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A PERSPECTIVE ON URINARY INCONTINENCE IN OLDER ADULTS LIVING IN THE COMMUNITY

BY

ANITA M. THOMAS

A THESIS

SUBMITTED TO THE FACULTY OF GRADUATE STUDIES AND RESEARCH
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The undersigned certify that they have read, and recommend to the Faculty of Graduate Studies and Research, for acceptance, a thesis entitled A PERSPECTIVE ON URINARY INCONTINENCE IN OLDER ADULTS LIVING IN THE COMMUNITY submitted by ANITA M. THOMAS in partial fulfillment of the requirements for the degree of MASTER OF NURSING.

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Date: 13 October 1988

ABSTRACT

Despite the quantity of research exploring the assessment, treatment, control and management of incontinence, there has been little research on the experience of the problem. This study explored that experience from the perspective of older individuals living in the community to gain an understanding of the impact of incontinence on daily life. Semi-structured telephone interviews were conducted with 60 men and women aged 51 to 88, with a mean of 70.6 years. Data were analyzed using a qualitative approach.

Most respondents were active, independent people who managed urine loss with innovative strategies. Incontinence seldom interfered with outings, although activities were planned according to the proximity of the next available toilet. A few individuals with excessive urine loss found their condition very distressing and desperately sought help. Only 75% had reported urine loss to a physician, and even fewer had disclosed the problem to a nurse. Thirty percent had not discussed incontinence with friends or family and most said it is "not talked about".

Implications for nursing have been identified. Research is needed to develop and test effective non-intrusive interventions. New practice settings must be planned to provide appropriate and available services.

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I. INTRODUCTION

The involuntary loss of urine has been described as a distressing and often devastating problem and, for the elderly, it has been called the "ultimate humiliation" (Palmer, 1985). Incontinence, considered by some to be a loss of personal control, may lead those who suffer to censor themselves or be subject to censor by others (Muir Gray, 1986). One meaning of incontinence which was in common use until the last half of the century (Smith & Smith, 1987) is that defined by Webster's Dictionary (1981) as the "failure to restrain sexual appetites, unchastity..." This definition, which links the involuntary loss of urine to immoral sexual conduct, has increased the perception of many older adults that urinary incontinence is something shameful (Smith & Smith, 1987).

In the western world the excretion of body waste is a very private function. Toilets are enclosed and usually locked. Passing urine in any place other than an appropriate receptacle is a taboo (Wells, 1984) and even communication about excretion is avoided, regarded as " not a subject talked about in 'polite' society" (Perston, 1981, p. 39). In fact, both health care professionals and lay people commonly use euphemisms, such as "water" when talking of urine.

Although incontinence is a serious and sensitive issue, it has historically been neglected by health care professionals. This fact is made particularly evident by Kirshen and Cape (1984) who conclude a study of the medical history of urinary incontinence with the observation that, although "major strides in the diagnosis and treatment of urinary incontinence have been made recently, current concepts are little different from those of 400 years ago" (p. 688). In support of that statement, the authors quote a pre-eminent physician of the mid-eighteenth century who wrote that incontinence is "a distemper very hard to be cured...in old persons it is altogether incurable, unless hot baths relieve them..." (p. 686). Such an attitude prevails to the present, professionals still tend to consider incontinence in the elderly difficult or impossible to treat (Simons, 1983; Mitteness, 1987a; Mitteness & Wood, 1986).

Stewart (1986) reinforces the notion that both health care professionals and their elderly clients have long accepted incontinence as the unpleasant but inevitable result of old age, while Freed (1982) makes a strong point noting that incontinence is usually considered a diagnosis, when it is, in fact, a symptom. Even the measures used to manage incontinence, such as catheters and pads, may contribute to pessimism and inhibit a thorough assessment and diagnosis of the problem (Blume, 1983; Freed, 1982). Also, the long-standing apathy toward the investigation and treatment of incontinence in the elderly is testimony to the lack of knowledge and education among health care professionals (Smith, 1982).

With little encouragement offered from the health care field, often older individuals do not seek help for incontinence and some even deny an apparent problem (Manley, 1984; Wells, 1984). Many attempt to cope on their own by using pads, restricting fluids and withdrawing socially (Brink, Wells, & Diokno, 1983; Brocklehurst, 1973).

A contrary view to the difficulties imposed by incontinence is found in some of the recent professional research, disputing suggestions that incontinence is devastating for the older individual. These studies suggest that many older adults with bladder control problems manage very well in spite of receiving little or no help from health care professionals. In fact, the major issue of incontinence may be the attitude of the health care providers (Mitteness, 1987a; Mitteness & Wood, 1986).

Such opposite positions reinforce the fact that little is known about the day-to-day experience of incontinence for the individual. Increased understanding of the issue is critical for health care professionals (particularly nurses) if they are to develop programs and strategies that are appropriate and useful to their clients. Incontinence must be brought out of the closet and accepted as a subject of discourse. It is unacceptable for people to "continue to endure recurrent incontinent episodes without benefit of appropriate health care services" (Mitteness, 1987b, p. 185).

Statement of the Problem

The purpose of this study is to examine the experience of incontinence for older adults living in the community, and to gain an understanding of the individual's perspective. The study has been guided by the following questions: What is the impact of incontinence on day-to-day life? What strategies do individuals use to manage the problem? How do people perceive the care they receive from health care professionals? What are the social implications of incontinence? And, what are the individual's expectations of the future?

II. LITERATURE REVIEW

Despite increased literature in professional journals and texts devoted to the assessment, treatment, control and management of incontinence, only a few studies have focussed on the impact of bladder control problems on the individual. The purpose of this review of the literature is to summarize the current knowledge about incontinence and to examine studies about the individual's response to this problem. Relevant literature was located in nursing, medical and gerontological journals and texts.

Defining Incontinence

The International Continence Society Committee for Standardization of Terminology (1979) was established to develop terminology for incontinence so that studies could then be compared. The society described urinary incontinence as "a condition in which the involuntary loss of urine is a social or hygienic problem and is objectively demonstrable" (p. 551). Unfortunately, even this definition has limitations; it allows for a subjective decision on what constitutes a 'social or hygienic problem.'

Brocklehurst (1984) suggested that incontinence be defined by the clients' affirmative answer to the question "Does urine ever come away unexpectedly and without you being able to stop it and you get wet?" (p. 4). This latter definition was chosen for the present study. is a very broad description and does not quantify incontinence but variations of it are widely used in the literature. The frequency of urine loss identified as incontinence differs considerably. For example, Mitteness (1987b) includes only those who report a loss of bladder control more than once a week. Thus, the term "incontinence" is very vague as it includes a wide variety of experiences (Wells & Brink, 1988).

Prevalence

Studies on the prevalence of urinary control problems in older adults suggest that it is a common condition of varied severity. Although many surveys have been completed, the extent of incontinence in the community remains unknown because the surveys include only selected age groups and in many cases use different definitions for incontinence. With the exception of the survey results, little is documented about incontinence as a result of "the iceberg phenomenon" (Muir Gray, 1986, p. 135); that is, because incontinence is not reported to health care professionals the prevalence remains unrecognized in the community. In fact, Haber (1986) reported a study in the United States which indicated that less than 10% of incontinent adults "had sought medical help because most of them considered incontinence to be untreatable" (p. 430).

Some evidence of the prevalence of incontinence is available in preliminary data from the 1984 National Health Interview Survey in the United States (Harris, 1986). Data about elderly people living in the community includes responses from 5,637 people over the age of 65 to questions on urinary control difficulties. Nine percent of the total group and 13% of those over 74 years of age report some difficulty with urinary control, indicating an increased prevalence with age. Women were slightly more likely that men to report such difficulty.

Similar results (i.e. prevalence of 12%) were revealed in a community-wide survey completed on all residents over the age of 75 in a British market town (McGrother, Castleden, Duffin & Clarke, 1986), which also found an increased prevalence with advancing age. A wide range of dysfunction was identified in the study: 7% were incontinent; 5% of the respondents reported difficulty with urinary control at least twice a week; 2% had overt incontinence (wetting external clothing); while 1% considered the problem to be minimal. This survey was undertaken to aid in planning specialist services for the area, and the authors conclude that "the problem that continues to undermine rational planning is where to draw the line between trivial and important disorders"

(p. 137). Mitteness (1987a) concurred that there is a lack of agreement on the volume of urine loss necessary to consider it a problem. This reinforces the need for health care professionals to reach a better understanding of incontinence as a perceived problem.

Two other large surveys to determine the prevalence of incontinence were undertaken in communities in South Wales. Yarnell and St Leger (1979) drew a random sample of men over the age of 70 and women over 75 years and found a prevalence of 11% incontinence in the males and 18% in the females. A follow-up study on those who reported incontinence was completed in the following year with the indication "that approximately a third of subjects with incontinence have the disorder for only a short period of time" (p. 85), suggesting that some incontinence had been temporary or resolved. A similar survey was conducted by Vetter, Jones and Victor (1981) on 1280 people over the age of 70 who lived at home. The researchers found that 7.3% of the men and 18.1% of the women responded with an affirmative answer to the question of incontinence. In accordance with the other surveys, they found an increased incidence with age. Also, although 5% of the population was severely incontinent with urine loss at least once a day, they found that almost three quarters of the study group had only a very small loss of urine.

With the estimates of incontinence ranging from 7% in men to 18% in women, Smith (1982) suggested that a reasonable estimate would be "about 3 million people who are incontinent living in the United Kingdom..." (p. 5). Similar surveys of the community dwelling elderly in Canada have not been done. However, based on the British and American findings, a Canadian prevalence may be estimated from population figures provided by Statistics Canada (1987). Using a conservative estimate that 10% of the senior population have incontinence, then more than one quarter of a million are affected across the nation, with some 19,000 in Alberta alone.

Micturition and Aging

Although incontinence is not the inevitable result of aging, Brocklehurst (1984) suggests that the two are closely linked as he notes "incontinence is one of the prime presenting causes of illness in the elderly...it is therefore reasonable to regard aging as a predisposing factor as far as incontinence is concerned" (p. 8). Thomas (1980) supports this conclusion, stating "the elderly are a high risk group for developing disorders of micturition due to physiological changes" (p. 533). Williams and Pannill (1982) offer a physiological basis for bladder changes during normal aging, explaining that "a gradual decline in overall muscular tone results in diminished strength of the pelvic floor muscles and external sphincters which can contribute to involuntary urine loss" (p. 896). Post-menopausal women may develop atrophic changes of the urethra due to estrogen depletion, which may also lead to urinary dysfunction and incontinence (Reid, 1985), as estrogen maintains the thickness of the urethral mucosa (Williams & Pannill, 1982). Elderly men may develop hyperplasia of the prostrate, with resulting symptoms of urinary obstruction (Thomas, 1980). Changes in the neurons of the cerebral cortex and in the long and complex tracts of the nervous system that occur with advancing age may interfere with bladder function and with the brain's ability to successfully inhibit detrusor contractions (Brocklehurst, 1978; Thomas, 1980). Wells (1980) also notes that mental impairment decreases the individual's ability to respond to body signals and chronic disease often impacts on mobility and the subsequent ability to reach a toilet in time.

A further factor in incontinence is the decreased capacity of the bladder with age, demonstrated in part by increased urinary frequency and nocturia (Brocklehurst, 1978; Palmer, 1985). As well, the reduced ability of kidneys to concentrate urine in older people (Kenney, 1982) contributes added urine volume, particularly at night. In fact, Barker and Mitteness (1988) found nocturia to be very common in their study of community dwelling elderly, with

93% of the sample reporting at least one night time trip to the toilet. However, it was not clear in their study how much nocturia was related to bladder capacity or kidney function and how much was due to sleep disturbance. One might predict that high urine output overnight would be a contributing factor to incontinence.

Overall, many age related factors predispose older adults to the development of incontinence (Wells, 1980), and as Williams (1983) points out, the complexity of age related changes and potential causes of incontinence in the elderly make assessment and diagnosis complicated. Zawada (1985) goes so far as to suggest that "voiding problems are so common in this population as to represent almost a normal consequence of aging itself" (p. 317), although most authors are quick to point out, that which is common is not necessarily normal.

