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Coping with urinary incontinence : a study of older women

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Coping with Urinary Incontinence:

A Study of Older Women

A Thesis

Presented to

The Faculty of the Department of Nursing

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In Partial Fulfillment

of the Requirements for the Degree

Master of Science

by

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May, 1989

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Abstract

Urinary incontinence is one of the leading problems in geriatric health care today. The purpose of this descriptive study was to explore the impact of urinary incontinence on the lives of older women. An interview guide was developed by the researcher. Nineteen women were interviewed. The subjects ranged in age from 41 to 88 years. The data was coded into 46 categories and analyzed using descriptive statistics and content analysis. Seven case studies were also presented and interpreted using the conceptual framework presented by Richard Lazarus. Significant findings supported those presented in the literature. There was often a significant delay between the onset of incontinence and reporting of symptoms to a physician. Approximately half of the women in the study remained incontinent despite treatment. Also, the women did report significant changes made in their daily lives to cope with their incontinence. The results of this study have significant implications for nursing in three areas: (a) improved case finding and referral of patients for treatment; (b) increased patient education and community education about the problem; and (c) increased nursing research in the area with potential for nurse-managed incontinence clinics.

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Chapter 1

INTRODUCTION

Urinary incontinence is one of the leading problems in geriatric health care today. It is often cited as the major reason given by caregivers when the final decision to institutionalize the older person has been made (Ourslander, Kane, & Abrass, 1982). It also predisposes patients to urinary and kidney infections, skin breakdown, and other medical problems (Mohr, Rogers, Brown & Starkweather, 1983).

Urinary incontinence is defined by the International Continence Society Standardization Committee as "a condition in which involuntary loss of urine is a social hygiene problem and is objectively demonstrable" (Palmer, 1985, p. 11). Despite estimates of high cure rates when assessed and treated properly, there remains a high prevalence of diagnosed and uncured women with urinary incontinence (Spiro, 1978). There is reason to believe that the number of undiagnosed incontinent women living in the community may be even higher due to lack of reporting symptoms to health professionals (Simons, 1985; Williams & Pannill, 1982). Many women find the problem to be an embarrassment and deny themselves the opportunity for cure (Yarnell, Voyle, Richards & Stephenson, 1981.)

Although minimal research has addressed the psychological and social implications related to the incontinent person's life, there has been much speculation about the suffering and behavioral changes that must be made by the incontinent person (Willington, 1976). It has also been reported that health professionals often regard incontinence as a hopeless, tedious, and undramatic problem (Hunter, 1977). The privacy with which women may handle this problem, the underreporting of symptoms, and the inadequate case management are all factors which contribute to the lack of knowledge about the human response of women to incontinence.

Statement of Purpose

The researcher will explore the human response of the incontinent woman to her incontinence. This includes ascertaining how she feels about being incontinent, what it means to her, and how she is currently coping with her situation. The purpose of this study is to increase the clinician's knowledge about incontinence so that he/she may more effectively deal with the problem in his/her practice. This study will not be able to make conclusions about efficacy of treatment choices. Also, it will not include women who have not reported their problem to a practitioner.

Problem and Research Questions

The clinician has little information about the needs of incontinent women due to lack of research in this area. It is frequently reported in the literature that there are substantial psychological, social and personal implications for the sufferer of urinary incontinence (Williams, 1983). Bartol (1980) describes the psychological implications of incontinence in elderly persons but also finds that no nursing research has been done in this area. Williams (1983) found that very little research had actually been done on elderly incontinent persons in the United States and that most of our information comes from England. It is also recommended in the article that research which provides more descriptive details of the incontinent person, both psychologically and functionally, would benefit the clinician.

The primary research questions are:

1. How does the incontinent woman perceive her incontinence to affect her well-being?
2. What behavioral changes in her daily life are due to her incontinence?
3. How has the incontinent woman chosen to cope with her incontinence?

The assumptions made by the researcher are that:

1. Women with urinary incontinence are likely to perceive it as a stressful event.

2. Urinary incontinence is a problem that has a capability to require some coping activity in the incontinent woman's daily life.

Definition of Terms

The terminology used in this study is defined by the researcher and the International Continence Society (Palmer, 1985) as follows:

1. Urinary incontinence is the involuntary loss of urine which is a social hygiene problem and is objectively demonstrable.

2. Stress incontinence is the involuntary escape of urine during any type of physical exercise. This includes coughing, sneezing, and changing positions.

3. Urge incontinence is defined as the involuntary loss of urine preceded only slightly before a strong desire to urinate.

4. Reflex incontinence occurs when the sensory pathways in the spinal cord are blocked and no desire to void or feeling of fullness precedes urination.

5. Overflow incontinence occurs when the bladder fills to capacity and yet the desire to void is impaired. The pressure within the bladder exceeds the urethral pressure

needed to maintain continence and urine spills out until this pressure gradient is resolved.

6. Stress appraisal as defined by Lazarus has three categories. They all involve some "negative evaluation of one's present or future state of well-being" (Lazarus & Launier, 1978, p. 303). The three categories are harm/loss, threat, and challenge with challenge having the least negative and most positive connotations.

Research Design

The descriptive research design was chosen to meet the goal of this research project which was to gain more information about the incontinent woman's life. The descriptive design is used when one attempts to "provide a picture of situations as they naturally happen" (Burns & Grove, 1987, p. 243). There was no manipulation of variables. A structured interview approach was used with closed-ended and open-ended questions. Multiple variables were looked at including perceived stress, coping methods, and alteration of daily functioning.

Setting and Sample Population

This study was conducted in Alameda and Contra Costa Counties in Northern California. Of 37 women contacted, 25 were willing to participate in the study and 19 were selected based on their history of incontinence. The six women who were not selected had presented histories of other

bladder problems requiring surgery but not incontinence. The women were informed that the interviews would involve a maximum of one hour in which they were asked questions relating to their incontinence.

The sensitivity of the topic was acknowledged and reassurance was given that the subjects' decision to participate would have no effect on their medical treatment. The sample was one of convenience and was not randomized. The location of the interviews was decided on between the participant and the researcher.

Subjects for this study were obtained by referral from the following two settings:

1. A Northern California urological surgeon who specializes in the treatment of urinary incontinence. The patients who were referred had been treated for incontinence within the last year.

2. A health clinic located in Northern California which specializes in the care of persons over 60 years old. Women were referred by the physicians, physician assistants, and nurse practitioners at the clinic.

The subjects met the following criteria: (a) over 40 years of age, (b) female, (c) ambulatory, (d) able to understand and communicate in English, and (e) incontinent of urine in a pattern consistent with stress incontinence.

Data Collection Instruments and Method

An interview schedule (Appendix A) which was developed by the researcher was used for the data collection. The interviews were scheduled by phone after an initial letter of introduction had been sent (Appendix D). The interviews varied in actual length from 1/2 to 2 hours. The open-ended interview questions were categorized under four headings: (a) demographic data, (b) historical context, (c) appraisal of their situation, and (d) coping modes. The interviews took place over a four-month period of time between May of 1988 and September of 1988.

The interview guide was presented to four home health nurses, one social worker, one nutritionist and two medical clerks to evaluate for clarity of questions, content validity and topics covered. Three revisions of the original questionnaire were made based on the input of these reviewers.

Data Analysis

Descriptive statistics were used to present and categorize the findings. These included frequency distributions, percentages and measures of central tendency. Nominal data were treated as nonquantitative, and ordinal data were presented using the percentile system. The actual number of respondents who answered a particular question

was also included, with the percentage, to facilitate interpretation of the results for the reader.

In addition to descriptive statistics, the data that remained uncategorized were subjected to content analysis. Recorded words were reviewed systematically and units of analysis were identified to determine categories of responses. Similarities and differences in the responses were noted. An extensive narrative description of the findings was developed with use of "quotes" and presentation of seven case studies. These case studies were interpreted using the model presented in the conceptual framework.

