists have done. (Eve)
Clara indicated that she had attended a presentation that I gave at the local health
club, something that she found very informative and comfortable.

Methodological Observations

Working with the Secrecy

While I expected that there might be some reluctance by older women to discuss
issues related to sexual intimacy, I was initially surprised by the reticence to discuss UI. I
am still not sure at this point whether it was the UI or sexual intimacy or possibly both
that diminished responses to my extensive search for participants. There were, however,
signs along the way that provided a clue to what lay ahead.

There was a smirk, which met me on several occasions, as I delivered project
flyers and provided information regarding the study. At the local health club, the manager
giggled uncomfortably when I explained the project prior to placing my poster on the
information board. He hesitated and indicated that he was not sure that it would be
appropriate for me to do so. After I reminded him that I had presented a program at the
club on that very topic, he relented and went on his way.

Two weeks after initiating the recruitment process, I remained positive that
participants would be forthcoming. I knew what I was trying to do was significant and
was confident that if made aware of the project others would recognize the value of the
study and come forward to participate.

After a month, still with no participants, I experienced my first concern that I
might have some difficulty in obtaining an adequate number of participants for my study.
The holidays were over; something that I thought had possibly influenced my lack of
volunteers. That’s when I made contact with my initial participant, Anna.

Gradually, over the next two months, participants trickled in with varying levels
of commitment to this project. In retrospect, the women could be categorized into three
groups: four appeared eager to participate; five went along with the project, offering no
indication that they would like to withdraw, and the tenth participant, the most reticent,
volunteered for the project, but severely limited her responses to my questions during
both interviews. I wondered why she had agreed to participate at all.

During my search for participants, I began to examine the qualities of the few
women who had come forward to be a part of this project and began to see similarities.
All participants appear energetic and proactive in their approach to life with the exception
of one woman, Anna, who was overburdened with caregiver responsibilities.

I also started to take a look at the sources from which participants were obtained.
Every participant, without exception, either knew me prior to my conducting this study or
was put in contact with me by someone else who knew me. Not a single contact was
made through physicians, nurse practitioners, or the numerous flyers posted in the
community. Participant sources are presented in Table 4.1.
Table 4.1
Participant Contact Sources

<table>
<thead>
<tr>
<th>Participant</th>
<th>Contact Source</th>
</tr>
</thead>
<tbody>
<tr>
<td>Anna</td>
<td>Contact was made through a relative, someone I have known for 16 years.</td>
</tr>
<tr>
<td>Bea</td>
<td>Contact was made through a woman featured in a local newspaper article related to incontinence. I have known Bea for over 30 years.</td>
</tr>
<tr>
<td>Clara</td>
<td>Contact was made through the office assistant at my physician’s office, someone I have known for 15 years. Clara had attended a program that I had presented and knew me from the local health club.</td>
</tr>
<tr>
<td>Dora</td>
<td>Contact was made through Clara.</td>
</tr>
<tr>
<td>Eve</td>
<td>Contact was made through Clara.</td>
</tr>
<tr>
<td>Freda</td>
<td>Contact was made through Bea, although I have known Freda for four years.</td>
</tr>
<tr>
<td>Gaye</td>
<td>Contact was made through a nurse that I have known for 15 years.</td>
</tr>
<tr>
<td>Hazel</td>
<td>Contact was made through her daughter-in-law who is a friend.</td>
</tr>
<tr>
<td>Ilsa</td>
<td>Ilsa is an acquaintance who I have known for over thirty-five years.</td>
</tr>
<tr>
<td>Jenna</td>
<td>Jenna is an acquaintance from the gym. I have known her for several years and she attended a program that I presented on UI.</td>
</tr>
</tbody>
</table>

I began to speculate regarding why participants were not coming forward. I felt that it was the sexuality piece of the study that might be putting off potential participants. I began to expand on the information provided when I mentioned the study. I let it be known to potential participants as well as potential sources such as physicians and nurses, that I was not looking for intimate sexual details as part of this project. That appeared to place some people at ease, but did not result in additional participants.

Living In the Research

As I recruited participants and conducted interviews for this project, I dealt with additional issues. Knowing that discussing topics related to UI and sexual intimacy could potentially cause discomfort, I took care in all phases of the research process to protect participants without compromising the integrity of the study. At times I tempered my questioning approach such as in the case of Dora, a recent widow whose grief was still fresh. I stopped to offer support and moved on to another line of questioning when one
participant became tearful when she shared the loss that she felt over the lack of sexual intimacy since her husband’s illness many years ago.

Additionally, I could have made better use of silence during the interview process. There were times when awkwardness was present when I asked questions related to sexual intimacy. For example, Ilsa appeared uncomfortable when I broached the topic of sexual intimacy, something that she had indicated that her mother had been uncomfortable addressing. It was not my own discomfort that influenced my decision to break the silence, but concern for the participant. There was definite worry on my part that the few participants that I had been able to recruit would decide not to participate.

Following the fourth interview, when I had two potential participants withdraw from the project, I began to recognize the courage of the women who stepped forward to be a part of this project. They trusted me with information, much of which had not been shared with family members, friends, or their physician. Bea shared her “fear” of having an accident in public and her frustrations at having continued involuntary urine loss following surgical intervention. Dora told me that once when returning home, following a family outing, she discovered that her clothes were soiled from an “accident” that she was unaware of. All 10 participants shared the physical manifestation of their incontinence as well as how they manage their incontinence (e.g., pads).