Types of Incontinence

Identifying types of incontinence in the literature may be a confusing process. Different terms for the same type of incontinence are often used, and some categories overlap. Some authors, such as Brocklehurst (1984), identified incontinence according to the pathology or disease involved, while Overstall, Rounce and Palmer, (1980) classified it by the physiological cause or diagnosis. Others (Thomas, 1980; Williams & Pannill, 1982) categorize incontinence into broad types, such as stress, urge or neurogenic incontinence. As well, it may be considered as transient or established (Griffin 1983). The confusion has been resolved to some extent by the work of the International Continence Society Committee on Standardization of Terminology (1981) which has defined some types of incontinence, and as Feneley (1986a) notes, gives a consistent framework to assist the clinician in identifying causes. The categories are not mutually exclusive, and different types of incontinence may be found in the same patient.

1. Stress incontinence is the involuntary loss of urine when the pressure within the bladder exceeds the maximum urethra pressure in the absence of detrusor contractions (International Continence Society Committee for Standardization of Terminology, 1979). The condition is common in women of all ages (Brocklehurst, 1978; Kendall & Stein, 1983) and may also occur in men (Ouslander & Elhilali, 1987). Poor perineal muscle tone related to aging, multiparity, pelvic surgery or estrogen depletion decreases the closing power of the urethra and alters the crucial angle of the bladder/urethra junction (Reid, 1985; Thomas, 1980; Williams & Pannill, 1982), and this "allows the proximal urethra to become functionally part of the bladder" (Marchant, 1983, p. 57). A sudden

increase in inter-abdominal pressure, as when coughing or laughing, results in an unexpected loss of urine. For some individuals with an unstable bladder, a sudden increase in abdominal pressure will stimulate a detrusor contraction, and they will have the symptoms of stress incontinence (Feneley, 1986b). It is critical to differentiate the diagnosis of genuine stress incontinence from an unstable detrusor prior to any treatment (Brocklehurst, 1978). However, a combination of stress incontinence and an unstable bladder may also be present (Kendall & Stein, 1983).

2. Urge incontinence, further divided into motor and sensory, is associated with a strong desire to void which cannot be postponed. Motor urge incontinence, also referred to as an unstable bladder (Overstall, Rounce & Palmer, 1980), is associated with uninhibited detrusor contractions. Sensory urge incontinence, often called uninhibited neurogenic bladder, is characterized by a loss of sensation related to neurological disease (Brocklehurst, 1984; Thomas, 1980). Sensory urge incontinence also refers to a condition of bladder hypersensitivity which interferes with normal filling (Feneley, 1986b), and may be related to infection, inflammation, or obstruction (Thomas, 1980; Williams & Pannill, 1982).

Williams and Pannill (1982) also discuss detrusor instability resulting from a deconditioned voiding reflex.

Chronic low volume voiding with resulting decreased capacity and increased detrusor tone is cited as one cause. This may be related to anxiety about possible incontinence. Alternately, Brink (1980) refers to a type of reverse conditioning with a resulting change in the stimulus to void as another cause. It has been noted that "the institutionalized elderly are especially vulnerable to a form of reverse conditioning" (Williams & Pannill, 1982, p. 900). A lack of privacy, inability to use the toilet independently, humiliation or the use of pads may cause patients to lose the incentive to remain continent. Freeman, McPherson and Baxby (1985) report a study of 57 women which supports a view that detrusor instability may also be a psychosomatic disorder. Obviously, diagnosis is complicated and time consuming, yet classification is often critical for appropriate treatment.

3. Overflow incontinence is almost self-explanatory. Severe retention causes distension of the bladder, resulting in atonia, and overflow incontinence occurs. A common cause is obstruction of the bladder outlet by prostatic hyperplasia (Ouslander & Elhilali, 1987). It may also be related to severe constipation, tumors, anticholinergic drugs and neurological lesions (Brocklehurst, 1984; Williams & Pannill, 1982). Resnick and Yalla (1987) report that the detrusor may be overactive but ineffective, with the result of urinary retention which

presents as outlet obstruction.

4. Neurogenic incontinence is the loss of urine in the absence of any sensation or desire to void. It may be referred to as autonomous, atonic, uninhibited or reflex neurogenic bladder, and it is caused by neurological destruction above the sacral reflex center (Thomas, 1980).

Williams and Pannill (1982) also identify functional and iatrogenic incontinence. Normally continent individuals may be unable to get to toilet in time due to functional causes, such as poor mobility, which may then "act synergistically with other urinary problems" (Williams & Pannill, 1982, p. 899). Iatrogenic factors include pharmacological treatments, such as diuretics, sedatives and muscle relaxants, which may cause or aggravate urinary problems. Physical restraints are also responsible for incontinence in some cases.

The literature presents a somewhat confusing picture on the prevalence of different types of incontinence. Ouslander, Hepps, Raz & Su (1986) studied incontinence in 263 elderly people at an incontinence clinic and found that most presented with a mixed type, followed by urge and stress incontinence respectively. Overstall, Rounce & Palmer (1980) had similar findings in a study of 309 older people as 57% were diagnosed as having an unstable bladder (urge incontinence); stress incontinence was rare and in most instances the loss of urine when laughing or coughing was due to an unstable bladder. In contrast, Wells (1987) found 84% of a sample of 338 women aged 55 and over had stress incontinence diagnosed by urodynamic studies.

Professional Attitudes

Although little has been written about the perceptions of the elderly in dealing with incontinence, there are reports in the literature about the attitudes of professionals. Wells (1975) notes that nurses have traditionally accepted incontinence as one of the "expectations for the old" (p. 1908). In fact, Tallis and Norton (1985) state that nurses tend to simply cope with incontinence in their patients, often without any further inquiry into causes or possible treatments, nor with much knowledge or understanding of the experience of incontinence. Harris (1984) describes the reactions of her colleagues to her decision to specialize as a Nurse Continence Advisor as "mostly horrified: You're going to do what...? You can't, what a waste..." (p. 158). These attitudes may inhibit the investigation and treatment of incontinence, and perhaps subtly hamper the client's desire to reveal problems with bladder control.

Breakwell and Walker (1988) found that professional nursing staff in a community home health agency "were aware of fewer than half the cases of incontinence found by the researcher" (p. 29). This finding points out the frequent lack of awareness of the problem by health professionals. In their excellent article on urinary incontinence, Wells and Brink (1988) admonish nurses for their neglect of assessment and suggest that this may be related to professional and social repugnance toward excretory behavior. As well, the nurse "may not know how to assess urine control difficulty or what to do with the data collected" (Wells & Brink, 1988, p. 493). Wells (1975) also suggests that nursing staff have been satisfied in managing incontinence with pads, emphasizing the importance of education for nurses on promoting continence. The value of assessment and investigation is also stressed by Palmer (1985) and reinforced by Millard (1981) stating that no-one should be condemned to life with pads or a catheter without evaluation.

Mitteness and Wood (1986) studied the response of social workers to clients with incontinence as compared to those with confusion and mobility problems. They found that social workers tend to have less sympathy for those with incontinence, and it is more likely attributed to old age. Williams (1983, p. 663) emphasizes that:

> The degree to which we, as health care providers, can assist incontinent elderly may reflect our understanding of human discomfort and our sensitivity to personal distress. It is unacceptable that over one-half of incontinent elderly feel they have to hide their difficulties and are not receiving treatment.

It is apparent that some health care providers recognize the need for more active intervention to help those with incontinence but many who are giving the direct care need education about effective assessment, diagnosis and treatment. Many approaches are identified in the literature and a description of some of these follows.

Assessment and Diagnosis

As Williams (1983, p. 657) notes, "the complex interactions between the presence of multiple disease-related physical limitations and the possible causes of incontinence can make the evaluation of elderly patients especially problematic." The medical diagnosis of urinary incontinence begins with a complete history, physical and basic laboratory tests (Keegan & McNichols, 1982). Diagnosis may often be made on the basis of a thorough office evaluation (Griffin, 1983; Gregory & Purcell, 1986; Williams & Pannill, 1982). Treatment depends most on identifying the type of incontinence, not on establishing the underlying cause (Williams, 1983). An incontinence chart, documenting the frequency and volume of voiding, is used as a valuable aid (Feneley, 1986b; Williams & Pannill, 1982). The vast assortment of sophisticated medical tests and studies available for the assessment of bladder and urethra function may be found outlined by Keegan and McNichols (1982), Robinson (1984) and Feneley (1986b).

Some authors suggest the assessment and treatment of the incontinent elderly should be considered the joint responsibility of medicine and nursing because of the contribution each discipline makes (McCormick & Burgio, 1984; Willington, 1975). Wells (1987) found that a clinical nursing investigation was very useful in establishing the diagnosis. Hargreave and Galloway (1983) advise that the first assessment of the elderly patient with incontinence be done at a home visit by a nurse, followed by referral to a medical specialist if necessary.

The assessment of urinary incontinence falls into the realm of nursing diagnosis. The purpose of nursing diagnosis is to "define nursing's domain, to facilitate communication and documentation, and to provide frameworks for research and education to improve patient care" (Voith & Smith, 1985, p. 723). Tunink (1988) reports that "at the 1986 Biennial Meeting of the North American Nursing Diagnosis Association, six diagnosis related to urinary incontinence were submitted for validation and testing" (p. 25). These diagnoses describe types of incontinence; stress, urge, reflex, retention, functional and total. Although somewhat contradictory to the definition of a nursing diagnosis as a 'patient response', Voith and Smith (1985) suggest these physiological terms are necessary for nurses to use as labels for the assessment of urinary problems and evaluation of interventions. Work is currently underway to validate these diagnoses.

A specialist role in nursing is developing in the United States and Great Britain to promote continence and assist clients and other care givers in managing intractable incontinence (Hamilton, Badger, Drummond, & Issacs, 1985). At a nursing clinic in one area of Great Britain, nurses assess and institute treatment, provide management advice or reassurance as appropriate and refer clients to medical specialists when the need is indicated (Shepherd, Blannin, & Feneley, 1982). Clients are given help with their immediate problems and advice on measures that may be instituted to promote continence; the diagnosis of physiological cause is secondary. At the University of Michigan, nurses have been instrumental in establishing a Continence Clinic for the elderly (Brink, Wells & Diokno, 1983). The term continence was chosen to provide a positive focus on attainment rather than the negative association with urine loss. Shepherd and Blannin (1986) outline the role of the continence nurse advisor as providing nursing advice to patients in all settings, acting as a resource and educator to other professionals and as a researcher collaborating with manufacturers in the development of effective incontinence products.

Nursing Interventions

Urinary incontinence must always be considered curable, controllable or, at the very least, manageable. Many interventions are well within the scope of nursing (McCormick & Burgio, 1984; Wells & Brink, 1988). For example, Maney (1976) suggests a fluid intake of approximately 2500 cc. per day may relieve incontinence. A full bladder is considered essential for normal bladder stimulation and function. Ebersole and Hess (1985) suggest drinking fluids, such as cranberry juice, to maintain an acid urine and reduce bladder infections. The control of constipation may relieve or prevent urinary incontinence (Perston, 1981). Wells and Brink (1988) also advise nurses to find alternatives to the use of hypnotics and tranquilizers and adjust the timing of diuretic drugs to early morning.

Training programs

The terms 'bladder training', 'habit training', 'scheduled' or 'timed' toileting and other concepts are used almost interchangeably in the literature (Greengold & Ouslander, 1986; Hadley, 1986), mainly as interventions for urge incontinence.

Despite the confusion of terms, there are two general types of training programs related to timed voiding. One program aims to train the bladder to "restore a normal pattern of voiding and continence" (Ouslander & Elhilali, 1987, p. 19) by gradually increasing the time between voiding. The other type trains the individual to void at regular intervals and this is useful for those with cognitive impairments or a neurogenic bladder (Hadley, 1986; Ouslander & Elhilali, 1987). Hadley (1986), in reviewing a number of clinical studies on bladder training, asserts that there is still much to learn about which programs work best with different client groups.