Scope and Limitations

The scope of this nursing research was concerned with revealing the complexities of the experience of the incontinent woman and how she adapts to the problem. It is expected that the knowledge gained from this study may be directly useful to the clinician in his/her practice.

The following limitations were identified in relation to this study:

1. The sample size is small and may not be truly representative of variables such as cultural difference, geographical differences, etc.
2. Interviewer effects may affect responses of the subject, such as: Revealing expectations, expressions of approval/disapproval, and non-verbal behavior may cause

respondents to tailor their answers. Self-report data is always subject to interviewer effects. There may also be denial and psychological defenses by the women interviewed which might hinder their memory or ability to give accurate responses.

3. This study relies heavily on interviewer skill in creating a non-threatening interview and establishing good rapport when discussing potentially intimate topics.

4. A vast amount of data may be generated from a small sample size with the resulting conclusions difficult to generalize to the total population. In addition, this sample group was obtained primarily by referral from a urological surgeon which may skew the results.

5. The interviewer must rely on the accuracy of the self-report data which is generated.

Chapter 2

CONCEPTUAL FRAMEWORK AND REVIEW OF RELATED LITERATURE

Conceptual Framework

The primary goal of this study was to elicit information about the lives of women who are incontinent: their behavior, and their feelings in relation to being incontinent. It will become clear in the following review of the literature that myriad responses to incontinence are possible with little research available to assist the practitioner in understanding the incontinent woman's reaction to this problem. The American Nurses' Association gives the following definition of nursing: "Nursing is the diagnosis and treatment of human responses to actual or potential health problems" (American Nurses' Association, 1980, p. 9). As a means of understanding and potentially treating this human response, nursing must have the ability to organize and evaluate these responses in a coherent fashion.

Richard Lazarus' (1978) theory on stress, appraisal, and coping provides a framework from which to organize this study and to interpret the findings. Use of Lazarus' theory allows the nurse to view the stressful event (urinary incontinence) and the adaptive behaviors as a process which can be interpreted and understood at various levels. Lazarus provides concepts which can be used to evaluate

behavior as part of a process which includes personal and environmental factors that shape responses. Lazarus proposes that when assessing a person's response to a situation, his/her cognitive processes (i.e., perception, thought, and judgement) are the most important determinants of his/her behavior and emotions. Therefore, it is how a person construes an event that will determine the emotional and behavioral response (Lazarus & Launier, 1978).

The person's cognitive appraisal of a situation has two main components. Lazarus refers to these as primary and secondary appraisals but denies that one has precedence over the other. The "primary" or evaluative appraisal asks what is the significance of this situation to his/her well-being? It may have three different responses: (a) irrelevant, which implies that the event has no perceived impact on his/her life; (b) benign-positive, which implies a pleasurable or positive outcome; and (c) stressful, which implies a negative outcome or consequence. Stress is viewed as a balance of forces which exists between the demands on a person and the resources he/she has for dealing with them. When a person judges a given situation as taxing or exceeding his/her resources, he/she will experience psychological stress. Lazarus defines psychological stress as "a particular relationship between the person and the environment that is appraised by the

person as taxing or exceeding his or her resources and endangering his or her well-being" (Lazarus & Folkman, 1984, p. 19). The stressful appraisal may be further categorized into: (a) harm/loss situation where damage has already occurred, (b) a threatening situation in which no damage has yet occurred but is anticipated, and/or (c) a challenging situation in which there is an expectation of mastery or gain in that situation.

At the first realization of incontinence in a woman she must either consciously or unconsciously make some cognitive appraisal of the situation which will then bear directly on her emotions and behavior. Her primary appraisal of the situation will reveal what impact she perceives her incontinence to have on her current and future well-being.

The "secondary" appraisal assesses available coping resources and options. These appraisals interact in determining the degree of stress and the strength and quality (or content) of the emotional response. This secondary appraisal shapes coping activity and "influences the primary appraisal process itself, mitigating or enhancing threat or the sense of harm" (Lazarus & Launier, 1978, p. 307).

This leads to a third kind of appraisal, which is simply reappraisal. A feedback loop is pictured in which the cognitive appraisal process is not stagnant but ever

changing. New information from the environment, further reflection, any new input will call for a reappraisal and possibly a change in behavior and/or emotion. The "primary," "secondary," and reappraisal process will determine the degree of stress and the strength and quality (or content) of the emotional response (Lazarus & Folkman, 1984, p. 35). One may feel hopeless, angry, helpless, anxious, hopeful, etc., dependent on this cognitive mediation.

When evaluating a woman's response to a condition which may span many years of her life (such as urinary incontinence), it is important to realize that she may undergo the appraisal, reappraisal process repeatedly. The appraisal process may result in different emotions and coping methods at different times in her life.

Lazarus has found that the available research on coping has focused primarily on describing coping traits or coping style rather than processes which explain how one handles (copes with) a stressful event. He defines coping as "efforts both action-oriented and intrapsychic, to manage (i.e., master, tolerate, reduce, minimize) environmental and internal demands, and conflicts among them, which tax or exceed a person's resources" (Lazarus & Launier, 1978, p. 311). By studying the coping process, he feels that researchers can learn more about effective and ineffective

forms of coping. Coping refers to all efforts made by a person to manage, regardless of their outcome. The coping process should not imply mastery. The goal of effective coping, as stated above, is to tolerate, to minimize, to accept, or to ignore what cannot be mastered.

In coping with urinary incontinence a woman may try to manage or alter the problem, and/or she might regulate her emotional response to incontinence. Lazarus defines these as the two overriding functions of coping.

Lazarus (1978) further describes four different coping modes which helps to classify coping behavior. The first mode is information seeking which will provide the basis for actions. The information may also be useful in understanding and feeling more in control of a situation. The second mode is the direct action mode. Here, the person does something physically to either alter oneself or to change the environment. The third mode is referred to as inhibition of action. To cease an activity may allow one to cope with a situation. The fourth coping mode is referred to as intrapsychic. The person is able to regulate his/her emotions to feel better about a situation.

A person does not cope with a situation as a single experience in a vacuum but has many personal and environmental factors which influence his/her response. A partial list of these factors would include: (a) his/her

health and energy; (b) positive beliefs such as hope, faith, belief that outcomes are controllable, belief in the efficacy of medical treatment, etc.; (c) problem solving skills, which may include access to information, ability to weigh alternatives with outcomes, or to follow a particular plan of action; (d) social skills in relating and communicating with others; (e) social support and ability to rely on others; and (f) material resources, which often greatly increase coping options.

In summarizing Lazarus' theory on stress, appraisal, and coping (1978), one can say that there are three key factors to the coping process. First, the researcher is concerned with what the person actually thinks and does. Second, this information is looked at within a specific context. The researcher must understand what the person is coping with. Third, one would try to examine how what is done changes over time as the stressful situation develops.

Review of Related Literature

Of the four major categories of incontinence which were defined earlier in this report, stress incontinence is the most prevalent type of urinary incontinence in elderly women (Kendall & Stein, 1983). For the purpose of this study, further discussion of urinary incontinence will be limited to stress incontinence.

When discussing the prevalence of stress incontinence in elderly women, a distinction should be made between identified cases which have been reported to a health care worker and estimates of women who are incontinent and have not reported their symptoms. Research has shown that specific questions related to stress incontinence must be asked to elicit an affirmative response in an interview. Yarnell et al. (1981) found that 84% of incontinent women interviewed, when asked directly, initially denied that they had any problem. When asked the question, "Does your urine come away when you cough or sneeze?", a prevalence of stress incontinence of between 12% and 31% was discovered (Willington, 1976).

Estimates also vary on the number of women who are incontinent but do not report their symptoms to a health care worker. One research study found the incidence of this "hidden incontinence" to be 50% of the incontinent women (Simons, 1985). It has been suggested by Willington (1976) that comparisons between surveys are difficult to make because of the wide variety of definitions and wordings used by each researcher. However, there is little dispute that the problem remains a highly prevalent one, especially for the older woman.

