

1998

Real and Perceived Barriers to Evaluation and Treatment of Urinary Incontinence in Nulliparous Women

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**REAL AND PERCEIVED BARRIERS TO
EVALUATION AND TREATMENT OF URINARY
INCONTINENCE IN NULLIPAROUS WOMEN**

By

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THESIS

Submitted to the Department of Physical Therapy
at Grand Valley State University
Allendale, Michigan
in partial fulfillment of the requirements
for the degree of

MASTER OF SCIENCE IN PHYSICAL THERAPY

1998

ACKNOWLEDGEMENTS

The researchers wish to formally acknowledge some of the many people who have assisted in the production of this thesis. We wish to extend a special thanks to our committee chairperson, Cynthia Grapczynski, for her encouragement, time, and many hours of earbending. Thank you to our committee members Gayla Jewell and Karen Ozga for their time and assistance. We would like to extend our appreciation to Patricia Douglass, our transcriptionist, and to Pat and Carol in the P.T. office. We would also like express gratitude to our families for their patience, encouragement, and support. Finally, we would like to thank all of the women in our study for their honesty and participation.

Real and Perceived Barriers to Evaluation and Treatment of Urinary Incontinence in Nulliparous Women

ABSTRACT

The incidence of urinary incontinence (UI) in women has been estimated to be as high as 50%, and ranges from 17-52% in nulliparous women (women who have never been pregnant). The purpose of this study was to describe real and perceived barriers for UI affected women to seeking evaluation and treatment. Seventeen women were interviewed. 410 surveys were sent to women living in Southern Michigan to identify participants. Twenty-one met the inclusion criteria and seventeen were purposively interviewed regarding their experiences with UI. Themes were identified and generated to increase awareness of attitudes toward UI.

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CHAPTER 1 INTRODUCTION

Background

For many people, urinary incontinence (UI) evokes the image of an elderly person in a nursing home wearing diapers or pads. For the purpose of this research, UI is defined as an involuntary loss of urine occurring with everyday activities such as laughing, coughing, sneezing and/or exertion, or the sudden loss of urine without sufficient warning, regardless of the physiological cause (Skoner, 1994; USDHHS, 1996; Wallace, 1994). Until recently, incontinence has been thought to be the inevitable result of aging. A growing body of evidence reveals that “urinary incontinence should not be considered a normal part of the aging process” (U.S. Department of Health and Human Services [USDHHS], 1996, p. 8). There are numerous causes of UI and most conditions are treatable. However, many women do not avail themselves of treatment, particularly young nulliparous women (women who have had no pregnancies). Instead, these women make increasingly more limiting lifestyle changes in order to prevent urine leakage. The focus of this research will be on the real and perceived barriers of these young, nulliparous women, to seeking evaluation and treatment for UI.

An estimated 10-12 million American adults suffer from urinary incontinence (Norton, 1990; Wallace, 1994), and prevalence of UI in women is as much as twice that of men, due to childbirth, surgery, and anatomical differences (Harvard Health Newsletter, 1996; Jolleys, 1988; Norton, 1990). Some investigators have estimated the incidence of urinary

incontinence in all women reaching up to 50 percent (Nemir & Middleton, 1954; Wolin, 1969). Researchers who have studied the non-childbearing population also found a higher than expected incidence of UI ranging from 17-52% (Jolleys, 1988; Nemir & Middleton, 1954; Scott, 1969; Wolin, 1969). This high incidence remains relatively unaddressed by health care professionals. Many professionals assume normal uro-genital health in young, nulliparous women and are not alerted to problems without complaint from the patient.

In all affected women “...urinary incontinence has multiple and broad-reaching effects that influence daily activities, social interactions, and self-perceptions of health status” (Wyman, Harkins, Choi, Taylor, & Fantl, 1987, p. 380). Despite these detrimental effects “...the condition is widely underdiagnosed and underreported” (USDHHS, 1996, p. 2). “Many health care providers remain uneducated about this condition, and individuals are often ashamed or embarrassed to seek professional help” (USDHHS, 1996, p. 2).

Many women suffering from urinary incontinence are choosing to change their daily activities to avoid the loss of urine. Changes in routine include altering exercise regimens to lower impact exercise, avoiding lifting or jumping, and reducing social activities (Crowley, 1996; Diokno, 1995). When an affected woman alters her routine, her lifestyle changes and she is robbed of her independence. Symptoms that are left untreated may increase and cause more modifications of daily life, including the consistent need for absorbent garments to catch unexpected urine loss.

Until recently, the major option for these women has been surgical correction. The only choices for a woman were which procedure to undergo and which specialist, a urologist or a gynecologist, should perform the surgery. The reason for surgical emphasis stems from insurance companies reimbursement for such surgical specialties as

gynecology and urology, while rejecting claims for pelvic floor rehabilitation (Richardson, 1993).

In the 1996 Clinical Practice Guidelines, the United States Department of Health and Human Services (USDHHS) recommended “as a general rule, the first choice should be the least invasive treatment with the fewest potential adverse complications that is appropriate for the patient. For many forms of UI, behavioral techniques meet these criteria” (p. 21). The more conservative behavioral efforts can be very appealing to patients in that compared to surgery, “...this therapy is significantly less costly, both financially and physiologically” (Brubaker & Kotarinos, 1993, p. 672).

Conservative treatment of UI consists of treating the muscles of the pelvic floor, which are often weak and fail to provide support for the organs in the pelvis (Brubaker & Kotarinos, 1993). “It is a natural area of clinical work for a multidisciplinary collaboration with patients, physicians, nurses and physical therapists” (p. 673).

Traditionally, this team has consisted of physicians and nurses. Only since 1976 has the American Physical Therapy Association (APTA) included an Obstetric and Gynecologic Special Interest Section, and provided a statement of practice for physical therapists interested in this field (O’Connor & Gourley, 1990). This section of the APTA is thriving and is today titled the Section on Women’s Health.

It is logical that physical therapists would have a vested interest in rehabilitating the muscles of the pelvic floor. Physical therapists are extensively trained in the treatment of muscular disorders and manual muscle testing, which require knowledge of muscle origins, insertions, actions, and innervations. They are educated in substitution patterns of other muscle groups, and are expected to be proficient in the palpation of muscles and

their tendons to assess not only strength, but tone, position, and pattern of movement. (Brubaker & Kotarinos, 1993; O'Connor & Gourley, 1990). With these skills in hand, physical therapists, although relatively new members, are critical in a UI care team.

Many researchers contend that young, nulliparous women do not realize that they can receive treatment for UI, and only a small portion of incontinent women seek help for their problem (Holst & Wilson, 1988; McDowell, Burgio, Dombrowski, Locher, & Rodriguez, 1992). Most delay seeking help due to a variety of real and perceived barriers.

A conceptual model for the study of individuals seeking professional help is the Health Belief Model (HBM) developed by Marshall Becker in 1974. The HBM is a psychosocial learning theory consisting of four dimensions: perceived susceptibility, perceived severity, perceived benefits, and perceived barriers (Champion, 1994; Grosser, 1982; Janz & Becker, 1984; Rosenstock, Strecher, & Becker, 1988; Thomas, 1995). The perceived barrier facet of the HBM provided the primary theoretical framework for this study. Perceived barriers are defined as possible negative aspects of a health decision, which may deter one from undertaking the recommended behavior (Janz & Becker, 1984). Bandura's social cognitive learning theory has been paralleled to the HBM and its concept of expectations about self-efficacy overlaps Becker's perceived barriers (Rosenstock, Strecher, & Becker, 1988). Efficacy expectation is defined as an individual's competence to perform the behavior needed to influence the outcome (Rosenstock, Strecher, & Becker, 1988). For example, if a woman believes she can decrease the incidence of UI in her life, she will seek out evaluation and treatment. If she has the confidence that she can make a change, then she will attempt to make those changes. Both theories work to explain the behaviors of people regarding their health care

decisions. This framework forms the basis of study of women's perceptions and attitudes toward seeking health care for UI.

Problem Statement

Many investigators have looked at the incidence and prevalence of UI in women who have had one or more children, but few have researched nulliparous women affected by UI and their real and perceived barriers to seeking evaluation and treatment.

Purpose of Study

The primary purpose of this study is to use grounded theory to describe the real and perceived barriers to seeking evaluation and treatment of women affected by urinary incontinence. The major questions guiding the research are: Do incontinent women seek professional help? Whom do they consult, and what response do they receive? If they are not consulting a professional, why? In this study, grounded theory is defined as a theory derived from general statements about data systematically obtained from social research (Erlandson, Harris, Skipper, & Allen, 1993; Glaser and Strauss, 1967).

