

**LIVING WITH INCONTINENCE: A QUALITATIVE STUDY
OF ELDERLY WOMEN WITH URINARY INCONTINENCE**

By

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B.Sc.N., University of Windsor, 1974

**A THESIS SUBMITTED IN PARTIAL FULFILLMENT OF
THE REQUIREMENTS FOR THE DEGREE OF
MASTER OF SCIENCE IN NURSING**

in

THE FACULTY OF GRADUATE STUDIES

The School of Nursing

**We accept this thesis as conforming
to the required standard**

**THE UNIVERSITY OF BRITISH COLUMBIA
July 1987**

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Abstract

Urinary incontinence has been described as a devastating symptom, an embarrassing condition, and a major geriatric problem, creating substantial personal, medical, and social difficulties. Urinary incontinence is a problem which affects men and women of all ages, but is predominantly a concern for elderly women. It is estimated that 50% to 75% of cases of incontinence are hidden or unreported.

A review of the literature on urinary incontinence reveals numerous studies describing prevalence rates and types of incontinence. Characteristics of incontinent individuals and experimental studies comparing different treatments are also available. However, qualitative studies of urinary incontinence as it is experienced by elderly women are nonexistent.

The purpose of this study is to explore and describe the impact of living with untreated urinary incontinence upon the daily lives of elderly women living in the community. The phenomenological approach to qualitative methodology was used for this study. This approach seeks to discover and describe the human experience as it is lived, and for this study, that experience was living with untreated urinary incontinence.

Incontinent women, 60 years of age and over, were contacted through seniors' community centres, seniors' newspapers, and community service agencies. Nine women served as informants and participated in intensive interviews guided by open-ended questions. Verbatim transcriptions of these interviews and field notes from

contact with seniors provided the data for analyses.

Four major themes comprise the research findings: the recognition of incontinence, the avoidance of exposure, the need for information, and the redefinition of normal. The first theme describes the women's struggle to recognize the incontinence for what it was, acknowledging to themselves that it was an ongoing problem. Even after incontinence was recognized, the women emphasized the importance of keeping their symptoms hidden. This avoidance of exposure necessitated reorganization of their lives and limited opportunities to talk about problems with incontinence. Despite their hesitation in talking about incontinence, the women identified a compelling need for information. Finally, over and above these three management strategies, living with incontinence led to an attitudinal strategy of redefining what would constitute normal. For these women, this new definition of normal included incontinence.

In light of these findings, implications for nursing education and practice are identified. Suggestions for future research stemming from this study conclude the discussion.

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Acknowledgements

I would like to thank those who encouraged, challenged, and sustained me during the completion of this study.

To my chairperson, Dr. Marilyn Willman, a heartfelt appreciation for your expert editorial assistance and for your encouragement to keep the ball rolling, even when I seemed to become sidetracked. In addition, I would like to acknowledge the contributions of Sally Thorne, who provided wonderfully detailed feedback and a clear understanding of the methodology. Your personal concern during difficult times was greatly appreciated.

I extend my thanks to Wendy who knows what it was all about. And finally to Ron, who didn't want to be mentioned, I give "more than a mention."

CHAPTER ONE

Introduction

Background and Significance of the Problem

Urinary incontinence has been described as a devastating symptom (Mandelstam, 1986), an embarrassing condition (Butt, 1979), and a "major geriatric problem, creating substantial personal, medical, and social difficulties" (Williams, 1983, p. 657). The Standardization Committee of the International Continence Society defined incontinence as an objectively demonstrable condition of involuntary loss of urine with social and hygienic consequences (Feneley, 1986).

While urinary incontinence is a problem affecting men and women of all ages, it is a predominant concern for elderly women. Due to differences in sample selection, research methods, and data sources, prevalence estimates vary considerably. Community-based surveys of elderly men and women in Great Britain and New Zealand report a prevalence of urinary incontinence ranging from 1.6% to 42% (Campbell, Reinken, & McCosh, 1985; Milne, 1976; Thomas, Plymat, Blannin & Meade, 1980). These same surveys frequently indicate a greater incidence of incontinence for women. Resnick & Yalla (1985) confirm that being female is an independent risk factor for incontinence. In a random sample of 1000 Welsh women, 45% acknowledged some degree of incontinence; more specifically, 51% of those women 65 years of age and over admitted to incontinence

(Yarnell, Voyle, Richards, & Stephenson, 1981). The prevalence of incontinence actually documented by health care providers is significantly lower, as 50-75% of cases are believed to be hidden or unreported (Brocklehurst, 1984; Gray, 1986; Simons, 1985; Thomas et al., 1980; Williams & Pannill, 1982; Yarnell et al., 1981).

Elderly individuals, and particularly women, may have numerous reasons for not reporting problems with urinary incontinence. Societal norms governing the elimination of body wastes can inhibit the disclosure of problems with incontinence. The attitudes of health care professionals can also be inhibitory for elderly incontinent women. If these professionals do not give serious and knowledgeable consideration to incontinence, women may be reluctant to pursue help for the problem. A number of authors report a lack of interest in incontinence on the part of physicians and nurses (Dobson, 1974; Robb, 1985; Simons, 1985). Incontinence has been dismissed as being insignificant, something to live with, and a part of growing old. Wells (1984) notes that elderly women are particularly victimized by the view that incontinence is inevitable. They are often seen as the weaker sex: frail, semi-ill individuals with declining bladder function. Physicians at the Urodynamic Clinic in Vancouver confirm that incontinence is probably not given serious attention in older women in that very few are referred for assessment. Thus, the attitudes of society in general and, health care professionals in particular may influence women to hide their incontinence.

Despite the traditions of privacy surrounding urination, the author encountered a group of community-based women who

obviously needed to talk about their experiences with incontinence. Women attending a community health drop-in centre not only pressed for information about options, but also ardently described their experiences with incontinence. The need to talk about one's experience with incontinence is also evident in the lay publication, H.I.P. Magazine (Help for Incontinent People). H.I.P. Incorporated functions as a clearinghouse of information and services for incontinent individuals, their families, and health care professionals (H.I.P., 1983). Incontinent individuals regularly contact the magazine with both questions and suggestions from their own experiences. Thus, it seems that there is evidence of the need for incontinent women to talk about their experience.

Not only do women need to talk about living with incontinence, but nurses and other health professionals who care for incontinent women need to know what that experience entails. They need to be able to identify the personal, social, and medical difficulties associated with incontinence, how women manage their incontinence, and why it remains a hidden problem. With those concerns in mind, the author reviewed the incontinence literature.

Numerous studies exist that describe prevalence rates, types of incontinence, characteristics of incontinent individuals, and treatment options. However, research into the psychosocial aspects of incontinence is sparse. Those researchers who address these aspects of incontinence seem to consider them secondary or minor. Most authors base conclusions on clinical experience or common sense, rather than on indepth personal accounts from the subjects

themselves. An extensive search revealed two qualitative studies describing life with incontinence. One study focused on younger multiple sclerosis (MS) patients receiving treatment at an MS clinic (Catanzaro, 1982). As part of a larger study on the health needs of seniors in a subsidized housing project, the other focused on a mixed age and gender group (Mittiness, in press). Qualitative studies of untreated urinary incontinence as it is lived by elderly women are nonexistent.

To address this gap in the literature, the author designed a study which focused on elderly women in the community who were living with unreported or untreated urinary incontinence. By understanding the experience of incontinence, as lived by these women, nurses could be more knowledgeable in identifying and assessing problems, providing support, and planning interventions.

Statement of the Problem

The general problem to be addressed is the lack of knowledge about the experience of untreated urinary incontinence for elderly women living in the community. Specific questions which provide direction are:

- 1) What is it like to live with untreated urinary incontinence?
- 2) What are the concerns of elderly women living with untreated urinary incontinence?

Purpose of the Study

The purpose of this study is to explore and describe the

experience of elderly non-institutionalized women who are living with untreated urinary incontinence.

Definition of Terms

Urinary incontinence: The existence of involuntary excretion or leakage of urine in inappropriate places or at inappropriate times, occurring a minimum of twice a month and of at least six months' duration.

Untreated urinary incontinence: Urinary incontinence which is not currently being treated through exercises, medication, or other medical, psychiatric, or nursing intervention, although it may be known to health care professionals.

Elderly women: Women 60 years of age or older.

Community living: Residing in a house or apartment as opposed to an institution where there are health care staff present daily.

Introduction to the Methodology

The phenomenological approach to qualitative methodology was used for this study. Current nursing research recognizes two broad research approaches: quantitative and qualitative. The traditional scientific method of quantitative research attempts to empirically verify preconceived hypotheses with little regard for the subjective states of individuals (Duffy, 1985). In contrast, qualitative research

does not seek to control or predict behaviour but rather to understand and describe it. The result is the generating of hypotheses rather than the testing of them (Knaak, 1984).

Phenomenology, a form of qualitative research, is an inductive process, which moves back and forth from theoretical abstraction to subjective data. The concern of the phenomenologist is to understand the cognitive, subjective perspective of the individual who has the experience as well as the consequences of that perspective for the individual's experience and behaviour (Omery, 1983).

The role of the researcher in phenomenological methodology is to enter into the phenomenon being studied. Rather than controlling for researcher bias, the phenomenologist recognizes that bias exists and accounts for its role in constructing the account of the phenomenon. It is important for the researcher to set aside or bracket preconceptions about the phenomenon under study. Oiler (1982) notes that bracketing does not eliminate bias but rather brings it into perspective.

The role of the subject in a phenomenological study also differs from that of the subject in quantitative research. The subject is considered a knowledgeable informant who engages in cooperative dialogue with the researcher. By discovering the expert, insider's perspective, the researcher gains understanding (Field & Morse, 1985).

Given the gaps in the existing literature on incontinence and the nature of the research question, the qualitative method of phenomenology is well-suited for this nursing study. As

phenomenology seeks to understand and describe "the unknown," this methodology will provide insight into the experience of living with untreated incontinence.

Assumptions

For the purposes of this study, the researcher assumes that urinary incontinence has an impact on the lives of elderly women. Furthermore, she assumes that women will be willing to talk openly and honestly about living with urinary incontinence, and thereby communicate this subjective experience in an understandable way.

Limitations

This study was limited to the city of Vancouver with the exception of one subject from Vancouver Island. In addition, subjects for the study were limited to those volunteers who spoke functional English. Participants were contacted through seniors' health drop-in centres, seniors' network publications, and community service agencies and therefore may have represented a specialized subgroup of elderly women. Furthermore, the difficulty in recruiting participants may be the product of extremes in elderly women's desire to hide their incontinence. Those who did volunteer might then be at the other end of the continuum and, therefore, a unique subgroup.

Summary

Urinary incontinence is recognized as a major problem for elderly women. It is believed to affect personal and social aspects of

their daily lives. At the same time, a majority of these incontinent women do not report their symptoms to health care professionals and, if they do, the complaints are often poorly addressed. Both clinical and research-based literature exists on the prevalence, assessment, and treatment of urinary incontinence. However, there is limited information about the subjective experience of living with incontinence. A qualitative, phenomenological approach will provide meaningful descriptive data for health care professionals. The findings of this study will provide direction for health care professionals working with elderly women in general and, more specifically, for those working with incontinent elderly women.

The following chapter provides a review of the literature pertinent to incontinence. Chapter Three describes the methodology used in this study. The findings and interpretation of the data are presented in Chapter Four. In addition to summarizing and concluding the thesis, Chapter Five provides implications for nursing practice, education, and research.

CHAPTER TWO

Literature Review

Introduction

This chapter reviews the current knowledge about the experience of living with urinary incontinence. Divided into six sections, this review includes: an overview of the significance of incontinence; societal attitudes; health care professionals' attitudes; the psychosocial experience; assessment and treatment of incontinence; and self-care strategies for managing incontinence.

Incontinence: An Overview

Urinary incontinence, a significant problem for the elderly, is often seen as a major catastrophe, "heralding the beginning of the end" (Williamson, in press). With prevalence estimates as high as 50% for those women 65 and older, elderly women are considered the most vulnerable (Yarnell, Voyle, Richards, & Stephenson, 1981).

Not only is incontinence a frequently occurring problem, but it is also a problem of major personal consequences: economic, physical, psychological, and social. First are the major expenses the individual must face when using disposable protective padding. In the United States, estimated individual costs for managing incontinence range from a minimum of \$2.90 to a maximum of \$11.09 per day (McCormick & Burgio, 1984), and one can assume that costs in Canada

would be comparable. Second are the physical complications. Incontinence predisposes an individual, and in particular an institutionalized individual, to urosepsis, decubitus ulcers, skin rashes, and falls (Resnick & Yalla, 1985). Third, the incontinent individual may experience psychological problems such as depression, anxiety, embarrassment, guilt, and poor self-esteem (Brink, Wells, & Diokno, 1986; Burns, Reis, & Pranikoff, 1986; Gray, 1986; Norton, 1982; Vetter, Jones, & Victor, 1981; Wells, 1984; Yarnell et al., 1981). Finally, relationships may deteriorate. Isolation can be a social consequence of incontinence (Catanzaro, 1982; Dobson, 1974; Norton, 1982; Wells, 1984). Thus, the individual with incontinence faces a significant problem with far-reaching effects.

Societal Attitudes

Incontinence occurs within a social context which influences the individual's response to it. Despite the significance of the problem, individuals often choose not to disclose it, managing the consequences the best they know how. Our society, averse to talking about excretory functions except in slang or childlike terms, fosters this reluctance to disclose incontinence. Wells (1984) notes that we often hide public toilets out of sight. Wastes, we flush away. Thus, because our society emphasizes that urination is a private act, an incontinent individual violates a societal taboo.

In addition to these societal constraints, individuals are exposed to gender constraints. Wells (1984) describes various ways that

gender influences toileting patterns. Even more than men, women are socialized to maintain privacy and modesty for toileting. If men must void urgently, they readily improvise behind a strategic tree or building; women rarely use anything other than a designated toilet. Designs for public toilets also illustrate gender-derived differences in urination freedom.

Violating a societal taboo generates a response from others, which is typically negative. "Publicly voiding in one's clothes is a highly censured act: so offensive and deviant from the norm, it imputes an extended and generalized ostracism from others" (Wells, 1984, p. 121). Given society's norms, it is not surprising that individuals are reluctant to disclose problems with incontinence.