Why women are reluctant to report symptoms to a health care provider remains mostly speculation at this time since

there is no available research on the subject. Hunter (1977) found that her incontinent clients had two basic attitudes about their problem. One was that the situation was hopeless, a natural outcome of childbirth, and that they should learn to live with it. The other attitude was that they were embarrassed by this, felt it to be a social handicap and found it to be stigmatizing. Her clients had stated that they didn't want to "trouble" the doctor, and indeed were occasionally told, "You'll just have to live with it." Wells (1984) identifies some other reasons for the incontinent person's efforts to keep their problem from others. Denial, embarrassment, fear of exposure and anxiety over threats to body image are all potential barriers to seeking help.

Hunter (1977) implicates those health professionals who also find the problem hopeless, tedious, and undramatic, and calls on nurses in all areas of nursing to be observant for cases of concealed incontinence. Although Simons' (1985) sample size was small, $n=43$, some interesting results were found. Fifty percent of the incontinent women had reported symptoms to their physicians, and of these women, 9% received no response from her physician, 18% were told not to worry about it, and 27% were told that it was normal for their ages. This underreporting of symptoms and lack of aggressive diagnosis and treatment by the practitioner

combine to contribute to the remaining high prevalence of diagnosed and undiagnosed women with stress incontinence who remain uncured.

There are a variety of normal and abnormal physical changes in the elderly woman which may predispose her to become incontinent. As one ages, the bladder capacity diminishes, resulting in increased frequency of urination (Wells, 1980). The amount of urine which remains in the bladder after voiding (the residual urine) may increase due to incomplete emptying (Hamdy, 1984). This creates a hospitable environment for bacteria and the propensity to become infected increases (Wells, 1980). Brocklehurst (1978) has identified the development of uninhibited contractions in the bladder with age that may lead to a sensation of urgency and possible incontinence.

In addition to these age-related changes which are occurring in the bladder, the elderly woman has an additional assortment of gynecological factors which may lead to incontinence. Childbirth, menopause, and past surgeries are implicated in the development of incontinence (Willington, 1976). Yarnell et al. (1982) found in their random sample of 1140 women that incontinence of all types is associated with inadequate perineal tone, and that parity (number of children) rather than perineal damage associated

with childbirth was highly correlated with the incidence of incontinence.

Post-menopausally, the tissues of the vagina, urethra, and pelvic muscles are sensitive to the estrogen deficiency which occurs. Hilton and Stanton (1983) studied ten women who demonstrated the atrophic vaginal change associated with estrogen deficiency and found them to have genuine stress incontinence, with post-menopausal onset of symptoms. The decrease in perineal tone associated with childbirth coupled with the atrophic changes of the vaginal tissue post-menopausally cause a loss of support to the urethra and bladder neck. The result is a decrease in the urethra's resistance to pressure and sphincter incompetence results (Kendall & Stein, 1983).

Clinical research indicates a high cure rate for urinary incontinence with estimates of 50% to 70% (Hamdy, 1984; Willington, 1976). Appropriate diagnosis, management and cure where possible requires a complete assessment by the practitioner, and presentation of the problem by the incontinent woman. Treatment for incontinence falls into four categories: (a) bladder training and re-education, (b) drug therapy, (c) surgery, and (d) use of protective devices.

Arnold Kegel in 1951 reported that stress incontinence was prevalent in 5.5% of all adult women and that in the

overwhelming majority of cases was due to inherent weakness of the muscles surrounding the bladder neck and vagina. Using exercise to strengthen these muscles, he found that of 500 women with stress incontinence, 84% obtained complete relief by means of this physiologic therapy alone (Kegel, 1951). Follow-up studies, although few in number, have continued to show the effectiveness of these pelvic floor exercises with success rates approaching 90% (Montgomery & Shepard, 1983; Stoddart, 1983).

Topical estrogen therapy is sometimes used to treat stress incontinence when evidence of atrophic mucosal changes related to estrogen deficiency are found (Palmer, 1985; Willington, 1976). Hilton & Stanton (1983) found that of ten women with stress incontinence due to post-menopausal changes, 70% of the women improved after 4 weeks' treatment with a daily dose of intravaginal estrogen cream. Mohr et al. (1983) reported nearly a 100% success rate in treating 46 ambulatory elderly women for stress incontinence by a combined estrogen plus pelvic floor exercises program. The researchers concluded that the majority of women with stress incontinence can be successfully treated without the need for expensive, invasive and potentially harmful diagnostic procedures.

Surgery is often the treatment of choice when uterine prolapse, urethral prolapse, or bladder prolapse occur as a

result of the loss of perineal support and tone resulting in stress incontinence (Palmer, 1985). There are over 50 surgical procedures which may be performed on the incontinent woman. The success rates reported for these procedures is between 50-60% (Palmer, 1985). Although the literature reflects these high surgical success rates, a complex ongoing study at the University of Michigan of 200 incontinent women has revealed that 25% of the subjects report one or more bladder surgeries in the past (T. Wells, personal communication, March 27, 1986). Of the ten incontinent women that Hilton and Stanton (1983) studied, five of them had undergone a total of nine surgeries for incontinence, yet had remained incontinent.

These three treatment modalities, pelvic floor exercises, estrogen therapy, and surgery, have all been used effectively to treat incontinence; however, it is unclear why, despite these findings, the problem remains so prevalent among the elderly. It is frequently reported in the literature that there are substantial psychological, social, and personal implications for the sufferer of urinary incontinence, but that remains an area in which little research has been done (Williams, 1983). Studies have shown urinary incontinence to be considered an embarrassing condition and one which the sufferer would prefer to hide (Wells, 1984; Yarnell et al., 1981). Another study (Simons,

1985) attempted to correlate a decrease in self-esteem with urinary incontinence. The sample size used in that study was found to be too small to generalize and the results inconclusive, but provided some beginning research into this much neglected area.

Despite the scant attention by researchers to study these psychological and social effects of incontinence, there is much speculation about the devastating changes that incontinence may bring to the sufferer's life. Wells (1984) discusses self-imposed social isolation, loss of self-esteem, depression, and withdrawal as possibilities. Others (Bartol, 1980; Brink, 1980; Hamdy, 1984) describe decreased emotional stability, a decline in personal care, decreased nutritional status, feelings of being different or inferior, increased tensions between the incontinent person and co-inhabitants, fear of loss of independence, and activation of the isolation/depression cycle, as potential outcomes of incontinence.

It is unclear why so little research in this area has been done. Some have suggested that women accept incontinence as a necessary part of life just as menstruation was, and that they manage this by using the familiar protective pads used previously during their menstrual cycles (Wells, 1984). Bartol (1980) details the psychosocial implications of incontinence in elderly persons

but also finds that no nursing research has been done in this area. Williams (1983) found that very little research had actually been done on elderly incontinent persons in the United States, and that most of our information comes from England. It is also recommended in the article that research which provides more descriptive details of the incontinent person psychologically and functionally would be beneficial to the clinician.

Another area of importance in which no research was found was in the provider response to the incontinent person. It is suggested that many providers feel hopeless when confronted with incontinence and resort to protective devices, or indwelling catheters immediately instead of a comprehensive evaluation (Williams, 1983). Nurses, who deal with the incontinent person in the hospital routinely, also feel hopeless about prospects for cure and focus their energy and time on changing linens and keeping their patients dry (Brink, 1980; McCormick & Burgio, 1984).

In reviewing the literature on the subject of urinary incontinence, it becomes clear that much is unknown about the incontinent person herself. It is also evident that this knowledge could prove useful to the practitioner who may not understand the depth and complexity of the problem to the sufferer and is satisfied with a negative answer when asked if she has a problem with urinary incontinence.

Chapter 3

METHOD

Research Design

The descriptive study design provides the structural framework for this research project. Some aspects of both the survey and case studies approach were utilized. Due to lack of previous research in this area, the researcher chose not to attempt to manipulate variables or establish causality but only to describe the situation as it presently exists. This data-gathering process enables one to describe the present more fully and adequately and presents no preconceived judgements, evaluations or statements of quality to prove (Fox, 1970). This method of study was felt to be most appropriate for answering the specific research questions proposed in this study.