Significance of the Study

The significance of this study lies in the lack of research involving nulliparous women, the need for more education of women of all ages, and the need for an increased awareness in the health care professions of the prevalence of UI. These deficits lead women to attempt to manage UI alone and to unnecessarily alter their lifestyles to

accommodate symptoms (Crowley, 1996; Diokno, 1995; Skoner, 1994; Wyman, Harkins, Choi, Taylor, & Fantl, 1987).

With more information on the barriers that prevent nulliparous women from seeking UI care, health care professionals could improve communication with their patients. In turn, educated women could see they have a treatable problem for which they could approach their health care professional. With increased recognition and diagnosis of urinary incontinence, allied health professionals, such as physical therapists, could conservatively treat these symptoms. Conservative treatment has been shown to improve symptoms of urinary incontinence and decrease unwanted loss of urine (Bump, Hurt, Fantl, & Wyman, 1991; Dumoulin, Seaborne, Quirion-DeGirardi, & Sullivan, 1995; Dunbar, 1996; Ferguson et al., 1990; Hahn, Milsom, Fall, & Ekelund, 1993; Olah, Bridges, Denning, & Farrar, 1990). Overlooked, nulliparous women could be diagnosed and treated successfully before lifestyles change and independence is lost.

Urinary incontinence is a widespread problem affecting women of all ages. It is not an inevitable part of aging or only the result of childbirth. Although a large number of women live with UI, very few discuss it with a health care provider, seek treatment, or are aware of their treatment options. The researchers' goal is to discover real and perceived barriers of nulliparous women to seeking evaluation and treatment for urinary incontinence. These themes may help increase the awareness of women and health professionals alike, and improve communication between them. An open line of communication can open doors to successful, early, and conservative treatment of urinary incontinence for this population.

CHAPTER 2 LITERATURE REVIEW

Introduction

Urinary incontinence has been studied for many years by urologists, gynecologists, and nurses. Those fields have recently been joined by physical therapists researching UI. A 1990 review of literature on pelvic floor exercises found "...physical therapists were the second-most active investigators in the area of pelvic muscle exercises" (Brubaker & Kotarinos, 1993). Studies have also included the prevalence of UI, health professionals' roles in evaluation and treatment of UI, and psychosocial and physical barriers to evaluation and treatment of UI. A selection of studies on these topics from the 1950s to the present have been reviewed and summarized in preparation for further research.

Prevalence

General Population

Results of a study on the prevalence of UI in the general population indicated 8.7% of men and 25.1% of women aged 5-85 years reported some incontinence. Another report estimates 10-35 percent of all adults are affected (Thomas, Plymat, Blannin and Meade, 1980; USDHHS, 1996). Most studies on the prevalence of UI in women concentrate on the elderly or women who have had one or more children. General female population studies show the prevalence of incontinence ranges from 9-55% (Deindl, Vodusek, Hesse & Schussler, 1994; Thomas et al., 1980; USDHHS, 1996; Yarnell, Voyle, Richards, &

Stephenson, 1981). “Data from surveys of middle aged women (45-65 years old) indicate that 22 to 53% report some degrees of incontinence...and a similar survey... indicated ...33% had experienced involuntary urine loss within the last year” (Burgio et al., 1991, p. 1255).

Varying results occurred between studies due to different and unclear definitions by the researchers on the severity of UI. These variations could be confusing to participants in the studies (Burgio et al., 1991; Holst & Wilson, 1988; Norton, MacDonald, Sedgewick, & Stanton, 1988; Norton, 1990; Nygaard, Thompson, Svengalis, & Albright, 1994). Exact numbers are also difficult to obtain due to the reluctance of women to share their symptoms and individual threshold for complaint (Norton et al, 1988). While UI is common in these general populations, very few studies have noted the prevalence in younger and/or nulliparous women (Holst & Wilson, 1988).

Urinary Incontinence and Nulliparous Women

Little research has centered solely on the incidence of UI in the nulliparous population, and “little is known about the etiology of incontinence in nulliparous women” (Nygaard, Glowacki, & Saltzman, 1996, p. 1050). Some investigators have included nulliparous women in their general population studies. Jolleys (1988) found 17% of nulliparous women overall reported UI, with 31% under the age of 25. Those numbers contrast with the seminal research of Nemir and Middleton (1954), Wolin (1969), and Scott (1969). Wolin (1969) found 50.7% of nulliparous women had some degree of stress UI (p. 546). Nemir and Middleton (1954) concluded stress incontinence in nulliparous women aged 17-21 years was present in 52.4% (p. 1167). Scott (1969) found an

“unusually high incidence, 40 per cent, [which] would tend to fortify the need for careful questioning of young women in relation to involuntary urine loss” (p. 97). He concluded “urinary incontinence cannot be attributed to parturition [childbirth] alone” (p. 97).

The contrasting results of recent versus seminal research could be due to the different methods and purposes of the researchers. Jolleys (1988) determined the prevalence of UI in a general population of women over 25 and women under 21 taking oral contraceptives. Of the seminal research, two used only nursing students (Scott, 1969; Wolin, 1969), one used freshman health education students (Nemir & Middleton, 1954), and all were trying to determine UI prevalence in nulliparous women only. Studies using those isolated populations could have produced exaggerated numbers regarding the prevalence of UI. In that case, a general population study with a few nulliparous women might produce different results.

Respondents to a survey in which they reported incontinence in adulthood, also reported incontinence as adolescents (Diokno, 1995). Crowley (1996) cited “a recent study by the Bladder Health Council [which] found three out of ten incontinent women develop leakage before age 35” (p. 108) and Nygaard et al., (1990) found one out of seven nulliparous women note leakage during exercise. She concluded, “[Forty-two percent of nulliparous women surveyed] noted incontinence with daily activities at least once and 18% at least occasionally” (p. 185). Burgio et al. (1991) reported 93% of women surveyed said the onset of their incontinence was not associated with pregnancy or childbirth.

Thus, early studies indicate a relatively high incidence of UI has been found in nulliparous women. The writers conclude a lack of literature exclusive to nulliparous females leads to the neglect of evaluation and treatment of UI in this population.

Barriers to Seeking Evaluation and Treatment

There are both real and perceived barriers to seeking evaluation and treatment for urinary incontinence. For the purpose of this research, real barriers are identified as physical barriers, knowledge barriers, and the actions and attitudes of others toward those with UI. Perceived barriers are considered attitudinal barriers of those with UI.

Information and Access Barriers

Real barriers include information and access. "...[I]nformation barriers...prevent women from recognizing illness or knowing how to prevent and treat it appropriately" (AbouZahr, Vlassoff, & Kumar, 1996, p. 451). Lack of education among the general public and some health care providers prevent many women from seeking available assistance for urinary incontinence. Another real barrier, access to treatment, "...prevent[s] women from seeking appropriate care" (p. 451). Access issues include proximity to health care services, transportation, and economic factors.

Other real barriers to treatment for women with UI are incidence of underreporting, undertreating, and the fact that the topic is poorly understood by both clinicians and patients (Norton, 1990). Nygaard et al. (1994), found "less than 5% of nulliparous women with UI had ever discussed urine loss with either a trainer, coach, physician, nurse or family member" (p. 185). Women who have UI and do not seek treatment adapt by

changing their activities, clothes, jobs, eliminating exercise and/or sexual activities from their lives, or wearing protective garments (Crowley, 1996; Holst & Wilson, 1988; Norton et al., 1988).

Health Care Providers and Barriers

The key players in the assessment of urinary incontinence are presumed to be primary care physicians, nurse practitioners, and physician assistants who see women regularly in their clinics. Unfortunately, underreporting of the symptoms of UI to health care providers is common and the result of women being reluctant to expose incontinence information about themselves to the providers. (Ashworth & Hagan, 1993; McDowell et al., 1992; Mitteness, 1990; O'Brien, 1991; Seim et al., 1996; Wallace, 1994).

Primary care health professionals are the first link in the chain to alleviating symptoms of UI. They have the opportunity to speak with and examine women on a yearly basis and “a pelvic muscle assessment should be part of a routine pelvic exam” (Wallace, 1994, p. 468). Questions about pelvic floor function can easily be incorporated into the patient history taken at each visit. Although these steps are relatively simple, many health professionals neither query nor perform an assessment of urinary incontinence during regular examinations (Cheater, 1992; Mitteness, 1990; Wispert, 1994).

In some cases, health care providers have been deprived of the skills necessary for the evaluation and treatment of urinary incontinence. In a recertification series for physician assistants, Wispert (1994) points out that “...many clinicians are inadequately trained to evaluate, diagnose, and treat this widespread problem” (p. 27). He instructs physician assistants to “...ask proper questions to uncover...urinary incontinence” (Wispert, 1994, p.

37) and to perform an adequate physical examination. He does not mention evaluating the strength of the pelvic floor musculature. Wispert also recommends treatment methods but does not encourage referral to any other health care professionals.