Contingency management

Contingency management or behavior modification is somewhat more complex as reinforcers are used to establish behavior. Attention to client rights and consent is stressed by McCormick and Burgio (1984), while Wells and Brink (1988) advise guidance from someone skilled in the technique and suggest much more research is needed in this area. It would be inappropriate to institute behavior management when treatable underlying causes have not been established.

Another form of behavioral therapy is biofeedback, which provides the individual with visual feedback of bladder and sphincter activity. Findings from a number of studies describing biofeedback programs are very encouraging (Gregory & Purcell, 1986; McCormick & Burgio, 1984). The opportunity for this method is limited by the requirement of special training and equipment (Ouslander & Elhilali, 1987).

Pelvic floor exercises

Pelvic floor exercises may be taught to men and women affected by decreased pelvic muscle tone (Shepherd, Blannin, & Feneley, 1982). Although improvement has been established in a much shorter time (Castleden, Duffin, & Mitchell, 1984), patience is vital as the program may take several months for success (McCormick & Burgio, 1984). The method named after it's advocate, A. H. Kegel (1951), has been clearly outlined by Mandelstam (1980). In one example, Taylor and Henderson (1986) report improvement in the pubococcygeal strength of all subject in a small pilot study of older women using Kegel exercises. This study included biofeedback as the subjects used an electronic device to register and display muscle activity.

Environmental interventions

Ebersole and Hess (1985) suggest that environmental modification is often overlooked and state the importance of calculating the time and distance a person must travel to reach the toilet. Chalifoux (1980) found that some continent older women had a warning time of less than three minutes between the urge to void and the need to void. Interventions include environmental modification and adaptive clothing (Perston, 1981; Wells, 1975).

Medical Treatment

Diagnosis is essential for effective medical treatment. Underlying or associated conditions must treated and iatrogenic causes eliminated (Williams & Pannill, 1982). When appropriate, surgery is considered for bladder neck prolapse or obstruction (Williams & Pannill, 1982). Drug therapy may be combined with bladder training programs (Griffin, 1983; Williams & Pannill, 1982). Treatment outcomes are optimistic. Williams and Pannill (1982, p. 903) state that "most patients can expect significant improvement or cure with different pharmacological regimens." Castleden, Duffin, Asher and Yeomanson (1985) found that two thirds of the clients treated with drugs and habit retraining improved, and almost one-half were cured.

Drug therapy for incontinence includes medications from five categories: cholinergics, anticholinergics, alpha-adrenergics, combined anticholinergics and alpha-adrenergics and estrogens (Griffin, 1983). Gregory and Purcell (1986, p. 258) caution that drugs used to treat incontinence are "not specific to micturition receptors and large doses are often required," with attendant side effects.

Incontinence Aids

Pads and pants are at present the best means of managing intractable incontinence in women. They provide security and protection, but it is stressed they should not be used instead of toileting (Ouslander & Elhilali, 1987). Individual product selection is made on the basis of absorption, size, esthetic needs, cost, laundry services and the dexterity needed to manipulate the product (Kennedy, 1984; Shepherd, Blannin, & Smart, 1980). Although necessary, incontinence pads may not be appropriately designed or accessible, and there is a need for further developments in this area (McGrother, Castleden, Duffin, & Clarke, 1986). Many use sanitary pads which have advantages for those with light incontinence as they are available and "normal" for women (Norton, 1985).

Although external collecting devices are available for both men and women, they are more satisfactory for men (Shepherd Blannin, & Smart, 1980). King (1984) notes that the use of condom catheters requires dexterity, cognitive ability and an adequate penis size while female urinals may be used by some women and are of value to individuals confined to a chair. Occlusive devices, such as, penile clamps and intravaginal devices, are noted but not recommended in geriatrics (Gregory & Purcell, 1986; Shepherd, Blannin, & Smart, 1980). Indwelling catheters, always a last resort, are still the most appropriate method of management for some individuals (Shepherd, Blannin, & Smart, 1980; Weiss, 1983). Self-catheterization is a valuable aid for those with overflow incontinence. An outline of the technique and a follow-up study may be found in Champion (1976); however, little literature specific to the use of self-catheterization in geriatrics was located.

The Experience of Incontinence

Throughout the professional literature reviewed, almost every article is introduced with a statement on the social consequences of incontinence, which are described as devastating, humiliating and embarrassing for the individual. These statements are apparently based on the experience or the perceptions of the authors as research references are absent, adding further support to the need for a clearer understanding of the social implications of incontinence. For example, it has been said that "incontinence can have a devastating effect on domestic life....the offensive nature of the condition can be the culminating factor in the final breakdown of family support" (Shepherd, Blannin, & Smart, 1980, p. 142). Ouslander and Elhilali (1987) suggest that the problem leads to placement in long-term care institutions. Maney (1976) states that incontinence leads to decreased self-esteem, social participation and, ultimately, social disengagement. Haber (1986) adds that on becoming incontinent individuals "must disengage themselves from society" (p. 42). It must be learned whether this is the perception of health professionals or a reflection of the experience of elderly individuals.

Statements about the impact of incontinence on the individual must be critically examined to avoid projecting an inaccurate image. For example, Yu (1987) developed an Incontinence Stress Index in a long-term care setting. She states the findings provide "tangible evidence that suggests what the literature has been saying, i. e. urinary incontinence is stressful for patients" (p. 25). Yu limited her sample to 27 patients with incontinence and did not provide comparative results from a continent group. The identified stress may have been related to many other factors.

Wells and Brink (1988) describe some of the taboos which exist in our society. As previously mentioned, excretion is avoided as a topic of social conversation; professionals use euphemisms such as "water works" to describe urinary function, and public toilets tend to be hidden and difficult to find or access quickly. Similarly, Perston (1981) states that individuals with incontinence "often feel unable to discuss their problem with others--it is not a subject talked about in 'polite' society. They are embarrassed about having to wear pads or appliances which they feel are detectable by all and worry about the presence of any odor or dampness on their clothes" (p. 39). Mitteness (1987a) adds a further dimension by suggesting that incontinence is not discussed because it is not a 'polite' topic and because it is not seen as a problem by professionals and lay people.

Lay literature describes similar sentiments. In a recent article about incontinence, the <u>Edmonton Journal</u> ("Millions live," 1988) states "it's talked about only in whispers and those who suffer seek to hide their shame...when a family discovers the problem it becomes the impetus for placing the individual in an institution." However, there is movement to change these social concepts. <u>Time</u> titled an article on incontinence "The last of the closet issues" (Toufexis, 1986) and described attitudes as the major problem for the victim of incontinence. <u>McCalls</u> (1986) also published a positive article, describing incontinence and its control, by a leading geriatrician. Support groups like the Simon Foundation have emerged to help more individuals with incontinence deal with the social and psychological problems of incontinence (Resnick, 1986; Toufexis, 1986).

Recent studies on incontinence

Recent literature has countered the view held by health professionals that the incontinent elderly lead lives of shame and despair. Simons (1983) in noting that "no studies dealing with the elderly person's perception of urinary incontinence and the impact it has on the image of self were found in a review of the literature" (p. 7) undertook a survey to investigate the potential relationship between these variables. Of the 43 elderly female subjects who participated in her study, no statistically significant differences were found in self-esteem as measured between the incontinent group (51% of the sample) and the continent group. Of the group who reported incontinence, one half had not discussed the problem with a health care professional primarily because they accepted it as a normal part of aging. Several of those who did seek advice from their physician were told not to worry about it or that it was normal for their age. The results of this study support the view that both individuals with incontinence and health professionals have an attitude of resignation toward the condition. It did not, however, give support to the concept of devastating consequences as the subjects "responded that urinary incontinence was not a great problem..." (Simons, 1983, p. 52).

Mitteness (1987b) further confirmed that the incontinent elderly were able to enjoy a fulfilling and independent life in the community. In a study (involving 30 seniors living independently in subsidized apartments) designed to explore the strategies older people used to manage incontinence it was found that "many elderly people displayed great resourcefulness and considerable psycho-social ability in organizing their lives so that they could effectively manage their bladder control problems" (p. 192). Significantly, she also found that most of the individuals managed their incontinence without the intervention of health care professionals. Mitteness (1987a) further concluded that there were strong contrasts between assessment and treatment objectives, professional and lay stereotypes, and the experience of incontinence. On one hand, incontinence was passed off as a normal part of aging, and on the other, the social consequences were seen as overwhelming to the individual. Even though the literature recommends assessment and treatment, the reality for many people with incontinence was quite different and specialized help was not available.

Breakwell and Walker (1988) studied the physical and psychological impact of incontinence and report that "no significant difference in personal adjustment between continent and incontinent women was contrary to what was expected" (p. 28) after a review of the literature. However, they found a statistically significant difference in social interactions between these groups as the incontinent women had less social contact with family members. The conclusions of these researchers were tempered with the noted limitation of a small convenience sample.

Preliminary data from the National Health Interview Survey, Supplement on Aging (Harris, 1986) included information on the prevalence of urinary incontinence, social activities and health status from interviews with 5637 people 65 and over. The findings conclude that "those with urinary problems have lower levels of social participation than did those who were continent...[and] were more likely to report their health as fair to poor and to report that their health had deteriorated over the past year" (p. 5). Thus, individuals with incontinence may also have other health factors that limit activity and, therefore, incontinence should not be singled out as the factor responsible for social isolation.

Conclusion

Much of the literature reviewed emphasized the role of health care professionals in the assessment, diagnosis, treatment and management of incontinence. However, many individuals must still manage on their own, without the expertise described in the literature, because professionals are not aware of the impact of this problem on their clients. Despite the prevalence of approximately 10% of older adults in the community with incontinence, there was evidence that only a few reported the condition to health care professionals, partly because mechanisms are not in place to encourage such reporting.

Almost every publication was introduced with a statement on the devastating social consequences of incontinence for the individual and family but seldom were these statements based on empirical findings. In fact, only a few recent studies were located that examined any aspects of the experience of bladder dysfunction and generally the findings have disputed these statements.

Smith (1982), in reporting on a large multi-disciplinary British workshop on incontinence, notes that "more research in this field is important, not only to identify needs and problems more accurately, but also to create the knowledge to be taught to practitioners so that their practice can be effective, efficient and appropriate" (p. 9). Mitteness (1987b) goes further and says, "if effective interventions are to be designed to reduce the negative consequences of urinary incontinence among the elderly, then an understanding of the strategies curr tly used by elderly people to manage this problem is sorely needed" (p. 185).

The purpose of this project is to study the experience of incontinence as perceived by those most affected--the elderly individuals who experience it. It is vital to gain an appreciation of their view of the condition and the consequences it has in their life. How does incontinence impact on day-to-day life? Does this problem keep people at home? Do older adults seek help from health care professionals? Do they subsequently receive advice and treatment? How do older adults feel about bladder control problems? How do they manage to control urine loss? Therefore, this research will address the question: What is the day-to-day experience of incontinence for the older individual who lives independently in the community?

III. METHODS

As stated earlier, professional literature has addressed the assessment, diagnosis, treatment and management of urinary incontinence, but little is known about the impact this problem has on day-to-day life; therefore, the method chosen must be one which would allow the issue to be studied from the perspective of the individual. A qualitative research method met this criterion. As Leininger (1985) notes, "the goal of qualitative research is to document and interpret as fully as possible the totality of whatever is being studied in particular contexts from the people's viewpoint or frame of reference" (p. 5). As an adjunct to the method chosen, a semi-structured questionnaire was used because some aspects of the experience of incontinence have been reported in the literature, however, sufficient information was not found related to the social implications, feelings or self-care practices. Therefore, unknown aspects of the experience of incontinence would be missed with a more structured approach. Such a use is acceptable when "not enough is known to be able to predetermine all possible responses to a question or all areas of the domain" (Morse, 1986).

This chapter is a description of the process used to collect and analyze data from a volunteer sample of older adults. The measures used to enhance the validity and reliability of the study are included, and ethical considerations are noted.