Subjects

The subjects who participated in this study were a convenience sample of 19 women. These women were part of a population accessible to the researcher, having chosen to have treatment for their incontinence and having consented to participate in this study. The subjects met the following criteria: (a) over 40 years of age, (b) women, (c) ambulatory, (d) able to understand and communicate in English, and (e) incontinent of urine in a pattern that is consistent with stress incontinence.

Subject Recruitment

Due to the sensitivity of the topic to be studied, subjects were recruited in two steps (as described below), to help ensure that the ethical standards of the research would not be violated. The director of the Over 60 Clinic and a local urologist signed letters of agreement to assist the researcher in obtaining subjects (Appendix C).

An agreement was made with the practitioners at the Over 60 Clinic that they would first ask their patients if they would be interested in participating in this study. The researcher would then contact them by phone to set up an appointment, further explain the study, and review their rights as human subjects.

The urologist's office prepared a letter of introduction which the researcher mailed out to patients identified as being incontinent (Appendix D). After they received the letter, a follow-up phone call was made. At that time they were asked if they would participate in the study and a further explanation of the study and review of their rights as human subjects was made.

The researcher also attempted to recruit women from the community by advertising at a local senior citizen center, but no participants were obtained through that method. Other urologists and gynecologists in the Bay Area were contacted

to request referrals for this study, but none of them was willing to assist the researcher.

Instrument

The researcher developed an interview questionnaire (Appendix A) which included closed- and open-ended questions. It was designed to measure the following information: (a) demographic information which included age, occupation, number of children and method of delivery, other members of the household, financial status, and educational level; (b) historical information about the woman's incontinence including years of incontinence, when reported to a physician, treatment suggested, compliance with treatment, outcomes, and current status of incontinence; (c) the woman's appraisal of her situation, including if the incontinence is perceived to be a risk to her health, if it is perceived to affect her future, if it is a problem for her, if it is stressful, and if it has had an effect on how she feels about herself; and (d) what effects, if any, has the incontinence had on her daily life, especially activities that have been changed, limited, or stopped due to the incontinence.

The interview guide was presented for content validity to four home health nurses, one social worker, one nutritionist, and two medical clerks to evaluate for clarity of questions, and topics covered. Three revisions of the

original questionnaire were made based on their excellent input.

Data Collection Procedures

Permission for this study was obtained from the Human Subjects Institutional Review Board at San Jose State University. Additional letters of authorization were obtained from the two agencies referring participants to the study (Appendix C). Those women who chose to participate in the study were asked to sign a consent form at the beginning of the interview (Appendix B). At that time, the researcher again assured her of anonymity, and the right to withdraw her participation at any time during the interview. The data from the questionnaires were coded at the end of each interview to protect anonymity.

Of the 37 women who were contacted by phone, 25 were willing to participate in the study. Of those, 19 were selected. The 6 women who were not selected presented histories of other bladder problems requiring surgery but were not incontinent. The participants were informed over the phone that the interview would involve a maximum of one hour of their time, and an appointment was made for the interview. Sixteen of the interviews took place at their residences, one was scheduled at the participant's church, and two were conducted over the phone.

The actual interview time varied from 1/2 hour to 2 hours, with many of the participants grateful to talk about a subject which they do not often have an opportunity to discuss openly. All of the participants expressed support for this type of study, and many expressed hope that the information they provided might help someone else with the problem. The interviews were all conducted in Alameda and Contra Costa Counties between May 1988 and September 1988.

Analysis of the Data

The data from the questionnaires were reviewed by the researcher and recoded into 46 categories. These categories were coded and analyzed by computer using descriptive statistics and content analysis. Nominal data were treated as nonquantitative and ordinal data were presented using the percentile system. The data were not appropriate for further statistical testing. The following areas were included in the presentation of the findings: (a) a profile of the respondents; (b) the history of their incontinence, including suggestions made, action taken and outcomes; (c) self appraisal of the problem; and (d) coping modes.

Seven case studies were also presented by the researcher to provide more in-depth information about the individual variations and manifestations of this problem. In this section the researcher concluded by using Lazarus' theories

on stress, appraisal and coping to provide a framework for assessing each woman's response to this problem.

Chapter 4

THE FINDINGS

This chapter describes the responses of 19 women to interview questions about their incontinence. The results will be presented in the following five sections:

(a) demographic profile of the subjects, (b) historical information about their incontinence, (c) description of their self-appraisal about being incontinent, (d) coping methods they have utilized including changes made in activities of daily living (ADL), and (e) seven case presentations. The subjects chosen for the case studies were thought to present a varied picture of the incontinent woman. Women were selected for case study presentation based on whether they had surgery, whether they remained incontinent, and whether they had problems after surgery. The researcher also felt that the information collected on these seven women was the most complete to present as case studies and would provide an in-depth view of some problems that incontinent women may experience.

Demographic Description

The study sample consisted of 19 women ranging in age from 41 to 88 years, with the mean age being 64. At the time of the interview 5 women were currently employed outside of the home, 4 women were homemakers, and 10 women were retired. The occupational status of those that have

been employed outside the home included 5 women who were professionals, 6 women who were office workers, and 4 women who were blue collar workers. Eight women had completed one or more years of college, 7 women had finished high school, and 4 women had less than a high school education.

Economically 16 women (84%) reported that they were secure financially, and 3 women (16%) reported having trouble making ends meet. Eight of the women lived alone, 7 women with their husband, 3 women with their husband and one or more children, and 1 woman with one child. Table 1 illustrates this demographic information to provide a complete description of the data.

Of 19 women, 1 woman had never been married and had no children. The range of number of children for the group was zero to seven, with the mean being 2.3. Thirteen women (68%) had one or two children, and 5 women (26%) had greater than 2 children. All of the women who had children had vaginal deliveries. The only woman who had a cesarean section did so after delivering two children previously by vaginal birth. The graph in Table 2 shows the distribution of number of vaginal deliveries per subject. There were no follow-up questions regarding vaginal trauma by difficulty of delivery or use of instruments during delivery. It was suggested in the literature review that parity was highly correlated with the incidence of incontinence, implying that

Table 1

Demographic Findings

Subject		Occupational	Lives	Education	Financial
#	Age	Status	With	Completed	Status
1	88	retired	alone	12th grade	secure
2	78	retired	alone	8th grade	secure
3	81	retired	alone	12th grade	secure
4	63	retired	alone	1 yr college	trouble*
5	55	unemployed	husband	1 yr college	trouble*
6	69	employed	alone	12th grade	secure
7	52	employed	husband	12th grade	secure
8	50	employed	1 child	college	secure
9	66	retired	husband	9th grade	secure
10	55	homemaker	husband	12th grade	secure
11	63	retired	husband	12th grade	secure
12	84	retired	alone	college	secure
13	64	homemaker	husband	10th grade	secure
14	63	retired	alone	college	secure
15	61	employed	husband	college	secure
16	73	retired	alone	12th grade	secure
17	41	employed	husb./child	college	trouble*
18	63	retired	husb./child	college	secure
19	47	homemaker	husband &	11th gr.	secure

7 children

*Trouble making ends meet

Table 2
Vaginal Deliveries Per Subject

women with large numbers of children were the ones that were incontinent (Yarnell et al., 1982). The data from this study indicate that the majority of incontinent women have only one or two children.

Historical Context

When asked if they had experienced losing their urine when they laughed, sneezed, or coughed, 18 women responded yes. The only woman who responded no reported that she urinated frequently enough so that she did not experience the incontinence. The mean number of years that the women had experienced incontinence was 9.4, with a range of 1 to 40. The median number of years reported was 5.0. Thirty-seven percent of the women immediately reported their incontinence to a doctor. Of the women who delayed reporting their symptoms, the range in number of years delayed was 1 to 25 with a mean of 6. Six women expressed feelings that their incontinence had been pregnancy related. Only two women reported any discomfort in discussing their incontinence with a physician.