Health Care Professionals' Attitudes

Just as societal norms and values affect the individual's response to incontinence, so too they influence the attitudes of health care professionals. In turn, these health care professionals can reinforce the individual's reluctance to disclose problems with incontinence. Not only can these professionals have disinterested and impersonal attitudes, but they may also adopt stereotypic beliefs about the incontinent elderly. A number of studies, both clinical and research-based, have examined the attitudes and responses of various health care professionals toward incontinence.

Sutherland's (1976) report of his clinical observations described one such response, denial, as a coping strategy for caretakers of

incontinent elderly. By denying the individual's personal qualities and relying on an overly technical approach to incontinence, caretakers dehumanize the patient. Symptom management becomes merely a technical exercise in which rehabilitation has no part. The only goals are staff efficiency and reduction of unpleasant side effects, such as odour. It is important to note that there is an absence of research support for Sutherland's conclusions. Nevertheless, it is likely that a technical, non-empathetic approach to incontinence would discourage individuals from discussing their problem.

Mittiness and Wood (1986) analyzed social workers' responses to elderly clients with three health problems: urinary incontinence, confusion, and mobility impairment. Within a randomly selected sample of social service agencies, 20 social workers volunteered to participate in this well-designed study. Qualitative data describing the social workers' experience with incontinent elderly clients were gathered via indepth interviews. In addition, the participants ranked incontinence along with 24 other health problems, comparing their perceptions of frequency and degree of impact. The findings of this study indicated that the social workers demonstrated greater uncertainty about the causes of urinary incontinence than about those of confusion and mobility limitations. One half of the respondents viewed incontinence as a result of the aging process. Thirty percent thought incontinence stemmed from behavioural or psychological causes, such as psychiatric problems, emotional stress, attention-getting or manipulation, depression, copying role models,

and/or reluctance to use a commode.

The affective responses of these social workers to incontinent individuals were generally more negative than their responses to confused or mobility-limited clients. These social workers demonstrated less sympathy and attributed greater blame to the client. Moreover, blame was closely associated with noncompliance. For these social workers, the solution to the problem of incontinence was greater compliance on the part of the patient, as opposed to accurate medical diagnosis and treatment. Furthermore, the respondents were more pessimistic about the future for their incontinent clients than for confused or mobility-impaired clients. "Once people lost control over their bladders, it was only a matter of time until everything else fell apart" (p. 73). As advocates for clients in the community, social workers are frequently involved in decisions about independent living, and yet they are vulnerable to negative attitudes about incontinence. These findings suggest that attitudes can prevent health professionals from responding to incontinence in a constructive way.

Nurses provide the most direct care for the incontinent elderly. Research regarding nurses' attitudes toward the elderly has been predominantly institution-based. However, the findings can provide insight into the health care context for incontinence. Using a pre- and post-test control design, Hu and colleagues (1984) studied the impact of a bladder training program on the residents and staff in four nursing homes. A staff of 156 registered nurses, licensed practical

nurses, and nurses' aides completed a Staff Reaction Questionnaire. This questionnaire was designed to elicit staff attitudes and emotional reactions to dealing with incontinence. The reactions were mixed over a range of positive, negative, ambivalent, and aesthetic. At least one-third of the staff reported positive feelings toward incontinent patients most of the time. However, over 50% of the staff reported frustration, fatigue, discouragement and irritation some of the time. The extra work associated with urinary incontinence sometimes upset one-third of the staff. Similarly, over one-third responded negatively from an aesthetic perspective. They disliked changing wet clothes or bedding, and disliked the odour associated with incontinence. The authors noted that there were opposing dimensions of nursing staff reaction to incontinence:

On the one hand, the staff reported that the situation was hopeless and that they felt helpless and guilty about their feelings toward urinary incontinent patients. But at the same time they reported feeling sympathetic (sorry) toward these patients and looked for ways to help them (p. 68).

As the Staff Reaction Questionnaire was designed and first used for this study, it would be valuable to retest it. Unfortunately, the authors did not describe the process of questionnaire development. They did note that, as a measure of staff stress in relation to urinary incontinence, the Staff Reaction Questionnaire had a reliability coefficient of .8399. Nevertheless, accounting for the need to retest the questionnaire, these findings regarding nursing staff attitudes

toward incontinence are no more encouraging than are the descriptions of social worker attitudes.

What are the attitudes of physicians to incontinence? Mitteness (in press) conducted an ethnographic analysis of urinary incontinence in the lives of elderly people. As part of a larger study on chronic disease, Mitteness interviewed 30 incontinent residents in a seniors' housing complex. Three of the 30 residents were under 60 years of age, with an overall age range of 41 to 97. Twenty-one residents had reported the incontinence to a physician and 48% of those physicians had totally ignored or dismissed the complaint. Two of the 21 physicians provided an explanation of sorts, unaccompanied by treatment or management recommendations. The remaining 42% had made treatment recommendations, some vague and poorly understood by the patient and others quite specific. Despite specific recommendations, eight elders themselves refused to consider treatment, stating they were too old for surgery. The limitations of these findings are that conclusions about physicians' attitudes are based on the perceptions of the elders as opposed to primary data from the physicians themselves. Nevertheless, the patient's perception of the interaction affects his or her participation and the overall outcome.

The literature suggests that health care professionals are generally pessimistic about incontinence. This pessimistic attitude which views incontinence as a hopeless or untreatable situation could cause health care professionals to appear disinterested when

confronted with an incontinent patient. Furthermore, health care professionals are often seen by patients as the only avenue for help and when that help is limited or unavailable, patients could become discouraged. Therefore, interactions with health professionals may influence the personal context within which incontinence occurs, that is, the psychosocial aspects of living with incontinence.

The Psychosocial Experience

Despite numerous publications on incontinence, information on the personal impact of incontinence is sparse. Authors allude to the social and emotional costs of incontinence but frequently neglect to base their conclusions on research findings. However, this "clinical and common-sense" literature can set the stage for research questions, and generate ideas for the analysis of data. Therefore, it warrants consideration.

Incontinence was frequently associated with a decrease in social interaction, and hence, social isolation (Catanzaro, 1982; Dobson, 1974; Norton, 1982; Sutherland, 1976). Wells (1984) described the varied nature of this isolation when she wrote: "The embarrassed incontinent individual may choose to decrease social interaction, avoiding its insecurity, or become so confined by toileting needs that self-isolation results" (p. 120). The literature was inconsistent about the degree of isolation resulting from incontinence. Some sources reported that individuals went out despite it; others stated that incontinent individuals never left the house. Certainly there is evidence that the

severity of the symptoms can influence the degree of isolation (Norton, 1978). Furthermore, Dobson (1974) noted that other chronic diseases restricted the activities of individuals to a greater degree than did the incontinence. What remains unclear, however, is how individuals determine a need or desire to withdraw from social interactions. Factors such as past experiences, the emotional response to incontinence, others' reactions to it, environmental constraints, and available resources are not sufficiently addressed in the literature. Individuals' indepth accounts of their life with incontinence may provide some insight into the process of social withdrawal.

In addition to social withdrawal, authors frequently described negative feeling states and changes in mental health status for incontinent individuals. Embarrassment, shame, fear, and depression were recurring themes in the literature. With regard to embarrassment, contradictory statements could be found. Mitteness (in press) described embarrassment as a prominent factor in the emotional lives of elderly informants while Yarnell and others (1981) reported that only three percent of a population of 433 women felt embarrassed. Similarly, shame was mentioned in one study of elderly women as the worst consequence of incontinence (Norton, 1982), and yet, not mentioned in other studies. Anxiety and fear associated with incontinence were attributed to the unpredictability of its occurrence by Norton (1982) and Yarnell and others (1981). Using quantitative research methods, Vetter and others (1981) found a statistically significant incidence of severe incontinence in those with clinical

anxiety and seemed to suggest that those with "mental disability" were more likely to be incontinent. However, the data suggested a correlation not a cause and effect relationship. Similar attempts to link depression and incontinence were contradictory and unclear (Vetter et al., 1981). Various authors who mentioned depression did not compare their findings to depression data for continent seniors (Mitteness, in press; Norton, 1982; Vetter et al., 1981). Thus, the literature does not sufficiently explain how much of the existing depression is directly the result of incontinence.

In general, the literature suggests that incontinence influences one's interaction patterns and emotional state. Quantitative surveys report contradictory results. At the same time, they provide minimal insight into the personal experience of living with incontinence. Due to the attitudes of both society and health care professionals, disclosure of incontinence is difficult and the lived experience remains untold. Furthermore, neither incontinent individuals nor health care professionals appear to benefit from the literature that is available. Established attitudes and a lack of familiarity with the literature may account for that gap. A review of the literature on assessment and treatment of incontinence will provide insight into what is known and, in turn, what still needs to be studied.

Assessment and Treatment of Incontinence

There is abundant literature in both medical and nursing journals describing the epidemiology of and clinical approaches to urinary

incontinence. Studies emerged in the late 1970's and early 1980's attempting to determine the prevalence of incontinence. With the growth in geriatric literature and the increasing awareness of the prevalence of incontinence, clinicians began to write about assessment and treatment options. These reports predominate in the literature.

Authors have described the role of an accurate and thorough assessment in the management of incontinence (Wells, Brink, & Diokno, 1985; William & Pannill, 1982; Williamson, in press) Each author emphasized the importance of a detailed history, including a description of where, when, and under what circumstances the individual is incontinent. Depending upon symptoms and initial findings, the specific components of the physical examination vary. The assessment of urinary incontinence can be a complex process due to the multiplicity of factors which cause or exacerbate incontinence. Despite the complexity, assessment protocols are clearly documented in the literature.

Equally plentiful are the descriptions of treatment regimens. The treatment of urinary incontinence consists of a wide range of interventions and the success of these is dependent upon the specific cause of the problem. Treatment options include environmental changes to facilitate toileting, medication changes, treatment of constipation, exercises, drug therapy, surgery, and bladder retraining with or without biofeedback (Burgio, Whitehead, & Engel, 1985; Burns, Marecki, Dittmar, & Bullough, 1985; Finkbeiner, 1980; Hu et al., 1986; Long, 1985; Tallis, 1984; Williams & Pannill, 1982). Based on

clinical experience, Willington (1980) estimates that 70% of incontinence in the elderly is curable. Resnick and Yalla (1985) view incontinence as transient in 50% of patients and claim that two-thirds of the remainder with established incontinence can expect a cure or at least marked improvement. Thus, the literature suggests that not only are the treatment options for incontinence numerous, but the likelihood of success is high.

There is no denying that information on assessment and treatment is useful to clinicians. However, without an understanding of the patient's perspective, treatment recommendations may fail. The success of treatment is dependent upon an awareness of the patient's perspective as treatment recommendations must complement the individual's view of his or her life with incontinence. Furthermore, without an understanding of incontinence as lived by the patient, health care professionals will lack insight into why the majority of incontinence remains hidden and consequently, what self-care strategies are used to manage it.

In addition to the literature on medical treatment, there is a limited number of studies concerning self-care strategies for the management of incontinence. The following section will describe what is known about these strategies and the beliefs that shaped them.

Self-Care Strategies for Managing Incontinence

Stereotypic beliefs about the degenerative process of aging have frequently led to a passive acceptance of incontinence by the elderly.

The absence of help-seeking behaviour has been described as passive acceptance of the condition (Dobson, 1974; Simons, 1985). Yarnell and colleagues (1981) found a wide threshold of tolerance in older women for symptoms of incontinence. They theorized that those women who did not seek medical help may have been reluctant to discuss incontinence or had a low expectation of treatment benefit.

In a more thorough survey of 200 women, Brink and others (1986) found that, apart from protective padding, self-management techniques were rarely reported. The authors theorized that over the course of many years of living with incontinence, the women who volunteered for their study had incorporated adaptive behaviours into everyday life and were no longer aware of these changes in life patterns. This would suggest acceptance of incontinence as a normal part of one's life.

Mitteness (in press) provides the most indepth approach to the self-care of incontinence. She analyzes the meaning attached to urinary incontinence by older men and women and describes it as a sense of acceptance:

For many of these people, the most striking feature of their understandings of incontinence was the clarity of their belief that urinary incontinence was not a problem, but a normal, predictable part of growing old, a "normal" disturbance in functioning for which there was no remedy (p. 14).

She reported that this belief in the normalcy of incontinence for the elderly clearly influenced the informants' approach to and acceptance

of medical care. Furthermore, she found that when complaints were made to physicians who failed to respond, the informants did not seem surprised or disturbed. The physicians had merely confirmed existing beliefs, reaffirming the need to "accept and manage rather than reverse or cure" (p. 51-52).

Strategies aimed at accepting and managing "ranged from emotional and cognitive attempts to control the impact of incontinence to rearrangements of the physical and social environments to accommodate incontinence" (p. 34). A number of informants attempted to strengthen their control over incontinence through pelvic floor exercises, controlling fluid intake to decrease voiding frequency, or by controlling the urge to void by frequent toileting prior to any urge sensation. In fact, control was a strong theme throughout: control of wetness, odour, and visibility.

Redefining the term control, to fit one's present abilities, was another commonly used strategy.

Incontinence becomes redefined from the medical definition of involuntary loss of urine to a social or personal definition that focuses on 'visibility' -- incontinence is voiding in a manner that allows urine to be visible to others either by eye (soiled clothing, floors, or furniture) or by nose (the smell of urine) (p.36).

Mittiness found that a distinction was made by the incontinent elders between public and private loss of control. An incontinent episode within one's own apartment was acceptable but a similar episode in a

public place was not.

Abandonment of control was also reported by Mitteness as one way of living with incontinence. Although abandoning control was utilized by only three of her informants, all of these were flagrantly incontinent. These individuals were the recipients of negative social sanctions, and publicly noted smell and wetness were the stigmatizing components of incontinence.

In a qualitative study of 126 incontinent individuals with MS, Catanzaro (1982) described the importance of the "awareness context" for symptom control and avoidance of the stigma of incontinence. Awareness context involves what the interactants in a situation know about each other and the effect on the interaction. Catanzaro described four types of awareness, as defined by Glaser and Strauss: open, closed, suspicious, and pretense. Both incontinent individuals and those interacting with them had to decide how much information to disclose about the incontinence. This form of control seemed particularly important during work interactions in which closed awareness was maintained. For example, Catanzaro described one woman's efforts:

The possibility that her attempts to continue to pass as normal would collapse at any moment were a source of anxiety to her. Her attempts to maintain a closed awareness context and to prevent her symptoms from becoming discrediting was an overriding concern in all her interactions at work (p. 55).