While I had initially allowed participants to select their own pseudonym, I reassigned pseudonyms in an attempt to protect participants during the reporting process. I felt concern regarding participants’ anonymity, especially in a relatively small community, and I worried that they may be hurt by my interpretation of what they had conveyed to me.

On a personal level, I began to value my nursing experience and the comfort that it has afforded me in dealing with what are perceived by some as difficult issues to discuss. I reflected back on my 16 years as a nurse and how my experiences as a nurse have changed who I am as a person. I have had the opportunity to meet people whom I would otherwise have never met and I have been able to connect with patients as well as their family members. Through our interactions, I have changed them and they have changed me. For example, at age 33, I worked with a young woman, “Emma,” also 33, who had experienced a devastating stroke. Prior to her stroke, she was the primary breadwinner in her family that consisted of her husband and a young son. Following her stroke, she ambulated with a cane, had limited use of her right arm, experienced difficulties verbalizing, and had impaired judgment, preventing her from driving or returning to work. Over the course of her rehabilitation, she had to deal with the loss of her husband, limited contact with her son, loss of her job, and loss of her independence as she was forced to return to her parents’ home to live. Because we were the same age, both with small children, we connected on many levels. We shared laughs and tears and I was able to offer her support and encouragement. I remained in contact with her and her family following discharge and was eventually able to help her get into a driving program that allowed her a level of independence, although she will never return to work. In return, she gave me an increased appreciation of the blessings in my life, time with my daughter, my job, and my independence, to name a few. I am forever changed.

I reflected back on my own family of origin and examined the messages given to me along the way as well as experiences that have allowed me to go beyond the boundaries of communication set during my childhood. As a child, issues related to
sexuality were not openly discussed in my home. My comfort level regarding issues related to sexual intimacy shifted after I entered the field of nursing. The main catalyst was a single interaction. On the rehabilitation unit where I worked, we made follow-up calls to our patients to track post-discharge progress. I called “Sam,” a 59-year-old man with whom I had enjoyed working. He was positive and fun to be around, always a bright spot in our day on a busy unit where work was challenging. As I finished the standardized set of questions and our phone conversation came to a close, I ask him if he was having any other problems. He replied, “I’m having trouble with my nature.” It took me a brief moment to realize that he was talking about erectile dysfunction. I could not get off the phone quickly enough. He had the courage and trust to share that information with me and because of my own discomfort, I was unable to provide information that might have changed that experience for him such as recommending that he talk with his doctor. He may never have brought the issue up again, influenced by my message that it was not acceptable to discuss the issue. That experience haunted me and I resolved that it would never happen again. The next time, I was prepared.

During the process of this study, I became frustrated at times, knowing that there were numerous women in my community experiencing UI who were unwilling to come forward to participate in this study. I also experienced disappointment regarding the limited responses obtained from willing participants. At one point, it felt like I was “pulling hen’s teeth.” This was especially true with Eve who often provided single word responses or simply a nod.

My perspective regarding the lack of data changed when I was able to see the value of the absence of data. I started to take a stronger look at what was not said and I began to speculate on what that meant collectively. Though I know that UI is prevalent among older women, there appears to be a code of silence regarding even admitting that it is an issue. Even between family members, closest friends, or with one’s physician, the topic is not openly discussed. Why then, should they be comfortable opening up to me?

Summary

In this chapter, I have presented my findings, the challenges encountered during my search for participants as well as the reluctance of participants to provide expanded responses. Despite these challenges, rich data were obtained from women who were willing to share their experiences of UI. In the final chapter, I will present discussions and final conclusions.
CHAPTER FIVE
DISCUSSION AND CONCLUSIONS

Overview

The purpose of this study was to gain insight into the experience of urinary incontinence as it relates to sexual intimacy for older women. Additionally, I wanted to identify perceived areas of intervention that might positively influence the experience of incontinence as it relates to sexual intimacy for participants. Threads of secrecy were evident throughout the process. While UI is common among women, affecting as many as 11 million (AHCPR, 1996) in the United States, a reticence to discuss the issue was apparent. This reluctance is consistent with previous research (Cohen et al., 1999), as well as my experience as a nurse.

Reluctance was also identified regarding the discussion of how UI relates to sexual intimacy for participants. It is the absence of data related to this topic, manifested in the lack of willing participants as well brevity of responses during my interactions with participants, that perhaps speaks the loudest.

This study was guided by the following questions:

1) What does urinary incontinence mean to older women and by what process was that meaning acquired?
2) In what ways have messages from system components such as partners, family members, and society influenced that meaning?
3) What are perceived areas of intervention that might positively influence the experience of urinary incontinence as it relates to sexual intimacy for older women?