The three suggestions most frequently made by physicians to relieve the incontinence were: (a) surgery (79%), (b) Kegel exercises (63%), and (c) medication (63%). Other suggestions reported were to go to the bathroom more often, use protective pads, and avoid lifting heavy things.

The average number of suggestions made for each woman was 2.4, with a range of 1 to 5.

When asked if they followed the recommendations of their doctors, 17 women said that they did and 2 women said that they did not. Of the 2 women that did not, 1 woman stopped taking her antispasmodic medication (Ditropan) because she did not like the side effects, and 1 woman did not agree to have surgery because she didn't feel that her problem was severe enough.

Thirteen women have had surgery, and all of these women have had surgery within the last 2 years. Five of these women (26%) have had two surgeries, and 8 women (74%) have had one surgery. In addition, 4 women who have had surgery remain incontinent and have had further surgery recommended to them. All four women are still undecided whether to undergo the recommended surgery. The researcher did not know the kind of surgical procedure performed on each woman, which might have ranged from minor to major. When asked what the result of the surgery was, 10 women felt that surgery had helped them, but 5 of these women continue to be incontinent. Eight women report no further incontinence, and of those, 3 women must self-catheterize themselves daily due to post-operative urinary retention.

Although only one woman expressed regret over having had surgery, 6 of the 13 women (46%) reported one or more

side effects. Four women reported post-surgical infections, 3 women reported post-surgical retention of urine which has continued to require that they self-catheterize their bladder daily, and 3 women reported a decrease in bladder capacity which has made them feel the need to urinate more frequently. These side effects are often an expected outcome of some surgical procedures to relieve incontinence and may resolve over time. Most of the women were interviewed within one year of their operation, which might be too early to evaluate surgical success (M. Sandler, personal communication, February 21, 1989).

Of the 6 women who have not had surgery, only one woman is no longer incontinent. She attributes her relief to medication. Three of the 6 women expressed some improvement in their incontinence after having done the Kegel exercises.

One can see in Table 3 that there is little correlation between age and length of incontinence. Also, there was no relationship between outcome of surgery and age.

Self-appraisal

When asked, "Do you think that the loss of bladder control is a risk to your health?", 16 women (84%) said no and 3 women (16%) said yes. The 3 women who answered yes had reported having multiple urinary tract infections after surgery and were worried that this could become more serious.

Table 3

Historical Characteristics of Sample

Subj.	#	Years of	Still	#		
#	Age	Child.	Incont.	Incont.?	Surg.	Comments
1	88	1	8	no	0	improved w/med.
2	78	0	2	yes	0	
3	81	2	3	yes	0	
4	63	2	1	yes	0	
5	55	6	25	no	1	must self-cath.
6	69	1	4	yes	0	surgery pending
7	52	1	6	no	1	
8	50	3	5	yes	2	poss. 3rd surg.
9	66	2	3	no	1	frequency, UTIs
10	55	4	25	yes	1	improved
11	63	2	5	no	1	must self-cath.
12	84	2	3	yes	0	
13	64	2	4	yes	1	improved
14	63	5	10	yes	1	poss. 3rd surg.
15	61	2	12	yes	1	poss. 2nd surg.
16	73	1	5	no	2	
17	41	1	8	no	1	must self-cath.
18	63	2	40	no	2	
19	47	7	6	yes	2	poss. 3rd surg.

Four women (21%) characterized the problem as very stressful, 6 women (31%) as somewhat stressful, and 9 women (48%) as not at all stressful.

The data presented in Table 4 compare age with stress-appraisal. It is interesting to note that only one women under 60 years of age found the problem to be "not at all stressful." In contrast, only two women in their 60's and 70's found it to be at all stressful. Although inconclusive, for women in their 80's it appeared that the stress level again rose.

Table 4

Comparison of Stress Appraisal and Age

Age	Stress	No-stress
40's	2	0
50's	3	1
60's	2	6
70's	0	2
80's	2	1

When asked to describe their feelings about incontinence, 5 women stated, "It's a nuisance." Other comments were that it was embarrassing, troublesome, irritating, aggravating, disgusting, or nothing to worry about. Seven women (37%) felt that their incontinence would affect their future adversely. Four of these 7 women were considering having a first or second surgery, and 2

women expressed concern about the long-term need for self-catheterization.

All 19 respondents stated that they felt positive about themselves. When asked if the way they feel about themselves had changed since becoming incontinent, 6 women felt that it had. The following responses were recorded. "I felt stupid not doing anything about it." "I can't go anywhere." "It made me nervous." "I feel clumsy and embarrassed overall." "It used to depress me." "You feel like an old lady when you wet your pants."

When asked if they expected to have this kind of problem as they got older, 4 women said yes, 13 women said no, 1 woman said she never thought about it, and 1 woman said, "Not at my age." When asked if they thought that most older women have this problem, 2 women said no, 6 women said yes, and 6 women said that quite a few do but probably don't talk about it. Five women said that they did not know.

Changes in Activities of Daily Living

The women were asked, "Have you had to make changes in your daily functioning because of this loss of bladder control?" There were 6 women who answered no, and 13 women who responded yes. Of the 6 women that answered no, 5 of them admitted to wearing a protective pad as a way of coping with the problem.

Of the 13 women who stated that they had made changes:

(a) 10 women reported making more frequent trips to the bathroom and needing to know where bathrooms in public places were; (b) 7 women reported wearing protective pads, and 2 women carried extra panties; (c) 6 women reported always urinating before leaving the house; (d) 4 women reported a general decrease in activity; (e) 4 women reported that they stopped traveling completely, 3 women said they would only travel by motorhome since there was a bathroom inside, and 1 woman would only travel by plane; (f) 3 women reported that they stopped lifting or doing heavy housework; (g) 4 women reported a change in their shopping habits, including shopping by mail, shopping frequently and limiting shopping time to one hour; (h) 2 women reported increased laundry and carrying extra clothes when out; (i) 4 women reported stopping an activity that they had previously enjoyed such as golf, jogging, hiking, and polka dancing; and (j) 2 women reported a decrease in sexual activity. Seven women reported 4 changes in their daily routine, 5 women reported 3 changes, and 1 woman reported 5 changes.

The women were asked how frequently they urinated during the day and how many times they were up at night. Of the 19 women in the study, 2 women stated that they had to urinate less than every hour, 9 women had to urinate every

1 to 2 hours, 6 women every 3 to 4 hours, and only 1 woman said that she could wait over 4 hours to urinate.

Case Study Presentations

Seven women were chosen by the researcher to be presented as case studies. These women were chosen to allow the reader to see the complexity and variety of experiences that are encountered when interviewing women who have this problem. Also, these particular women were chosen because they presented the most complete responses to the interview questions. The case studies will be briefly analyzed utilizing the conceptual framework by Richard Lazarus described earlier.

Case #1: Mrs. A.

Mrs. A. is an 84-year-old retired fifth grade teacher who has been incontinent for 3 years. She has two children, both delivered vaginally, and she lives alone. The onset of her incontinence coincided with a urinary tract infection. She continued to have frequent urinary tract infections and her regular physician began her on 1 Macrochantin (an antibiotic) daily for prevention. She was referred to a urologist in 1987 who, after "stretching my bladder," started her on Ditropan, which is an antispasmodic medication. She decided to stop taking the Ditropan due to the side effect of a dry mouth. She stated that her problem is not severe enough "to go through that."

Surgery was presented to her as an option, but she feels that the problem would have to get much worse before she would consider surgery. Mrs. A. was taught how to do the Kegel exercises, and feels she should be doing them more often, but says, "I get busy and forget." She does continue to take the Macrodantin daily.

She copes with her incontinence by wearing a mini-pad, changing her underwear more often, and making a preliminary trip to the bathroom before leaving the house. She does not feel that she has had to restrict any of her activities and described the problem as "a nuisance." She also copes by becoming more informed about her problem. She receives a copy of The Informer, Helping People with Incontinence, which is a quarterly newsletter published by The Simon Foundation. She says of her incontinence, "I'm sure it has to do with age. I want to do all I can to help it, but I don't think I am really worrying about it."