Thus, the need to keep incontinence hidden in order to avoid

stigmatizing reactions may also be an influential factor for those elderly living with untreated incontinence.

Due to the complexity of neurological deficits such as MS, Catanzaro recommends future research with incontinent individuals whose symptoms are unrelated to a specific disease. In addition, she recommends studying men and women separately, in order to determine if there is a sex-related difference in the experience of incontinence. The social norms surrounding urination would suggest that differences may exist.

Thus, although there has been a number of different research methods used to study the problem of incontinence, there has been no phenomenological approach to understanding it. As health care professionals have limited information regarding those individuals living with untreated urinary incontinence, this author has chosen to investigate that phenomenon in a way that addresses the gaps in the literature, and hopefully leads to a better understanding of what it is to live with untreated urinary incontinence.

Summary

In light of the literature review, this author concludes that the attitudes of society and health care professionals can inhibit disclosure of incontinence. Furthermore, the psychosocial aspects of incontinence can challenge emotional and social well-being. Limited knowledge exists concerning the self-care strategies used to manage incontinence and, in particular, medically untreated incontinence. This information

would be beneficial to health care professionals interested in the problem of incontinence.

The majority of the literature focuses on prevalence, assessment, and medical treatment of incontinence. This current knowledge base does not provide sufficient understanding of the experience of elderly women living with untreated incontinence. Those qualitative studies which begin to address the incontinent individual's perspective focus on the middle-aged with multiple sclerosis (Catanzaro, 1982), or a mixed age and gender group (Mitteness, in press). Therefore, this study will complement and build on the existing research concerning urinary incontinence by providing insight into elderly women's experiences with untreated urinary incontinence.

CHAPTER THREE

Methodology

Introduction

The methodology for this research was one of phenomenology. As noted in Chapter One, phenomenology provided the opportunity to discover and describe "the human experience as it [was] lived" (Oiler, 1982, p. 178). As little knowledge about the day-to-day experience of living with urinary incontinence is available, this particular methodology provided a mechanism to gain such an understanding. This chapter will address the following aspects of the method as it was applied in this study: setting, criteria for participant selection, sample size, sources and characteristics of participants, data collection, data analysis, and ethical considerations.

Setting

Data collection was conducted in the informants' homes. This provided a comfortable and confidential location for the interviews, as well as providing the researcher with an opportunity to observe environmental and familial factors pertinent to living with incontinence. Despite the opportunity for input from three spouses, married informants chose to be interviewed alone. Field notes provided additional data from three seniors' education sessions, two at health drop-in clinics and one at a seniors' housing complex.

Criteria for Participant Selection

Six criteria were used in selecting women for this study.

- 1) Participants experienced untreated urinary incontinence for a minimum of six months, occurring at least twice a month.
- 2) Participants were 60 years of age or older.
- 3) Participants were verbally fluent in English.
- 4) Participants did not experience faecal incontinence in addition to urinary incontinence.
- 5) Participants did not use long-term urinary catheters or diversion devices.
- 6) Participants lived in their own home as opposed to long-term care facilities or apartment type seniors' housing with attendant health care staff.

Sample Size

The purpose of qualitative research, and in particular phenomenology, is to understand a phenomenon. This differs from the purpose of quantitative research which seeks to examine the distribution of an already understood phenomenon through random sampling techniques. The qualitative researcher selects a sample based on the purpose of the research rather than the relationship of the subjects to the overall population (Field & Morse, 1985). Furthermore, in a phenomenological study, the length of the data-gathering interviews and the detailed descriptions that result influence the sample size (Field & Morse, 1985; Omery, 1983). This researcher made a preliminary decision to seek eight to ten

participants, based on time constraints and the experiences of other phenomenological researchers. Limited by the number of actual volunteers, the final sample size was nine.

Sources of Participants

Participants for this study were obtained in a variety of ways. Contact was made with five Seniors' Networks in the Vancouver area. The researcher provided an advertisement (see Appendix A) to be published in the monthly Network newsletters. The advertisement invited elderly women who had regular episodes of incontinence, and who were not receiving treatment to contact the researcher. At that time participant criteria were clarified, further information provided and, if agreeable, a home visit arranged. An additional advertisement was posted in a Vancouver seniors' housing complex known to the researcher through nine months of clinical work with the health department. Interested women were asked to contact the researcher by telephone. Individuals who telephoned but did not meet the criteria for the study were offered information and given the opportunity to talk about incontinence over the telephone. Three women called but refused to leave a message when the researcher was not home; none of these women called again.

Since a total of only four women responded to the advertisements, the researcher pursued additional participants via homemaker agencies and the provincial Long Term Care programme. Staff in these agencies distributed the information and consent letter (see Appendix B) to clients who met the study criteria. On two

occasions, an advertisement was placed in the local neighbourhood newspaper. In addition, the researcher presented the study, its rationale, and its importance to nursing at three seniors' health education meetings. Colleagues who knew of incontinent elderly women were also asked to distribute the information and consent letter.

A total of nine informants was obtained: four contacted via the Network papers, two via the health drop-in clinics, two via Long Term Care/homemaker agencies, and one via a nursing colleague. One man contacted the researcher hoping to be included in the study.

Information was exchanged over the telephone but the data were not used in this study. Similarly, a middle-aged woman with multiple sclerosis and an elderly woman with cystitis were enthusiastic about participating. However, they did not meet the criteria for the study and the information obtained through discussions was not included.

The author had assumed that finding ten incontinent women to participate in the study would be relatively straightforward. However, despite the intensive and varied approaches, spanning a four month period, recruitment was difficult. Frequently, women at seniors' groups were quick to state that they didn't have problems but a friend did, and then ask questions specific enough to suggest personal familiarity with the experience of living with incontinence. Following the presentation, they did not volunteer for the study. When the author contacted a seniors' group to explain the research, she was advised by the leader, a senior herself, that: "Our group is too active, and not really suitable for your study. We don't have that sort

of thing." Explanations of the degrees of incontinence and the fact that activity level was not the issue failed to clarify the request. Similarly, a woman who had received the information letter from a homemaker agency called the researcher and expressed anger at someone suggesting that she had incontinence. As the homemaker agency staff had been explicit about the criteria for the study, one wonders whether this lady, like the seniors' leader, was perhaps uncertain of publicly acknowledging the existence of incontinence. Thus, one can surmise that the confidential and potentially embarrassing nature of the subject under study significantly hampered the recruitment of participants.

Characteristics of Participants

The women who participated in this study ranged in age from 60 to 86, with a mean age of 71. Their experience with incontinence was quite variable from as short as 8 months to as long as 26 years. The majority (n=7) had lived with incontinence for less than 3 years. Two-thirds of the women (n=6) experienced mild incontinence in that they had infrequent episodes of minimal leakage, with only occasional total loss of bladder control. Two women described a moderate degree of incontinence and one, a severe loss of bladder control. Living arrangements were either of two categories. Six women lived alone while three lived with a spouse. The number of pregnancies experienced by each woman varied from 0 to 4 with no identifiable pattern or relationship to degree of incontinence. In addition, none of the women was obese. Finally, the majority of the women lived with

chronic diseases, usually multiple in nature. Examples of these included stroke, cancer, bronchitis, hypothyroidism, manic depression, osteoporosis, arthritis, and heart disease. In general, the demographic characteristics of these women are within the range of characteristics expected for this group.

Data Collection

Data were collected through in-depth interviews, ranging in length from one to three hours. An open-ended approach to interviewing is recommended when little is known about the phenomenon. Field and Morse (1985) describe a "process of exploration" in which "the interview may be directed by the informant's responses into areas previously unanticipated by the researcher" (p. 65). Initial interviews were guided by the overall question: What is it like to live with urinary incontinence? A number of sample questions provided a general guide for these initial interviews (see Appendix C). These questions were generated in relation to the problem statement and recurrent themes in the literature. However, the nature of the questions, including the sequence and phrasing of them, remained flexible, in order to follow the participant's lead. The researcher used reflective listening to encourage the participants to explain their comments more fully.

As data collection progressed, the depth and specificity of the questions increased. Seven of the women were interviewed twice, the remaining two only once: one woman lived on Vancouver Island and the other volunteered late in the study during the period of

second interviews. The second interviews generally occurred eight to ten weeks after the first and were guided by the preliminary analysis of categories within the data. Often the researcher referred to previous statements made by the participant and to both similar and contrasting themes identified by the others. These second interviews were used not only for clarification and validation of emerging categories, but also for rejection of those categories which were not validated by the informants. Thus, the second interviews helped to refine or alter early conceptualizations, so that these conceptualizations evolved over a period of time to a point of relative certainty.

In order to facilitate data analysis, all interviews were audio-taped. In addition, the researcher kept written field notes of the interviews and telephone conversations. Further discussion often occurred as the researcher was leaving the womens' homes. This information was also recorded as field notes.

During education sessions with groups of elderly women, the researcher noted the types of questions asked concerning incontinence, these providing additional field notes. In the social hour following the lecture the women also provided rich data on their perceptions and concerns regarding incontinence, even though they did not become specific informants for the study. These discussions were used in a different way than the actual interviews, in that they provided the researcher with a significant amount of exposure to the issue of incontinence. This exposure occurred in public forums and provided a sense of how incontinence was handled in general by

society and in particular by groups of seniors.

During the data collection phase, the researcher became increasingly aware of a research dilemma, the nurse as researcher restricting the nurse as clinician. The participants brought to the discussion their primary agenda of obtaining information. The researcher clarified her role as researcher not clinician. However, the women persistently wove questions throughout their answers. Wrestling with the ethical dilemma of maintaining the role of researcher and yet addressing the needs of the participants, the researcher turned to methodology literature. Wax (1971) described fieldwork, a form of qualitative research, as a social process including reciprocity and mutual assistance. She noted that participants provide the researcher with "instrumental membership" (p.50), in which they allow one to function in a manner that is useful and agreeable to them. We are "nudged into roles for which, in their opinion, we [are] particularly suitable" (p. 51). This researcher felt nudged into the roles of clinician, educator, and resource consultant. This process and the resultant attempt to balance roles and simultaneously build trust are an integral part of the data and will be discussed in Chapter Four.

Data Analysis

Data analysis occurred simultaneously with data collection. For purposes of analysis, the audio-tapes were transcribed by the researcher after each interview. This fostered greater familiarity with the data.

The author used Giorgi's framework as described and enlarged by

Wertz (1983) to analyze the data. Outlining the process of going from "everyday, 'naive' description" to a deeper level of psychological understanding, Wertz described various components to the researcher's attitude toward the data. These included: 1) empathetic immersion in the world of description; 2) slowing down and dwelling; 3) magnification and amplification of the situation; 4) suspension of belief and employment of intense interest; and 5) the turn from objects to their meanings (p. 204-206). Adopting these attitudes, the author was able to pursue openly and deeply the women's descriptions of life with incontinence.

Not only did Wertz outline the attitude of the researcher, but he also described various activities that would facilitate qualitative analysis. Those that proved most useful to this researcher included: 1) "reflection on judgement", that is, asking the question: "How am I understanding this phenomenon and how do I determine its relevancy?"; 2) "penetration of implicit horizons" so that the informants' implicit assumptions are understood and incorporated; 3) "making distinctions" so that one understands what each statement expresses and how it differs from the others; 4) "thematization of recurrent meanings or motifs" in which one looks for the unity and consistency between experiences; 5) "interrogation of opacity" whereby the researcher pursues further those areas that remain perplexing; and 6) "imaginative variation" in which one varies all aspects of the experience, attempting to grasp the essential elements (p. 207-210).

Using these components of data analysis, each interview was

considered on its own merit, but also viewed in light of the other interviews. Both field notes and the verbatim transcriptions were reviewed and compared for recurring themes. Eventually, "the ingredients of the phenomenon and the way the ingredients relate to each other" (Oiler, 1982, p. 180) were identified. By moving back and forth between the transcriptions as a whole, the major themes, and the smaller points of meaning, the researcher was able to begin to conceptualize the overall experience, and yet describe, differentiate, and link the categories within it. This permitted the researcher to be true to the overall intent of the participants and yet, pursue deeper levels of meaning (Field & Morse, 1985).

In order to validate data, the researcher described these ingredients and recurring themes to the participants during the second interviews. "A successful description directs the listener to his own experience of the phenomenon" (Oiler, 1982, p. 180). The participants not only acknowledged, "That's exactly the way it is," but also challenged the ideas, helping the researcher clarify and refine them. Once all the interviews were complete, data analysis continued until the themes solidified into a broad framework which described the experience of living with incontinence for these nine women.

Ethical Considerations

Approval for this study was obtained from the University of British Columbia Screening Committee for Research Involving Human Subjects. The rights of participants were protected through standards as set by the Screening Committee for Research.

Participation was voluntary and no interviews were conducted without the written consent of the participant. A written description of the study along with an explanation of the researcher's expectations (see Appendix B) were made available to participants prior to the signing of consent forms. Prior to the interview, participants were reminded that they could withdraw at any time or refuse to answer any question without fear of a negative response from the researcher or jeopardy to further health care.

Confidentiality was ensured. The names of those who chose to participate in the study were not revealed to anyone, including the referring agencies. All taped and written material was kept confidential and anonymous. Access to the tapes was restricted to the researcher and the two members of her thesis committee. Written material for this study used no names or identifying information. Audio-tapes and computer discs will be erased when the study is completed and all scholarly papers have been written.

Participants were informed that participation in the study involved no anticipated risks. Individuals seem to have benefitted from the opportunity to talk about their experience to an interested and empathetic listener. One woman summed up the interview by saying: "I'm so glad I had someone to talk to about it." In addition, the women benefitted from the exchange of information which occurred during and following the final interview. Upon completion of the interviews, participants were provided with information regarding assessment and treatment options if they so requested.

The researcher agreed to share the research findings with the

participants and referral agencies who were interested. A summary report was mailed to each of them once the thesis was completed.

Summary

This chapter described the methodology used in this study. The description included the setting, the criteria and process for participant selection, sample size, data collection and data analysis. Ethical considerations as outlined by the University of British Columbia were discussed.

CHAPTER FOUR

Findings and Interpretation

Introduction

This chapter addresses the findings of the research. Throughout the chapter the findings are followed by their interpretation in order to provide a more concise and integrated report. As support for the interpretation of the findings, the author draws from the literature in Chapter Two. In addition, the findings directed the author to new literature in order to explain the unforeseen aspects of life with incontinence.