Conclusions

As a result of analyzing these data in six coding families, I further reduced the data into three major conclusions which include: “Secrecy and Unspoken Messages,” “It’s My Experience and I Can Handle It,” and “What Would Make It Better?” To do so, coding family 200, “We Just Don’t Talk About It,” became the first major conclusion, “Secrecy and Unspoken Messages.” Elements, (specifically, “What Do You Know?”) of coding family 100, “Perceptions of Urinary Incontinence and Sexual Intimacy” and coding family 400 (specifically, “Perceptions of Husband’s Reactions”) were also included in this conclusion. The second conclusion, “It’s My Experience and I Can Handle It,” is composed of coding family 400, “My Aging Body” as well as elements (specifically, “I Just Can’t Hold It,” “What’s In a Pad,” and “It’s a Little Thing and I Can Handle It”) of coding family 100, “Perceptions of Urinary Incontinence and Sexual Intimacy,” and coding family 300, “What Do Others Think?” (specifically, “Smell”). The third conclusion contains coding family 500, “What Would Make It Better?” as well as elements (specifically, What Do You Know?” and “What’s In a Pad?”) of coding families 100, “Perceptions of Urinary Incontinence and Sexual Intimacy” and “We Just Don’t Talk About It” (specifically, “Attitudes About Communicating With Doctors”). Coding
family 600, “The Process of Conducting Research” runs throughout all three parts of the final conclusions. This process is presented in Table 5.1.

Because there is an overlap, data from more than one major conclusion were utilized to answer each research question. The association between the research questions, coding families, and major conclusions are presented in Table 5.2.

Table 5.1
*Major Conclusions Linked to Coding Categories*

<table>
<thead>
<tr>
<th>Major Conclusions</th>
<th>Coding Categories</th>
</tr>
</thead>
</table>
| 1. Secrecy and Unspoken Messages    | 101 What Do You Know?  
|                                    | 205 What My Mother Taught Me  
|                                    | 206 Sister to Sister  
|                                    | 207 Friend to Friend  
|                                    | 208 Attitudes About Communicating With Doctors  
|                                    | 209 S-E-X  
|                                    | 311 Perception of Husband’s Reaction  
|                                    | 616 Pulling Hen’s Teeth  
|                                    | 617 My Impact As a Researcher  
|                                    | 618 My experience As a Researcher |
| 2. It’s My Experience and I Can Handle It | 102 I Just Can’t Hold It!  
|                                    | 103 What’s In A Pad?  
|                                    | 104 It’s a Little Thing and I Can Handle It  
|                                    | 310 Smell  
|                                    | 412 Self Concept  
|                                    | 413 Almost Picture Perfect  
|                                    | 616 Pulling Hen’s Teeth  
|                                    | 617 My Impact As a Researcher  
|                                    | 618 My experience As a Researcher |
| 3. What Could Make It Better?       | 101 What Do You Know?  
|                                    | 103 What’s In A Pad?  
|                                    | 208 Attitudes About Communicating With Doctors  
|                                    | 514 A Dribble here, a Dribble There  
|                                    | 515 Who Could Make a Difference?  
|                                    | 616 Pulling Hen’s Teeth  
|                                    | 617 My Impact As a Researcher  
|                                    | 618 My experience As a Researcher |
Table 5.2  
*Research Questions Keyed to Codes and Conclusions*

<table>
<thead>
<tr>
<th>Research Questions</th>
<th>Coding Families</th>
<th>Major Conclusions</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. What does urinary incontinence mean to older women and by what process was that meaning acquired?</td>
<td>100s 200s 400s</td>
<td>1 2</td>
</tr>
<tr>
<td>2. In what ways have messages from system components such as partners, family members, and society influenced that meaning?</td>
<td>100s-600s</td>
<td>1 2 3</td>
</tr>
<tr>
<td>3. What are perceived areas of intervention that might positively influence the experience of urinary incontinence as it relates to sexual intimacy for older women?</td>
<td>100s-600</td>
<td>1 2 3</td>
</tr>
</tbody>
</table>

**Coding Families:**  
100s Perceptions of UI and Sexual Intimacy  
200s We Just Don’t Talk About It  
300s What Do Others Think?  
400s My Aging Body  
500s What Would Make it Better?  
600s The Research Process  

**Major Conclusions:**  
1. Secrecy and Unspoken Messages  
2. It’s My Experience and I Can Handle It  
3. What Could Make It Better?
Secrecy and Unspoken Messages

Feelings of secrecy seemed to permeate this project. In spite of the frequency of UI in older women, participants reported having little or no knowledge regarding UI when they initially experienced involuntary urine loss themselves. This lack of knowledge regarding incontinence was potentially influenced by the absence of communication related to incontinence on multiple system levels (von Bertalanffy, 1968).

Within the participant’s immediate family, rules were established regarding what one does and does not talk about. In the case of UI, it is likely what was not said between mothers and daughters that had the greatest impact on participants’ perceptions of the experience. Lack of communication within their families regarding UI potentially provided these women with the initial message that UI is “just not something that we talk about.” Participants indicated that communication related to UI was virtually nonexistent within the family with responses such as, “I think she had it” or “I’m really not sure.”

Continuation of the lack of communication was evident between participants and generations that followed. When asked what her grandchildren knew about her incontinence, Bea replied, “They all knew grandma had her little operation.” When asked if her daughters are aware of her incontinence, Ilse replied, “Well, I don’t know.” The silent interchange related to UI between the generations contributes to a continuation of the taboo nature of the topic.

The secrecy related to incontinence was evident in the lack of communication between siblings and between friends, reinforcing the rules of communication that were established within the family. Only one participant indicated that she had knowledge of her sister’s UI, but even so, she described the details of her condition as “sketchy.”

Communication between friends related to UI appeared to take on a tone of depersonalization. Participants indicated levels of communication regarding incontinence between friends that ranged from no communication to general statements such as “group potty trips” when discussing their shared need for frequent toileting. It is an atmosphere of sharing the experience, without sharing details.