General practitioners may also be the first professionals to diagnose UI. Seim et al. (1996) studied the treatment of incontinence in general practice and found many treatment options suitable but not widely used. Their study concluded "...that urinary incontinence in women can be effectively managed in general practice...if the doctors are interested in continence care, gain competence in a few fairly simple treatment options, and preferably work in a team, including a nurse or physiotherapist" (p. 1461). Another study involving physicians in Massachusetts and Oklahoma found that only 21-23% of primary care physicians inquire about UI in their elderly patients and only 46-62% rated themselves as "somewhat prepared" to evaluate UI (USDHHS, 1995). Many general practitioners do not feel prepared to deal with the physical or psychological aspects of urinary incontinence in the elderly population and do not address UI as a problem at all in the younger population (Seim, et al., 1996; USDHHS, 1995).

Attitudes of physicians can also prevent them from asking their patients about incontinence. These include the belief that there is "...lack of time (36%), lack of available and effective treatments (28%), and patient embarrassment (26%)" (USDHHS, 1995, p. 47). Specific attitudes toward the younger population are largely unknown but it has been suggested "...that incontinence in younger adult women is underreported because it is seen as yet another aspect of 'female troubles,' for which medical care is of dubious value" (Mittiness, 1990, p. 377). O'Brien et al. (1991) state that it is a "...widely held belief among the medical and nursing professions that incontinence is more of a

nuisance than a real problem...” (p. 1308). Attitudes such as these point toward biases about evaluation and treatment of UI and further discourage health care professionals from pursuing the issue with their patients.

Discrepancies between knowledge and beliefs of health care workers versus laypeople are also barriers. Mitteness (1990) and Ashworth and Hagan (1993) found that one belief held by laypeople is that UI is a normal part of aging. This is perpetuated in part by health care professionals. Lay beliefs are reinforced when “...a substantial number of incontinent people are told by health care providers that nothing can be done about incontinence and that it is a normal part of aging” (p. 375). Misconceptions about incontinence, along with the divergent knowledge of laypeople and health care professionals, lead to a vague and inconsistent understanding of UI. This lack of clarity breeds negative psychosocial attitudes in both patients and health care providers and can prevent prompt evaluation and treatment of urinary incontinence.

Perceived Psychosocial Barriers

Incontinence is still considered a taboo topic for many women. UI can have deep-seated effects on the women who experience symptoms. Studies have shown that “...urinary incontinence is a highly prevalent condition, and that its consequences could be devastating to the life...of the affected person...” (Diokno, 1995, p. 481).

The negative psychosocial aspects of urinary incontinence have received little attention from researchers. Of the few studies, Ashworth and Hagan (1993) qualitatively researched the definition of incontinence among those who are affected. Their goal was “...discovering the meaning of their conditions for the sufferers themselves” (p. 1415).

The in-depth study of 28 non-geriatric women led them to conclude that “...incontinence is a socially unacceptable topic of conversation (inhibiting the approach of sufferers to health professionals)” and that incontinence is seen as a loss of self-control (Ashworth & Hagan, 1993, p. 1415). They also found the concept of UI was difficult for people to grasp, even for those experiencing the symptoms. The word incontinence itself was rarely used by the subjects due to the stigma of having UI (Ashworth & Hagan, 1993). O’Brien et al. (1991) concluded that many patients are reluctant to bring their problems to the attention of their primary health care provider.

Wyman et al. (1987) quantitatively examined the psychosocial impact of UI on women. A small sample of community dwelling adults over the age of 55 was surveyed with the Incontinence Impact Questionnaire to measure the effect of UI on psychosocial functioning. They found that UI seems to affect self-perception and daily activities more than social interactions, but they did not look at the effects of UI on health behaviors, such as seeking treatment. The results “...illustrate[d] the heterogeneity of response to urinary incontinence, and indicate[d] that perception of the severity of incontinence is unique to each individual” (Wyman et al., 1987, p. 381). The uniqueness of the problem lends itself to more in-depth study of the perceptions and actions of affected women. Wyman et al. points out that although their study may not represent incontinent women in general, the “...psychosocial impact is an important consideration when evaluating urinary incontinence...and also...when assessing treatment outcome” (p. 381). Therefore, the literature suggests that the psychosocial aspect plays an important role in women seeking evaluation and treatment for urinary incontinence.

As a psychosocial tool, the HBM can be valuable in the investigation of barriers to seeking evaluation and treatment.

Mittiness (1990) states that a confounding factor in the study of the psychological distress and under-utilization of health care services is the knowledge and beliefs that people have about urinary incontinence. She expresses a distinction must be made between “...(1) the knowledge people have about incontinence; (2) their beliefs about the meaning of incontinence; and (3) their reactions or attitudes toward people who are incontinent or toward their own incontinence” (p. 374). The distinction lies in that knowledge is a real barrier. Beliefs, reactions and attitudes can be distinguished as perceived barriers according to the HBM. Mittiness (1990) points out that little research has been done on knowledge, beliefs, and responses to UI, and that the research is especially lacking in the non-elderly population. She also reports on lay knowledge and beliefs versus health care workers beliefs, as many consider UI a normal part of aging (Ashworth & Hagan, 1993; Mittiness, 1990).

Health Belief Model

The perceptions and factors that influence health care behavior have been addressed in the Health Belief Model (Bowers, 1980; Champion, 1994). This psychosocial tool has been used to “explain interindividual differences in the abilities to make decisions about adopting certain [health care] behaviors” (Thomas, 1995, p. 247). According to the HBM, there are four belief variables guide and affect health behaviors, such as seeking treatment for incontinence (Champion, 1994; Janz & Becker, 1984; Thomas, 1995). The variables are perceived susceptibility, perceived severity, perceived benefits, and perceived

barriers. Of those variables, Janz and Becker (1984) found ““perceived barriers’...to be the most powerful of the HBM dimensions across the various study designs and behaviors” (p. 29).

Along the same lines as Becker’s perceived barriers is Bandura’s concept of self-efficacy, as noted by Rosenstock, Strecher, and Becker (1988). Self-efficacy is also an important factor in women’s health seeking behaviors regarding UI. Rosenstock, Strecher, and Becker (1988) stated that self-efficacy can add to the HBM “...in working with chronic illness, particularly those requiring long-term changes....It requires a good deal of confidence that one can in fact alter such lifestyles before successful intervention is possible” (p. 179). Therefore, the HBM and self-efficacy can work hand-in-hand to determine women’s barriers to healthcare with regard to urinary incontinence.

According to Bowers (1980), some of the questions implied by the HBM are:

1. Do the patients themselves believe they are ill?
2. What do the patients perceive as the consequences of their disease?
3. What do the patients believe to be the effects of the suggested therapeutic regimen on their conditions?
4. What will prevent the patients from undertaking the prescribed action? How can it be avoided?
5. Does the condition generate benefits for the patient in a social sense?
6. What are the treatment options available to the patient?
7. Did the patient seek health care?
8. What are the economic considerations of the proposed regimens for this patient? (p. 45).

These questions helped guide the researchers in their interviews to discover potential barriers to seeking evaluation and treatment in women with UI.

As only a small portion of women seek health care assistance for UI, that “may reflect both reluctance to discuss the condition and a low expectation of benefit from treatment” (Yarnell et al., 1981, p. 73). A study by Thomas et al. (1980) concluded that “regular incontinence is common,...and...there may be considerable scope for improving its management” (p. 1245). Some investigators believe women with UI delay seeking treatment for a number of reasons including embarrassment, belief they will recover without treatment, fear of surgery, lack of education or information, low expectations of treatment benefit, and/or a belief that their symptoms are normal (Holst & Wilson, 1988; Norton et al., 1988). Holst and Wilson (1988) also found women 25 years old and younger were less likely than older women (greater than 75 years) to seek treatment for UI.

Many real and perceived barriers to seeking evaluation and treatment exist. This includes information and access barriers, attitudes toward health care providers and perceived psychosocial barriers. Used as a qualitative research tool, the Health Belief Model can be used to discover these barriers in a given population.

Physical Therapy

Urinary incontinence is not a normal part of aging (Kulpa, 1996; USDHHS, 1996). It is a treatable condition for which there are many treatment choices, not just medications and surgery (Kulpa, 1996). “Conservative management of urinary incontinence is the wave of the future” (Brubaker & Kotarinos, 1993, p. 672).

Conservative treatment for urinary incontinence has been in use since the 1940s, when Arnold Kegel reported that “...every case of genital relaxation...is benefited by physiologic therapy, which may be employed with preventive, curative, or palliative intent...” (1956, p. 546). He advocated physiologic therapy “...at any period of a woman’s life...” (p. 546), not just when symptoms become unbearable.