Data Collection

Telephone interviews were convenient as the respondents were able to be interviewed in their own homes at a time of their choice. In a study comparing telephone and face-to-face interviews, Janofsky (1971) found that "in 10 minute experimental interviews between strangers, interviewees were equally willing to talk about themselves and express their feelings in telephone as in face-to-face interviews" (p. 101). Rogers (1976) also reports that the quality of data obtained by telephone is comparable to face-to-face interviews and notes that the telephone provides for greater anonymity. As telephones are used as a means of normal discourse, these interviews are considered valid and reliable; whereas, during face-to-face interviews, the tape recorder and the stranger conducting the interview may interfere with disclosure (Colombotos, 1969). Also, the telephone reduces the awareness of the tape recorder, and "as people are used to speaking on the phone, it is easier for them to speak freely" (Field & Morse, 1985, p. 69).

Instrument

The semi-structured questionnaire (Appendix A) was used to guide tape recorded telephone interview. The questions covered the following areas: (1) the day-to-day experience of incontinence, (2) the perceived cause and course of the problem over time, (3) the self-care practices used to manage and control incontinence, (4) the professional advice and treatments received, (5) the social ramifications of the problem for the individual and (6) expectations of the future. The types of questions used by Mitteness (1987b) and Simons (1983) were used as a basis for the interview guide. Each interview lasted an average of 30 minutes, with a range from 15 to 90 minutes.

The questionnaire was revised following a critique by a nurse-researcher. The questionnaire was then pretested on two elderly individuals with urinary incontinence to ensure that the questions were understandable, would elicit the type of information required and that the questions were in a logical order. A second revision followed a review of the pretest interviews with the thesis supervisor.

Sample selection

The sample selection was based on the following criteria:

1. The ability to communicate in English and to converse over the telephone.

2. Self-described incontinence that matched the definition from Brocklehurst (1984, p. 4): "Does urine ever come away unexpectedly and without your being able to stop it and you get wet?"

3. The individual was an older adult. (All notices and handouts asked seniors to respond and share their experience. As people over the age of fifty often participate in seniors activities and seniors centers, they were therefore contacted through the advertising).

4. The individual volunteered to participate in study.

5. The individual provided verbal (telephone) consent (Appendix A).

6. The individual was living in the community, in his or her own home, apartment or lodge.

Sample recruitment

A volunteer sample of respondents was solicited by the following means:

1. A paid advertisement was placed in a weekly paper, the Edmonton Examiner on six occasions over the course of the study. This paper is delivered free of charge to 143,000 homes in the city.

2. A notice was submitted to the two large city

newspapers and all of the community newspapers in the area surrounding the city, with a request that it be placed in a seniors or neighborhood events section of the newspaper. The notice is known to have appeared in the <u>Edmonton Journal</u>, the <u>Edmonton Sun</u>, and the <u>Stony Plain Reporter</u>.

3. A notice and article were printed in a senior's newsletter, <u>News For Seniors</u>, that is distributed free of charge to individuals, seniors centers, residences and other groups in the city.

4. A handout was distributed to all seniors' centers and most seniors residences and lodges in the city and surrounding area. Approximately 1000 handouts were distributed in total. The management in each setting was informed about the study and permission was obtained to place the handout in an accessible site. A number of handouts were left in each area to allow people to take one to their home or room for later reference.and, therefore, eliminate the necessity of potential respondents writing down the telephone number.

5. Presentations on incontinence were given at two of the seniors' centers in the city to a total audience of 45 people. The presentations were accompanied by the handout describing the study.

6. Posters were placed in the city public health centers and a home care office, with business cards in attached envelops identifying the researcher and providing

telephone numbers.

7. The handouts were provided to the two day hospitals in the city and were made available to their clients by staff.

8. A rural health unit distributed the handouts to clients.

9. A retail supplier of incontinence aids and garments made the handout available in their customer waiting area.

10. Respondents were solicited through a visitation to an incontinence clinic.

11. Respondents were asked to tell others about the study.

The individuals who called in response to the handout or advertisement were informed of the purpose of the research project. Consent for the research was taped prior to the interview.

Copies of the handout and poster are found in Appendix B.

Sample size

Sixty individuals over 50 years of age responded to the request for subjects. This number represents the minimum sample size as Morse (1986) recommends 100 to 200 cases for qualitative studies using semi-structured interviews. Strategies to increase the sample size through staff contact in community health offices and day hospitals had very limited success, and almost all respondents called on their own initiative.

Data Analysis

All of the taped interviews were transcribed verbatim and the transcripts were compared to the tapes to ensure accuracy. A printed transcript was then cut up and sorted according to the interview questions. Content analysis was undertaken, and a coding system developed. The resulting categories (Field & Morse, 1985) were sorted and counted. The data provided a rich source of descriptive information which suggested a number of areas for future study. Summary tables were developed to display the frequency of categorized responses. Ten year age groupings were convenient for the purposes of analyzing possible relationships between different responses and age. Hypotheses were then developed with regard to selected variables. Further tabulations were made and associations between the selected variables were tested using Chi-square analysis.

Reliability

In qualitative research, the focus of reliability is on accurate identification and documentation of the reality experienced by the participants (Bogdan & Biklen, 1982; Leininger, 1985). In this study, data were obtained from a sample of individuals who have difficulties with bladder control and who volunteered information about their experiences. As the sample was a self-selected group, it was not possible to seek out informants with different views in order to examine all aspects of the experience of incontinence (Field & Morse, 1985), and this represents a limitation of the study. A wide range of advertisement methods were used to solicit informants, and therefore, it is reasonable to expect that a large number of seniors were given the opportunity to participate in the study.

The confidentiality of telephone interviews assisted the respondents in discussing the sensitive nature of this topic. However, only those volunteers who were fluent in English and able to hear on the telephone were included in order to eliminate any obvious communication problems. Although this factor may have contributed to self-selection, no respondents were eliminated from the study.

Field and Morse (1985) suggest that the status of the researcher can affect the reliability of the data collected. In this study, the researcher was always clearly identified as a nurse, and it was felt that this information assisted the respondents in discussing the rather intimate and private nature of this subject. The guided interviews ensured that all subjects would be asked to respond to the same questions.

Validity

Leininger (1985) describes validity in qualitative research as "gaining knowledge and understanding of the true nature, essence, meanings, attributes, and characteristics of a particular phenomenon under study" (p. 68). In order to gain an understanding of the experience of incontinence, the respondents were asked to describe their problems with bladder control in their own words at the beginning of the interview, and subsequent questions were used to obtain detail on specific areas. In this way, the focus was maintained on the perspective of the respondents. According to Sandelowski (1986), "a qualitative study is credible when it presents such faithful descriptions or interpretations of a human experience that the people having that experience would immediately recognize it from those descriptions or interpretations as their own" (p. 30).

The interview transcripts were reviewe with the thesis supervisor regarding interview style, category identification, coding and other analysis. As well, colleagues were consulted with regard to the understanding of the material (Field & Morse, 1985). The results of the study cannot be generalized; however, "generalizability is not the purpose of qualitative research but the purpose is rather to elicit meaning in a given situation...." (Field & Morse, 1985, p. 122). Assuming, as Bogdan and Biklen (1982) do "that human behavior is not random or idiosyncratic" (p. 41) a careful documentation of experience y lead to understandings of other similar situations.

Ethical Considerations

This study relied on a volunteer sample who were invited to participate through the use of advertisements and handouts distributed through a wide variety of means. The study was described to each individual who replied. An informed telephone consent was obtained from each individual who met the study criteria and agreed to participate. The respondents were not asked to give their names, and any names mentioned were removed from the transcribed interviews. The actual tapes were coded for reference. All tapes were kept in strict confidence and heard only by the principal investigator, the thesis supervisor and the typist. The raw data was viewed only by the three individuals noted above.

At the termination of each interview, the respondents were all offered an opportunity to ask questions about incontinence and were encouraged to seek health care as indicated. As well, referrals were made to other appropriate sources of information.

IV. FINDINGS

Sixty individuals telephoned in response to the question posed on hundreds of handouts and advertisements in the city: "Seniors -- what is it like to have problems with bladder control?" All met the selection criteria and were interviewed. The ages of the respondents ranged from 51 to 88 years, with a mean age of 70.6 years. Seven were male and 53 were female. All lived independently; 56 in their own home or apartment, three in a lodge and one with her daughter's family.

All respondents were asked to describe, in their own words, the nature of the problem they experienced with bladder control. The responses have been broadly categorized into the following areas: day-to-day problems with bladder control, social ramifications of incontinence, history and course of the problem, professional advice and treatment, self-care practices used to control or reduce unexpected urine loss and expectations of the future. The respondents were also given an opportunity to ask questions of the researcher.

Day-to-Day Problems with Bladder Control

The participants described problems with bladder control in terms of being unable to prevent urine loss.

Most (63%) described difficulty holding urine long enough to get to a toilet (Table I). They spoke of having a "strong" and often "sudden" urge to void. The volume of urine loss varied. As one informant reported,

> Suddenly it seems to be that the bladder is full and don't tell me, and just suddenly it comes and so I get to the bathroom or I don't get to the bathroom...but very often I don't get there in time before I dribble.

A number of people said that there were environmental cues that precipitated the urge to void. Cold weather was frequently identified as a contributing factor, and going out in the winter was often problematic. Another very common cue was unlocking the front door. As one man said,

> It's always, I'll be all right until I get right to the door. I feel that when I go to the washroom uptown, that should do me for at least an hour or so, or a couple of hours, but it don't seem to, it will come on all at once.

A number of female respondents (40%) spoke of losing urine when laughing, coughing or sneezing. Again, the amount lost might be only a few drops or a "pool of urine." Many said this could present extreme difficulties if they had an upper respiratory infection with constant coughing. As well, some activities, like dancing or jogging, resulted in urine leakage.

> If I have a cold and I sneeze, I do, it does spill...If I laugh quite a bit it's not as bad as it used to be since I had it stitched up, but there's still a problem...I have to walk slowly, you know, not to be a jolt on my body.

Table I

Descriptions of Problems with Bladder Control by Age of Respondents

Type of Problem	Age (years)				Row total
	50 - 59	60 - 69	70 - 79	80 - 89	n
Unable to Hold Urine	3	13	10	12	38
Loss of Urine on Coughing	5	11	4	4	24
Dribbling	3	7	3	3	16
No Control	1	3	1	3	8
Column total	12	34	18	22	86[a]

Note [a] $n > 60$ as 18 respondents described two or ~~more~~ types of problems.

Some respondents (27%) described their problems with bladder control as a "dribble". Most said this happened when they were active. For example, sitting and watching television would not present a problem but active housework or walking to the bus stop would result in a steady, but small, loss of urine. Two men and two women described a post-urination dribble, as an 81 year old woman said, "My trouble is when I, uh, go to the bathroom is finishing off, it just seems to want to dribble on and on." Another said, "I don't seem to be able to completely empty the bladder...I feel I'm through...and I have a little bit more of a leakage."

Eight people described almost complete lack of control over bladder function: "There's no control of it at all...it just seeps through." A respondent in her mid sixty's described a lifelong problem of daily incontinence and, in fact, had never been continent. Two subjects described incontinence clearly related to diagnosed neurological conditions. One had multiple sclerosis and the other was paraplegic. Neither had any sensation of bladder fullness nor of voiding. The respondents who described a total loss of bladder control also had a large volume of urine loss.

> I have to go to the bathroom every half hour. I have no control over my bladder at all, and when I have to go to the bathroom, I have to go right now, and I just can't make it....It's an awful feeling to go through this every day, wet all the time.

For most individuals, the frequency of urinary incontinence seemed to fluctuate as some days or weeks would be better than others. Seventy percent of the respondents (Table II) indicated that they usually had some urine loss on a daily basis, for others it was less frequent. One person could not estimate any pattern, and another did not experience any urine loss due to self-catheterization. Most respondents found it difficult to estimate the amount and frequency of urine lost:

> I dribble so much. They give me these pads, but they sure don't help. My underwear still gets wet. Sometimes I dribble all the time, and, then again, there's a streak when I don't need no pads or nothing. I don't know why that is.

As 86% of those over 80 years of age but 63% of those in their sixties were incontinent daily it was hypothesized that age may be related to frequency of urine loss. A Chi-square analysis between the variables (two age categories; 50 to 69 and 70 to 89 and two frequency categories; daily and weekly/monthly were used to fill the contingency table) revealed no association: $\chi^2(1, \underline{N}=58) = 0.25$, N.S.