This atmosphere of the unspoken regarding UI offers reinforcement of previously constructed perceptions regarding the experience of UI. Daughters continue to refrain from forbidden communication reinforcing the taboo nature of the subject at multiple levels of the system.

There was an indication of continuation of the secrecy between participants and their partners. While two participants, both of whom came from families in which there was open communication related to their bodies and health, indicated perceived support from their spouses regarding their incontinence, five participants indicated that their spouses had little or no knowledge regarding their incontinence, further perpetuating the secrecy surrounding UI.

Respondents indicated a perceived overall lack of communication between themselves and their physicians regarding UI that might have provided reinforcement of preset communication rules. When asked if she had discussed her incontinence with her physician, Anna responded, “No, not lately. He’s so busy anymore.” When asked about her physician’s comfort in answering her questions regarding her UI, Hazel replied, “He didn’t talk a whole lot about it. Sometimes, you just wonder.” Conversely, Dora, who is currently under the care of a urologist, describes him as “A nice person, easy to
talk to.” Failure of physicians to address issues related to UI might be perceived as reinforcement for family messages, contributing to continuation of unspoken communication related to UI.

Communication related to sexual intimacy indicated a similar phenomenon. Participants indicated an overall lack of communication between themselves and their mothers regarding issues of a “personal nature.” According to Gaye, as she moved through puberty, her mother never addressed issues of a “personal nature.” Instead, she got her information in school health classes. Like Gaye, Hazel received no communication from her mother regarding physical changes that occur during puberty and she feared she was dying when she started her first period. Eve, the most reticent participant, indicated that her mother had been comfortable discussing issues related to sexuality with a mumble so faint that I had to clarify her response. Her body language remained closed and her answers brief throughout the entire interview.

Decreased willingness to discuss such issues was noted during the interview process. For example, when talking about sexual intimacy, Anna stated, “We haven’t you know in years.”

It’s My Experience and I Can Handle It

Participants perceived UI as being normal, an unavoidable aspect of aging. This is consistent with previous research findings on UI (Dugan et al., 2001; Goldstein at al., 1992). There was a tendency to minimize their incontinence as well as the influence that it has on their lives. Seven participants have self-managed their incontinence without assistance from a medical professional, utilizing a pad or frequent bathroom trips to minimize uncontrolled urine loss or protect clothing from wetness. This form of compensation (Baltes & Carstensen, 1999) allowed participants to cope with UI without limiting social activities. The three participants who have received treatment only did so after self-managing for a period of time. Bea coped with her incontinence using a variety of pads and went for treatment when her incontinence became “extra heavy” and limited her social activities. All three women currently experience some involuntary urine loss and have elected not to seek additional medical treatment at this time, accepting that UI is “simply part of growing older.”

Though only one participant indicated that UI was reflected in her self-portrait, when discussing their portraits three participants indicated a level of acceptance regarding their UI that included: “I’m just aware it’s an aging process,” “I’m just, I’m realistic about things,” and “I guess I just accept it as part of growing older.”

Three participants, who minimized the overall influence of UI on their lives, indicated that the most “devastating” part of UI is the fear they will have a urine related odor that could be noticed by others. Anna described her concern as having a “horror that somebody’s going to smell me.”

Two other participants shared what has influenced their perspectives regarding their experience of UI. When discussing her incontinence, Hazel, who underwent a radical mastectomy several years ago, stated, “It ain’t bothered me too much. I’m more self-conscious of this.” She placed her hand on her chest indicating the absence of her breast. Freda, who has difficulty verbalizing as a result of a stroke several years ago, nodded and said “yes” as her husband and primary support offered, “This came out of a horrendous stroke that had to do with being unable to swallow for awhile and still she
can’t use her leg and arm and speak, so all these things occurred at once, so to isolate one of them.”

**What Could Make It Better**

Participants were able to offer possible interventions that might improve their experience of UI. Bea, one of the two most proactive participants voiced frustration that information related to the potential for incontinence was not made available to her prior to her experiencing incontinence. Bea also felt frustration with the lack of post-operative follow-up care after her surgical procedure. She suggested follow-up visits at intervals over one year post-operatively. This would allow an opportunity to provide ongoing assessment of the effectiveness of the surgical procedure. The visits would also give patients an opportunity to ask questions related to their condition and to get reinforcement regarding what is normal and what to be concerned about.

Gaye, who would have liked to have received information related to UI prior to experiencing involuntary loss of urine, felt that brochures in physicians’ offices would be helpful for women who might not address the issue with their physician. She also felt that community educational programs would be helpful. Two participants, Clara and Jenna, had attended educational programs related to UI and felt that they had been helpful for them. Although they did not share in what way they felt them to be helpful.

Jenna, a woman who is proactive in her management of her incontinence, measured her urine at home in an attempt to determine her bladder capacity. When asked about possible interventions that might improve the experience of UI for women, Jenna indicated that incontinent product advertisements that feature a well-known actress may be useful in letting women know that they are not alone. Two participants indicated that making samples of incontinent products available would be an effective way to teach women about available products. Two participants voiced aggravation regarding the advertisement of “personal products” on television, something that they felt was inappropriate.

When asked from whom they would like additional information related to UI, responses focused on medical professionals, but noted the dilemma of interacting with younger male doctors. Two participants indicated that they would like the information to be presented by a female, possibly a nurse practitioner.