More recently, Wallace (1994) reiterated that an “emphasis should be placed on prevention of dysfunction through education and exercise before problems arise” (p. 459). She advocates promoting awareness and proper exercise with early education of children during bladder training and in schools, education of females in high-impact sports, adult fitness classes, and screening during regular pelvic examinations (Wallace, 1994, p. 468).

Many studies have been done on effective treatment for urinary incontinence symptoms. Kegel and others have advocated the use of muscle education, identification, and the use of biofeedback. Women are often unaware of the location and function of the pelvic floor musculature and require help identifying exactly which muscle they are using. Only 47% of subjects have ideal Kegel efforts and “...the improper exercise techniques observed could potentially promote the deficit responsible for incontinence” (Wallace, 1994, p. 475). Trained health professionals should help women appropriately identify and use their pelvic floor muscles.

Conservative treatment options should be the first line of defense against urinary incontinence (USDHHS, 1996). Health care providers such as physicians, physician assistants, nurse practitioners, and physical therapists should all play an active role in the prevention, evaluation, and treatment of UI. “The role of the obstetric and gynecologic physical therapists in the United States has expanded greatly over the last 15 years”

(O'Connor & Gourley, 1990, p. 13). Women's health is a natural area of practice for physical therapists because of the muscle physiology and mechanics of the striated muscles of the pelvic floor (Brubaker & Kotarinos, 1993; O'Connor & Gourley, 1990). Physical therapists can utilize their extensive training in muscle disorders to accurately assess pelvic floor strength and select appropriate treatment (Brubaker & Kotarinos, 1993).

Summary

While there is extensive research on urinary incontinence, very little of the research focuses on nulliparous women and the barriers to seeking evaluation and treatment. Most studies provide statistics on prevalence and populations, yet offer limited insight into the attitudes and feelings of incontinent women on seeking help. The above literature review reveals the importance and need for a study of nulliparous women with incontinence and their barriers to seeking evaluation and treatment. The researchers believe this study will benefit those women with UI, as well as health care providers who treat them.

CHAPTER 3 METHODOLOGY

This research design was a sequential combination and triangulation of qualitative and quantitative methods. In sequential triangulation the “results of one method are essential for planning the next method” (Morse, 1991, p. 121). A primarily qualitative approach best suited this research due to the sensitive nature of the topic and the need for insight into the attitudes and feelings of the participants. Quantitative surveys were completed and studied before qualitative interviews began. The surveys were used to identify participants for the study. Confidential individual interviews were utilized to generate themes about the perceived and real barriers to seeking evaluation and treatment by nulliparous women with urinary incontinence. Discovering the incidence and prevalence of incontinence relied on the truthfulness and accuracy of the subjects. “Diokno et al. found an 83% agreement between self reports about incontinence and clinician assessment” (Sandvik, 1997, p. 2). The study was approved by the Grand Valley State University Human Subjects Review Board prior to implementation.

Sample

The interview sample included 17 nulliparous women with symptoms of urinary incontinence. They were chosen from approximately 410 surveys distributed to female faculty, staff, and students at Grand Valley State University (GVSU), and some community members in Southern Michigan. The names were semi-randomly chosen from

the GVSU Faculty and Staff Directory and a list of all female undergraduate students obtained from the GVSU Academic Records Office. Most women were health professional students or health professionals. To eliminate the possible confounding factor of economic status and health insurance coverage, participants were asked on the survey if they have health insurance and were excluded if they did not.

From the survey responses, 19 participants were selected for confidential individual interviews. Of those, 17 were audiotaped, transcribed, and used for data analysis. Criterion sampling, a purposive sampling strategy, was used to determine which participants were eliminated (Erlandson, et al., 1993). Only cases that met the inclusion criteria were selected for interview. The inclusion criteria were women with no reported pregnancies, with health insurance, reported incidence of UI, willingness to participate in the interview, and between ages of 18-55 years old. For the purpose of this research, UI was defined as any accidental urine leakage.

The number of interview subjects was limited by the time frame available for the study and the desire to get as much information as possible from each interview. The small number of subjects allowed in-depth interviews, which provided rich and valuable information (Erlandson et al., 1993). Purposive sampling rather than random sampling was used because the "...major concern is not to generalize the findings of the studies to a broad population...but to maximize discovery of the heterogeneous patterns and problems that occur in [the]...particular context under study" (Erlandson, et al., 1993, p. 82). Purposive sampling seeks "...sources that will most help to answer the basic research questions and fit the basic purpose of the study" (p. 83). Participants were selected because their cases are "...information-rich...[and]...one can learn a great deal about issues

of central importance to the purpose of the research...” (p. 82). The data collected through interviews was ripe with insight into the attitudes and feelings of this participant group, and provided basis for further research.

Instruments

A confidential survey and explanatory cover letter were the instruments that determined the selection of interview participants. Some survey questions were formulated from those used by several researchers in past studies of UI (Crist, Shingleton, and Koch, 1972; Iosif, Henriksson and Ulmsten, 1981; Jolleys, 1988; Nemir & Middleton, 1954; Scott, 1969; Wolin, 1969). These researchers studied the incidence and prevalence of urinary incontinence in various populations. Questions were developed for the purpose of discovering nulliparous women with a history of UI. The survey consisted of ten questions and was distributed to 410 members of the described population. The questions were four yes/no, four short responses and two to obtain demographic information. Participants were asked if they were interested in participating in a confidential individual interview, and if so, to write their name, phone number, and best time to be contacted at the bottom of the survey. Surveys were returned in a sealed envelope to ensure confidentiality of responses (see Appendixes A and B).

The 17 participants obtained from the surveys were each interviewed by one of the two researchers. Interviews were developed using questions implied by the Health Belief Model (Bowers, 1980) and modified by the survey responses. The questions were expanded to glean information to develop themes regarding real and perceived barriers to

seeking evaluation and treatment of UI. Interviews were audiotaped and transcribed without names to ensure the anonymity and confidentiality of participants.

A pilot test of the survey questions was conducted prior to mass distribution. Four surveys were sent to nulliparous women between the ages of 18-55 to establish the face validity of the survey and to improve questions and format (Creswell, 1994). Comments obtained from the pilot study were utilized to revise the instrument before final distribution. After the collection and compilation of surveys, interview questions were determined and piloted on four nulliparous women with complaint of UI symptoms. Each researcher interviewed two of the women with the other researcher present to observe interview techniques. Following the interviews, techniques were discussed and refined for consistency between researchers. Information gathered from the pilot was used to modify and clarify interview questions before the 17 participants were interviewed.

Procedures

Informed consent was obtained from each interview participant through written forms requiring a signature (see Appendix C). The format was semistandardized interviews, in which participants were asked 11 predetermined questions (see Appendix D). The interviewer was also able to probe beyond the given answers (Berg, 1989). Interviews were one-on-one sessions, lasting 20-30 minutes each. They took place in either the Grand Valley State University Physical Therapy Department or location of the participant's choice, based on the convenience and comfort level of the participant. Interviews were audiotaped and transcribed to provide an accurate description and to give

credibility to the study (Erlandson et al., 1993). Member checks were performed by sending the transcriptions back to each subject for verification. This further supported the credibility of the research. Each participant was assigned a code to ensure anonymity during data analysis.

Trustworthiness

Using interviews to collect raw data requires the use of a human instrument -- the interviewer. Establishing the trustworthiness of a human instrument is much the same as a paper-and-pencil instrument and can be refined just as easily (Lincoln & Guba, 1985, p. 194). The individual interviewers functioned adequately as human instruments following training guided by an experienced mentor (p. 195). The interviewers agreed on specific interview questions and where they might lead. If a participant was not giving detailed answers to the questions, the interviewer was allowed to ask her to expand or explain her response. The researchers also reviewed individual surveys during the interview, and used those responses to probe for further information. They agreed on a neutral tone to use and non-verbal messages to avoid. No information regarding UI was given to the participants prior to the interview. If the participants had questions about evaluation and treatment, they were answered after the interview was completed. The two interviewers were instructed and guided by the committee chair to increase the reliability between interviewers.

Trustworthiness was further built during the implementation of the research. Each investigator maintained a field journal containing three different types of entries. First were field notes taken after interviews or observations. A log of day-to-day activities

containing dates and times was also kept by each investigator and resembled a calendar of appointments. Finally, a methodological log was kept by one inquirer in which methodological changes were recorded as the design emerged (Lincoln & Guba, 1985). These logs, along with the transcribed interviews, data analysis notes, and pilot surveys and interviews, provided an audit trail which "...may be the single most important trustworthiness technique available..." (p. 283).