The need to get up at night was a common experience for the respondents (Table III). An age-related pattern was not apparent, as an identical ratio (67%) of those 50 to 69 years and those 70 to 89 years of age reported nocturia. For the most part, needing to get up to void was not considered to be a major problem, and some respondents

Table II

Frequency of Episodes of Urinary Incontinence by Age of Respondents

Frequency	Age (years) 50 - 59	60 - 69	70 - 70	80 - 89	Row total n	Row total %
Daily	7	14	9	12	42	70
Weekly	1	5	4	1	11	18
Monthly	0	3	1	1	5	9
Other	0	0	2	0	2	3
Column total	8	22	16	14	60	100

Table III

Described Frequency of Nocturia by Age of Respondents

	Age (years)					
Frequency	50 - 59	60 - 69	70 - 79	80 - 89	Row total n	 %
Seldom or never up to void	4	3	5	2	14	23
Up to void 1 - 3 time	3	13	8	10	34	57
Up to void more than 3 times	1	3	2	0	6	10
Night time incontinence	0	3	0	2	5	8
Not applicable	0	0	1	0	1	2
Column total	8	22	16	14	60	100

related it to difficulty sleeping. One 81 year old woman said,

> I'm a poor sleeper. I wake up, 3:00, and I have to get up and go to the bathroom, and if I can't get back to sleep, I'm up three or four times before it's time to get up in the morning. And then if I do get back to sleep, I sleep till about 5:00, and then, from then on I'm getting up.

Very few respondents identified any other physical symptoms that could be related to incontinence. Some had experienced chronic bladder infections, but all received treatment for the condition when it occurred. Although the literature describes skin breakdown as a complication of incontinence, none of the respondents had problems with irritation in the groin, including three individuals who used a wheelchair on a daily basis. Many were conscious of the need for careful hygiene and indicated that they always washed after an episode of incontinence. Interestingly, one person had a perineal skin rash in hospital when required to use a bed pan. She attributed the rash to a lack of opportunity to wash after voiding. Perhaps skin breakdown is less of a problem for those who control their own hygiene.

Social Ramifications of Incontinence

The literature suggests that incontinence leads to humiliation and isolation, and it was expected that a major component of the day-to-day experience would have to do with social factors. The respondents were asked if they talked to others about bladder control problems, that is, did they tell others about their own problem and did they know about people in similar situations. All were asked how incontinence affected their daily activities and if there was any activity they did not undertake as a result. The responses are outlined in the following section.

Silence and secrecy

Incontinence is not a subject of social conversation. Women, in particular, said this was a subject you "just don't talk about." Most respondents (Table IV) knew of at least one other person with incontinence; a close female friend, a sister or a neighbor, but no one really shared their experiences. As one woman of 61 years reflected:

> I've heard different women say, "Well, I get that too." But very seldom ever talk about it, [they] just say "Oh, I've had that" or "I get that"....Over the years just different people have said "Yeah, I get that," it seems to me like they don't want to talk about it.

Although 70% had told someone, again usually a close friend or relative, about their own problems with bladder control, 30% had not discussed this matter with others. Some women even kept their incontinence a secret from their husbands. In fact, nine women had not told anyone; not

Table IV

Reported Social Discussion of Problems with Urinary Incontinence by Age of Respondents

Report	Age (years) 50 - 59	60 - 69	70 - 79	80 - 89	Row total n	Row total %
	Aware of others with incontinence					
Friends	4	10	6	6	26	43
Family	0	4	2	2	8	13
Family and friends	0	0	2	0	2	4
No one	4	8	6	6	24	40
Column total	8	22	16	14	60	100
	Told others of own incontinence					
Friends	3	7	5	2	17	28
Family	3	5	4	4	16	27
Family and friends	0	5	2	2	9	15
No one	2	5	5	6	18	[illegible]
Column total	8	22	16	14	60	100

family, friends nor health care professionals:

> No, you don't talk about that....How do you start a conversation like that? They're not like you, making a study of this.

> I don't talk anything, except casual to most of the people here....I just have two daughters. I can never mention to them much.

> No, I guess it's mostly because people don't talk about it too much. Not at my age anyway. If you're in the nursing home or something, maybe they do.

Interestingly, social discussion of incontinence did not seem to be an issue for the male respondents. All of the men had told either family or friends. They approached this topic in a "matter of fact" manner.

A few women elaborated on the social support of having someone with whom to share the problem. For example, one woman of 82 years said, "If you can talk to someone once in awhile it makes all the difference in the world....I talk to my youngest sister--she has bladder trouble--we talk back and forth and it helps." Another woman remarked:

> I think if more of them talk about it maybe they would help each other. First time I've had anybody except my sisters or one sister say anything to me was yesterday, and this one lady told me what pad she uses. That's the first time anybody's ever let on about it! Most of us, I'm sure, down at the senior's club must have the troubles....That's the first place that's looked for--is everybody finds out where the washroom is.

Socializing: going out

Fifty respondents (83%) said they did not significantly limit or reduce activity outside the home. In fact, they were quite emphatic that activity out of the home represented an important component of their quality of life and said they made an effort to go out on a daily basis.

Ten reported limitations due to mobility problems or other physical conditions. Of these ten people six were over age 80 and described restrictions related to arthritis, cardiac conditions or other physical ailments. The other four people were younger but identified specific restrictions: one was disabled with arthritis, one with multiple sclerosis, another was paraplegic and one complained of chronic debilitating fatigue. It is interesting that of these ten people with activity limitations, eight denied that incontinence was a contributing factor. For example, one 87 year old woman said,

> I can't go out anyway very much. I'm not able to go out on the bus. I'm not able to go shopping unless I have somebody with me. I've got arthritis very bad. I get dizzy, and they don't want me to fall. [Does the incontinence keep you home?] No, I just take extra pads. I go [to son's home out of town] for two or three days, and I take a lot of extra ones, but when I go to my son's here [in the city], I just go for four or five hours, and I just take an extra one.

A majority of the sample, 53 individuals (88%), clearly stated that problems with bladder control did not reduce their activities.

> No, oh my goodness, no. Oh, no way! Oh my no. No, it hasn't house-bound me.

> I try to go out every day. No, I'd double-pad myself rather than sit here and feel sorry for myself.

One 79 year old woman with a seven year history of stress incontinence symptoms said,

> For awhile I thought my life was just about over--that I was going to be a prisoner. But it isn't bad at all, it doesn't bother me, you get used to everything, you know. I thought it would keep me from doing things....If I want to go out and I'm going to go out, it doesn't bother me. I know that I can--I'll be all right.

Thus incontinence was something these subjects "got used to" and coped with. They did whatever was necessary to contain urine loss and continued to go out as they wished.

However, seven others felt restricted in their daily activities because of incontinence: "It's not easy to find a convenience in the city--So, [I don't go out] because I don't want to be taken by surprise. It's annoying because it doesn't allow me to do the things that I would like to do." Or as a 67 year old woman, who said she had lost all urinary control following bladder repair surgery 2 years ago, stated, "I just go downtown for my groceries, I don't go out that much, I stay home. It confines me to stay home." This woman was desperate for treatment and was anxiously waiting for a scheduled specialist appointment.

Feelings

Described feelings about incontinence were sorted into four categories: accepting, annoyed or bothered, disgusted and afraid of smell or embarrassment (Table V). The most common response was that incontinence is annoying or a nuisance:

> I guess I just feel why do we have to be this way? That's what it feels like. You know, you have to be bothered with these pads all the time....It's something I have to live with.

> Annoyed. That's the best I can tell you, annoyed. But it's a relief now to have these pads that I'm using now. Because I don't have to bother that I'll be soaked when I get home.

Others described incontinence as something "you put up with" and accepted. These people often said they decided not to let it bother them. As one 82 year old woman reported, "I got used to it--it's been so long. It bothers me, yes, but I try not to let it." A male informant who was alert, active and happy with his life, described his perspective as:

> You see, I'm so lucky in some ways, I'm 86 years old, I tell people--well, I can walk a little bit, I can hear a little bit, I can see a little bit and I'm so lucky that I can't complain about this little bladder problem as long as I've got it under decent control.

Seven people, five women and two men, were much more troubled by their problems with incontinence and expressed feelings of disgust or distress, such as the following

Table V

Reported Major Feelings About Urinary Incontinence by Age of Respondents

Report	Age (years)				Row total	
	50 - 59	60 - 69	70 - 79	80 - 89	n	%
Accepting	0	6	6	5	17	28
Annoyed	6	7	5	6	24	40
Disgusted	0	3	2	2	7	12
Afraid of smell or embarrassment	2	6	3	1	12	20
Column total	8	22	16	14	60	100

comment; "I don't want to express it but--it's really something. It's hell. I know there are many people like me but...." For these respondents incontinence interfered with daily life and was difficult to manage.

Other respondents expressed their feelings in relation to concerns about odor or possible embarrassment:

> I don't feel clean. I remember when I was a kid...getting beside people that smelled, I used to call them pissy.....I don't want to have people feel that way about me.

> I'm always afraid that maybe there's going to be a time when I'm not going to be safe. Like it's going to let loose on me and I am really embarrassed.

They described careful attention to hygiene, washing after incontinence and being careful to change wet pads or clothes immediately. Some women spoke of the difficulty trying to wash with paper towels in public washrooms. One said she looked for a wheelchair toilet that had a sink in the cubicle in order to wash in private. Another said she would go home immediately if her underclothing became wet.

It was difficult to divide the responses into discreet categories as there is overlap in descriptions. In general, the majority of subjects described feelings about incontinence in a passive manner, as unpleasant and troublesome, but manageable. It is however, noted as a constant worry. Many spoke of planning their destination in relationship to the availability of toilets and always taking care to void before leaving home.

History and Course of the Problem

Most of the subjects reported years of experience with bladder control problems (Table VI). It was interesting to note that of the subjects over 60 years of age, 42% first experienced urinary incontinence before their 60th year.

Generally, those who had a long history with incontinence had the most difficulty estimating when the incontinence first occurred. Some had difficulty identifying when the problem started because the nature of the incontinence may have changed over time. One woman who described several types of problems with incontinence stated,

> I couldn't never tell you the exact year, like it was always if I sneezed or laughed sometimes, you know, I would pass my water for quite a few years I would say. Not twenty or thirty years ago, but, like I had a stroke in '84 and that's when it really started.

Almost half of the subjects could not identify any particular change in their problems with incontinence over the years (Table VII). Thirty five percent stated that the situation had become worse over time, and of these, four people had received some medical treatment. For others, treatment had reduced the problem. Nine percent noted an improvement after "bladder repair" surgery. Two people stated they had improved after starting a medication specifically for incontinence, and two reported improvement following pelvic floor exercises. Although almost all

Table VI

Reported Years Since Start of Urinary Incontinence by Age of Respondents

	Age (years)				Row total	
Years	50 - 59	60 - 69	70 - 79	80 - 89	n	%
Less than 2 years	2	4	4	7	17	28
From 2 to 10 years	3	6	7	4	20	33
From 10 to 20 years	1	4	2	1	8	14
More than 20 years	2	8	3	2	15	25
Column total	8	22	16	14	60	100

Table VII

<u>Reported Course of Urinary Incontinence by Age of Respondents</u>

Course	Age (years) 50 - 59	60 - 69	70 - 79	80 - 89	Row total n	%
No change	2	11	11	3	27	45
Increased frequency or amount	5	7	1	8	21	35
Decreased frequency or amount after surgery	1	2	1	1	5	9
Decreased frequency or amount after medication	0	0	1	1	2	3
Decreased frequency or amount after pelvic exercise	0	1	1	0	2	3
Fluctuating pattern	0	1	1	1	3	5
Column total	8	22	16	14	60	100

subjects reported that the situation fluctuated from day-to-day or week-to-week, three people reported a very erratic pattern of incontinence. As one man recalled,

> I had it in, let's see 1945--or 43. 45. Then I had it--didn't have it--until 1947. Then I had no trouble with it until the 60s, the late 60s, and then it was gone again beginning of the 70s, I had no problems until now....