**Limitations**

There are several limitations to this study. While utilizing a qualitative approach may have provided an opportunity for rapport building as well as pre- and post-interview exchange, the idea of face-to-face verbal exchange may have made potential participants reluctant to be a part of this project. One possible approach to potentially open the lines of communication would be to establish a support group for women who experience UI in which the first few sessions offer education regarding the frequency of UI and well as the reluctance to discuss the issue. Once comfort levels are improved and communication more open, the sexual intimacy piece could be introduced. Another possible approach to obtaining data related to UI and sexual intimacy is to utilize a survey approach that would be filled out during a regular physician visit. I would review the data for use in the development of future research projects.
Additionally, in spite of extensive effort to recruit participants of a more diverse nature, only middle class Caucasian women agreed to be a part of this study. This is a common limitation in research on older women as most research is conducted on middle-class white women (Henderson, 1994). Utilizing a more diverse group of women would provide valuable data regarding the cultural influences that contribute to the construction of the experience of UI as well as attitudes related to sexual intimacy.

Implications for Practice

Findings from this study have multiple implications for practice. First, participants perceived UI as a normal part of the aging process; therefore, gerontological researchers, professionals, practitioners, and older women themselves must go beyond normalization of UI in order to facilitate open communication between women experiencing incontinence and those with whom they interact (i.e., partner, mother, friend, physician). The educational process by which this might occur must have multiple components. The women who participated in this study were receptive to information related to UI as well as sexual intimacy, but few had received such information. Educational material related to UI needs to be made available to women in a way that does not require that they request such information. For example, brochures may be placed in physicians’ waiting rooms or information related to UI and sexual intimacy may be included in community presentations. I have presented three such sessions and women have consistently been receptive to the information that I presented.

Educating women alone is not the solution because without open communication between women experiencing UI and their physicians, women will be less likely to seek needed treatment and will be more likely to self-manage. Because treatment options for UI are available, women who might be successfully treated may suffer in silence, therefore, it is essential that physicians take the time to assess continence status as part of a physical examination in order to facilitate open patient-physician communication regarding UI. Physicians need to know that women may not broach the subject and may therefore suffer needlessly. They need to be reminded of the frequency with which UI is experienced as well as the wide reaching consequences of untreated incontinence that include social and psychological well-being (Norton, 1982). This process might take the form of continuing education programs for which physicians can obtain continuing education credit. While educating physicians currently in practice regarding the need to address issues related to UI, which includes UI and sexual intimacy, is important, long-term changes might best be brought about through the addition of such information in medical school curriculums.

In addition to physicians, other health care professionals play a pivotal role in assisting women who experience UI and are therefore in a position to let women know that they are not alone and that treatment options may be available. For example, a nurse assisting a woman following an unrelated surgical procedure has the opportunity to assess bladder functioning as part of the physical assessment and may identify unreported UI. The nurse may then encourage the patient to discuss her UI with her physician and provide information related to product availability.

Efforts must also be made to facilitate open exchange regarding what are perceived to be such “personal issues” among family members. This includes communication between partners as well as intergenerational communication. The
intervention of providing educational material, both verbal and written, to women prior to them experiencing UI may help to alter the symbolic meaning established during childhood that UI is an unavoidable aspect of aging or that UI is something that is not talked about (Potter & Perry, 1997). For example, including questions related to UI and general information regarding frequency of UI as part of a routine physical examination for women of all ages could decrease the stigma regarding incontinence. Another potential approach to breaking down the walls of secrecy related to UI would be to establish a series of educational programs designed to educate women of all ages. Having women of varying ages who are comfortable discussing their own UI present at such programs might begin to contribute to more open intergenerational communication.

There are also practice implications beyond the medical setting. Educators who prepare gerontologists, social workers, therapists, and others who assist the aging population need to be aware of the reluctance of older women to disclose their UI in order to prepare future professionals to meet the multi-dimensional needs of aging women. For example, a woman who socially withdraws due to the fear of involuntary urine loss may refuse to attend an adult day care center creating an unnecessary challenge for overburdened primary caregivers. Recognition of the woman’s incontinence and concerns related to having “an accident” would provide an opportunity to educate the woman and her caregiver regarding available products for managing UI. A referral to a urologist could also be made for possible treatment.

Though incontinence is not always successfully treated, decreasing the incidence of UI by even a fraction can have a profound financial impact on older adults, many of whom live on a fixed income. It is estimated that approximately $1.5 billion is spent each year on incontinent related products (Ignatavius, Workman, & Mishler, 1999). This is money that might be spent on food, medications, or to otherwise improve life-quality. Incontinence is not just a health related issue, but reaches across many levels of a person’s life. For example, one may not be able to dine out with friends as a result of financial constraints. Resulting social isolation might possibly contribute to depression.

Recommendations for Future Research

The need for future research in the area of UI and sexual intimacy for older women is reinforced by this study. The challenges faced in the recruitment of participants as well as reluctance of some participants to provide expanded responses indicate to me that there are walls of secrecy that must come down and additional data to be gathered to fully understand the influences on the experience of UI as it relates to sexual intimacy for older women. Utilization of younger participants, in their 40s to 50s, to repeat the current study might provide data that could be utilized to reconstruct the experience of UI for older women. By sharing the experiences of women in their 40s and 50s with older women, the threads of secrecy initiated early in life may begin to unravel as a result of new messages such as, “You are not alone,” or “We can talk about incontinence.”