Another source of trustworthiness was triangulation of multiple and different sources (Lincoln & Guba, 1985, p. 305). The 17 transcripts served as multiple copies of the same type of source, while the interview transcripts, surveys, and field notes acted as different sources of information to compare. Interview transcriptions were compared and individual responses were used to credit each other. Similar responses were grouped together as themes. The interviews were also checked against the surveys, using different sources of the same information to triangulate the results (Lincoln & Guba, 1985). Triangulation was further reached by using two investigators to do interviews and to keep field journals that were later compared.

Peer debriefing was done with members of the research committee who acted as "...noninvolved professional peer[s] with whom the inquirer(s) can have a no-holds-barred conversation at periodic intervals" (Lincoln & Guba, 1985, p. 283). These debriefings included questioning of the inquirers as to their methods, expectations, and time line. Notes were taken during debriefings by both the inquirers and the committee chair to be included in the audit trail (Lincoln & Guba, 1985).

Member checks were done to establish the credibility of the interview information. Each transcript was sent back to the participant to be reviewed for accuracy and to ensure

that the participant's views were expressed adequately. Each participant was provided with a stamped, addressed envelope to return the transcript and their comments.

According to Lincoln and Guba (1985), "...the investigator[s] [are] not bound to honor all criticisms that are mounted, but [they are] bound to hear them and weigh their meaningfulness" (p. 315). All comments were noted and accounted for in the data analysis.

These steps were undertaken to provide credibility, transferability, dependability, and confirmability of the study. This established trustworthiness, and therefore, usefulness of the results of the study.

Data Analysis

Data analysis was conducted concurrently with data collection, interpretation and narrative report writing. Simultaneous analysis allowed emerging themes to be identified from the surveys and interview material. The qualitative analysis provided an abundance of information that was reduced into categories, patterns or themes. To accomplish this, content was analyzed and "coded to identify themes that seem meaningful" (Berg, 1989). Once reduced, the information was interpreted with "the final goal...[as] the emergence of a larger, consolidated picture" (Creswell, 1994). This larger picture is presented in a grounded theory. The information gathered provided a thick description to generate theory for further testing and give transferability to the study.

Analysis of unstructured data obtained from interview transcriptions was accomplished through a series of eight steps developed by R. Tesch. These are:

1. Get a sense of the whole. Read through all of the transcriptions carefully.

...jot down some ideas as they come to mind.

2. Pick one document (one interview)...go through it, asking..., What is this about? Do not think about the “substance” of the information, but rather its underlying meaning.
3. When you have completed this task for several informants, make a list of all topics. Cluster together similar topics. Form these topics that might be arrayed as major topics, unique topics, and leftovers.
4. Now take this list and go back to your data. Abbreviate the topics as codes and write the codes next to the appropriate segments of the text. Try out this preliminary organizing system to see whether new categories and codes emerge.
5. Find the most descriptive wording for your topics and turn them into categories. Look for reducing your total list of categories by grouping topics that relate to each other. ...[D]raw lines between...categories to show interrelationships.
6. Make a final decision on the abbreviation for each category and alphabetize these codes.
7. Assemble the data material belonging to each category in one place and perform a preliminary analysis.
8. If necessary, recode...existing data (Creswell, 1994, p. 155).

These eight steps created a systematic process to analyze contextual data.

Throughout the entire process, the investigators kept field notes, audiotapes, methodological notes, and pilot forms as an audit trail to provide dependability and confirmability of the research (Lincoln & Guba, 1985).

Limitations

The very nature of this study presented some limitations. The topic of urinary incontinence is sensitive, and as discussed previously, can be a taboo topic. This may inhibit individual willingness to participate in open and frank discussion of incontinence. Those participants who are very willing to discuss the subject may also be inclined to seek treatment for their symptoms. Conversely, incontinent women might not answer truthfully or deny UI due to embarrassment or concomitant handicaps (Sandvik, 1997). Targeting participants who will share the sources of barriers to seeking treatment might be difficult.

A small sample size was used due to time constraints and difficulty locating women who were willing to share stories about urine leakage. The use of a small participant group, limited to Southern Michigan, also prevents generalization to other populations. The use of only women with health insurance eliminates the confounding factor of health insurance but also greatly limits generalization to other populations. Another limitation can be the interview process.

Interview methods make it possible to explore issues in greater detail, and... generally get higher response rates than...questionnaires. On the other hand, interviews are less standardized. Yarnell et al. used five interviewers, and found that the prevalence reported by each interviewer ranged from 29% to 51%. There is also the possibility that responses elicited by interview are most susceptible to social desirability bias than those elicited by post [mail] (Sandvik, 1997, p. 3).

It was hoped that with a small sample size, rapport was built between the participant and interviewer to get the most accurate response. Using two interviewers and a semistandardized format also provided more consistent reporting.

CHAPTER 4 RESULTS

Approximately 410 surveys were distributed to students, faculty, and staff at Grand Valley State University and other community members in Southern Michigan. The rate of return for the surveys was 32% or 132 surveys returned. Out of the responses, 33% replied they never had an incidence of UI and 33% replied that they had been pregnant. These respondents were excluded from the study. The remaining 33% or 44 respondents were nulliparous women who reported episodes of urine leakage. Of those, 21 agreed to be interviewed for the research project. Their ages ranged from 23-52 years old, with the majority between 20-35 years old. Survey responses did not reveal any significant information regarding UI and trends in occupation, activity level, or circumstances that trigger UI symptoms.

Due to time constraints, 19 of the 21 participants who agreed to be interviewed were purposively chosen. They were chosen because of their survey responses, and they were the first 19 who were available to interview. Of the 19 interviews, 17 were viable for data analysis and two were unsuitable due to poor tape quality. The viable interviews were audiotaped, transcribed, and coded to ensure anonymity. Each researcher received a copy of the 17 transcripts for individual data analysis, then independently reviewed the transcripts and developed coding to identify common concepts. The researchers used a variety of categorization methods, which included color coding, numerical and alphabetical assignments, and cutting and pasting. Data categories were then compared

and themes evolved. Themes identified independently by each researcher were correlated and merged into a single set. The data analysis revealed themes about real and perceived barriers of urinary incontinence that corresponded with Becker's Health Belief Model. The HBM "...attempts to explain the health behavior of individuals...[and]...is helpful...in particularly difficult patient education situations," such as dealing with urinary incontinence (Bowers, 1980, p. 42). The perceived barriers component of the HBM provided a base to analyze the reasons why people do not seek health care for incontinence. Four categories and 13 themes regarding reluctance to seek treatment for UI emerged as a result of the data analysis. The categories were information barriers, access barriers, psychosocial barriers, and feelings regarding health care professionals. Specifically, those themes that made up information barriers were: UI is normal, women do not recognize UI as a treatable problem, they consider it to be a natural part of aging, and they did not intend to seek medical treatment or advice unless the symptoms increased over time. They also contended that there is not enough public information and education regarding UI. Other themes that emerged as access barriers were time and money factors. Psychosocial barrier themes included embarrassment and life style modifications. Attitudes about health care professionals were also themes among the women.

Themes that emerged as information barriers included the mistaken belief that UI was "normal," and the women who participated in the study did not recognize UI as a treatable problem or illness. This reflects Bandura's concept of self-efficacy as the participants did not realize they could implement a change in their lives. Many of the women felt occasional leakage was a normal part of the aging process and they did not

intend to seek help until it got worse, which they fully expected it would. Participants stated there was not enough public information and education regarding UI, and expressed a desire to know they “were not the only ones.” This agrees with Ashworth and Hagan’s qualitative study on non-geriatric women (1993), in which their participants, “...routinely assumed that no one else had incontinence – or their particular version of it – and they feared they would be ‘horribly unique’ if discovered” (p. 1419). These ideas are contrary to the literature, as the researchers noted previously that UI is common but should not be considered normal. UI is treatable and not a normal part of the aging process.

Access barriers were defined as time and economic factors. Subjects validated this definition by expressing difficulty with the time it would take to drive to a clinic and the number of times per week they might need to be treated. Economic factors included time off work for appointments and insurance issues, such as co-pays, no coverage, or out-of-pocket expenses.

The primary psychosocial barrier revealed in this research was embarrassment about UI. This included embarrassment when there was urine leakage in a public place and when lifestyle changes occurred. Surprisingly, discussion about UI with interviewers was not an embarrassment issue with the majority of participants.

Several themes emerged involving the feelings of the participants toward health care professionals. Many of these women would refer a friend with UI to a doctor but would not undertake the action themselves. Fourteen of the women who participated had not asked their physician or other health care professional for help regarding UI. They stated that they would not be embarrassed to bring up the topic with a health care professional

when or if their UI symptoms increased. The participants also expressed the belief that it is the health care professional's job to broach the topic verbally or on patient history forms filled out prior to examination.