The experience of living with incontinence as described by these women involved four components: 1) recognizing the problem; 2) avoiding exposure; 3) needing information; and 4) redefining normal. Recognition of incontinence, an initial milestone, led the women to avoid exposure through symptom management and to seek new information. Living with incontinence also led to a shift in attitude as these women had formed a new definition of what would be normal for them. These four components are discussed in turn.

Recognizing the Problem

For the study women, recognition of incontinence was a critical, and often initial point of discussion. This recognition evolved from a growing awareness of their symptoms. Despite the occurrence of symptoms, recognition of incontinence was frequently delayed. The

women cited a number of reasons for this delayed awareness.

Developing Awareness

In their accounts of living with incontinence, each of the women described a point of recognition. For these women, recognition involved admitting to themselves that they had ongoing problems with bladder control. For six of the women this awareness had already occurred at the time of the study, but for the remaining three, the realization that they were incontinent happened during the introduction to the study. One woman described this realization clearly when she said:

So obviously after I started thinking about it, that indicated to me that I was really pursuing something on this. Because I had realized that this is what is, that it is incontinence, and that it had a name. Before that it wasn't. It was just. . .um. . . [lifts hands to gesture "the unexplainable"].

Similarly, another said: "I didn't take it seriously. I didn't think of it as an incontinence to be truthful. I just thought of it as an accident, . . . something that just happened." Gradually, these women became aware that the incontinent episodes could no longer be viewed as accidental. For the three women who recognized their incontinence at the time of the study, the author's introductory information letter (see Appendix B) caused them to realize that even minor leakage of urine, as infrequently as twice a month, could be considered incontinence. Each of them had equated the term incontinence with copious and frequent loss of urine, as opposed to what was happening to them.

As was the case with the introductory letter, the women commonly credited new information with the development of awareness. Looking back at her point of recognition, one woman articulated the shared experience:

So you do rationalize for a long period of time and decide: "Well OK", and then suddenly it dawns on you... There is a kind of dawning and I think it comes from something on the outside. It's not something you decide on by yourself. Like information from the outside. I think in my case it came in just from the outside and then I probably decided to explore it more. It's an awareness and then of course, if I'm aware, I have to explore it and find out what it's all about.

In addition to outside information, a recurrence of the incontinence led the women to recognize it as significant. "At first you say: 'It's such a little bit.' But that little bit eventually gets to a point where you think: 'No! Who am I kidding?' It's happening more and more." Thus, reaching a point of recognition could develop from the introduction of new information or from the repeated occurrence of what had been viewed as relatively minor or accidental symptoms. At the same time that the women were describing this recognition, they noted that recognition was frequently delayed. Reflecting on their experience with incontinence, they provided various reasons why this recognition had been delayed.

Rationalizing a Delayed Recognition

Part of the difficulty in recognizing incontinence came from the

infrequent and seemingly temporary nature of the symptom. As one woman said:

Before it was a nuisance whenever it happened. I felt disgusted and thought it's just something that happens occasionally. But now I've had time to think about it more and I realize that it has been happening over a period of time and I hadn't really been paying attention to it.

The continuing hope that incontinence was a temporary symptom, one that would eventually go away, also delayed recognition. The following explanation typifies the shared hope that incontinence was transient:

I think probably myself, that I've never thought it was that dreadfully important, that it was just one of those things that I would get rid of or get over. I haven't said anything to a doctor, or anyone in medical circles at all, because I thought it was something that would probably pass.

If the incontinence had begun during the time of a temporary illness such as flu or bronchitis, the women assumed it would pass when their health stabilized. It was only when the incontinence persisted after the temporary illness cleared, that the women started to question and thereby, came to recognize the incontinence. One of the women described the questioning that had occurred when she was approaching a point of recognition:

But you had to come to a point before you go to the doctor. "Is this for real? Is this as bad as I sometimes think it is? No it isn't! There's no point in wasting the doctor's time. He can't

help me anyway." And there's a bit of denying that comes into it too-- "it's only a little bit. It's such a little bit."

Thus, recognition of incontinence was hampered by the seemingly infrequent and variable nature of the symptoms, along with a tendency to underestimate the degree of the problem.

Another factor which delayed recognition was the women's ability to separate themselves from others who had incontinence. Frequently the women spoke of "those people," expressing empathy for those who had incontinence, the real kind of incontinence. As one said: "What I knew of incontinence, I would put into the category of very old people who have gone senile or direct sickness but I didn't think that my little problem was incontinence." Describing her experience on the bus system for the handicapped, one woman who had had a stroke, said:

This [wet clothing] used to happen in the Handidart. You often used to get the handicapped people who had this problem. I mean they really had this bad.... I didn't have it like the kind of people that, you know.... These things happen to those kind of people.

Despite her visible physical handicap and an episode of public wetness, this woman saw herself as different and, hence, not really incontinent. Similarly, another woman in her 70's saw herself as different from "some of these sweet little ladies" at the seniors' centre and their problem with urine odour. These feelings of being separate or different made it hard for the women to categorize their symptoms, along with the visible symptoms of others, as incontinence.

Once a point of recognition is reached, one has the option to take the incontinence to a physician. In order for symptoms to be presented to a doctor, they must first be viewed as a problem, then defined as a suitable problem for the doctor, and finally, acted upon. Tuckett (1976) describes this process as having three steps: recognition, definition, and action. The informants in this study tolerated living with incontinence because they neither recognized it as a problem, nor defined it as a medical problem. Thus, incontinence, as a hidden problem, is clearly influenced by the individual's ability to recognize and legitimize the symptom.

Analyzing the issue of symptom recognition and subsequent action, Kelly (1986) presented autobiographical data to describe his adjustment to ulcerative colitis. Initially Kelly and his family related the symptom of diarrhea to an ordinary stomach upset. Only when it progressed beyond his family's normal range of experience did they consult with a doctor. Subsequent to medical consultation, Kelly continued to assume that he was not ill, refusing to accept the existence of ulcerative colitis. Like the women in this study, he associated his lack of recognition with the fact that the symptoms were intermittent and of low visibility. Furthermore, Kelly noted how leaving his symptoms as unnamed events, permitted him to not deal with the colitis, and thereby gradually adapt to an unpleasant reality.

One final point with regard to symptom recognition and action is the need to consider the perceived threat of the "illness." Kelly (1986), described the role of a sick person as an openly deviant one, a role which was avoided if at all possible. Similarly, Catanzaro (1982)

noted that visible incontinence could place people in a deviant and threatening position. She described the embarrassment and potential stigma of incontinence. It is possible that recognition of incontinence presented a threat for the women in this study as recognition could lead to action and possible exposure.

Recognition of incontinence was a critical point in the women's accounts of living with the condition. Recognition can be viewed as a milestone or marker event in these women's lives. It commonly marked the beginning of a search for information and help. Due to a variety of factors, the point of recognition was frequently delayed. To begin with, the women were hopeful that the urinary symptoms were of a rare and temporary nature. Comparing themselves to others with more severe or visible symptoms allowed the women to view their symptoms as "a little problem" and not legitimate incontinence. By admitting to themselves that they had incontinence, the women were acknowledging a threatening and potentially stigmatizing reality. Recognition of incontinence could jeopardize their powerful need to avoid exposure.

Avoiding Exposure

Despite the generally milder nature of their incontinence, all of the women in this study emphasized the importance of avoiding public exposure. The following statement typifies this concern for exposure:

I try not to get into a situation where I might feel embarrassed, although when it has happened I haven't been

embarrassed because I found ways and means of...um...curing the problem.

When asked to elaborate on the phrase "curing the problem," the woman explained further: "Keeping it confidential--that's part of it, not letting anyone know that you're having troubles." Two women who had homemaker help each week described their efforts to "get rid of the stuff" before the homemaker arrived:

I have done it [bed-making] myself, but it's been agony to do it, you know, to change it myself. Rather than have her know, I'd do it myself. Isn't it silly?

Despite physical handicaps which made changing the bed difficult, both women felt it was important to avoid public exposure.

Not only were efforts made to avoid exposure after wet episodes, but efforts were also geared toward preventing wetness and hence exposure. Preventive efforts involved a careful reorganization of one's daily life in order to prevent "accidents."

Reorganizing Daily Life

Describing the reorganization of their daily lives, the women identified a need to be careful, to avoid factors which precipitated incontinence, and to map out public bathrooms.

All nine women coped with incontinence by being careful or planning ahead. The following statements are illustrations of the women's use of extra care:

I've had to be very careful to be sure to go to the bathroom before I go downtown or someplace.

.....

I have to keep planning it [going to the bathroom].

.....

I have to think really twice about whether I'm going to join
in.... I have to watch that I don't get too active.

.....

It just makes you feel you've got to remember, you see, what
you have to do.

Each of these examples illustrates a different aspect of being careful: careful to go to the bathroom before activities, careful to plan bathroom breaks, careful about certain activities, and careful to remember. As one woman explained: "You only have to be embarrassed once, to be careful all the time." Despite this extra care, the women described a feeling of being vulnerable to the dictates of their bladders. A large portion of this vulnerability, and hence the need to carefully reorganize their lives, stemmed from the unpredictability of incontinence.

The unpredictability of their bladder control increased the risk of exposure for these women. The women seemed uncertain and even frustrated when they spoke of the difficulty knowing what their bladders would do, never mind when and where. One woman recalled the uncertainty of knowing what would happen when she had delayed using a public toilet:

And I wouldn't go because there was no door. And I thought maybe I should have done. And so I had this uncomfortable feeling, wondering when the next lunch stop will be. I

wondered how long I will have to wait. Will I be able to wait?
And I didn't have any pad or anything, and I thought of that
as well.

Other women spoke of the difficulty knowing how to interpret their feelings of bladder urgency. The following account illustrates the difficulty in being able to accurately interpret bladder signals:

Sometimes the urgency is greater and the contents whatever is less. And then you think you really have to go and then sometimes it doesn't seem that urgent and then when you go you think: "How did my bladder ever hold that much for that long?" So it's an unusual thing.... It's, I don't know, it's unpredictable and I can't understand it either, why there should be a fuller bladder and the urgency not as great and then vice versa. I don't really know.

Unpredictability was also evident at night, with episodes of waking that varied from none at all to five or six in any one eight hour period. The women had tried to determine what factors precipitated night time urgency and frequency, but accurate prediction and control proved difficult. Thus, the women's efforts to avoid exposure were jeopardized by the unpredictability of their incontinence.

Despite this unpredictability, the women tried to prevent public exposure by avoiding factors which seemed to precipitate urgency or loss of bladder control. Balancing fluid intake with the availability of bathrooms was a favoured strategy. One woman recounted her method of withholding fluids before and during outings, and then "flushing" her system with copious amounts of water when she had

returned home. Similarly, others considered water to be beneficial, but were not always certain of their reasons:

I've tried to drink more water. I don't know why. Ordinarily you would think you wouldn't want to try and drink more water but I thought it would be better for me to drink more.

Limiting fluids after dinner was practiced by three of the women. Coffee, tea, and acidic juices were noted to be particularly troublesome and were limited if the situation warranted it. For example, one woman described the effects of tea:

I notice when I drink tea it's even more impossible to try and hold it for an hour or so. It's probably more like 30 or 40 minutes. I don't find coffee bothers me to that extent but it's still liquid so you've got to do something about that too. But tea seems to aggravate the bladder much more.

Beyond the type and quantity of fluid intake, the informants reported a variety of factors they believed were related to bladder control. These included cold weather or feeling cold, inflammation of the urethra, scented panty liners, vigorous exercise, bumpy bus rides, colds and coughs, uproarious laughter, diuretics, psychological stress, and previous catheterizations. Whenever possible the women tried to avoid these factors or at least limit their impact. Examples of this avoidance included wearing woolen underclothing during colder weather; changing to smoother, more direct bus routes; and missing one's diuretic on a shopping day. These reorganizing strategies allowed the women to take self-directed action in an effort to both minimize the degree of incontinence and avoid public exposure.

Another reorganizing strategy for avoiding exposure was the development of a "safe route" through the use of a bathroom map. Not only did the women know where public bathrooms were, but also which ones provided easy access. One woman presented a typical description of mapping:

Well I know where the bathroom is. It's the availability [which] comes mostly through you have to go into a restaurant and you have to buy something.... I mean you get to know where there are some public ones but there aren't that many. Like up at the mall there is one public one.... If I'm going to have anything to drink I know there's a washroom close by.

A number of the women stated that, when considering participation in social activities, the availability of bathrooms was a major and often deciding factor. The woman with the most severe incontinence felt severely limited by access to bathrooms, even when in private homes:

But I do get out occasionally. You know, when I know where I am going I can judge more or less.... I could go lots of places but I don't go because it is not convenient for the toilet or I don't know where it is and I don't want to ask.

When asked to explain further, this woman reiterated her reluctance to ask for directions to a bathroom:

I would rather stay home [than have to ask] ...if I am going to a circle meeting, our mission circle and that, I know the people and I know their homes usually and I can just slip out and nobody notices it one way or another.

Thus, the women used bathroom mapping to avoid exposure and

provide a safeguard by which they could carefully plan their day.

Mapping out safe routes is also a known and successful strategy for coping with various chronic illnesses (Fagerhaugh, 1975; Kelly, 1986; Reif, 1975). Emphysema patients utilize the strategy of "routing" in order to deal with problems of mobility (Fagerhaugh, 1975). Routing involved planning routes to include "puffing stations," places to catch one's breath in order to minimize the expenditure of oxygen and energy. As an emphysematous person maps out "puffing stations," the incontinent person maps out bathrooms. Similarly, the patient with inflammatory bowel disease (IBD) must map out routes according to the availability of bathrooms (Kelly, 1986; Reif, 1975). Describing this strategy as protective in nature, Reif (1975) noted that for the person with IBD, mapping safe routes kept the odour and excrement from becoming visible in social situations. In each of these conditions, the use of planned and "safe" routes provided the individual with a means of minimizing both the impact and the visibility of the symptoms.

Thus, in order to minimize the visibility of their symptoms, the women in this study had reorganized certain parts of their lives. They took extra care with activities and planned bathroom breaks throughout their day. As incontinence is unpredictable in nature, the women also tried to determine what factors precipitated urgency or loss of bladder control. They identified a variety of possible factors and attempted to limit their impact. Finally, bathroom mapping allowed the women to organize their daily activities around accessible bathrooms. All of this reorganization was geared toward avoiding

exposure.