Additionally, the three non-married participants in this project were unattached at the time the interviews were conducted. Utilization of a non-married dating sample for a future study using the same approach would provide an opportunity to explore the influence of UI on relationship avoidance. Data from such a study could be utilized on multiple levels. For example, participants would have an opportunity to explore their perceptions of UI as it relates to sexual intimacy during the developmental stages of an
intimate relationship. Findings could be utilized to educate partners regarding the concerns of women experiencing UI. For example, a woman may fear leakage during intercourse and may feel the need to empty her bladder prior to sexual activity. Understanding perceptions involved in relationship development when one partner experiences UI is also important for professionals working with individuals as well as couples. For example, a therapist counseling a woman who avoids intimate relationships needs to be aware of the potential influences of UI. Finally, researchers could use data collected in such a study in the direction of focus groups in which older couples explore life challenges.

Finally, established codes of secrecy might be lowered by examining congruity of perceptions between partners regarding UI in women as it relates to sexual intimacy. One approach would be to conduct a case study in which one or more couples are interviewed over a period of months, both individually and together. Education related to UI could be provided throughout the process in order to evaluate the receptiveness to and influence of educational interventions related to UI on perceptions. Because of the secrecy surrounding both UI and sexual intimacy, women experiencing UI may have preconceived notions regarding how their partner will respond to their incontinence. Gaining understanding of the experience from both partner’s perceptions could be utilized to open dialogue between the partners which could be beneficial to the overall relationship.

Summary

In this chapter, I have reviewed the final conclusions as well as limitations to this study. Additionally, I have presented implications for practice and recommendations for future research. In order to facilitate open communication between women who experience UI and the people with whom they interact, change must take place not only at the professional level, but also within the older population.
REFERENCES


of family theories and methods: A conceptual approach (pp. 135-166). New York: Plenum Press.
Rowe, J., & Kahn, R. Successful aging. New York: Dell.


Justification of Project

The purpose of this study is to gain insight into older women’s perceptions of the experience of urinary incontinence (UI) and sexual intimacy and the process by which that experience unfolds. Urinary incontinence is estimated to affect 13 million Americans. Common among older women and a major contributor to institutionalization, loss of bladder function may result in decreased self-esteem, social isolation, and feelings of shame. While social and psychological well-being have been identified as areas affected, little research exists that examines the experience of UI as it relates to sexual intimacy for older women.

Gaining insight into factors that influence successful adjustment related to UI and sexual intimacy will set the groundwork for future studies which include partner’s perceptions of the experience of UI. Results of this study may provide an opportunity to normalize the experience of UI which could facilitate a positive interchange between individuals experiencing UI and partners, as well as those within the broader system such as family members, health care professionals, and society.

Procedures

Participants will include 20 women over 65 who are experiencing uncontrollable urinary loss. Participants will be obtained through physician referrals as well as through referrals from an ostomy appliance consultant at a local medical supply company. Additionally, notices requesting participation will be posted on incontinent product displays at two locally owned drugstores as well as on the information board at a fitness club. Individuals who “manage” and hide their incontinence will be recruited utilizing this approach. Women without current partners will not be eliminated as they may be able to provide insight into relationship avoidance and perceived previous partner attitudes. They will not exceed 50% of participants.

Face-to face interviews will be conducted in the participant’s home or a location of the participant’s choosing. Structured and open-ended questions will be utilized
(Appendix D). Initial questions will be related to demographic data that will include age and overall medical condition. Open-ended questions related to current relationship status, personal concerns, partner’s attitude, and effect on sexual intimacy will provide a basic framework for less structured questioning. One hour has been allocated for initial interviews and 30 minute follow-up interviews will be scheduled at the time of the initial meeting. Interviews will be tape recorded with permission of participants. Additionally, field notes will be kept.

**Risks and Benefits**

Some individuals may experience discomfort or anxiety related to discussing personal information such as intimacy issues. A list of counseling resources, which could be utilized should such discomfort occur; will be provided to participants at the time of the initial meeting. Each participant will be informed that she may choose not to respond to questions. Participation is voluntary and participants will be informed that they may withdraw from the project at any time.

Through opening conversation and examining perceptions of the experience of UI as it relates to sexual intimacy for older women, we can begin to understand influencing factors such as multiple components of the family and societal system. This is a necessary aspect of meeting the needs of older adults and the promotion of successful aging.

**Confidentiality/Anonymity**

Pseudonyms will be utilized to assure anonymity. Tape recordings will be stored in a locked container in the researcher’s home and will be destroyed when the study is complete.

**Informed Consent**

See attached form (Appendix C). The form will be reviewed with the participant to assure full understanding prior to signing.

**Biographical Information**

Sue Creech is a doctoral candidate in Adult Development and Aging in the Department of Human Development. She is a Registered Nurse and is recognized as a Clinical Nurse Specialist, a Certified Rehabilitation Registered Nurse, a Certified Rehabilitation Provider, a Certified Case Manager, a Geriatric Care Manager Advanced Professional, and a Certified Gerontology Nurse. She has completed requirements for a Post-Masters Certificate in Marriage and Family Therapy.

Dr. Katherine Allen is the advisor for the investigation. She has considerable experience conducting qualitative research on older women’s lives. She teaches graduate and undergraduate courses on qualitative research and family diversity.
VIRGINIA POLYTECHNIC INSTITUTE AND STATE UNIVERSITY

Informed Consent for Participants

Project Title: Urinary Incontinence and Sexual Intimacy: Older Women’s Perceptions

Principal Investigator: Sue Creech, RNC, CRRN

I hereby agree to participate in an interview in connection with the research project known as “Urinary Incontinence and Sexual Intimacy: Older Women’s Perceptions.” I understand that participation is voluntary.