These themes that emerged from the data analysis helped to answer the questions guiding the research as stated in the purpose. Those questions were: Do incontinent women seek professional help? Whom do they consult, and what response do they receive? If they are not consulting a professional, why? From the study, a grounded theory was derived by "comparing incidents with incidents until categories emerge[d]" (Creswell, 1994, p. 156). This was accomplished through the sampling of interviews which led to the development of categories (Creswell, 1994). The grounded theory described the real and perceived barriers to women seeking evaluation and treatment for UI. The general statements and grounded theory are presented in the discussion section.

The interviews with 17 nulliparous women complaining of symptoms of UI provided information rich with themes regarding their individual feelings about barriers to seeking evaluation and treatment of urinary incontinence. Interviews gave the participants the freedom to express their thoughts on UI and how it affects their lives. Analysis of these thoughts allowed the researchers to identify prevalent themes of this section of women, supplying insight into real and perceived barriers.

CHAPTER 5 DISCUSSION

Discussion of Findings

“The Health Belief Model suggests an explanation for health behavior...Most actions have both good and bad consequences. How a patient will view potential consequences depends on his individual outlook” (Grosser, 1982, p. 1056). An individual’s outlook can be influenced by her feeling (or lack) of self-efficacy. The HBM and the concept of self-efficacy can be used to explain, predict, and influence health behaviors. In this research, themes that emerged to form the grounded theory were a result of the individual experiences of the 17 women interviewed.

Information Barriers

One common theme was the presence of information barriers to seeking evaluation and treatment. As previously stated, information barriers “...prevent women from recognizing illness or knowing how to prevent and treat it appropriately” (AbouZahr, Vlassoff, & Kumar, p. 451). This manifested itself in the prevailing belief that UI is normal and not a treatable problem or illness. Contrary to researchers’ expectations, most participants did not consider their UI symptoms a problem. One participant commented, “...it never even dawned on me that this is an issue.” Another said, “I didn’t really know much about it...I didn’t realize that it was treatable. I just assumed it was something that women had to deal with.” A third stated, “Well, I always thought it was something normal. You just get used to it...I would just say that it is normal as far as I know.” In

general, most participants did not recognize UI as a health problem that could be addressed.

The women shared a common assumption that UI was a natural part of the aging process. For that reason, UI was something to which they expected they must adapt and they did not seek treatment. As an example, one participant said, "I don't really think of it [UI] as a problem now, but I just think that as I get older and have kids...I think of it [UI as a problem] then." Another woman said, "...I thought as you get older, this is a common problem for women over 45." Yet another stated, "I thought it was like getting wrinkles and whatever else happens [as you age]." At this point in their lives, most of the participants chose not to seek help because they felt UI was a normal existence for them and felt no perceived ill effects of lifestyle changes.

Nine of the women stated if the problem got worse with age (such as increasing frequency or visible leakage), that they would need to seek help. Rosenstock, Strecher, and Becker (1988) stated,

...individuals...will attempt to change if they believe that (a) their current lifestyles pose threats to any personally valued outcomes, such as health or appearance; (b) that particular behavioral changes will reduce the threats; and (c) that they are personally capable of adopting the new behaviors (p. 176).

These women did not express a desire to change behavior by seeking treatment because they did not feel that they were experiencing a serious threat to "any personally valued outcomes" at this time. This lack of action can also be explained by the perceived severity aspect of the HBM. Although not originally addressed in the framework of this research, perceived severity emerged from the interview responses. This component of the HBM is

“the patient’s perception of the severity of the disease or condition. If the patient doesn’t believe the disease or condition is serious, she is not likely to take action...” (Grosser, 1982, p. 1056). The above barriers – UI is normal, UI is not treatable, and UI increases with age – are contrary to the literature. The USDHHS Clinical Practice Guidelines (1996) “recommends that the public be advised to report incontinence problems once they occur and be informed that incontinence is not inevitable or shameful but is a treatable or at least manageable condition” (p. 5).

Participants did not feel their present conditions were severe enough to seek treatment. One woman reported, “I would wait until I was really having problems...I’d put it off and say, ‘Oh, it’s not that bad.’ Until one day it would get so bad that I would have to go do something about it.” Another said, “I guess I have thought about if it gets worse I will [seek help], but not at this time...If it happened more frequently and if the leakage did have more quantity...so that it would become an embarrassing problem. But I don’t have that problem as of yet, so until it happens...” A third mentioned, “If it got a lot worse, I would definitely need to do more about it.”

Previous research by Skoner (1994) found that “some women had limited knowledge about urinary incontinence” (p. 341) and that “knowledge about incontinence varied” (p. 342). Consistent with Skoner’s research, this research found that women feel they need more education regarding UI and that public information should be provided to women concerning this issue. “I mean, I don’t think that anybody knows where to go for this problem,” was one comment. Another woman said, “I think that people in general need to know more about it, because I think that the way that the media portrays it, women assume that it is something that happens as we age...and that they just have to deal with

it...[There] needs to be more education, I guess, in society, so that they understand that it is something...treatable." A final comment: "In fact, when it first started happening, I had no idea that it was actually a problem that you could do something about. So I think education is important."

Many participants offered recommendations for better public information. "Maybe some commercials on TV so that women...have an idea that it is treatable, so that maybe it is talked about a little more." Another said, "If maybe I read an article or heard somewhere that [UI] was not normal..." Others suggested materials such as posters, signs, brochures, or pamphlets. "I think that once people know that it's out there, I think people are more apt to go get something done about it...[For example] everyone knows about overuse injuries so they're not so afraid to go to the doctor because they have carpal tunnel or tingling in their hands."

These women also felt that public acknowledgment would increase awareness that UI is a common problem affecting many. Research participants felt that if they had known UI was a common treatable problem, their overall embarrassment would be decreased and approaching a health care provider would be easier. One woman said, "...knowing that it is a common problem would probably make me feel like it was o.k. that it was happening." Another reported,

If more information was out there...so that you don't feel like you're the only one who has the problem. If you knew that it was more typical...[then] people would talk to you about it [and] they wouldn't look at you funny and say, 'Boy, you pee your pants.'

A third participant stated,

I think maybe if they would put it on those physical forms or something...I think that

sometimes when you see it in writing, like it's a check yes or no if you have ever had the following condition...I think that makes you feel more normal...If it's on there, then obviously other people have had this same problem.

Access Barriers

Another theme that emerged was access barriers. "Access to health care is determined by physical and logistical factors" (AbouZahr, Vlasoff, & Kumar, 1996, p. 455).

Examples of logistical factors are time and money, which were identified by women in this study as primary access barriers. They felt that getting treated for UI might involve a large time commitment. When asked about obstacles to treatment, the participants said "[A]...detriment...is the time commitment" and "taking the time to get it done and taking the time to deal with it." Another said, "I don't have time to deal with that right now, I have to deal with my normal life." Most spoke about taking time off work, commuting to a clinic for treatment, and the number of treatments per week.

Although the confounding factor of having no health insurance was removed through the inclusion criteria, participants still expressed a financial concern and were uncertain of insurance coverage for treatment of UI. "It could probably be costly if it is not covered by insurance...I don't even have insurance that I think would cover [UI]." Others said detriments to seeking treatment were "...any cost if they don't have medical insurance" and "having to pay for it. I don't know what kind of insurance coverages there are for this kind of thing." Participants said the issues regarding coverage, co-pay, or out-of-pocket expenses would be barriers.

Psychosocial Barriers

Psychosocial issues developed as a final barrier to seeking evaluation and treatment. These barriers were primarily the result of embarrassment at different levels. “[M]ost affected individuals do not seek help for incontinence, primarily because of embarrassment or because they are not aware that help is available” (USDHHS, 1996, p. 3). Women involved in the study found incidences of leakage in public to be sources of self-consciousness and these incidences left powerful memories. Participants also found the idea that they did not have control over urinary continence at a young age to be disconcerting and revealing this to people would be undesirable. Ashworth and Hagan (1993) stated the “meaning of incontinence is inextricably linked to the idea of lack of control...[M]any adults who develop incontinence feel this symbolizes a threat to their maturity” (p. 1417). Participant statements included: “...emotionally it’s kind of a little...scary...and it’s embarrassing is probably what I would say is...my main reason for not [seeking treatment].” “Embarrassment. I think that is probably the biggest [reason]. I’m...29 and to think that I have this problem is kind of embarrassing. I have to face it.” “I feel like I am too young to be having these kinds of troubles.” Finally:

I think that there [is]...a certain amount of shame...Urinary continence is such a basic function that to actually verbally admit that you don’t have the control over that anymore, I think that would be very disturbing for most people.

Researchers’ field note reflections indicated that a few participants appeared hesitant, nervous, and embarrassed while answering interview questions. However, most participants seemed comfortable and honest with their answers as demonstrated by their detailed responses.