Perceived causes of incontinence

Forty five percent (Table VIII), which included all the males in the sample, said they had "no idea" why their problem with incontinence had started: "I don't know," or "I have no idea--it's too far back now." As the literature suggests that older adults attribute incontinence to age, it was interesting that a larger percentage of people in the older age group said they had "no idea" why it started than those aged 50 to 70 years. It was postulated that a relationship may exist between age and reported perception of cause. Accordingly, a Chi-square analysis was conducted using two age categories (50 to 69 and 70 to 89) and the five perceived causes of incontinence (listed in Table VIII). The analysis did not reveal a significant relationship between age and perceived cause of incontinence: $\chi^2(4,\underline{N}=60) = 6.66$, N.S.

Only eight people specifically identified age as the probable cause. One woman expressed this view very succinctly;

Table VIII

Reported Perception of Primary Cause of Urinary Incontinence by Age of Respondents

Cause	Age (years) 50 - 59	60 - 69	70 - 79	80 - 89	Row total n	%
Does not know	3	8	7	9	27	45
Old age	0	2	4	2	8	13
Decreased muscle tone	2	2	1	2	7	12
Childbirth	2	4	2	0	8	13[a]
Illness or surgery	1	6	2	1	10	17
Column total	8	22	16	14	60	100

Note. [a] represents only women

> I think it's just old age, that's what I think, 'and we're like a machine and we wear out. It's kind of sad after you go through an operation and that doesn't stop it.

Perhaps expressing a concept similar to advancing age, seven respondents felt incontinence was due to decreased muscle tone. Eight others suggested childbirth was the major cause and, of these, several implied that this was due in part to old age. "I didn't have it till after my child was born...so I don't know, as I say, it seems like my bladder is sagging." As some of the respondents indicated, their perception of cause reflected information provided by health professionals. "I've had...I've delivered eleven children, and they figured my bladder was affected."

Ten people attributed incontinence to the result or aftermath of an illness or surgery. As one woman said, "Well then, I don't know whether something happened during the operation or what, but I had a terrible time. I was on the catheter for a number of days."

Reported Medical Advice and Treatment

Almost three quarters of the individuals interviewed had sought medical advice for bladder control problems (Table IX). Of these, two thirds (29) reported that they had seen a urologist or a gynecologist, and the other

Table IX

Reported Medical Care by Age of Respondents

Report	50 - 59	60 - 69	70 - 79	80 - 89	Row total n	Row total %
			Reported discussion with physician			
Has talked to a physician	6	18	11	9	44	73
Has never talked to a physician	2	4	5	5	16	27
Column total	8	22	16	14	60	100
			Reported advice		n	
Surgery	4	8	3	3	18	
Pelvic exercise	0	2	0	0	2	
Medication	0	6	2	3	11	
Nothing can be done	0	1	0	2	3	
Referral to specialist	3	5	2	2	12	
Advice unknown	1	4	5	3	13	
Column total	8	26	12	13	59[a]	

Note. [a]n > 44 due to multiple responses given by several respondents.

third (15) indicated only that they had seen a physician.

A number of individuals had not seen a doctor for several years. All respondents indicated, as the following example suggest, that they received little or no information about possible treatments, and medical care had often been sporadic;

> I haven't talked to my doctor for fourteen years about it. When he said that the operation was a failure, I never bothered going back. They did say they could do an extension [more extensive surgery], but I'd have to take the weight off--cause if I didn't take the weight off, there was no sense in doing it.

The medical recommendation most frequently reported by the respondents was surgery; that is, a bladder repair for women or a transurethral resection for men. In fact, five of the male respondents had a transurethral resection. In one case, the operation was performed for cancer of the prostrate, but the other four men were unclear about the reason for the surgery. One said it had something to do with incontinence.

Two men had a "prostate operation" about two years ago and had subsequently started taking Ditropan (Oxybutynin, an anticholinergic drug). Both said they had not seen the surgeon since the operation and had remained on the medication without any further advice. Neither knew if they were expected to return for a follow-up appointment. One man called the researcher, in part, to question if he should remain on this medication.

Of the 14 women for whom surgery had been suggested, three chose not to have the operation. These individuals considered surgery to be a more undesirable alternative than the incontinence they experienced. Of the 11 women who reported that they had surgery at some time, five felt that the problem was lessened while six stated that there was no improvement. None reported a total cure. One 73 year old woman had surgery four times in twenty years, and only the final operation provided any substantial relief. She said, "It was just like, well, just like a miracle."

Only two women said that their physician had told them to try pelvic floor exercises. One of these women was also advised that her incontinence could be surgically corrected.

Medication was prescribed for the treatment of incontinence for eleven subjects. Two respondents were taking Ditropan at the time of the interview (as noted above). One stated that the drug was of some help and the other had felt there was no improvement. One respondent refused medication (a bladder installation), and two others discontinued medication (Ditropan) without medical advice because of side-effects. Another two were unable to identify the medication they used except to say that it was intended to reduce the sense of urgency; neither had noticed any improvement in their incontinence. Four subjects had been treated with medication for chronic urinary tract infections on several occasions. One noted a decrease in incontinence as a result.

Three women were told by a physician that "nothing could be done" to control their incontinence. One woman had lifelong incontinence of unknown cause, one reported no sphincter control and lost urine without any awareness, and the other, in her eighties, was told that surgery may help, but that she would not be able to tolerate the operation.

Over 20% of the respondents were unable to describe any medical advice. They said their physician knew of their problem but had not "said anything", or they were unsure as to the response. Some believed that no response from their physician meant that nothing could be done.

Twenty seven percent of the sample had not reported the condition to a physician. This group was comprised of one man and 15 women. Of these a slightly higher percentage were those in the older age divisions (70 to 89). A Chi-square analysis did not reveal an association between the variables of age (again, two age categories) and report to a physician: $\chi^2(1, \underline{N}=60) = 1.36$, N.S.

The problem with incontinence was often considered too insignificant to report to a physician:

> I'm not a person that runs to a doctor with every little thing.

> No, I've never mentioned it to my doctor at all. I have a young lady doctor now and I am very pleased with her. I was down to see her last week but I didn't mention that. Because I just take it for granted.

Other respondents indicated that they didn't think the doctor would be interested in the condition or there was not enough time when other more "serious" conditions had to be addressed:

> I feel I'm taking up too much time, and so I think, "Oh, old lady, get out of there and go home!" I sort of think they're not that interested, and quite often if I've been in there, say fifteen minutes, she'll say "Well you've taken up all your time, I can't spend any more time with you."

One woman said she just didn't want to talk to the doctor about it:

> No, I haven't, because the last time I went to the doctor he asked me how my water works were, and I said "okay"--ha, ha! I just didn't want to talk to him about it, I guess.

This woman was unable to say why she did not respond to the physician's question, but did say it was different when she telephoned the researcher because "you're a woman."

Reported Care From Other Health Professionals

Only 28% of the respondents had at some time discussed urinary incontinence with a nurse. Two had also talked to a physiotherapist (Table X). This contact was more coincidental than planned. Ten of these people had discussed their need for urinary incontinence garments with a nurse, and arrangements had then been made to supply the

Table X

Reported Care From Other Health Care Professionals by Age of Respondents

Report	50 - 59	60 - 69	70 - 79	80 - 89	Row total n
Reported discussion with other health care professional					
Nurse	1	7	3	6	17
Physiotherapist	0	2	0	0	2
No other discussion	7	15	13	8	43
Column total	8	24	16	14	62[a]
Reported advice					
Incontinence garment	0	3	2	5	10
Pelvic exercise	0	1	0	1	2
Referred to physician	0	0	0	1	1
Other	1	1	1	0	3
Advice unknown	1	2	1	1	5
Column total	2	7	4	8	21[b]

Notes. [a] n > 60 as two participants discussed their condition with both a nurse and a physiotherapist.
[b] n > 17 due to multiple responses given by several respondents.

garments through the Alberta Aids to Daily Living Program.

Six respondents had spoken with a nurse during a past hospitalization; however, only three could recall receiving any advice or teaching. One was told to allow herself time to sit on the toilet to empty her bladder: "I remember her words. She said that I should sit there and allow it time to drain. So I try to do that." One was told to drink less fluid in the evening. Another stated that when bothered with urinary retention, she would "even straddle a little can of hot water to let the steam on me. A nurse told me this years and years ago. An old wife's tale most likely! But anyway, I would even do that!" This indicates that nursing advice, even when doubted, is followed. One woman recalled learning of pelvic floor exercises at a Health Center, apparently from a Community Health Nurse and another learned of the exercise from a physiotherapist. Others, however, could not recall any suggestions or counselling from the nurses they had seen.

Most respondents had not spoken to a nurse, physiotherapist or other health care professional about incontinence. They simply answered "no" to this question; however, two people remarked that they did not "have a nurse in their family", suggesting that they did not know how to contact a nurse. One 85 year old woman said that she thought health problems were to be managed by her doctor. A few had regular contact with a Community Health Nurse but did not ask about incontinence:

> Lots of nurses come here [senior's residence], but I never say anything to them--I haven't got the gall.

> No, the health nurse comes periodically...she said we could talk to her about any problem, but it never occurred to me to talk to her about this.

> It's a long time since I had children. I thought the health unit was just for babies.

One respondent recalled her attempts to approach a nurse as demeaning. She said the nurse was a student doing a presentation at a senior's center.

> She was asking different ones at the table...well, I was sort of a little embarrassed. There was a lot of men sitting there and I talked to her kind of on the Q.T. She said "Oh, I have nothing to do with that and that's not a subject I'd like to bring up with seniors." I felt kind of, I don't know how to put it, but I was asking a sensible question and she was putting me down as though nobody else would have something like that. And I thought to myself, we don't know how many people in this room might be going through the same thing and they're embarrassed to talk about it.

The expressed reluctance of some respondents to inform health care professionals about problems with bladder control led to the hypothesis that a relationship may exist between feelings about incontinence and the report of symptoms to a professional. A Chi-square analysis was completed (Table XI) to examine the potential relationship between these variables. The analysis did not reveal an association.

Table XI

Contingency Table: Major Feelings About Urinary Incontinence and Reported Discussion With Health Care Professional

	Accepted	Annoyed	Disgusted	Afraid	Row total
Reported	14	17	5	9	45
Not reported	3	7	2	3	15
Column total	17	24	7	12	60

Chi-square=0.762 df=3 N.S.

Reported Self-Care Practices

Predictably, reported self-care strategies included the use of different pads, self-imposed fluid restriction and frequent or regular toileting patterns (Table XII). Most respondents used more than one method, evaluating each through an ongoing trial and error process. Few self-care practices reflected professional advice, however, women sometimes passed information on pads to a confidant.

Pads and padding

Some type of pad was used to control urine loss at least some of the time by 78% of the respondents. Twenty seven used sanitary pads, nineteen a commercial incontinence garment and seven a homemade pad of cloth, facial tissue or toilet paper. These groups are not mutually exclusive. Many used homemade or sanitary pads at home, reserving the heavier, more absorbent garments for outings.

Generally, commercial incontinence garments were not considered to be very comfortable nor acceptable and were used only out of necessity to absorb the volume of urine. They were described as hot, bulky and diaper-like. One 82 year old woman, who said she had briefs and pads supplied by "the government" for the past five years, complained

Table XII

Reported Self-Care Practices by Age of Respondents

Practice	Age (years) 50 - 59	60 - 69	70 - 79	80 - 89	Row total n
	Management of urine loss				
Incontinence garment	0	8	3	8	19
Sanitary pad	6	12	5	4	27
Home made pads	1	4	2	0	7
Frequent voiding	3	2	4	2	11
Changing underwear	1	5	4	3	13
Self catheterization	0	0	1	1	2
Limit fluids	2	6	3	1	12
Column total	13	37	22	19	91[a]
	Self treatment for incontinence				
Other	0	2	0	1	3
Pelvic exercise	0	3	1	1	5
Column total	0	5	1	2	8

Note. [a] n > 60 as some participants reported more than one practice.

that the brief had a rubber lining which was hot at times and the pads were "much too wide" to be comfortable. She added that they did "work well." She wore the pads night and day because she would get wet "as soon as my feet touched the floor." Four of the seven men in the study used incontinence pads, and all of these individuals had a commercial product supplied by the Alberta Aids to Daily Living Program.