Despite all of their preventive strategies, the women were at risk for public exposure when they experienced actual wet episodes. The management of such episodes served as another category of activities designed to avoid public exposure of incontinence.

Managing Wet Episodes

For all of the women the management of wet episodes was an integral part of living with incontinence. The most common, and often the only, strategy for dealing with wetness was the use of panty liners or sanitary pads. Some used a variety of thicknesses depending upon the circumstances. For example one woman stated that if she was "on the go," a thicker pad would be warranted. The women equated the use of pads with a sense of security:

Whether it's a psychological thing, just putting on that mini-pad seems to, it absorbs a little bit of the moisture that maybe collects during the day, a little small leakage or something, it seems to me to have--it has given me more confidence maybe or something. I don't feel as stressed with the situation... and it seems to provide a certain amount of protection, that I don't feel as if I'm going to wet myself quite as much.

Finding it difficult to shop for pads or even know what was available, one woman had developed her own means of dealing with the wetness. She "stuffed [herself] with paper, toilet tissue, about three and it seemed to take some of the pressure." As this method

eventually created problems with itching, it could only be used for short periods of time. For this lady, a frustrating aspect of managing wet episodes was the lack of access to supplies, and not knowing why certain methods worked better than others. She, along with seven other informants, had no idea about the variety of sanitary pads, let alone the newer varieties of incontinence pads.

Only one of the nine women was familiar with the specific incontinence pads. Since her incontinence was quite severe, she was keen to try a new form of protective padding, currently advertised for moderate or severe incontinence. However, in contrast to the other women using sanitary pads, she would not feel secure with this product until she had specific information regarding absorbency and the length of time it would keep clothing dry. This informant had called drug stores, medical supply firms, and finally, the researcher in order to obtain this information. Prior to using these new pads, she had used an elaborate scheme of plastic with numerous overlapping sanitary pads. Similarly, another woman with night time incontinence, devised a detailed method of protecting the bed. She described this method by listing her "paraphernalia:" plastic sheeting, towels, pads, a bed pan, and a pail. From these accounts it would appear that as incontinence becomes severe, women use rather elaborate strategies to manage wet episodes. Certainly the severity of the incontinence would influence the individual's fear of exposure, and hence the elaborateness of the management strategies.

The women's concern for odour was also related to their need to avoid exposure. As the women managed episodes of wetness, they

were very much aware of the risk of exposure from the odour of urine. The following description typifies their concern for odour:

I think it is one of the most embarrassing things, to think that you smell, you know, from urine.... And with the pads, I feel more comfortable, and the smell is removed because they seem to absorb it. Whereas if you urinate in your panties that smell stays, but the pads seem to counteract that.

In addition to using absorbant, disposable pads to deal with the odour, the women were attentive to cleanliness.

Because first of all there is the odour of urine [that] might be a dead giveaway, so I've been scrupulously clean and kept all my clothing clean.... I had wet enough that my slacks got wet, but I was in a position where I could take them off, wash them, and sort of towel dry them and put them back on.... It was uncomfortable being wet but still they were dark enough it didn't show. It was better to have them wet and washed than maybe smell of urine. I never do that.

The women who seemed particularly concerned about odour cited experiences with incontinent friends or acquaintances: women who were being ostracized for their problems with odour, or whose husbands were too embarrassed to take them anywhere. In all cases, odour was closely linked to the embarrassment of public exposure.

Mitteness (in press) reported similar findings in her discussion of the stigma associated with incontinence. Not only visible wetness, but also odour were cited as the stigmatizing components of incontinence. Comparing incontinence to other symptoms, Sutherland (1976) noted

that incontinence has a unique relationship to social isolation because of the problem of odour. However, odour has been discussed as a problem with inflammatory bowel disease (Kelly, 1986; Reif, 1975) and chronic infectious processes (Howe, 1983). Similar to the women in this study, patients with inflammatory bowel disease and chronic infectious processes placed great emphasis on the need to avoid the potential stigma associated with noticeable odour.

Due to the strong societal norms regarding bladder control, it is not surprising that the study women tried to limit the visibility of their symptoms, thereby avoiding stigma. Authors note that individuals often try to escape the stigmatizing effects of disability by concealing any outwardly visible signs (Catanzaro, 1980; Goffman, 1963; Kelly, 1986; Weiner, 1975; Wright, 1983). Goffman (1963) noted that visibility is a crucial factor in the development of stigma. Catanzaro (1980), drawing from the work of Glaser and Strauss, described the strategies that certain incontinent MS patients used to maintain a "closed awareness," in order to avoid stigma and shame. Similarly, Weiner (1975), working with rheumatoid arthritics, identified the strategy of covering-up, whereby the individual conceals his or her disability and pain. Thus, it would seem, as with chronic disease, keeping symptoms invisible to others is an important part of learning to live with incontinence and yet, minimizing its social impact.

At the same time as the women were attempting to avoid exposure, they were also weighing the risks and benefits of talking to others about their incontinence. If public exposure is avoided at all

costs, opportunities to share one's experiences and benefit from the experiences of others are limited. For these women, the decision to talk about incontinence or remain silent presented a major dilemma.

Talking About Incontinence

This dilemma of talking or remaining silent was evident in the women's initial telephone calls to the researcher. Many seemed nervous, and unsure, with one woman stating: "I really don't know about this. I've never really talked to anyone about this before; I don't even tell my daughter." At the time of the interview, this woman was clearly apprehensive that her daughter would find out about the incontinence:

My daughter was here just now and I didn't tell her you were coming. I was nervous that you would come before she left. I thought: 'Oh Lord, how am I going to explain you?'

Despite the embarrassment and fear of exposure, some of the women chose to share their experience with family and friends. Daughters and sisters were frequent confidantes as the women felt they would understand better than the men in their lives. One woman wanted her daughters to know so that they could try and avoid the problem when they reached older adulthood. Another informant's discussion with her daughter became a comparison of symptoms, with the daughter advising mom that "it was woman's lot in life and therefore we had better accept it."

In addition to being confidantes, family members were often asked to be sources of information. Keeping watch for new technology

and pricing incontinence pads were two tangible ways of providing information. Furthermore, for those informants whose families were aware of the incontinence, empathetic but often silent support was valued. It remained silent support because family members seemed aware of the difficulty but no one addressed it directly: "My daughter pretends she doesn't know and it protects everyone's modesty." The women described one very practical way that silent support was demonstrated in that they, as the incontinent family member, had primary access to the bathroom at all times.

Talking with friends about incontinence seemed to be a decision that was made with great care. Wide variations were noted among the nine study women, ranging from not talking at all, to soliciting friends' help. Suspecting that a friend may be having similar difficulty often opened the door to tentative discussion. If an empathetic enquiry was well-received, the women felt sanctioned to disclose some of their own difficulty.

A shared experience or a shared body of knowledge also made talking about incontinence easier and lessened the fear of exposure. For example, stroke club members sharing their difficulty with incontinence were responding to the shared experience:

People at the stroke club used to talk about that [being close to the bathroom] because almost everyone was on diuretics. That was not a taboo subject because practically everybody was.

One women described the increased level of comfort when people shared a common body of knowledge and a long term relationship:

I walked home with Betty after your talk the other day. I was talking to her quite openly about it. Of course we've known each other for a long time. I couldn't have announced it to the whole group.... [but] because she had information I had and she knows that I have to go to the bathroom often. So she sort of -- she didn't know but if she had been thinking about it at all, she might have suspected.

Similarly, another explained: "You just wouldn't acknowledge it, unless it is somebody you can trust with it." Thus, disclosure of incontinence to family and friends was often a tentative action, dependent upon shared knowledge, shared experience, long term friendship, and trust.

For those who were thinking about sharing their problem, but feeling hesitant, the most common strategy was the use of humour. Seven of the study women referred to the benefit of humour in the early stages of disclosure. In addition, humour helped the women learn to live with incontinence. It not only provided an opening for discussion but also reduced embarrassment, a major factor in the avoidance of exposure. "Making light" of the situation was seen as a way of dealing with potential embarrassment. As one woman said:

They [friends] make fun of it you see. They'll come out with, "Just about didn't make it" or "Didn't make it" and then we have a good laugh. But we don't stress on it -- only very lightly, you know.

Similarly, another described humour's role in a relaxed social situation:

And the young and old, we [women] were all dashing to the

bathroom. Only the men sat there, and they were highly amused at what was happening, that the women were rushing out. And we weren't even embarrassed.... It's taken frivolously like but I don't know if we were sitting at the table dining or a serious affair, I think it would be an embarrassment. It would be harder to talk about.

Discussing their use of humour, the women explained that humour helped them in four important ways. Firstly, it provided a means of avoiding embarrassment and thereby saving face. Humour helped the women feel more comfortable about an embarrassing problem. Secondly, humour allowed the women to find out what the others thought or experienced without totally disclosing their own situation. Furthermore, humour could let others know about your problem in a non-serious way, so that people "didn't dwell on it." And finally, as noted by one woman, humour prevented her from getting too upset by her predicament: "If you don't laugh, you cry."

The literature provides evidence that humour can be both a positive and a negative coping strategy. Positively, humour can help establish or preserve relationships. It can relieve tension, release hostility, and help individuals avoid or deny feelings which are too painful to deal with at that time (Locker, 1983; Robinson, 1978; Wright, 1983). Humour provides options within which communication can advance or retreat without creating offence or embarrassment for either party (Gartley & Holdren, 1985). By acting as a stepping stone, humour permits acceptance, further discussion, or retreat from non-serious business (Williams, 1986).

On the other hand, humour has been viewed negatively when it implies a means of avoiding life's difficulties rather than confronting them (Robinson, 1978). In addition, humour can be a manifestation of self-depreciation for those with stigmatizing behaviours (Miller, 1983). For these women, humour could be viewed negatively in that it seemed to deny them the opportunity to look seriously at incontinence. Without opportunities for serious discussion, the informants likely missed important information from other incontinent women: what they knew and how they managed.

A key factor in appraising the use of humour is understanding what each individual gains and loses by utilizing this strategy. Overall, for the women in this study humour appeared to be a functional strategy for coping with a very difficult situation. Humour allowed the women to make tentative advances in talking about their experience, and yet it provided them with some protection from exposure.

Avoidance of exposure was a central theme in the women's accounts of living with incontinence. Not only did these women reorganize their daily lives, but they also devised multiple and elaborate strategies for managing wet episodes, thereby limiting the visibility of their symptoms. As a result of the need to avoid exposure, talking about incontinence to others presented a major dilemma: the women's desire to share concerns and seek support versus their fear of exposure. Any discussion of incontinence with family, friends, or health professionals was tentatively pursued, and certainly dependent upon a trusting relationship. Humour proved to

be the most common approach to talking about incontinence as it ensured some safeguard from exposure.

While the women acknowledged a concern for exposure and subsequent stigmatization, they also recognized their need for information. This need for information became self-evident once the women reached a point of recognition. Once incontinence was recognized, the women tried to meet their need for information.

Needing Information

By participating in this study, the women were able to address their need for information in an environment that presented minimal risk of exposure. During the interviews they described the kind of information they wanted and previous attempts to obtain it.

Pursuing Information

Throughout the phase of data collection, the women seemed to have a primary agenda which they pursued relentlessly. All informants reported that they had volunteered for the study primarily in hopes of getting information. The women's pursuit of information presented a role conflict for the researcher as it became increasingly difficult to separate the role of researcher from that of clinician. As a consequence of that role conflict, in which the researcher had tried to avoid "contaminating" the research, one woman described her unmet need for information following the first interview:

I thought now I can get to the bottom of this. You can tell me

what I can do, and you didn't. I just thought you weren't interested. I just thought what did you come for? I thought you had come to help me and you didn't.

Certainly after the second interview the researcher was able to freely answer the informants' questions and thereby attempt to meet their expectations of the interaction.

The seeking of information may appear to contradict the women's need to avoid exposure. Information seeking can certainly expose one's symptoms. However, when asked what prompted them to seek information from this research project, all of the women stated that they were encouraged by the fact that someone was interested enough to study incontinence. They surmised that an interested person must already know something about the subject and be willing to listen to their concerns. In addition, when responding to the advertisement, one of the women strongly emphasized the term confidentiality. This suggests that an assurance of confidentiality is important if women are to disclose incontinence. A genuine interest in the concerns of incontinent individuals may also encourage them to seek much-needed information, despite their fear of exposure.

All of the women described being attentive to any incoming information on incontinence. Prior to and during the study, the women followed both the lay literature and television for any helpful information. Magazines and television were two visible, but inadequate, sources of information. While this study was being conceived and in progress, the growing interest in the subject of incontinence was remarkable. Columnists in the local newspaper

described incontinence as a "dilemma coming out of the closet" (Bailey, 1985; Parton, 1986). The editors of Time ran a full page article on incontinence in their health and fitness section (Toufexis, 1986). Even more indicative of this heightened interest was the proliferation of advertisements in magazines, on television, and in drug stores for incontinence pads. Trial offers for sample packages and coupons for discount prices were distributed to people's homes in the Vancouver area. The power of mass marketing and the media was clearly evident: the power to sell a product and the power to bring a hidden subject to the forefront. One can surmise that the women in this study were influenced by this new publicity about incontinence. Perhaps these advertisements were a stimulus to their recognition of incontinence as a significant problem.

Despite their potential for stimulating recognition, these advertisements and articles were inadequate to meet the information needs of the informants. To quote one woman: "Anytime I see it [T.V. advertisement] on there I watch it to find out and they tell you a little bit, you know, but not enough to know anything very much." Similarly, another woman noticed a brief and nondescriptive advertisement in a catalogue:

I was noticing in the catalogue here that they had some kind of pad that you can get. I may try to get some of them to see if they are any good. I don't know, unless they have something underneath them it won't help much."

Moreover, the advertisements focused on only one product and the women were generally unaware of the variety of products available.

Knowing where to go for product information was also difficult. Describing her frustration at trying to obtain product details, one woman said:

I have some samples friends have brought me now. But I have to know before I went out two, three, four hours, am I going to be safe? And I have tried to find that out. I have phoned drugstores that I know of and they have recommended to me a pharmacy where the pharmacist must know. They don't know.... They couldn't tell me anything. So then they sold them but they didn't know anything about them. When they put those things out they should have all that information because sometimes somebody is going to ask.

Hence, advertisements in magazines and on television lacked indepth product information, much to the disappointment of the women. In addition, these advertisements lacked information on the causes of incontinence and possible treatment options. For some of the women, health care professionals were the more obvious and hopeful source of that kind of information and help.