In Skoner's research (1994), participants reported behaviors representing life style changes. These included (1) modifying or avoiding activities associated with a loss of urine, (2) keeping the bladder empty, (3) avoiding or limiting beverages that stimulate voiding, and (4) wearing protective pads (Skoner, 1994). While the participants stated they had not made any lifestyle changes, further probing revealed subtle changes the women had already made. Examples of these changes were, "I may take more regular trips to the bathroom," "I just make an effort to go to the bathroom more frequently," and "I wear a light, thin pad when I play softball." Another stated, "I just feel it and...stop my activities and...change my level of activity to accommodate." One woman said UI had not affected her lifestyle, but went on to say,

If I'm working out and have to go...it's...on my mind...so I have to stop my activity and go. I won't run...If I feel the urgency on the Stair Master, I will go to the bathroom because I just can't handle that feeling.

Finally, "It is inconvenient because I wet my exercise clothes and I feel like I need to go change before I can finish my workout...and obviously that [is]...a problem." Although many participants did not feel that UI was having a major effect on their lives, they cited various examples of modifications they had already made to their activities and lifestyles.

Health Care Professionals

Although the researchers proposed that health care professionals' reluctance to address incontinence with nulliparous women would be a barrier to women seeking help for UI, women in this study did not cite health care professionals as a major barrier. In fact, most participants stated that they would recommend that a friend with symptoms of UI contact

her physician for advice. Several also said that they would not be opposed to talking to their physician if UI became more of a problem in their lives. One woman commented, "I don't see them [health care professionals] as unapproachable...I have never been timid with my health care provider." Another said, "I don't think that I actually need encouragement to talk to my doctor...I'm not embarrassed to talk to my doctor about anything."

Three participants discuss UI with their health care professional. Two spoke with their physicians and one to a physical therapist. The two who had approached their physicians suggested that women should be more aggressive in requesting treatment because their experiences had not stimulated adequate responses from their physicians. One physician and the physical therapist verbally instructed the women to do Kegel exercises, the other physician "didn't say a whole lot. She just made a mental note...that was about it...She didn't give me any recommendations at all." Research has "concluded that simple verbal or written instruction does not represent adequate preparation for a patient who is about to start a Kegel exercise program" (Bump, Hurt, Fantl & Wyman, 1991, p. 322). The three participants reported though, that they would not feel the need to find a different health care professional to approach next time. One woman revealed that she would not see her physician for UI, she would first attempt to address the problem herself. The reason she would not choose to seek advice from her physician was, "I would almost think that the doctor might blow it off, like it wasn't very important."

Despite the fact that most of the women stated they would approach a health care professional if they felt they needed treatment or advice for UI, many also reported that they would prefer if the health care professional broached the subject with them during a

regular examination. They felt the situation would be easier to discuss if the health care professional brought it up and let them know that UI is not an unusual problem for nulliparous women. For example, one participant said, “I think that that would be much...easier if the health care person...[brought] it up. You would obviously think that it is more common if they [brought] it up.” Another commented “I think if they [health care professionals] could be pro-active. If they could...(especially if it was a pelvic examination) mention, ‘have you had any kind of incontinence?’ Have them ask the patient the question and not put the patient in an awkward position.” One woman, when asked what would make health care professionals more approachable, responded, “I suppose that...when patients are going in for a physical or yearly exam... something that would help would be if that were a question that was asked, rather than the patient having to bring it up.” Although the women expressed a preference for health care practitioners to discuss UI first, the USDHHS (1996) concluded, “...evidence exists that practitioners are hesitant or ill prepared to discuss, diagnose, or treat the problem” (p. 3).

Only one participant did not agree with health care professionals taking the initiative. She stated, “I think it is the concern of the patient to act...My point of view is that if I go to the doctor...[and] I have concerns...I would address them.” However, she also felt that other women might be too embarrassed to bring up UI during an exam and would benefit from questions either on a medical history form or directly from their health care professional.

The participants in this research gave conflicting responses in regard to health care professionals as a barrier. Most did not find the idea of approaching a health care professional to be a significant barrier to seeking treatment for UI, but acknowledged that

they had never asked a health care professional about UI. They also reported that they would recommend that a friend talk to her physician if she had symptoms of UI, but had not taken this action themselves. They also suggested that seeking treatment or advice would be much easier if they did not have to broach the subject themselves and expose themselves to possible embarrassment or dismissal by the professional. This is supported by Bandura's concept of self-efficacy in which women who do not believe that they can make a significant change in their health status they will not undertake health-seeking behaviors.

Theory Development

In qualitative research, grounded theory evolves from the categories and themes derived from the data analysis. The Health Belief Model provided a valid framework that led to the theory that each woman's experience with UI is different. Each woman requires an individual approach to evaluation and treatment of UI. Not only does this suggest the need for individual approaches to evaluation and treatment, but more universal issues, deep-seated in the attitudes of society toward women. This research reflects a subtle, hidden cultural bias of health care practitioners toward women. AbouZahr, Vlassoff, and Kumar (1996) discussed the position of women in the health care continuum. They stated that women tend to be the primary health care providers for their families, and "in clinics, women are faced with a 'top-down' situation in which they are told what to do and dialogue is discouraged... Thus, the possibility of effective action is taken out of women's hands, and they are left powerless in an area where they once had considerable autonomy" (p. 456). Over the years, women's roles in society have grown, but this

research implies there is still an unresolved gender bias in health care towards women. This provides validity for education, future studies, and therefore empowerment of women to carry out positive health seeking behaviors.

Application to Practice/Education

Implications for application to practice and education can be extrapolated from this research. This research demonstrated the need for both health care professionals and women to be involved in education regarding UI. Health care professionals should be aware of the prevalence of UI in nulliparous women, the feelings of women regarding UI, the need for education, and evaluation and treatment techniques.

Education about UI for professionals, paraprofessionals, and survey teams is urgently needed. First and foremost, information about UI should be included in the curricula of undergraduate and graduate health care professional schools. Schools of nursing and physical therapy and for physician assistants should consider educating specialists on incontinence care who can then serve as expert advisors to other health care providers regionally, on the [s]tate level, in teaching hospitals, and in every nursing home (USDHHS, 1996, p. 62).

It is hoped that health care professionals, when functioning as health educators, can utilize the HBM to identify the educational needs of their patients (Rosenstock, Strecher, & Becker, 1988). Health care professionals can "...ascertain...which members of the target population are interested in health matters, feel susceptible to a serious health problem...and believe that the threat could be reduced by some action on their part, at an acceptable cost (Rosenstock, Strecher, & Becker, 1988, p. 181). As patient advocates,

members of the health care community have a responsibility to promote wellness and prevention information.

Health care professionals and others who work with nulliparous women can utilize the findings of this research as a basis for understanding and education. Although this research cannot be applied to the general population, it lends itself to insight into the feelings of nulliparous women with UI. Armed with this information, health care professionals can feel more comfortable in approaching women and guiding them to the proper treatment for their symptoms.

“Teaching should be a collaborative effort involving medical, nursing, and allied health care providers working with education and communication experts and local, regional, and national government employers. Education should be individualized for each patient...” (USDHHS, 1996, p. 61). Physical therapists should be a vital part of this collaborative effort and they can utilize this information gained from this study to enhance their role on the health care team. Physical therapists have many opportunities to educate women in clinics, hospitals and nursing homes, as well as the general public and other health care practitioners. Physical therapists active in women’s health have a responsibility to advocate evaluation and treatment for UI and actively seek referrals from physicians.

“It would appear that the object of patient education, as prescribed by the HBM, is to afford to the patient an awareness of the presence of illness and available treatment options, as well as the potential consequences of the treatment and disease” (Bowers, 1980, p. 46). The researchers feel that nulliparous women and health care professionals such as primary care physicians, physical therapists, RNs, athletic trainers, and other

professionals dealing with young women, would benefit from education regarding UI. With this awareness, nulliparous women will know their problem is not unique and is treatable at any stage.

Limitations of the Study

There were several limitations to this study. They included a small sample size largely composed of physical therapy students and women with advanced education in a limited geographic area. The health care education of many of the participants may have influenced the direction of the results of the study, therefore the results cannot be applied to the general population. Many of the participants were also familiar with the researchers. This could have acted as a benefit since little rapport-building was needed, but could also have been a detriment due to the discomfort of sharing experiences of UI with an acquaintance. Overall, not knowing the effect of familiarity on the responses was a limitation.

Of the 44 surveys returned that met the inclusion criteria, 23 declined to be interviewed. The sensitivity of the topic and the overall feelings of women toward UI and discussing the subject one-on-one likely decreased the number of participants. According to survey responses, most of the participants were not severely affected by UI. Most of these respondents appeared to be reasonably comfortable discussing UI with the interviewers. It is possible women with more severe UI either did not return surveys or declined interview because of their comfort level.