The evaluative or "primary" appraisal that she made of her urinary incontinence is that it is "somewhat stressful," which Lazarus defines as causing some negative consequence. She also categorized this event as a "nuisance" right now in her life. She perceived it as threatening to her future because it may worsen and require that she decide to have surgery. Perhaps because of her age, she found the prospect

of surgery more threatening to her than putting up with the incontinence.

The "secondary" appraisal she made reflects her available coping resources and options. She took the necessary action to minimize the problem by wearing pads and becoming more diligent about increasing her trips to the bathroom. She also did exercises which may help. In addition, she sought out information about incontinence, which has increased her understanding of the problem and has enabled her to have more control over the decisions she makes.

Case #2: Ms. B.

Ms. B. is a 78-year-old woman who has been incontinent for about 1-1/2 years. She is the only woman in the study who has had no children. She lives alone in a senior housing apartment. In 1940 she suffered a "mental and physical breakdown" for which she was placed in a psychiatric hospital. She stated, "I couldn't pass the IQ test. They told my father and stepmother that I had the mentality of a nine-year-old." She was placed in a state mental hospital, during which time she states she had her tubes tied to prevent pregnancy.

Ms. B. places the onset of her incontinence after a bout of pneumonia in which she did a lot of coughing. During this time she said, "I had some trouble downstairs,

in the bladder department, and it was on the lounge downstairs. They complained about it and told me to do something about it." When asked who complained, she replied, "The manager."

Ms. B. went to her physician and was told to begin wearing a pad, to increase her fluid intake, and begin the Kegel exercises. She now wears a pad during the day when she is out at the senior center and makes frequent trips to the bathroom. She feels that the incontinence has improved and attributed much of her relief to the exercises.

The "primary" appraisal that Ms. B. made of her incontinence was that it was initially very stressful because she perceived that it could jeopardize her living situation. There might have been a feeling of loss that occurred to her privacy when confronted by the manager with such a personal complaint. The threat that she must do something about the problem made her "very nervous."

The action which she took to cope with this problem was to go to her doctor to seek professional advice. She has coped with her incontinence by carefully following the recommendations of her doctor. It might be reflective of her mental deficit that she relies heavily on the recommendations of others and trusts in the positive outcome of following that advice. It appears that she has made some intrapsychic changes in her attitude about the problem,

which she now finds "not at all stressful" even though she continues to wear a pad and to be incontinent. She stated very positively that this does not inhibit her activities as long as there is a bathroom nearby.

Case #3: Mrs. C.

Mrs. C. is 69 years old and lives alone in a trailer park. She had one child by vaginal delivery. She is currently working as a press operator in a factory. She has been incontinent for 4 years and is currently waiting for her surgery to be scheduled. Her regular physician treated her for bladder infections with sulfa antibiotics, and recommended increasing fluid intake and drinking cranberry juice. She was also told to begin doing the Kegel exercises. After having six infections in the past year, she was referred to a urologist at her request. She read about his incontinence clinic in the newspaper.

She twice described feeling disgusted with the incontinence, and was emphatic about not wanting to wear a pad for the rest of her life. She was very hopeful that the surgery would relieve the problem. She wears a Depends undergarment for protection. She described the exact times that she would go to the bathroom throughout the day to coincide with her busy job schedule. She wanted to prevent both having an "accident" at work and spending all of her break time going to the bathroom. Therefore, she would go

to the bathroom usually about 1/2 hour before each break and lunch. Mrs. C. denied having limited any activities in her daily life and has been very active. However, she must wear a diaper and be able to urinate every 2 or 3 hours around the clock.

Mrs. C.'s primary appraisal about being incontinent was that it is "somewhat stressful." Her emotional response to the problem was very strongly negative. The damage that has occurred has been to her self-image, evidenced by her statement that she feels "disgusted" with herself.

The "secondary" appraisal she made of the situation reflects the action-oriented approach which appeared to be characteristic of her general problem-solving mode. At her request, she was referred to a urologist by her primary physician and she was waiting for her surgery to be scheduled. She was positive that it will eventually cure her and that she will no longer have the problem. She expressed no fears about undergoing surgery, and said that just knowing that she will have surgery has made her feel better.

Case #4: Mrs. D.

Mrs. D. is 63 years old and has been incontinent for about 5 years. She had two children by vaginal birth. She lives with her husband and is a retired inspector for the telephone company. She reported the problem to her

physician in January 1987, and was immediately referred to a urologist. She was given some medication (which she does not know the name of), was told to empty her bladder more frequently, and was tested for bladder function. She was told that she was retaining some urine. After trying these things with no improvement, surgery was recommended.

Mrs. D. had surgery in May, 1987. After surgery she said, "I healed all right, but I couldn't use the bathroom. I couldn't void the way I should, so I needed to be catheterized." She has continued to have problems with urinary retention, and over 1 year later continues to self-catheterize herself every 2 hours during the day after voiding, and every 4 hours at night. She noted how much urine is retained and found that it is usually about 4 ounces. She has also stopped drinking fluid after 6 p.m. She has had some infections during the last year, but the interviewer did not ask how many.

Mrs. D. described her incontinence as "a troublesome problem," and stated that she does not let it affect her life. She was planning a trip to Alaska the next week and had recently been to Hawaii. She felt she could go anywhere as long as she took her catheter with her, and was hopeful that the problem would "straighten out." "I went through the motions to stop it and I still have it."

Mrs. D. categorized this problem as "not at all stressful," and although admittedly troublesome, denied any important impact on her daily life. According to Lazarus, her "primary appraisal" in this case would be that the problem was "irrelevant." It was interesting to note the self-blame that she revealed when she spoke of her incontinence. "I feel disgusted with myself because my body won't function like it should." "This doctor is supposed to be the best. This is the first operation that backfired on me."

Her coping methods were to minimize and to tolerate the situation by intrapsychic means to the point that she would no longer consider her incontinence to be stressful. She summed up her situation by saying, "You know, my arthritis is much more limiting!"

Case #5: Mrs. E.

Mrs. E. is fifty-two years old and lives with her husband. She had one child by vaginal birth. She was incontinent for about 8 years until her surgery in 1986. There was a 5- to 6-year delay before reporting it to a doctor because "my mother had the same thing and had surgery five times. None of them lasted." The problem finally became bothersome enough in 1986 that she went to a urologist. First she took some medication to help "empty

the bladder," but after tests were done surgery was recommended.

Mrs. E. had surgery in October 1986 because "I felt I was going to have to wear a Kotex all the time like my mother. I'd rather stay home than wear a pad to go shopping." Deciding to have surgery was also complicated by her need to talk to her husband and her employer about her problem. "I didn't really say anything to my husband about it. When we were at the beach in our motorhome, I would refuse longer walks because I had to make sure I was always close to a bathroom. I hadn't talked to anyone else about this, and then I had to tell my bosses since I was going to have this surgery."

While Mrs. E. was still incontinent, she reported making some changes in her daily life, which included: increased laundry, refusing some trips, and doing "fast shopping" for only 1 hour at a time. Her surgery has completely relieved her incontinence, and she is sometimes able to go 5 to 6 hours between voidings. After her surgery she said, "I wanted to look better in my clothes again and I felt like I wanted to lose weight." In retrospect, she did feel that her self-image had been affected by her incontinence, making her concerned with a negative general appearance.

The "primary" appraisal Mrs. E. made of her incontinence was that it was "somewhat stressful" but is no longer stressful. Although her initial response was to tolerate the problem by inhibition of action for six years, she changed this coping response to direct action and attempted to eliminate the problem. Despite her doubt about the efficacy of surgery, she was able to weigh the alternatives with outcomes and change her initial appraisal of surgery. Her case shows how the coping actions may change over time and how this affects the primary appraisal process.