Seeking Professional Help

Prior to the study, five of the women had decided to seek information and help from a health care professional--in all five cases, a physician. They had hoped for a sensitive and encouraging response. Unfortunately, they were often disappointed. Four of the five informants expressed feelings similar to that described by one woman:

I felt let down, because I had banked on it. I thought, 'I'm fed up with this and I'll take it up with him'. He's a doctor. [But] I felt he was disinterested.... I felt he was so mediocre. I thought it must be me because he just gave it the brushoff.... When I mentioned it to the doctor and he made such light of it, well if it's not important, I guess I made a fuss about nothing.

Unfortunately, the response of these health care professionals served to reaffirm the women's view that incontinence was an insignificant problem, one that lacked treatment options. Receiving a nonenthusiastic response when one has finally found the courage to talk about incontinence, can certainly be disheartening: "You finally bring it up once, and then you think they're not interested. That's all there is to it." Describing her doctor's lack of interest as being "up against a brick wall," one woman concluded: "There's nowhere else to go. It looks like it is just hopeless."

The descriptions that these women gave of contact with physicians are, unfortunately, consistent with the findings of other researchers (Dobson, 1974; Mitteness, in press). A perceived lack of interest on the part of British physicians and nurses was noted by incontinent individuals in Dobson's (1974) community-based study. Twelve years later, Mitteness (in press) described the same kind of response on the part of physicians in the United States. Of the 30 informants in Mitteness' study, 21 had reported their symptoms to a physician. However, 48% of those 21 physicians had either ignored the patient's complaint or provided a dismissive statement.

Dismissing the incontinence included telling the patient that it was an expected part of aging, that there was no treatment available, or that the patient was too old for treatment. Thus, over the years, the reactions of health care professionals to incontinence seem to follow a consistent but discouraging pattern.

In contrast, however, one woman described a memorable and enlightening medical appointment. It involved "a very thorough and very sympathetic [approach] and a very nice, full explanation of what might happen." When asked what they would want from health care professionals, all of the women valued a sensitive and sympathetic response. Beyond sympathy, they sought information. This information needed to include an honest discussion of various options, providing both benefits and risks. As opposed to strictly medical interventions, such as surgery, seven of the women wanted to know more about treatment options that they could pursue themselves at home, treatments such as exercises or diet changes. Describing this interest in alternative treatments, one woman said:

It seems to me that when you have a [health] problem there are no options given to you... All they offer us is a pill. If somebody said to me that I should exercise 50 times or take this non-drug that might help, or drink quarts of carrot juice... Maybe these are all non-consequential [but] I'd like some alternative besides a surgical one.

Not only does this description emphasize the need for treatment options, but it also typifies the women's strong desire to do what they could themselves; they valued the self-care component of symptom

management. In fact, several informants asked the researcher what the others had said or found helpful. They clearly missed that opportunity to share and benefit from another's self-care strategies. Thus, a sympathetic approach, a detailed discussion of treatment options, and a recognition of the self-care components of symptom management are all important aspects of the provision of information on incontinence.

As a final point regarding this need for information, it is noteworthy that, prior to the study, none of the women had viewed nurses as sources of information on incontinence. None reported ever seeking out a nurse for information or emotional support. In contrast, during these interactions, the women regarded the nurse researcher as a source of information: a clinician, an educator, and a resource consultant. When asked why, in the past, they had not viewed nurses as a resource, the women replied that nurses had never asked them about their incontinence. Had a nurse ever initiated such a discussion these informants claimed that they would have been willing to disclose their difficulties. Unfortunately, the women found that among nurses and doctors the question of incontinence was never asked. Certainly health care professionals may be reluctant to pursue symptoms which they perceive as irrelevant or untreatable. Hence, the question may not be asked, and the information may not be received.

In summary, the informants recognized their need for information when volunteering for this study. Previously, they had sought information through the popular literature and television, but

found these sources to be inadequate. For those women who had sought professional help, the responses had been predominantly disappointing. This left the women with few choices for treatment and management other than the choices they devised themselves.

As the informants described the strategies they had devised to cope with incontinence, the researcher realized that they were also describing how incontinence fit into their lives. In contrast to managing incontinence through environmental or informational changes, this latter account was an attitudinal strategy. As the women described making sense of life with incontinence through a change in attitude, they provided a shared view of that reality. The emerging theme was one of redefining what was normal for them.

Redefining Normal

For the women in this study, learning to live with incontinence entailed fitting this symptom into the everyday aspects of their lives. In order to adapt to life with a hidden problem, one that to date had not offered many options for treatment, these women redefined what would be normal for them. Normal was redefined to include incontinence. In order to arrive at this redefinition of normalcy, the women needed to develop their own explanation of causality. Furthermore, they had to place the incontinence in perspective, balancing its impact with that of other health concerns. Finally, in their efforts to establish a sense of normalcy, the women created their own definition of continence, including new criteria for what constituted bladder control.

Explaining Causality

All of the women reported that they had struggled to find an explanation for their incontinence. These attempts actually began early in the experience of being incontinent, and were shaped by the women's exposure to symptoms and to interactions with others.

The most frequent explanation for incontinence, one cited by all nine women, was old age. The belief that incontinence was an expected part of aging provided the women with a way of rationalizing its existence in their lives. A typical statement was: "I'm just accepting that it's maybe part of the aging that I'm experiencing." Lack of exposure to younger people with incontinence and advertisements for protective padding which were primarily directed at seniors, reaffirmed the belief that incontinence must have something to do with aging.

You just feel between T.V., newspapers, and magazines, elderly people are sort of told that these are the things that can and do happen in old age. So when something doesn't fit your previous pattern, you automatically assume: 'Oh it must be my age' and you hear old people saying it.

Those women who had taken their problem to a doctor were also advised of the link between aging and incontinence, thereby confirming the explanation they had already given themselves.

Mitteness's work with incontinent seniors (in press) supported this finding: the aging process was the most frequently given explanation for incontinence. Mitteness also found that those who were not offered treatment by their doctors expressed neither

surprise, anger, nor disappointment. They did not anticipate treatment for something that was a normal and expected part of aging (p. 30).

The women in this study linked age to weakened bladder muscles but, in contrast to Mitteness's findings, they resisted accepting in total the assumptions about aging. Throughout the interviews the women wanted not only to question the researcher about the "fact" that aging was the primary cause of incontinence but also to express their ambivalence and, at times, anger at assumptions about aging. The following quotation typifies the women's need to question:

But I've been such a well person all my life and it is very difficult to accept the running down of the system. I mean I know up here [her head] and I do accept that this is part of it and then I don't know if I should do anything about it or just accept it and go along with it.

Beyond questioning, some women were even angry at feeling lumped into the category of "old and incontinent."

At first when this started happening, I said that's part of old age. But I said: "Damn it! A lot of people have this problem. Now why have I got it?"

Similarly, another resisted the age label, and sought a sense of normalcy, when she emphatically stated:

Well I don't know what it is. I think people would say: 'It's your age, your age, your age. Well I know I'm at that age but I don't want to be at that age. I want to be normal.

Therefore, the women were prepared to credit aging with some change in bladder function, but resisted that as the total picture. If

aging was the primary cause then treatment options were certainly limited. By questioning the idea of age as the only cause of incontinence, the women were able to maintain some sense of normalcy and some hope for treatment.

Another possible explanation of why these women were not prepared to totally accept age as a cause was that many of them attended seniors' health drop-in clinics or were involved with the seniors' networks. Fostering a positive outlook, these organizations refute the illness-oriented view of aging. Questioning that illness-oriented view, the women sought additional and, perhaps more acceptable, causes.

Information from friends and family often provided the women with other theories of causation. The link between weak muscles and incontinence was a commonly held theory:

This girl or somebody told me that one of the reasons that my bladder is like this is that I lifted too heavy weights. Now I don't know if that's true or not but I said to my daughters: 'Don't lift heavy weights because that is what happened to me.' This is what they told me.

And yet the women did not understand the anatomical factors behind this link. Vague connections were made to pressure and "loose tummy muscles."

As you grow older, your muscles are more lax. I think everything starts pulling down and pressuring. My stomach is enlarged and its pressing down on the bladder half the time and I sort of sense it or know it. I don't know how I know it.

But I just feel sometimes as if there is a great deal of pressure.

This link to anatomical changes and, in particular, to muscular control was also reported by Mitteness (in press). She noted that this link to structural changes was most commonly reported by women (p. 27). Some authors explain women's emphasis on anatomical changes when they note that body awareness, both form and function, is greater for women than for men (Brownmiller, 1984; Lipsitt, 1982).

Taking this relationship between female incontinence and changes in body function one step further, the informants often categorized incontinence under the term "women's troubles." The location of the bladder and urethra within the pelvis, in close proximity to the uterus and vagina, made this a logical connection. The women also reported that incontinence was viewed by their friends as a woman's complaint. Attempting to discuss her difficulty with a male friend, one woman found him to be "typically male, dismissing it [incontinence] as one of those women's complaints."

Those women who had experienced pregnancies recalled feelings of bladder urgency and frequency not unlike what they were experiencing now. The women's understanding of the post-pregnancy changes often included ideas about loss of muscle control and "things dropping down" putting pressure on the bladder.

You know now that you mention it, my mother had the same trouble. But she always blamed it on the fact that her last child ripped the womb, the whole thing. She had prolapses right down.

For two of the women, difficulties with a burning sensation and urine

loss during intercourse reinforced the relationship between the bladder and the reproductive system. Describing her thoughts on the link between incontinence and women's problems, one woman said:

I think we associate it with internal organs, childbearing organs, and pressure on the bladder or whatever. As you get older they say you have a lot of pressure on the--what would you call-- a prolapse and you wonder: 'Have I got that?'

The association of incontinence to reproductive problems may account for some of the difficulty in presenting the symptom to a physician. Women often tell of feelings of discomfort and embarrassment at pelvic examinations; a number of the women in this study described themselves as extremely modest when it came to bodily functions commonly enacted in private.

In a discussion of women's attitudes toward their bodies, Simone de Beauvoir (1976) supports the informants' explanation of the theoretical link between incontinence and women's troubles. She suggests that women are passive recipients of their bodily functions, in particular, their monthly reproductive cycles. "It [a woman's body] is a burden: worn away in service to the species, bleeding each month, proliferating passively..." (p. 619), a process which escapes a woman's control. She also notes a lack of control of bodily fluids during sexual excitation when women "get wet" and "liquid flows out passively" (p. 386). Comparing this "getting wet" to episodes of bed-wetting, de Beauvoir links feelings of humiliation to this loss of control. Coupled with the humiliation is a sense of acceptance in women, acceptance of this loss of control of bodily fluids.

Certainly, the women in this study did not use words in de Beauvoir's dramatic style to describe their bodies. However, they did express concern for discharge and possible odour. The link they made between women's troubles and incontinence may have led to an acceptance: we lived with our monthly fluid losses, so we learn to live with this additional fluid loss. Moreover, these women lived through a time when women had less control over reproduction: contraceptive products were not well accepted and of limited variety. Therefore they accepted and adjusted accordingly. Women's troubles were just that: changes in their bodies that they had to adjust to, "part of the business of being a woman" (Zola, 1966, p. 619).

The acceptance of explanations of causality in these women's accounts suggest that incontinence was linked to the inevitability of womanhood and old age. By linking incontinence to expected and inevitable aspects of their lives, the women were able to place this symptom within normal boundaries.

Maintaining a Balanced Perspective

Another means of developing a new definition of normal was for the women to put incontinence into perspective. By balancing the impact of incontinence with other aspects of their lives, the women were able to come to a point of resolution. They could experience difficulties with incontinence and yet maintain a sense of normalcy.

Comparing incontinence to the other medical problems they were dealing with was one way that the women maintained a balanced perspective. Incontinence was often viewed as a secondary or minor

problem. The medical problems that loomed larger than incontinence could be those in the past or in the present. One woman described a past experience with severe depression which put incontinence in perspective:

Incontinence, nothing! I'd take it any day over the other [depression]. It's something that is a nuisance, something you want to get rid of. So naturally, being a human being you're going to do the best you can for yourself.... And it's certainly not something to bring the walls down. It's just something that's there and you want to deal with it the best you can.

Similarly, other women were presently coping with chronic diseases that limited them far more than the incontinence did.

When you've got a leg like mine, you're not going to worry about anything else.

Another informant weighed the three health problems in her life:

The incontinence is very small in relation to the other things in my life. I'll have to put up with it.... My sight is very, very bad. Very serious apparently. If I had to put them in order, my sight is more than anything. Then the leg, and then the urine.

While comparing their situation to the "worst that could happen," the women categorized symptoms as life and death issues, and therefore serious, or not life threatening, and therefore, not so serious. One informant succinctly explained: "The others are life and death and incontinence isn't. It's just not that big a thing." Another was more specific in her comparison: "It is not like you knew you had a

growth in your breast or something like that. Nothing really drastic. In my mind, it is just an inconvenience really." The women noted that health education via television and magazines often emphasized life threatening and high profile ailments: cancer, heart attacks, accidents, kidney failure, and strokes. Incontinence was placed in the category of low profile problems, and therefore, problems that did not get taken to the doctor.

This ability to weigh one's symptoms in light of other health problems, both real or potential, has been described by other researchers. Mitteness (in press) noted that seniors formed a "distinct hierarchy of disorder, a hierarchy in which incontinence was not a very important problem." (p. 51). She also confirmed people's tendency to categorize symptoms according to their life threatening potential. Those disorders that restricted life rather than threatened it could be tolerated.

In a qualitative study of 16 women who were considering breast reconstruction following mastectomies, Claydon (1986) found that this comparison to other misfortunes was also part of the search for normalcy. Despite the fact that these women had experienced a potentially life threatening illness, they were still able to think of other situations that could be worse, and seek consolation from not having those other ailments. Wright (1983) describes this process as the "perceptual factor of contrast" (p. 168). When individuals are aware of others with different disabilities, their own assets are highlighted, their disabilities diminished. Thus, the ability to make comparisons and look for the positive aspects of one's health can be

viewed as a conscious effort to create a sense of normalcy.