I am aware that I will be asked to participate in an initial interview which will take no longer than one hour and one follow-up interview lasting approximately 30 minutes. I can choose not to answer questions and may withdraw from the interview and project at any time without penalty. I am aware that some individuals experience discomfort related to discussing personal information and I have been provided with a list of counseling resources should such discomfort occur. Researchers conducting this project are not responsible for the cost of therapy services should such discomfort occur. I understand that interviews will be audio-taped and that I will be identified by a pseudonym so that I may remain anonymous in any transcripts. If I should choose to withdraw, any interview recordings will be destroyed or given to me and no transcripts will be made of the recording.

I understand that I will receive no compensation for participation in this project. A copy of the transcript of my interview may be made available to me.

I understand that the Review Board for Research Involving Human Subjects at Virginia Polytechnic Institute and State University has approved this project.

If at any time I feel that my rights as a research participant have been violated during the course of this project or that I have not been treated according the descriptions in this form, I am aware that I can contact Dr. David Moore, Chair, IRB, Research Division, Virginia Tech, Dr. Katherine Allen, Professor, Virginia Tech, or Sue Creech, Principal Investigator, at the numbers listed below.

Should I have any questions or concerns regarding this research project or procedures, I may contact:

Sue Creech  Dr. Katherine Allen  Dr. David Moore
(434) 239-6037  (540) 231-6526  (540) 231- 4991

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PARTICIPANT'S PERMISSION

Signature _____________________________________  Date_________________

I have read and understand the Informed Consent and the conditions of this study. I have had all of my questions answered and I agree to participate in the study described above. I will be provided with a copy of this consent form.
December 3, 2001

Dear potential participant:

I am currently a Doctoral Candidate at Virginia Polytechnic Institute and State University. As part of the requirements for completion of a Ph.D. in Human Development, I am conducting a research project related to urinary incontinence (involuntary loss of urine). The Review Board for Research Involving Human Subjects at Virginia Tech has approved this project. If you are a woman over 65 who is experiencing urinary incontinence and are interested in participating in this study, please contact me at 239-6037 or screech@lynchburg.net. Your assistance would be beneficial to this project.

Please respond by January 15, 2002.

Sincerely,

Sue Creech, M.Ed.
Certified Rehabilitation Registered Nurse
Interview Guide

I. Introduction (rapport building)
   A. Explanation of the project
      i. My background (Doctoral Candidate, Registered Nurse)
      ii. Voluntary
      iii. Time allocation
      iv. General format
      v. Confidentiality
   B. Participant questions
   C. Review and signing of consent
   D. Selection of pseudonym

II. Demographic data
   A. Current age
   B. Ethnicity
   C. Highest level of education completed
   D. Primary occupation
   E. Annual income range
      (< $15,000, $15,000-$25,000, $25,000-$50,000, >$50,000)
   F. Overall medical condition? (i.e., depression, anxiety, impaired physical mobility, altered respiratory or cardiac status, major surgeries…)
   G. Marital/partner status
      i. Years with current partner or
      ii. Years since last relationship
      iii. Partner’s general state of health
      iv. General relationship satisfaction

III. What does urinary incontinence, as it relates to sexual intimacy, mean to the individual and by what process was that meaning acquired?
   A. Tell me about your incontinence (i.e., severity, onset, frequency, perceived influence regarding relationships, activity limitation, social contact …)
   B. How do you manage your incontinence? (i.e., medications, pads, limit outings, relationship avoidance…)
   C. How do you feel about your incontinence? (unavoidable aspect of aging, uncomfortable discussing, unaware of treatment availability, anxious, depressed…)
   D. How does it make you feel about yourself as woman? (i.e., self esteem, body image, desirability…)
   E. How have your feelings about yourself changed since you started to experience UI? (or increased…)
   F. Has UI influenced your intimate relationship/relationships? In what way? (increased closeness or withdrawal, avoidance of new relationships, fear of rejection…)

IV. In what ways have “messages” from system components such as partners, family members, and society influenced that meaning?
A. When you first experienced UI, how much did you know about it?
B. Where did that information come from? (family member, doctor, media…)
C. Have you ever known anyone else who has experienced UI? (relative, friend, acquaintance …)
D. How did they handle it?
E. Were you aware of how others (spouses, partners, family members…) handled that?
F. What did your doctor tell you about incontinence? (i.e., sexual intimacy, management, expectations…)
G. How has your partner responded to your UI?
   i. In what ways has he/she offered support?
   ii. In what ways could he/she have been more supportive?
H. How has that influenced how you feel about yourself as a partner?
I. How has that influenced how you feel about yourself as a woman?
J. How has that influenced your sexual relationship?
K. What would be different about your intimate relationship/relationships if you were not experiencing UI?

V. What are perceived areas of intervention that might positively influence the experience of UI as it relates to sexual intimacy for older women?
A. What might have made the experience of UI different for you? In what way?
B. Where would you like to see that information come from?
C. Is there something that your doctor could have done to change your experience?
D. Is there something that your partner could have done to change your experience?

VI. Wrap-up
A. Is there anything else you’d like to tell me about this experience?
B. Request self-portrait (provide paper)
C. Schedule next interview.