Case #6: Ms. F.

Ms. F. is a 50-year-old woman who had three children by vaginal birth. She lives with one teenage son and is a full-time registered nurse. She has been incontinent for 5 years. After a delay of 3 years, she decided to go to a physician. She knew of the surgeries that were being done successfully and was interested to find out if she was a candidate.

Ms. F. had tests taken and surgery was advised and performed in September 1986. "It really didn't work. I also had a total hysterectomy, which had been recommended for years due to a fibrotic uterus. The incontinence was almost worse than before. I got tired of wetting my pants." In March 1988, she went to a urologist and had surgery

again. The results of that surgery were described as "much better." Ms. F. takes Ditropan two times a day, which worried her because she knew that hypertension is a possible side effect. Ms. F. already took hypertensive medication which she feared she might have to increase. She now wears one pad instead of the two pads she wore before surgery, and does not have to get up at night.

When asked why she waited almost two years for her second surgery, she said, "I was hoping for a miracle." She continued to be hopeful that "it will get better so that I don't have to wear a pad or take medication."

She described her incontinence as a "nuisance" and her disappointment that surgery didn't work for her, especially after the second time. When asked whether her feeling about her self-image has changed since becoming incontinent, she replied, "Yes. It's like wearing these pads. They really don't show, but you feel that maybe they're bulging. It makes you feel like an old lady when you wet your pants. I've gotten used to the pads and the quick trips to the bathroom, but you know that this is not natural." The main changes in her daily life that she reported are planning her frequent bathroom trips, and stopping both jogging for exercise and ethnic dancing for recreation.

Ms. F. stated that she finds this problem to be somewhere between "very stressful" and "somewhat stressful."

Her primary stress appraisal was strengthened by the failure of two surgeries to correct the problem. It appeared that the reason she has not categorized this problem as "very stressful" is because she has been hopeful that things will improve over time. However, she clearly articulated a loss of self-esteem and harm to her self-image by being incontinent.

Ms. F.'s "secondary" appraisal involved her attempt to tolerate the problem for the time being by inhibiting those actions which aggravate the incontinence. She has made some intrapsychic adjustments as well by focusing attention on the improvements made with the second surgery.

Case #7: Mrs. G.

Mrs. G. is a 41-year-old woman who lives with her husband and 8-year-old son. She has been incontinent for 8 years since her son was born by vaginal birth. She is self-employed as a massage therapist. Her incontinence began with a prolapsed bladder. "I experienced burning with urination, so I looked with a mirror and saw a pink ball at the end of my vagina. The doctor said that my bladder had dropped but that unless there was bleeding surgery was not really urgent. I did the Kegel exercises, but I guess I didn't do them long enough. I didn't see any results. I had other things on my mind with a new baby. I didn't want to leave him to have surgery." The problem began getting

worse, initially with leakage when doing aerobics, but progressed to having leakage when sneezing or coughing. Mrs. G. said she tolerated it. She also reported, "I had trouble with intercourse due to pain and pressure of the penis against the bladder in the female superior position."

In April 1988, Mrs. G. had surgery which included a partial hysterectomy and vaginal repair. After surgery she has no further incontinence, "but cannot urinate at will." She has been self-catheterizing her bladder at least once daily, and has had three bladder infections since April. When asked if she felt the incontinence was a risk to her health, she said, "It seems that I'm going to continue to get infections. Although it is not life-threatening, it's irritating. I don't like taking a lot of medications." She felt better because she has been more physically active, but also stated, "I am scared and afraid to have another surgery." Mrs. G. is now training to be a body builder, and is concerned that if she needed to have another surgery it would take too much time away from training.

Although she did not describe her incontinence as limiting her day's activities, she did find it embarrassing to make the frequent trips to the bathroom when out with friends or family. Her son would comment on shopping trips about how much "mommy goes to the bathroom." She found herself reluctant to go on ski trips with her husband

because he too would comment on the frequent stops that she needed to make.

Due to her post-surgical complications, she feels the problem is very stressful. "I went through surgery and I don't feel healed. I'm annoyed and angry that they didn't fix it!" Her primary stress appraisal revealed a "harm/loss" situation where damage had already occurred in several areas of her life: (a) her family relations were altered and she feared criticism from her son, husband and friends; (b) her sexual relations with her husband were altered; (c) her self-esteem was damaged and she revealed some guilt for not having exercised as much as she should have; and (d) her work was altered by the prolonged absence while recovering from surgery.

There is also the future threat for her that she may either continue having frequent bladder infections, or that she may face another surgery. She did not express much hope that the situation will improve over time, even though she now only catheterizes herself once daily. It appeared that she was so emotionally overwhelmed by the problem that she had not been able to effectively cope with it.

Summary

This study has been conducted to elicit descriptive information about the incontinent woman. Although it is generally thought that there are significant psychological,

social, and personal implications for the incontinent person, there has been little nursing research in this area. The findings from this study suggest that these implications for the incontinent woman have been true for the women interviewed. The data from these 19 women also reveals how different each woman's case history is, and although similar coping methods were used, a large variation of appraisal was reported.

The literature suggests that there is a high prevalence of diagnosed and uncured incontinent women. The women in this study had all been diagnosed and had undergone some treatment. Of these 19 women, 11 women (68%) remained incontinent. These findings are in agreement with the premise that many incontinent women are diagnosed and yet remain incontinent despite treatment.

It has also been widely reported that many women who are incontinent do not report their problem to physicians. Although 7 women did report their symptoms soon after the onset of incontinence, the other 13 women reported a mean of 6 years that they delayed in reporting their problem to a physician, which is also consistent with the literature.

The first research question asked how the incontinent woman perceives her incontinence, with the assumption by the researcher that it would be perceived as stressful. Slightly over half of the respondents (53%) stated that it

was "not at all stressful." There was no real correlation with those women who were no longer incontinent and those that found the problem to be "not at all stressful." Several of these women had been incontinent for years. It appeared that other factors in their personalities and ways of coping with problems may be influencing their perceptions about being incontinent, rather than the severity of the problem.

Also, it is important to realize when asking questions about a problem such as urinary incontinence that the woman has had to deal with the problem for many years. What may today appear as casual acceptance is the product of years of coping.

The second research question asked what behavioral changes have been made to cope with incontinence. Six women denied having made any changes in daily living to cope with incontinence, but all 6 women admitted to wearing protective pads when out. The other 13 women reported extensive changes in their lives caused by their incontinence. Only 1 of the 19 women wore a protective diaper. The other 18 women controlled their leakage by wearing a sanitary pad. If that was not enough, the alternatives were to carry extra clothes or try to use two sanitary pads. It was earlier reported that some women may accept incontinence as an ordinary part of life. Because of menstruation, they are

comfortable with using the familiar sanitary pads. This study did not address this question, but the interviewer noted that most of the women were adamant about their problem not being "that bad." They would not wear a diaper even though it may give them some increased freedom.

This sample population was skewed in that all of the women had sought professional help for their incontinence. They did not report the problem to be as devastating as implied in the literature review. Most continued their lives as best they could, and many indicated that there were other problems in life more important to worry about. These women also did not report difficulties in relating this problem to a physician or that there was an inadequate provider response to the problem. This would be expected since most of these women were treated in a clinic specializing in incontinence.

In summary, these research findings add to the literature in revealing more descriptive detail about the multiple changes in daily life that women make to cope with incontinence. These findings and case studies also reveal how much variation there may be in each woman's attitude and history in relationship to her incontinence.

Chapter 5

Conclusions and Recommendations

The results from the 19 interviews have provided the researcher with a rich collection of data from which to formulate some conclusions. There were three clear findings which corroborated with expectations based on the literature review. They were: (a) many women delay reporting symptoms of incontinence to a practitioner and attempt to manage their incontinence alone; (b) even after reporting symptoms, many women remain incontinent despite treatment; and (c) being incontinent requires significant alterations in the woman's daily life.