Time constraints also restricted the research by reducing the population from which the researchers could draw and the number of interviews possible. Needleman and

Needleman (1996) state, “Social scientists doing field studies often find that the data revealed to them initially are very superficial, and that an entirely different picture emerges as the research subjects feel more confident in making sensitive disclosures” (p. 332). In this study, only one short interview was conducted with each participant. This might not have given the participants enough time to develop rapport with the interviewers to reveal their true feelings.

Another limitation was the human aspect of the study. This included the researchers’ inexperience in qualitative studies, interview techniques, and the nature of the data analysis. Qualitative data analysis is “...messy, ambiguous, [and] time consuming...It is not neat (Erlandson, Harris, Skipper, & Allen, 1993, p. 111).

Transcription of audiotapes was not error free due to tape quality, the speed of casual conversation, and grammatical differences between verbal and written communication. This made the member check difficult for participants, as they felt compelled to correct grammatical errors in the transcripts. Despite these limitations, the researchers felt the themes that evolved provided a plausible framework for further research.

Suggestions for Further Research

This study opened up the possibility for other researchers to continue studies regarding nulliparous women with urinary incontinence. In this research, nulliparous women shared their feelings regarding UI and health care professionals. Studies involving health care professionals could provide a different perspective on urinary incontinence and nulliparous women. Directions of research might be: information regarding patient inquiry by practitioners, their knowledge of diagnosis and treatment, incidence of referral,

awareness of physical therapy treatment advances in this field and other conservative approaches. Another study could be done on the need for UI in the basic education programs of health education professionals

This particular study could be replicated using different populations. These could include a larger population with diverse backgrounds, (such as educational and economic levels), different age groups, duration of UI, and groups tailored by type of incontinence. Other modifications of this study would be longer interviews over a span of time, with more specific questions of participant's knowledge of physical therapists involvement with UI treatment. Comments made by some participants expressed an interest or concern regarding sexual activity and incidence of urine leakage.

A combination of qualitative and quantitative studies based on actual versus perceived amount of leakage during episodes of UI could be developed to explore more deeply the perceptions of women about UI. Further research could also involve the use of efficacy studies comparing perceptions and beliefs of women to health care providers. Pure quantitative studies could be utilized based on this research by incorporating pelvic floor exercises into women's fitness classes and analyzing results.

Conclusion

The results of this study conclude that nulliparous women with urinary incontinence do not feel they have a problem, that urinary incontinence is normal to them, and they are not aware of conservative approaches to treatment. The research demonstrated the need for education of both nulliparous women and health care professionals on prevalence and treatment of UI. Health care professionals need to promote self-efficacy in their patients

for the patients to be successful in the management of their problem (Rosenstock, Strecher, & Becker, 1988). Kasal and Cobb note that “successful treatment almost always depends on the initiative of the patient in seeking diagnosis and treatment,” and this would develop from the motivation of educated professionals and patients (Bowers, 1980). It is the hope of the researchers that this study will be useful for practitioners wishing to further investigate urinary incontinence in nulliparous women, and that it may be applied to a larger social picture, as well as to individual women.

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Appendix A

Cover Letter

August 1997

To Whom It May Concern:

We are two graduate students in physical therapy at Grand Valley State University. We are conducting a study for our master's thesis on why women who experience accidental urine leakage do not seek health care assistance. We are targeting women who have had no pregnancies and have these symptoms of urine leakage. Through surveys and confidential interviews, we hope to discover some reasons why women choose not to seek treatment.

Enclosed is a survey on which we will base our interviews. We would like women between the ages of 18 and 55 years old and not currently being treated for accidental urine leakage to fill them out. Also enclosed are sealable envelopes to place each survey to ensure your confidentiality.

At the bottom of the survey is a space for name, phone number, and the best time to reach you, if you would like to assist us by participating in an individual **confidential** interview. By filling out this survey, you are in no way obligated to participate in an interview and you may choose not to put your name on the survey.

We greatly appreciate the time you are taking to help us gather information for our research. If you have any questions or concerns, please contact us.

Thank you very much for your assistance,

Roxanne Kudwa
616.895.3356

Kelli Thompson
616.895.3356

Cynthia Grapczynski, MS, OTR
Committee Chair 616.895.3356

Paul Huizenga
Human Subjects Review Board Chairman
616.895.2472

Appendix B

Survey

GRADUATE RESEARCH SURVEY

This is a confidential document. An envelope will be provided in which to return your response.

Age: _____

Occupation: _____

Do you have health insurance? yes no own spouse's parent's

Would you describe your job as: (Please check as many as apply)

active

sedentary

lifting (11lb.-10lb.)

lifting (greater than 10lb.)

operating heavy machinery

prolonged sitting

prolonged standing

other (please describe): _____

Have you ever been pregnant? YES

NO

IF YES, STOP HERE. IF NO, PLEASE CONTINUE.

Have you ever had an accidental loss of urine? YES

NO

If yes, circle which circumstances trigger this loss of urine (you may circle more than one answer):

Laughing

Coughing

Sneezing

Hearing running water

Excitement

Lifting

Climbing Stairs

Putting the key in door lock

Straining

Exercise

Fear/Nervousness

Other: _____

How often does this occur?

daily

weekly

monthly

every few months

once

Have you ever spoken with a health care professional (such as gynecologist, physician, nurse practitioner, physical therapist, or other) regarding involuntary loss of urine?

YES

NO

If yes, what was their response? _____

If no, why not? _____

Would you be willing to participate in a confidential individual interview to enhance our understanding of reactions to involuntary loss of urine?

YES

NO

If yes, please list your name and phone number, the best time to reach you, and an interviewer will contact you.

Name: _____

Phone Number: _____ Best time to call: _____

Thank you very much for your participation,
Roxanne Kudwa and Kelli Thompson

Appendix C
Informed Consent Form

I understand that this is a study of the perceptions of women on seeking evaluation and treatment for leakage of urine during the performance of activities. The knowledge gained from this study is expected to improve communication between health care professionals and their female patients, as well as increase general awareness of conservative treatment options for UI.

I also understand that:

1. I have been selected as one of 18 participants in this research because I completed a survey and reported that I *have not* had any pregnancies, that I *have* experienced unwanted urine loss during activity, that I am *not* currently undergoing any treatment for this condition, and that I *have* health care coverage.
2. participation will involve one 20-30 minute interview regarding my attitudes and feelings about urine leakage during activity, seeking health care assistance for it, or not seeking health care assistance.
3. this interview will be audiotaped and transcribed for accuracy.
4. following transcription and verification, audiotapes will be destroyed.
5. it is not anticipated that this study will lead to physical or emotional risk to myself.
6. the information I provide will be kept strictly confidential and the data will be coded so that identification of individual participants will not be possible.
7. a summary of the results will be made available to me upon my request.

I acknowledge that:

“I have been given an opportunity to ask questions regarding this research study and that these questions have been answered to my satisfaction.”

“In giving my consent, I understand that my participation in this study is voluntary and that I may withdraw at any time.”

“I have been given the phone number of Paul Huizenga, Chairman of the Grand Valley State University Human Subjects Review Board to contact him if there are any questions concerning my rights as a participant in this study.”

“I hereby authorize the investigators to release the information obtained in this study to scientific literature. I understand that I will not be identified by name.”

“I have been given the phone numbers of Kelli Thompson, Roxanne Kudwa, and their advisor, Cynthia Grapczynski, so I may contact them at any time if I have questions.”

“I acknowledge that I have read and understand the above information, and that I agree to participate in this study.”

Witness

(Participant Signature)

Date

(Date)

_____ I am interested in receiving a summary of the study results.

Appendix D
Interview Questions

1. On a scale of 1 (least control) -10 (most control), rate your own sense of control over urine leakage. Explain your rating.
2. Discuss what you know about urinary incontinence.
 - a. Where did you get your information?
3. In what ways do you consider urinary incontinence a problem?
4. Imagine a friend came to you with concerns about urine leakage with activity. What would you suggest she do to get help or deal with it?
5. Please complete the sentence: "The most powerful memory I have about an incidence of urine leakage is..."
6. In what ways has occasional leakage affected your lifestyle?
7. Have you ever spoken with a health care provider about urine leakage?
 - If yes,
 - a. Which provider?
 - b. What was the provider's response?
 - c. What was the outcome?
 - d. Would you approach a different provider next time?
 - If no,
 - a. Have you ever thought about approaching a health care provider?
 - b. What do you feel would encourage you to seek help/advice?
 - c. What would make health care providers more approachable?
8. What do you know about evaluation and treatments for urinary incontinence? What treatments that you know about do you think would be effective? Why?
9. What benefits do you think would you receive from seeking evaluation and treatment?
10. What detriments are there to seeking evaluation and treatment for urine leakage?
11. Would these detriments keep you from seeking treatment? Why or why not?