VII. Self-portrait questions
A. Tell me about your picture.
B. How is UI reflected in your picture?
C. Would your picture be different if you were not experiencing UI?
APPENDIX F
Demographic Data

Date ____________

Pseudonym ______________

Current age _______

Ethnicity ______________

Highest level of education completed ___________________

Primary occupation ___________________________

Annual income range
< $15,000,       $15,000-$25,000,       $25,000-$50,000,       >$50,000

Overall medical condition? (i.e., depression, anxiety, impaired physical mobility, altered respiratory or cardiac status, major surgeries…)
________________________________________________________________________
________________________________________________________________________

Medications?
________________________________________________________________________
________________________________________________________________________
________________________________________________________________________

Marital/ partner status _______________________

Years with current partner _________

Years since last relationship _________

Partner’s general state of health ______________________________________________

General relationship satisfaction
________________________________________________________________________
Anna
Bea

I'm still learning to listen; to see beauty; to smell the roses; to laugh more; to love more; to care more.

The gap is wide; I need to complete like my list. But there's much room for improvement. Me to really appreciate myself more.

God isn't through with me yet. I'm becoming and growing and living God intended.
Clara
Dora

Bkey
Neck

BIG
Gaye
Hazel
Ilse
CODING SCHEME

100 Perceptions of Urinary Incontinence and Sexual Intimacy
101 What Do You Know? (information they had regarding UI, including definition)
102 I Just Can’t Hold It! (or How it hits) (physical manifestations, their actual physical experience of UI)
103 What’s In a Pad? (how they manage UI and attitudes regarding pads)
104 It’s a Little Thing and I Can Handle It (Accepting life’s challenges/ attitude, proactive, minimization)

200 We Just Don’t Talk About It.
205 What My Mother Taught Me (communication, spoken and unspoken between mothers and daughters related to UI)
206 Sister to Sister (communication, spoken and unspoken between sisters)
207 Friend to Friend (communication, spoken and unspoken between friends) i.e. “We all have it, we just don’t talk about it” “group potty trips”, depersonalization.
208 Attitudes About Communicating With Doctors
209 “S-E-X” (spoken and unspoken communication)

300 What do others think?
310 Smell (perceptions of odors)
311 Husband’s Perceived reactions

400 My aging body
412 Self-Concept – Women and Aging
413 Almost Picture Perfect (descriptions of self-portraits)

500 What would make it better?
514 A Dribble Here, a Dribble There (“little bits of information along the way,” throughout the aging process (include the ideas that the women had regarding where they would like to see information come from)
515 Who Could Make a Difference? (regarding the women’s perception of what might make the experience better.

600 Methodological (Process of conducting research)
616 Pulling Hen’s Teeth (the tremendous effort required)
617 My Impact as a Researcher
618 My Experience of Being a Participant
VITA

SUE CREECH
1512 Sangloe Place
Lynchburg, Virginia 24502
(434) 239-6037
e-mail: screech@lynchburg.net

EDUCATION:

Ph.D. 2002 Virginia Polytechnic Institute and State University, Blacksburg, Virginia
Department of Human Development
Major Area: Adult Development and Aging
Certificate in Gerontology

1997 Virginia Polytechnic Institute and State University, Blacksburg, Virginia
Department of Human Development
Post-Masters Certificate in Marriage and Family Therapy

M.Ed. 1994 Lynchburg College, Lynchburg, Virginia
Master of Education from Lynchburg College
Major Area: Agency Counseling

1991 Liberty University, Lynchburg, Virginia
Bachelor of Science in Nursing

1986 Tidewater Community College, Portsmouth, Virginia
Associate Degree in Nursing

CERTIFICATIONS

Certified Rehabilitation Provider through the Board of
Licensed Professional Counselors, Marriage and Family
Therapists Department of Health Professionals

Certified Gerontology Nurse through the American Nurses
Credentialing.

Clinical Nurse Specialist through the Commonwealth of
Virginia, Department of Health Professions.

Certified Case Manager through the Certified Insurance
Rehabilitation Specialist Commission.

Certified Rehabilitation Registered Nurse through the of
Rehabilitation Nursing Certification Board.
Geriatric Care Manager Advanced Professional through the National Association of Professional Geriatric Care Managers.

EXPERIENCE

1986- Present  Virginia Baptist Hospital, Lynchburg, Virginia
    Position: Clinical Nurse II-IV Acute Rehab/ Home Health/Medical-Surgical

2000  Health Administration in Gerontology Practicum at Johnson Health Center.

1994  600 hour internship at Pathways Treatment Center, Virginia Baptist Hospital, Lynchburg, Virginia

1990  Spinal Cord Preceptorship, including experience with Woodrow Wilson Rehabilitation Center, Neurological Intensive Care Unit, Home Health follow-up, and community rehabilitation.

WORKS PUBLISHED

“Kate’s Comeback”, published by Springhouse Publication in the October issue of Nursing 90.

Co-authored Clean Intermittent Self-Catheterization For Women, and Clean Intermittent Self-Catheterization For Men, staff and patient teaching manuals utilized by Centra Health.

AWARDS AND HONORS

1995  Recipient of ARN HealthSouth Staff Nurse Award which recognizes outstanding clinical practice and professional excellence. This award is presented to one rehab nurse in the United States each year. (1995)

1992  Recipient of the Craddock-Terry Excellence In Nursing Award.