There were other findings which were interesting to note even though they are not generalizable due to the nonrandom sample and the small size of the sample. Although impossible to evaluate the success of surgery due to inadequate information about the specific procedures performed, 30% of the women reported uncomfortable side effects from surgery. Only 3 women reported a successful surgery and no problems from the surgery. This information had not been encountered in the literature when reporting on success of surgery, and should be addressed in future studies. It may be that the women who were willing to participate in this type of research were primarily those who had continued to have problems after surgery. This bias

should also be accounted for in future studies by randomizing the sample.

It was found that none of the incontinent women had cesarean sections for delivery of their children. The implication that vaginal birth is more highly correlated with incontinence may also be a subject for future study. It would be worthwhile to examine the benefits to post-partum women of doing the Kegel exercises to improve perineal tone and prevent future incontinence. Many of the women interviewed knew about the Kegel exercises and said that they did them, but had a vague idea of the pelvic muscles they were contracting. It would be very interesting to continue to expand on studies that have been done with women doing Kegel exercises. However, this researcher believes that frequent reinforcement of the Kegel technique would be necessary to evaluate the effectiveness in relieving incontinence.

Caution in accepting findings that Kegel exercises are not effective should be exercised, due to the difficulty many women have expressed over isolating the correct muscle and performing the exercises properly. This is not to imply that it is the woman's fault that they do not succeed, but to alert the practitioner that these exercises must be learned correctly to improve perineal tone.

Evaluating the study findings in light of the conceptual framework allowed the researcher to utilize the theories that Lazarus (1978) presents in a pragmatic way. The Lazarus framework proved to be useful in assisting the researcher in understanding and explaining the data collected. For example, it was unexpected that so many respondents reported "no stress" in dealing with their incontinence. One might be led to conclude from this information that this is not really a problem for these women. However, when looking at these results using the Lazarus model, one can see how the woman's effective coping actions allowed her to minimize the stress of such a problem. In most cases coping was at great cost to her personal freedom. Therefore, more detail about the women's daily lives and changes they have made are important pieces of information the practitioner needs to understand the scope of this problem.

As stated previously, there was much variety encountered with each of the interviews. There was no typical incontinent woman. What did link the women and was not revealed in the data was the sadness perceived by the researcher in each of the women who were still suffering from this problem. Although many had lived with it and coped successfully for years, it was apparent that it was distressing. When reviewing the case studies, there are

threads of guilt, shame, self-blame, and embarrassment, which many of the women interviewed shared.

These findings led the researcher immediately to see a role for nursing practice to assist with the problem. Nurses may tackle this problem through many channels. The community health nurse, or hospital nurse, may become more astute at case finding and referral to appropriate sources. Nurse educators may more actively inform the community about the problem and resources available by speaking to different groups. Nurses may manage their own incontinence clinics and conduct further research on the problem. In summary, managing incontinence is a problem where nursing may be effective in making a positive contribution. Better management may have widespread benefits to older women and possibly to the incontinent elderly now in nursing homes.

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APPENDIX A
Interview Guide

Interview guide

Demographic data:

Age _____

Occupation _____

How far did you go in school?

Number of children _____

Type of deliveries? Vaginal _____

Cesarean _____

Who lives in your house with you?

Do you consider yourself to be:

well off financially? _____

secure financially _____

having trouble making ends meet? _____

Historical context:

Have you experienced losing your urine when you

laughed, sneezed or coughed? yes__ no__

In what year did this first occur? _____

When did you first report this to a doctor or a
nurse? _____

What year or month?

What suggestions did they make? _____

Did you do this? (for each suggestion)

What was the result?

Are you doing any of those things now?

Do you have to use a protective pad?

yes_____ no_____ What kind? _____

Is it effective? _____

Did you feel comfortable talking with the doctor or nurse
about this? yes_____ no_____

Have you had other medical problems related to your bladder,
such as infections, stones, bleeding, etc.?

Have you read any information about loss of bladder control?

yes_____ no_____

Where? _____

Appraisal of the situation:

Do you think that the loss of bladder control is a risk to
your health? yes _____ no _____

How? _____

How do you think this might affect your future?

Do you consider this to be a problem in your life that you
worry about? _____

Have you had to make changes in your daily functioning
because of this loss of bladder control? yes _____ no _____

What activities in your daily routine have you had to
change, stop or partly limit because of this?

What about the following activities?

cleaning

laundry

vacuuming

shopping

going out with friends

working at a volunteer or paid job

hiking/walking for exercise

having company to your house

traveling

Do you consider this to be:

very stressful somewhat stressful not at all stressful

Do you generally feel positive about yourself?

Has the way you feel about yourself changed since having
this problem with your bladder? How?

Did you expect to have this kind of problem as you got
older? yes _____ no _____

Do you think that most older women have this problem?
yes _____ no _____

Any other comments? _____

How many hours can you wait to urinate during the day? _____

How many times do you get up at night to go to the bathroom?

Can you compare your feelings about this situation now with
when you first started having this problem?

APPENDIX B
Consent Form

Statement of Consent

You are being asked to participate in a study conducted by Diane Kratljan, R.N., to fulfill her requirements for completion of a Master's degree in nursing. The subject she is studying is urinary stress incontinence, which is the involuntary leakage of urine when you cough, sneeze, or laugh. In this study, she will be asking you questions related to your incontinence. The purpose of this study is to find out how women feel and cope with being incontinent.

You will be asked to grant Diane one interview at a place that you both agree on. The interview will last no longer than one hour. No tests will be made. The risks to you are that the questions may be personal or embarrassing and/or that you may be fatigued by the hour's length interview. The benefits of this study are that it may improve the care that incontinent women receive. The information you provide will not be identified with you. No names will be used in reporting the results. The interview will be tape recorded only with your permission.

If you have medical questions about your condition, attempts will be made after the interview to refer you to the appropriate sources. A copy of the results of the study will be mailed to you at your request. If you have any questions about your participation in this study, please call Diane Kratljan (236-5363). If you have any complaints

about the study, please call Sharon Hogan, Graduate Coordinator, (408) 924-3134. If there are complaints or questions about research subjects' rights, please call Serena Stanford, Ph.D., at (408) 924-2480.

Your signature indicates that you have decided to participate and have read the information provided above. You may withdraw your consent at any time during the study.

Signature: _____ Date: _____

APPENDIX C
Agency Consent Form

Agency Consent Form

Study title: Coping with urinary incontinence in older women

Investigator: Diane Kratljan, R.N.

Diane Kratljan is a nurse studying how incontinent women feel about their incontinence and ways that they are coping with the problem. She believes that this study will increase the knowledge of practitioners about how urinary incontinence affects the lives of these women.

Agency participation in this study is voluntary. If there are any questions or complaints about the study, please call Diane Kratljan, 236-5363. If there are any questions or complaints about the research, please call Sharon Hogan, Graduate Coordinator, (408) 924-3134. If there are any questions or complaints about human subjects' rights, please call Serena Stanford, Ph.D., (408) 924-2480.

The subjects in the study will be required to be interviewed for a maximum of one hour about their urinary incontinence. No tests will be made. No treatment will be recommended. Your signature indicates that your agency will assist the researcher in obtaining subjects from your facility.

The results of the study will be shared with your agency at your request either in the form of a presentation

or a written copy of the thesis.

Signature: _____

Date: _____

APPENDIX D
Introductory letter

Dear patient,

This is a letter of introduction for Diane Kratljan, who is a registered nurse currently studying the effects that loss of bladder control has on the lives of women with this problem. She has asked me to help her to obtain participants for her study, and I have agreed to contact some patients who may have this problem. She will phone you to invite you to participate in her study. This would involve being interviewed in your home, once, for up to one hour. Any information that you give in the interview will be confidential. Participation is completely voluntary on your part and will in no way have any effect on your medical care. Participation involves no risk to you, and she hopes that information she obtains from her study will be of benefit to other women who have experienced this problem. If you have any questions about this study, Diane will be happy to answer them when she contacts you.

Thank you,

Dr. Maurice Sandler