In marked contrast to the majority of women in this study, one woman defined incontinence as a major problem. Asked about the prioritizing of illnesses and where incontinence fit for her, she replied: "It is the only thing right now. I don't have any other trouble as far as I know now." Having been a very healthy person all her life, this woman had no other personal health experiences with which to compare incontinence. In addition, the degree of incontinence she experienced was the most severe of the nine: bed-wetting and complete involuntary emptying of the bladder, not just dribbling. Defining it as a major problem, one that did not fit with her concept of normalcy, may be what changed the way this woman dealt with incontinence. As she stated: "I had to do something." Rather than accepting it totally as her own private responsibility, she took her symptoms to a family physician and a specialist, following through with surgery. Unfortunately, the surgery was only minimally successful and no further treatment options were suggested. She continued to regard incontinence as a major problem, and had discussed her difficulty with close friends, seeking their assistance. This woman seemed prepared to "go public" with her symptoms, public with health professionals and friends, because incontinence did not fit within her definition of normal, a definition that had not been shaped by the existence of other ailments.

In addition to comparing the incontinence with other health conditions, the women maintained a sense of normalcy by balancing incontinence with the psychosocial elements of their lives. Following

the initial interviews with the nine women, the researcher realized that no one had mentioned depression, severe anxiety, or poor self-esteem secondary to being incontinent. As the incontinence literature had suggested that individuals experienced changes in mental health status, changes that included depression, anxiety, and low self-esteem (Norton, 1982; Vetter et al., 1981; Yarnell et al., 1981), the researcher pursued this discrepancy. The women acknowledged feeling embarrassed at times, linking the embarrassment to real or threatened public exposure. However, the women denied feeling depressed or diminished by incontinence, stating it was neither their fault, nor something that they could control. While all informants described a part of themselves as distinct from the incontinence, one woman expressed the shared sentiment. Separating what happens to her physical self from that of her spiritual self, she provided a moving account of this distinction:

We may be old, we may look old, but we are not old inside. We are young. We are we and we have carried us all along and so it doesn't matter what happens to our body. Not that it doesn't matter but that is not us. We are we inside and we are a person, a being and the body is what we use.... The person, we all have the same needs, to be loved and cared for, to be able to give and to do, and new experiences, and so on. It has very little to do with the physical, except when the physical breaks down and you are not able to fulfill all these kinds of needs that make you a more vibrant and creative person. That's when it's really devastating for people; that's

when depression would come. If you had a lot of other kinds of ill health then this [the incontinence] becomes another burden. Then maybe, maybe, the you inside has a hard time of keeping a balance of the burden it's carrying.

As noted by this woman, multiple and/or severe health problems can be threatening to one's self esteem and jeopardize one's ability to maintain a normal life. While none of the women volunteered information concerning a threat to self esteem, they all adamantly expressed the belief that severe incontinence, that is, incontinence which was frequent, uncontrolled, and occurring in public places, would jeopardize their sense of a normal self. However, these women made great efforts to avoid that public exposure, thereby protecting themselves and their sense of normalcy.

This strategy of protecting one's self from the impact of chronic illness or disability has been discussed by various authors. Several of these claim that disabled people struggle to protect their egos and affirm their own worth (Field, 1976; Kaplan, Boyd, & Bloom, 1968; Kelly, 1986; Miller, 1983; Wright, 1983). Furthermore, Wright (1983) claims that those with disabilities modify their own values and, being highly selective, learn to sort the views of others from their own. Providing a personal account of life with ulcerative colitis, Kelly (1986) described a process of self-preservation analogous to the process used by the incontinent women in this study. He developed a stoical but partial acceptance of colitis, he maintained his own lay account of the disease and, as a result, he preserved his self-image as a normal person (p. 658).

Thus, an important part of redefining normal was the women's ability to maintain a balanced perspective. Normal meant not having those other symptoms, symptoms that could signal major diseases or a threat to life. Normal also meant avoiding exposure and thereby protecting one's self-esteem despite the incontinence. This emphasis on avoiding exposure led the women to redefine continence according to their ability to limit public exposure. This redefinition of continence was a major contributor to their definition of normal.

Redefining Bladder Control

In the process of making sense of their life with incontinence, the women developed new standards of what was acceptable and "normal" bladder function. They shared a belief that if they were continent in public places and avoided exposure, all was well. "Being home is all right. You can guide yourself but if you happen to be out...." Another woman spoke of the need to be "comfortable and decent," which, when asked to explain, she defined as clean and outwardly dry. Using pads was fine as long as the pads prevented exposure. For these women being incontinent within one's own home was inconvenient but acceptable because no one else knew and one could change immediately.

With their efforts to redefine bladder control, the women described a degree of acceptance of incontinence. However, they qualified this acceptance: incontinence was acceptable, but only to a point. At what point did incontinence no longer fit within their definition of acceptable bladder function? The women were

unanimous that incontinence could not be accepted as a "normal" part of their lives if they had episodes of public wetness or bed-wetting.

To make a big mistake in front of a lot of people, when you're out visiting. Oh God! If I made a fool of myself I would be so embarrassed. At that point I would go back to the doctor and say: 'If you can't do something, send me to a gynecologist or someone, and see what they can do about it.'

The severity of the incontinence along with the degree of inconvenience were criteria used by the women to project a likely point of unacceptability. At this point, their symptoms would no longer fit within their redefinition of bladder control.

I think if I was wetting the bed, or I didn't make it to get up at night. Or if I had a lot more accidents, you know, if I wasn't able to make it. If it happened two or three times a week I would be concerned that maybe I should seek help.

The woman with the most severe incontinence, incontinence which included bed wetting and public exposure validated this criterion. She had gone beyond acceptance to the point of actively and persistently seeking treatment.

The findings of Mitteness (in press) support the findings of this study with a description of seniors' redefinition of incontinence. In Mitteness' study, 56% used some sort of containment device such as pads, pants, towels, or catheters. These seniors viewed themselves as acceptably continent. Urinating in a towel or pad was not defined as incontinence because one's clothes or the floor did not get wet.

Therefore, "incontinence was voiding in a manner that allows urine to

be visible to others, either by eye (soiled clothing, floors, or furniture) or by nose (the smell of urine)" (p. 36). This new definition allowed the incontinent seniors to match their actual bladder functioning to an alternative norm for bladder control. In a similar way, rheumatoid arthritics have been shown to revise their expectations regarding what constitutes a normal or acceptable level of activity (Weiner, 1975). In both instances, as with this study, individuals are redefining acceptable boundaries for their symptoms in order to establish a sense of normalcy.

A number of authors have used the term normalization to describe the strategy of maintaining a sense of normalcy (Davis, 1972; Strauss et al., 1984; Weiner, 1975). Strauss and others (1984), in their work on chronic disease, note that chronic diseases are viewed as incurable, diseases that one learns to live with. As with the incontinent individual, the chronically ill must learn to fit the disease and its symptoms into their day-to-day lives. They learn to prevent medical crises, to control symptoms, to carry out regimens, to prevent isolation, to adjust to changes, and to normalize their lives. This effort to maintain a normal life is dependent upon how intrusive the symptoms are, and the knowledge that others have of the disease; when the regimen, symptoms, and public knowledge are intrusive, the individual must exert great effort to have some semblance of a normal life.

In an earlier work, Davis (1972) described the efforts of families of children with polio to maintain a normal life:

Without his [or her] attempting to pass, those aspects of his

person that distinguish him from and cause him to be viewed as different by "normals" are made light of, rationalized in a variety of ways, viewed from a less disadvantaged perspective, and denied to be of any importance (p. 106).

Like the women in this study, families affected by polio found rational explanations for symptoms and compared their situation with that of families more severely affected by polio. As a consequence of these strategies, not only does the individual view him or herself as normal, but he or she also expects the same from others.

Summary

Based on the women's accounts of living with untreated incontinence, it appears that there are four central issues.

Recognition was an essential and preliminary issue in the women's experience with incontinence. Recognition was a point at which they admitted to themselves that they had ongoing problems with bladder control. Marking the beginning of a search for information and help, recognition could be viewed as a milestone. Certainly reaching this milestone was necessary before the incontinence could be actively dealt with. However, the women described a number of factors which delayed the milestone of recognition: the infrequent and seemingly temporary nature of their symptoms, the wide variations in severity, and their attempts to separate themselves from those with severe and visible incontinence. Visible incontinence was viewed as a major threat, something to be avoided at all cost.

This effort to avoid exposure was a recurrent theme throughout the accounts of living with incontinence. Much time and effort was spent attempting to prevent public exposure of incontinent episodes. Through a reorganization of their daily lives, the women tried to be extra careful, they avoided precipitating factors, and they made mental maps of bathroom locations. Despite these preventive measures, the women periodically still had to deal with wet episodes.

The episodes of wetness increased the women's concern regarding public exposure. The primary focus of their management was to avoid visible wetness or odour as these two aspects of incontinence could be embarrassing and potentially stigmatizing. While using a range of protective padding, the women actually had limited knowledge about the diversity of commercial incontinence products. As a consequence of their efforts to avoid exposure, the women had limited opportunities to find out about these products.

One of the ways that the women might have obtained product information was through talking to others about their experience. However, for these women, talking about incontinence presented a dilemma. The fear of exposure and the potential for embarrassment were two factors which made talking about incontinence difficult. While some had chosen to remain silent, others had talked to friends or family about their problem. Both for those reluctant to talk and for those willing to talk, humour was a useful form of communication.

Concurrent with the women's internal debate about whether to talk about incontinence was their awareness of the need for information. Despite an influx of information on incontinence from the

popular media and product manufacturers, the women felt a lack of useful information. This study in particular provided them with an avenue to pursue this information. In the past a number of the women had sought professional help but were disappointed by their doctors' dismissal of the problem as a part of aging and by their overall lack of interest. Unfortunately, previous contacts with health professionals had not met the women's need for information.

The final theme which emerged from the data was that of redefining normal. While the women had to recognize their incontinence, manage it to avoid exposure, and find information about it, they also had to maintain a sense of normalcy. This need for a normal life despite incontinence was addressed in three ways: 1) the women developed their own explanations of causality; 2) they maintained a balanced perspective, comparing incontinence with other life-threatening symptoms; and 3) they redefined acceptable bladder control in a manner that fit for them.

CHAPTER FIVE

Summary, Conclusions, and Implications for Nursing

Summary

This study was designed to explore and describe the experience of elderly non-institutionalized women living with untreated urinary incontinence. Urinary incontinence, the condition of involuntary loss of urine, is believed to create major personal, medical, and social difficulties. However, the personal impact of urinary incontinence is relatively unexplored as the majority of cases remain hidden, undisclosed to health care professionals. Furthermore, a predominant portion of the incontinence literature focuses solely on the medical aspects: assessment and treatment protocols. If 50-75% of cases never reach the point of assessment and treatment (Brocklehurst, 1984; Williams & Pannill, 1982), the benefit of this literature is limited. If health care professionals are to begin to reach incontinent individuals, they need to understand what the experience of living with incontinence entails. Understanding what it is that incontinent individuals do in order to manage their undisclosed symptoms and why they do it can provide health professionals with invaluable information.

In order to gain that understanding, the phenomenological approach was used to guide this research. Phenomenology, a form of qualitative research, seeks to discover and describe "the human experience as it is lived" (Oiler, 1982, p. 178). In order to understand

the experience of living with incontinence, the subjects are viewed as co-researchers, knowledgeable informants who work with the researcher to fully explain their "inside" perspective. Little is known about the day-to-day experience of living with untreated urinary incontinence and phenomenology seeks to discover the unknown. Therefore, this particular methodology is well suited for answering the research question, "What is the experience of living with untreated urinary incontinence?"

Nine women were recruited to participate in this study. The criteria for participation included the following: 1) duration of untreated symptoms for 6 months and minimum frequency of twice a month; 2) 60 years of age and over; 3) verbally fluent in English; 4) no faecal incontinence; 5) did not use a catheter or diversion device; and 6) non-institutionalized. The women functioned as informants, responding to open-ended questions during in-depth interviews.

All interviews were audiotaped and verbatim transcriptions were made of all tapes. Field notes from contact with senior' groups also provided important data about incontinence. Data analysis occurred simultaneously with data collection. As informants described living with incontinence, the researcher became aware of previously unanticipated ideas. Pursuing these ideas with the women led the researcher to a deeper and richer understanding of life with incontinence.

Data analysis involved reviewing and comparing the transcriptions and field notes for recurring themes. The researcher moved back and forth between the transcriptions as a whole, the

major themes, and the finer points of meaning. Awareness of the assumptions held by both the researcher and the informants was a necessary part of data analysis. As the researcher became immersed in the data, both major themes and the subcategories within evolved. In order to validate the themes and their relationship to each other, the researcher returned to the women for both clarification and acknowledgement.

Four major themes comprise the research findings: the recognition of incontinence, the avoidance of exposure, the need for information, and the redefinition of normal. The first theme describes the struggle to recognize the incontinence for what it is, acknowledging to oneself that it is an ongoing problem. During the early stages of this research, finding elderly women willing to volunteer was quite difficult, thereby suggesting that recognition of the problem was a significant milestone. Once this milestone was reached, the women were able to take concrete steps to deal with the incontinence and begin the search for information. The women who did volunteer described a number of factors which had delayed recognition for them: 1) the infrequent and seemingly temporary nature of incontinence; 2) the wide range in severity of symptoms; 3) the tendency to draw a distinction between themselves and those who had severe incontinence; and 4) the embarrassing and private nature of incontinence. This last factor, the embarrassing nature of incontinence, not only delayed recognition but also placed the women in a position of potential stigma. Thus, even after incontinence was recognized, the women emphasized the need to avoid exposure.

The fear of public exposure was an overriding concern for those living with urinary incontinence. The women used numerous strategies to reorganize their daily lives in order to avoid exposure. Not only were they particularly attentive to factors that seemed to precipitate loss of bladder control, but they also planned bathroom breaks into their day. Part of this planning involved having a mental map of available bathrooms, thereby ensuring safe routes.

Even with this reorganization and planning, the women had to deal with actual wet episodes. When these episodes occurred, the women used various methods to protect themselves, mostly menstrual pads. The primary focus for the management of wet episodes was the avoidance of visible wetness and odour, as these two aspects of incontinence could be embarrassing and potentially stigmatizing. However, there was a noticeable lack of knowledge about the protective pads specifically designed for incontinence, this being one of the likely consequences of avoiding public exposure. The need to keep incontinence a hidden symptom limited the women's opportunities to find out more about incontinence products.