Thirteen people had the products provided by the Alberta Aids to Daily Living Program and all but one person used these garments on a daily basis, usually night and day. Two people said they even had to use two pads at a time, one on top of the other, to adequately absorb urine. Another complained that despite the bulk of the garment, urine leaked around the edges. Five others who purchased commercial products used them only on special occasions when a toilet might not be quickly accessible, such as on a trip or when out in the evening. One individual who said she had garments donated by a nurse when she was a patient in the hospital did not know where to obtain more. At home she used a pad made of facial tissue to avoid the expense of purchasing pads.

Only women reported the use of sanitary and homemade pads. Of the twenty seven women who used a sanitary pad, nine used a small mini pad or panty liner, and the others used a regular sized napkin. Again, a heavier pad was often used when out of the home and a mini pad or facial tissue when at home. Some used the mini pad as a back up precaution: "I wear these pads. Not very big ones, just little tiny ones because I seem to get to the bathroom before anything too much happens." Cost was a consideration for some people, and a number of older women remarked that they purchased sanitary pads at seniors sale days in department stores or collected coupons. One woman was not satisfied with the sanitary pads: "It's soaked enough -- it's different than when you're menstruating." Although not satisfied, she was not prepared to request a supplied commercial product: "I don't figure we should take advantage of the extended services." She went on to describe her system of reusing pads during the day to save money:

> The last time I went, I mean I try to get the coupons and all that, but I got the regulars...because they're thicker. They had a new one called "Maxi", it's thinner but it's supposed to absorb as much....The cheapest you can get them is three and a half or something like that....I only use one (at a time). I'm kind of frugal, I have a spot where I'll put it up to dry and put the other one on.

The use of a homemade pad was a matter of preference. Some used them part of the time and others on a regular basis.

> I bought some of these things (pads) but I never trusted them that much. What I do use, and I find it very convenient for me, [is] an old wash cloth that I fold lengthwise and over again. And then I use, in case something happens, I use a plastic bag all folded up under that. That works for me.

> People have suggested those pads and panty liners. They'd probably be okay, but I have found that when I go to the bathroom I just change it...so to me toilet paper's better. Whereas, if I was using pads and every time I went to the bathroom, it would be kind of expensive.

Thirteen people chose not to wear a pad at all but to simply change any wet clothing. Laundry was not considered to be a problem. A few people said that they had extra washing, they either washed underwear daily by hand or used automatic washers in their home. For most of this group, urine loss was infrequent, but three respondents indicated that they have some incontinence every day:

> I did for awhile [use pads]. I thought it would keep from staining my pants because it's just a spot about, I think maybe three inches in diameter...but then like I say, they get smelly so fast. [Now] I don't do anything. I have pants that are all stained up.

Other self-care methods

Another common strategy to prevent incontinence was frequent and regular toileting. As one 73 year old woman described her management:

> I got the daytime business straightened out by timing myself, you know, at least every hour....If I've gone at 2:00, I'll go at 3:00. I have these pads...which I never use in the daytime....No, not if I time myself.

The most extreme example was that of one woman who voided every half hour during the day. Her life-style was controlled by extreme incontinence.

Respondents were questioned about fluid intake, to determine if increasing or decreasing fluid intake or changing the type of fluid consumed was a strategy used to control incontinence. Over half of the subjects (32) said they did not vary their fluid intake because of incontinence (nine said that they drink a lot of fluid generally because they have been told it is considered to be a good health practice). Seven people said they were now drinking more water or fluid than before, usually because of advice from others:

> I had a friend, a patient, in the renal functions area, and they were always told to drink lots of apple juice and cranberry juice, so I've got a gallon of each in my refrigerator....I feel that I've got to keep flushing it out.

> If he, my doctor, had his way he wouldn't have me drink tea, but he likes me to take cranberry juice which is good for bacteria....I've been drinking a lot, so maybe this has been helping me.

A further twelve people indicated they did cut down or reduced the amount of fluid consumed on a daily basis: "Not as much [fluid] as I'd like, because I want to be careful." The most extreme example was a retrospective story told by one woman who had practiced severe fluid restriction in the past:

> Ordinarily I try to control the amount that I drink. I did it to the extent that I had to go to the hospital and that was foolish really. I would drink as little as possible....I would only drink a cup of coffee in the morning.

A common strategy was planned fluid reduction prior to special events (such as travel or an evening out), those times when a toilet may not be easily available.

> Sometimes if I'm going to go out I think, well, I won't have a cup of tea.

> There are time when I'm travelling I make very sure that I cut back on fluids....Then I make up for it later.

Only three people reduced coffee or tea because they found incontinence was worse if they drank these liquids. Several had tried this strategy without any noted results. They said the type of fluid consumed did not seem to make any difference.

Five women stated that they practice a pelvic floor exercise. One individual was taught to do this exercise by a physiotherapist, one person learned of it from a public health nurse, two people were told by their physician, and the remaining person learned about this from a newspaper. All of these women used pads as well to manage their incontinence. When asked how the exercise was done, one 79 year old woman said,

> It's good, you could be urinating and you stop suddenly....The best thing is, if you're sitting [illegible] the toilet, and you're urinating, to stop and hold and then release....You can do that when you're just sitting around....I saw that in the paper. That Dr. Donahue!

Despite the fact that all respondents had invented their own strategies for coping with incontinence on a day-to-day basis, only two people identified a practice that could be considered unusual. For the first practice, a 82 year old woman said she sometimes drank a little "pickle juice" (the vinegar from a jar of mixed pickles) just before going out of her home as "I think it restrains it [the bladder]...like an astringent". She was careful to point out that she only used a very small amount, "about half a teaspoon". The second practice, described by a male respondent who heard of a "cure" from a friend years ago, was to soak in a very hot bath until the "kidneys were heated." This man believed that a chill contributed to his problems with bladder control which he tried to prevent by wearing warm clothing. "I've switched to long johns now, it helped me when I lived in Saskatchewan." A number of others also expressed the view that one could be "chilled" sitting on cold ground or cement and this could cause problems with the bladder or kidney.

Expectations of the Future

Over half of the respondents (55%) expressed a rather accepting view of the future, stating that they had given it little thought, and expected the incontinence would continue as at present or that they hoped the situation would not become worse. Incontinence was simply dealt with as part of day-to-day life. One respondent said, "I don't know, so far I'm getting along all right. Maybe something else, maybe I'll have a heart attack or something else might knock me over and the bladder won't count. I don't know, it doesn't bother me too much."

The other respondents (27) expressed a plan or wish to have more control, particularly if incontinence increased in frequency or amount. In fact, over half of this group said they would seek treatment if the problem got worse: "I don't know if it increases more so, I'll either go to my doctor and get a referral--maybe to a urologist--I don't know whether that would be right or not."

When each individual was asked if they had any questions that they would like to ask the investigator. Nineteen people said they had nothing they wanted to ask, and four asked if they had been any help to the study. However, 37 requested more information about incontinence or asked if there was anything else that they could do about it. As one 85 year old woman said,

> I picked up the sheet [handout on the study] quite awhile ago. I kept thinking I'd call. I was curious more than anything else. Also I thought--well, maybe it's good to confer with somebody. Maybe they can tell me how to handle this so that it doesn't get any worse--because if I live much longer....

Another woman of 55 said, "I would like to get a start on the exercises. I know there is a book of exercises that are supposed to give you bladder control or help, and I don't want to have to pay a doctor's fee to get this." A number of people called primarily for the opportunity to ask questions. In all these situations the respondents were directed to other sources of information for follow-up.

Case Study

This case study is presented to illustrate a number of key points from the findings. It describes the experience of Mrs. A. a 67 year old widow who: 1) has managed daily excessive incontinence for years without assistance or advice from health care professionals, although she is under regular medical care and was aware of community health nursing services, 2) managed urine loss through trial-and-error methods using products that were easily available and familiar, 3) has tried to hide her incontinence and had not spoken to anyone about it until she read the advertisement about this study in a local newspaper, 4) passively accepted incontinence as a normal part of the aging process, 5) avoided strange places because of difficulty finding toilets and 6) stated she benefited from the opportunity to discuss the problem openly.

> It took awhile for Mrs. A. to gather enough courage to call in response to the newspaper advertisement about this study. She said she felt very self-conscious and had not spoken to anyone

about her incontinence before. Mrs. A. was aware of the local community health services and although she knew some of the staff at the health center, she had not thought to ask them for help: "I don't even talk to my doctor. He's always in such a tearing hurry.....If I can hide it I will. It's just one of those things I don't want to talk to anyone about it, [but] You're interested in it and you're a lady."

Mrs. A. first noticed incontinence when laughing about ten years ago. Since then, it has gradually become worse, and now "I can't hold any urine...[it] trickles between voiding every day." She said she was not sure what may have caused the problem: "I thought it was something older persons had to put up with." As commercial incontinence briefs from the store were expensive, she uses seven or eight large size sanitary pads a day which keep her outer clothing dry. Odor or embarrassment from wetness are a constant worry: "I would die of shame if I had an accident." She has been looking for a waterproof panty that was available years ago for use with sanitary products and asked the investigator how to obtain this product.

At the age of 67, Mrs. A. cannot walk far or drive a car. She said incontinence does not keep her at home but "If I'm asked to go to a strangers place I just won't go." She travels considerable distances (by car and by air) on a regular basis to visit her children. She has not discussed incontinence with her family, even though she suspects most family members are aware of her problem because of the continual need for supplies. About the future she reported, "I don't know. If it gets any worse I will have to find more effective protection. I'd be scared of an anesthetic."

At the conclusion of the interview Mrs. A. said she felt much more comfortable "You made me feel a lot easier about the subject, maybe now I can even talk to my doctor....Incontinence is the last thing that's coming out of the woodwork."

V. DISCUSSION

In summary, the purpose of this study was to gain an understanding of the experience of incontinence for older adults. Data were obtained about day-to-day problems, self-care practices and social implications that are unique to the literature. The purpose of this chapter is to 1) discuss the research method, 2) examine the findings with reference to relevant literature, and 3) detail recommendations for nursing practice and research.

Discussion of Research Method

Sixty respondents were recruited through posters, advertisements, presentations, handouts and referrals (Table XIII). All were useful methods to obtain respondents willing to discuss incontinence. As well, older adults often do not report incontinence to health care providers (Breakwell & Walker, 1988; Mitteness, 1987, Simons, 1983) and, therefore could not be reached by other means.

The single most successful strategy for obtaining respondents was through the advertisement in a seniors' newsletter and all who responded indicated that they regularly read the entire paper. Several seniors stated that they had kept the newspaper notice or handout for several weeks or even months before calling. Some said that it required a certain amount of "nerve" to make the call.

Table XIII

Response to Methods of Advertisements for Study by Age of Respondents

Source	Age (years) 50 - 59	60 - 69	70 - 79	80 - 89	Row total n
City or community newspaper	2	7	2	0	11
Seniors newspaper	3	3	4	2	12
Presentation	0	1	0	1	2
Seniors center	2	6	5	2	15
Seniors residence	0	2	1	6	9
Referred from health professional	0	1	2	3	6
Snowball	0	1	0	0	1
Incont. clinic	1	0	1	0	2
Lodge	0	0	0	2	2
Column total	8	21	15	16	60

Most residences, lodges and centers were cooperative and helpful, readily agreeing to display handouts or posters. Two centers further agreed to facilitate an oral presentation to a group of older adults, although in one, males were excluded from the presentation. Most newspapers were receptive, however, one large city newspaper refused to place an advertisement in the seniors section in case readers might be offended at "the implication that they all wet their pants". Clearly some agencies were not comfortable with the topic.

The semi-structured telephone interviews were ideal for collecting information on the experience of incontinence. The open-ended format allowed for an informal conversational tone and provided freedom for the respondents to relay their story in their own words, followed by an opportunity for the researcher to probe for detail or explanation. When asked to describe day-to-day experience, some respondents went on to provide a lengthy dialogue that covered most of the questions on the interview guide. Use of the guide ensured that all informants were asked the same questions.