Keeping incontinence hidden also limited opportunities to talk about the problem. Talking to others provided a means of obtaining new information. However, talking about incontinence presented a dilemma in that it risked exposure. In weighing whether to talk to friends or family about their incontinence, the women described shared knowledge and experience, a long term relationship, and feelings of trust as important considerations. While some of the women had chosen to talk to family and friends about incontinence,

others avoided any discussion. While reflecting on the issue of talking or remaining silent, seven of the women identified humour as an important form of communication. For those women who used it, humour provided options within which communication could advance or retreat without creating offence or embarrassment. It was often the tentative beginning to more serious discussion or the veil behind which to hide one's symptoms.

The third theme, one that appeared to contrast the avoidance of exposure, was the need for information. The women were very aware of their lack of knowledge about incontinence and actively pursued new information during the course of this study. All nine women saw the study as a means of gaining information, this being their primary motive for volunteering. They surmised that an interested researcher would be knowledgeable about incontinence and would be willing to listen to their concerns. Thus, they were prepared to take a risk in hopes of obtaining much needed information.

In their pursuit of information, the women had previously turned to the lay literature and the media, as well as health care professionals. The women viewed the lay literature and the media as inadequate for providing them with detailed information on assessment, treatment, and management of incontinence. Unfortunately, health care professionals had proved to be no more informative. Those women who had taken their problem to a physician were, for the most part, disappointed. Incontinence was often dismissed as insignificant or an expected part of aging. Furthermore, before this study, the women had not viewed nurses as

sources of information on the subject of incontinence. In reflecting on their past experiences, the women realized that neither nurses nor doctors had initiated discussion about incontinence. As the question was never asked, the problem was rarely discussed.

As a result of the lack of information and available help, these women had learned to live with untreated incontinence. In the same way that individuals learn to live with chronic diseases and yet maintain a seemingly normal life, these women redefined what would be normal for them. This new definition of normal included incontinence. In order to arrive at this redefinition, the women needed to develop their own explanation of causality. This explanation included old age, weakened muscles, and "women's troubles." Thus, by linking incontinence to the inevitability of womanhood and old age, the women were able to place this symptom within normal boundaries.

While shaping explanations of causality, the women were also setting incontinence into perspective, balancing its impact with that of other health concerns. Comparing incontinence to major or life threatening illnesses allowed the women to place it in perspective. Life threatening symptoms were high priority, while inconvenient ones, such as incontinence, were viewed as minor and unworthy of a doctor's attention.

In an effort to feel normal, the women not only differentiated incontinence from other symptoms but they also differentiated what was happening to their physical self from their spiritual or inner self. It was noteworthy that despite what had been suggested in the

literature regarding the psychosocial impact of incontinence, not one of the women mentioned depression, severe anxiety, or poor self-esteem. Certainly these women acknowledged feeling embarrassed at times, and linked this embarrassment to real or threatened public exposure. However, when questioned about this, they were able to describe a part of themselves that was untouched by the incontinence. These efforts to make a distinction between one's symptoms and the normal parts of one's life are a common strategy with the disabled (Wright 1983) and, like the disabled, it helped these women maintain a sense of normalcy.

A final component of the redefinition of normal was the creation of a new definition for what constituted bladder control. The women developed new standards for what was acceptable and "normal" bladder function. For these women, being incontinent within their own home was inconvenient but acceptable because no one else would know. However, episodes of public wetness or bed-wetting would be unacceptable and outside their definition of normal. Once again, public exposure of incontinence was the threat to be avoided. If they were at that point of exposure, another milestone in living with incontinence, the women theorized that they would actively and persistently seek help.

Conclusions

The research findings lead to a number of conclusions about the experience of living with incontinence for the nine study women.

- 1) In the course of living with incontinence, recognition of bladder control problems was a significant milestone, one that was frequently delayed.
- 2) Urinary incontinence was commonly viewed as a normal part of aging and an inevitable part of being a woman.
- 3) While managing incontinence in a variety of ways, these women were often prepared to live with the inconvenience of untreated incontinence in order to avoid public exposure.
- 4) For those who tried to seek treatment, health care professionals were often disinterested and discouraging.
- 5) The need for information concerning treatment and management of incontinence was a major concern for the study women.
- 6) The women redefined normal to include their experience with incontinence, but public exposure of incontinence went beyond the women's ability to normalize and was described as a potential milestone that would lead to active and persistent pursuit of treatment.

Nursing Implications

The findings of this study suggest a number of implications for nurses working with elderly incontinent women. Not only do the findings have implications for nursing practice, but also for nursing education, and nursing research. The following and final section will discuss the implications of the research findings.

Implications for Nursing Education and Practice

This phenomenological study provides an indepth account of what it is like for elderly women to live with untreated urinary incontinence.

One of the most disconcerting aspects of the research findings is the fact that the incontinent women did not view nurses as sources of information or support. In order to be of help to elderly incontinent women, nurses must become informed practitioners who examine the problem of incontinence with genuine concern and knowledge. In order to do this, nurses need to familiarize themselves with the current knowledge of assessment and treatment for urinary incontinence and incorporate that knowledge into practice. Nursing education can include a positive approach to incontinence, emphasizing assessment and treatment, and in particular, the potential for cure. Furthermore, nursing education can include content on the various symptoms associated with incontinence and the variety of treatment options. Thus, through education and knowledgeable practice, nurses could become more visible to the elderly public and, as a consequence, more supportive and more informative.

The findings indicate that recognition of incontinence as a significant and "medically legitimate" problem is an important milestone. However, this milestone can be difficult to reach and even when it is reached, subsequent disclosure of the problem to health care professionals or friends and family may be difficult. Nurses need to be aware of the difficulty inherent in recognition and disclosure of

incontinence. Teaching nurses about the concern for exposure of incontinence is important as it can lead to more creative and sensitive approaches to the issues of recognition and disclosure. Making information on incontinence readily available to the public can begin the process of recognition. Furthermore, nurses could facilitate disclosure of incontinence by showing interest and being sensitive to tentative pieces of information, for example, humorous remarks about bladder function. By asking the right questions, the nurse would get beyond humour and facilitate disclosure.

The study proposes that elderly women often redefine incontinence in order to accommodate their own personal situation. Incontinence is redefined as loss of bladder control in public places. Loss of bladder control in private is no longer viewed as abnormal. Therefore, by asking the question, "Are you incontinent?", nurses may not elicit what is really going on. The findings of this study suggest that nurses who ask more subtle questions might be more likely to identify a potential problem. Such questions might be: "Have you experienced any changes in your toileting pattern?" or "Have you experienced any changes in voluntary control of your urine?" In this way, nurses might begin to get a clearer picture of voiding patterns, habits and outcomes.

Another implication for patient assessment is the need to be aware of milestones in the experience of living with incontinence. The nurse may encounter elderly incontinent women who have not yet recognized incontinence as a fact in their lives. For these women, the most helpful intervention may be the provision of general

information: a discussion of the nature of incontinence along with assessment and treatment options. In light of the concern for exposure, to ask these women about their voiding patterns may be threatening and thereby jeopardize future opportunities to intervene. However, nurses could provide this general information in a non-threatening way by speaking to groups of seniors or contributing to their newsletters.

Information can also be helpful for those senior women who have reached a point of recognition. However, if elderly women have recognized incontinence and are managing it successfully, nurses may have to accept these management strategies as sufficient. If these women are successfully avoiding public exposure, they may prefer to pursue neither medical treatment nor nursing measures. Ruling out infectious processes and additional ideas for self-care strategies may be all that the women will accept. If acceptable, nurses could intervene by supporting the women's success, augmenting the current strategies used, and being a resource for a wider variety of protective pads. At the same time, they would leave the door open in the event the women wish to pursue assessment and treatment.

As some elderly incontinent women cope successfully and independently, nursing education should explore the concept of normalization as a beneficial coping strategy for those with incontinence. Nurses would benefit from discussions about how to recognize and support this strategy. In general, nursing education would be richer if it included content about the subjective experience of living with untreated incontinence.

Being knowledgeable about resources and, in particular, protective padding is a logical role for nursing. Elderly women with incontinence can be quite vulnerable to the advertising tactics used by product manufacturers. Mobility and finances may hamper access to a variety of products. And, as noted in the study, the quality of information available about incontinence protection is poor. Nurses interested in the problem of incontinence can be a central resource for patients and health professionals, simplifying and correcting the maze of information about protective padding.

In addition to advising about protective padding, nurses can help elderly women to differentiate between normal physiological age changes and abnormal or pathological changes. As incontinence is often categorized as part of aging and synonymous with "women's troubles," elderly women need guidance in what is normal and what is not. Certainly women's efforts to normalize their lives despite incontinence is to be supported as a positive form of coping but information concerning normal physiological age changes can provide helpful guidelines.

Not only the women themselves, but also health care professionals can dismiss incontinence as a normal part of aging. Nurses should become more sensitive to the values and beliefs that they bring to their work with the elderly. Nursing education can focus on and challenge the belief that aging is synonymous with health problems and, in particular, loss of bladder control. This belief is especially prevalent in long-term care institutions where incontinence is viewed as a given (Hu et al., 1984), but it also affects nursing

interventions at the community level. Education can also challenge nurses' beliefs regarding their own aging and body image. As most nurses are female, their beliefs about "women's troubles" and the need to accept and adjust to these, can influence interventions with elderly women. Increased sensitivity to hidden assumptions can help nurses take a fresh look at the problem of incontinence. Finally, concerned and knowledgeable nurses can be advocates for elderly incontinent women, helping them navigate through a potentially disinterested, insensitive, and stigmatizing health care system.

Implications for Nursing Research

This study has focused on the experience of elderly women living with untreated urinary incontinence. It is important to acknowledge that this study is a beginning effort, and that further research could yield a greater depth of understanding.

In order to build on this knowledge base, future research can examine the experience of elderly incontinent men. The influence of women's body image and the belief that incontinence is related to "women's troubles" may result in a very different experience for elderly women as opposed to men. Similarly, elderly women may experience a different doctor-patient relationship as the majority of physicians are men. Male physicians may react differently to men's complaints of urinary problems. Do these complaints receive greater attention? Therefore, it would be fruitful for subsequent research to focus on the experience of elderly men with untreated incontinence, and their experience with the health care system.

Similarly, it would be enlightening to assess the impact of age on living with incontinence. A study of both young and elderly incontinent women may provide interesting and comparative data. Both age and gender are variables that may influence life with incontinence; thus, research into their relationship to the experience of incontinence is essential.

The need for information was a key finding in this study. However, future research would do well to question what effect information has on those living with incontinence. Does additional information on assessment and treatment of incontinence lead to greater treatment seeking? A follow-up study of these women, six months to one year later would offer some insight into this issue. In light of the information provided at the end of the second interview, did the women pursue medical interventions? Would the provision of information change the pattern of normalizing that occurred in this study? Similarly, would the provision of information and the development of additional coping strategies make women any less fearful of public exposure? Along the same lines, what impact would a nurse continence advisor have on the beliefs and help-seeking behaviour of elderly men and women living with untreated incontinence?

In this study, recognizing and disclosing incontinence was a major issue in the women's lives. The findings suggested that societal attitudes, lack of informative media coverage, and the responses of health care professionals led to some of the difficulty with recognition and disclosure. As continence clinics develop in Canada, providing a

supportive environment for the pursuit of information and treatment, it would be beneficial to study the impact of these clinics on patient recognition and disclosure. Would continence clinics advertising that term inhibit or encourage women to seek help? Would women's involvement with such a clinic influence the social and emotional aspects of a problem that is characterized by attempts to hide it?

Another area for future research would be the concept of milestones in the lives of those with incontinence. This study indicates that the women experienced two milestones: the first was recognition of incontinence, and the second, real or pending exposure of their symptoms. These findings suggest that there may be stages in the experience of living with incontinence. However, as this study was a preliminary approach to understanding life with untreated incontinence, further research into the concept of stages is necessary.

One particular milestone, that of real or pending exposure, suggests that severity of symptoms can influence one's response to incontinence. However, the number of informants and the minimal variations in symptom severity within this study limit any conclusions. Further phenomenological research can investigate the influence of symptom severity on the experience of living with incontinence.

Finally this study indicated that incontinent women were interested in knowing how others coped with incontinence. Furthermore, they emphasized the importance of the self-care component of symptom management. Self-help groups are credited with assisting people to feel accepted, providing them with

information on how others cope, and above all, providing mutual support (Weiner et al., 1984). What would be the benefits of a self-help group for incontinent individuals? What impact would the fear of public exposure have on the development and viability of a self-help group for incontinent individuals?

In conclusion, this study has described the subjective experience of elderly women living with urinary incontinence. It contributes to the knowledge base nurses can use in working with elderly incontinent individuals. As is often the case with research, it generates many more questions than it answers, demanding further attention to the issue of life with incontinence.

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Appendix B: Information and Consent Form

My name is Pat Foster. I am a registered nurse who is completing a master's degree in nursing at the University of British Columbia. I wish to learn more about what it is like for older women to live with urinary incontinence. Urinary incontinence means an involuntary loss of urine in inappropriate places or at inappropriate times. This information will help nurses and doctors to understand the issues associated with incontinence and how best to be of help.

If you agree to participate in this study, you and I will meet for two interviews, each approximately 1-1/2 hours in length, and approximately 6 weeks apart. I would be happy to meet in your home, at your convenience. At that time we will discuss what it is like to live with urinary incontinence. If you wish, you may refuse to answer any questions during the interview, and at any time you may withdraw from the study. The interviews will be tape recorded, but every effort will be made to avoid the use of names or identifying information. Taping the interviews allows me to pay more attention to important issues which you discuss and avoid the intrusion of trying to take notes. The tapes will be heard only by myself and my thesis advisors.

All information will be treated in a confidential manner. I will be writing a report of my study and excerpts of the interview may be included in the report. However, no names or identifying information will be used. When the study is finished, the tapes will be erased.

There is no financial benefit to participating in this study. Any

Appendix C: Sample Questions for Initial Interview

1. What is it like for you to live with urinary incontinence?
 - a) When did the urinary incontinence begin and how has it progressed?
 - b) Have you made any changes in your day-to-day life as a consequence of living with incontinence?
 - c) Has this experience affected how you feel about yourself?
 - d) Has this experience affected your family life and/or your relationships with others?
2. What management strategies do you use, if any, to deal with the incontinence?
 - a) Do you use any equipment or aids and have they proved satisfactory?
3. Have you ever sought help for urinary incontinence? Tell me about the experience?
 - a) What experience have you had with the health care system, with regard to urinary incontinence?
4. What is it like for you to talk about this experience with urinary incontinence?