Telephone interviews were convenient for both the participants and the researcher and a separate telephone line in the home of the researcher made it possible for interviews to be conducted during the evening or weekends. Only three face-to-face interviews were done: one respondent came to the researchers office (without an appointment) and two were conducted in a clinical setting. Most subjects were reassured by the anonymity of the telephone, while others were unconcerned and volunteered their name. Several had not told anyone of their incontinence and said they would not have been able to talk about it without anonymity.

As data were collected, it became obvious that most respondents were independent people who managed incontinence and maintained an active daily life. In an effort to broaden the sample to include people who had greater difficulties in managing urine loss, two health units, two day hospital programs and an incontinence clinic were approached and asked to inform their clients about the study. One health unit agreed to display posters but would not allow staff to distribute handouts at clinics or on home visits, explaining that their clients are asked too often to participate in research. It was unfortunate that the clients themselves were not given the choice to participate.

A number of people who were unwilling to participate in this study or who did not meet the criteria (younger adults or family members) telephoned to request information on incontinence. For example, one woman who was not incontinent telephoned to say she had "something hanging out" of her vagina. She was very concerned and to unable to obtain a medical appointment for three days. She said she was afraid "everything would fall out," did not know where to turn for help, and from her description it was apparent that she had a prolapsed uterus. It is clear that many of these people were looking for new sources of information. This demonstrates a need for additional services, such as a telephone information and referral line or an incontinence clinic open to self-referrals.

Given the range of advertising strategies over a five month period, 60 people agreed to be interviewed. This sample size was adequate as major categories were saturated with data. Additional respondents may have provided a wider range of experiences. For example, it would have been useful to have interviewed people with more extreme difficulties, and in retrospect, presentations to clients in the day hospitals may have resulted in more respondents.

Limitations of the study

The major limitation of this study was that the sample was self-selected. It represents an independent group of older adults living in the community who are able to manage urinary incontinence with little outside help. The sample included only those able to speak English and converse over the telephone. Future surveys conducted on a random sample of community dwelling adults would be useful to examine the impact of incontinence on day-to-day life in all groups.

Another limitation is that information about care and advice from health professionals is based on the recollection and perspective of the participants and presents only one side of the story. However, it is important to know how older adults perceive the information and service provided to them, even though their recollection may be inaccurate. A study that includes interviews with professionals would provide data to compare what was said or done with what was understood. This type of project could also investigate the knowledge and attitudes of professionals.

Only seven men participated, which limits the understanding of a male perspective. These data suggests that there are some differences between the experiences of men and women. For example, six (86%) of the men had seen and were treated by a physician, whereas only 38 (70%) of the women had consulted a doctor. The small number of male participants made an analysis of differences between male and female experiences impossible. Future research should include strategies to increase male participation to a level that is more representative of the general population. Men could possibly be contacted through service clubs or organizations such as The Royal Canadian Legion.

These limitations do not detract from the value of the study. As little research has documented the perspective of the individual, the data collected contributes significantly to information about incontinence in the well elderly who live independently. Further knowledge may be obtained through future research projects that examine similar questions with alternate approaches.

Findings: the Experience of Incontinence

The participants in this study outlined a wide range of problems with uncontrolled urine loss that varied from the woman who lost a few drops (just enough to make her underwear damp as she rushed to the toilet) and the man who had "seconds" to the woman who emptied her bladder without any control or awareness that it was about to happen. Some had lived with incontinence for many years, while for others it was a recent problem. The informants managed these problems without professional help and related innovative strategies to prevent or absorb urine loss and maximize their quality of life. From these descriptions, some vivid concepts emerged on professional and self-care and on the social implications and feelings about incontinence.

History of the problem

Many informants in this study had incontinence throughout adult life as 39% reported a history more than ten years and 25% reported more than twenty years. These findings support those of Wells (1987) who found that 37% of her sample of 338 women over age 55 had incontinence for more than ten years; however, few other studies have recorded the length of time people experience incontinence. Furthermore, they support the view of Wells (1984) tha elderly people with incontinence comprise three groups: those who have continued incontinence for years, those who have maintained continence until age changes precipitate problems with bladder control and those who develop incontinence in later life. It could be that incontinence is an adult health issue, as well as a seniors health issue, and therefore, programs that provide resources and interventions should be widely available.

Day-to-day management

Respondents tended to organize their day around the problem of unexpected urine loss. They wore pads for security when going out (but not at home), wore slacks (noting that wet spots are more obvious on a skirt), often delayed drinking for several hours at a time and went to the toilet before leaving for an event. In many ways, they described the management of urine loss as a routine personal care issue, like dressing for the weather. It was always "in mind": few allowed the possibility of unexpected urine loss to limit day-to-day activity, and in fact, many were quite emphatic that it would take far more than incontinence to keep them home, even though it required constant vigilance with hygiene, careful calculations of the location of toilets and manipulation of fluid intake. When incontinence became overwhelming, with large amounts of urine lost at one time, it became a serious management problem, and for some it limited activities outside the home, so we know that everyone is not coping well.

Mitteness (1987b) describes three groups of elderly incontinent people from her study of 30 subjects (all residents in three apartment buildings) differentiated by their level of success in managing urine loss. One group (10% of the sample) are resourceful, capable and generally well seniors who manage independently to prevent external wetness or odor and public knowledge of their problem. The second group (80% of the sample) are described as having fewer resources, "physically ill or just less able to plan or work so effectively" (p. 190), and having to resort to some degree of social isolation. The third group are unable to manage and their flagrant incontinence is public information due to their physical or cognitive inability to keep it secret" (p. 191).

In the present study, 88% of the respondents were resourceful, capable and were obviously representative of the highly successful group identified by Mitteness. Only 12% said they limited their social activities because of incontinence. None were unable to manage or were publicly shamed and only a few reported ever having had an embarrassing accident, and then only as an isolated incident; although, many worried about possible embarrassment and odor. This differs with the sample studied by Mitteness as she apparently encountered a more frail group of respondents.

Harris (1986) found that people with urinary problems reported lower levels of social activity and more health problems than a comparative continent group which suggests that "the impact of urinary incontinence should be examined in the framework of other medical illnesses and limitations" (p. 3). For this reason respondents in this study were asked to report the reason for limiting their activity. Most said other conditions, such as arthritis, created greater restrictions than incontinence. Possibly, social isolation is frequently attributed to incontinence because authors have failed to clarify the reason their subjects stay at home.

It was evident that most of the individuals in the sample undertook self-care through a trial-and-error process, using what worked the best in each situation. For many women sanitary pads were convenient, familiar, easily available and satisfactory. Men and women both used the commercial adult briefs and pads when necessary, but they were considered "diapers": clumsy and uncomfortable. There is little, if any, reference in the literature with regard to the type of pads people use or their preference. Manley (1984) suggests that some women use sanitary pads, rather than incontinence products; whereas, Jeter (1986, p. 5) states that "makeshift products such as sanitary napkins and paper towels may seem to be an inexpensive remedy but they are rarely effective", however, in this study many women found sanitary pads preferable. Mitteness (1987, p. 189) notes only that the use of "urine collecting devices" was the most common strategy employed by subjects in her sample. Descriptions of other methods could not be located in the literature.

The fact that people used a variety of products in different situations (but seldom found any product completely appropriate) is a testament to the limited choice of a person experiencing incontinence. This clearly is an area that deserves attention, and it seems unfortunate that the multi-million dollar business in incontinence products does not provide a wider variety of designs. The diaper style garment may be satisfactory for bed patients, but for mobile, upright adults, there is a lot of pad in the wrong place. The informants in this study provided new information about the product needs of incontinent people.

Other self-care practices reflected similar analysis and decision-making of the individual. Fluid restriction and frequent voiding were used to reduce incontinence. Falconer (1979) found that 28% of her small sample of older women (14) reduced evening fluids to try to prevent nocturia. Mitteness (1987b) states that 26% of her sample reduced fluid intake and 27% used frequent toileting. The literature maintains that bladder function is dependent on an adequate volume of fluid and that some incontinence may even be reversed with a moderate to high fluid intake. Also the management of urgency by bladder training is recommended. None of the respondents in the current study expressed any knowledge of these strategies. Some people thought that drinking extra fluid would reduce infections, but no one said that they thought it would reduce incontinence. Knowledge about bladder function and programs to promote continence must be made available to the public.

Social activity

Incontinence is a very private and secret problem, a subject to be avoided and only talked about in whispers. Mitteness (1987b) describes this as a psychological approach people use to deal with incontinence. The silence surrounding incontinence was identified by most respondents as they told only a close friend of the same sex, spouse or relative. Women might tell a friend about the type of pad used or about surgery but little more. And, in fact, 15% had not discussed the matter with anyone. A few individuals remarked that it helped to have someone else to laugh with and share. As well, some respondents commented that it was easy to talk to the researcher as a female and a nurse. Again, these comments point to the need for nursing services that provide opportunities for clients, singly or in groups, to talk and obtain accurate information from professionals.

Twenty seven percent had not told their doctor and indicated that they did not think the problem was important or serious enough to "bother" their physician. Some asked the researcher about the point at which they should consult a doctor. Both Simons (1983) and Mitteness (1987b) found that up to one half of their samples had not consulted a physician for similar reasons. Simmons-Tropea, Osborn and Schwenger (1986) reflect this problem in a broader context by noting that older Canadians do not report health conditions that are not perceived as serious or are considered under control.

Most respondents described incontinence as a nuisance or a bother. Mitteness (1987b) reported similar results, but considered this to represent positive thinking, a psychological strategy used to "protect the sense of self" (p. 189). It is beyond the scope of the current study to draw conclusions about the feelings described by the subjects, although it is evident that the independent elderly may develop a passive approach to incontinence.

Professional care

There is reason to support the arguments put forth by Wells (1975) and Mitteness (1987b) that health professionals do little to assess or treat symptoms of incontinence. Although most respondents had at some time told their physician and several had been referred for specialist care and treatment, none recalled receiving specific information about the medical findings or the range of possible treatments. For example, only a few had received instructions on the use of Kegel exercises.

Few respondents recalled discussing incontinence with a nurse. As thirteen subjects had incontinence pads and garments supplied through the Alberta Aids to Daily Living Program, they had discussed their needs with a professional authorized to order the product. However, there was no indication that any kind of assessment process was undertaken and very few were advised of measures, such as increased fluid intake or pelvic floor exercises, to control urine loss. This suggests that nurses manage, but do not seek to prevent or reduce, incontinence.

In general, nurses were apparently not seen as approachable. Although several seniors knew of Community Health Nurses, they had not asked about problems with bladder control. Further, as some of the advice that was provided by nurses is questionable, it may be that nurses do not have adequate basic knowledge. These problems would be overcome with an incontinence clinic staffed by nurse-clinicians as the specialists would be a source of information for the public and the professionals. Mitteness and Wood (1986) suggest that a reliable referral source is critical if professionals are to respond appropriately. This would appeal to those respondents that raised questions about bladder control and management. As well, a program of this nature would enhance public awareness that incontinence is a treatable symptom.

The Implications for Nursing

Effective nursing practice must develop the following: protocols for the assessment and management of urinary incontinence; strategies to ensure that nursing knowledge is available to the public; and further nursing research on incontinence. Each is important, and to a large extent, and dependent on the other.

In Alberta, Community Health Nurses are potentially accessible to any member of the public. A medical referral is not required nor is coverage under health care insurance. The service is free of charge. Nonetheless, community health nursing was not recognized by the respondents as a source of information or assistance with incontinence. Community Health Nurses are well situated to be instrumental in the establishment of new services and programs and their role and availability of could be more widely publicized.

Strategies to provide nursing knowledge to the public

1. Recommendation: A public telephone information and referral line be developed to provide expert information and counselling on incontinence.

Today, sophisticated telecommunications systems offer multiple options for telephone services. Networks may operate 24 hours a day, play prerecorded tapes, offer personal counselling and store messages for follow-up during working hours. One alternative may be an expansion of the city "Health Line", which now offers only prerecorded tapes on a wide variety of subjects, to include access to professional advice. At the International Conference on Incontinence in Australia a public telephone advisory service was made available by specialist nurses. The response extended beyond all expectation as "hundreds of people sought advice from nurse continence advisors" (Fine, 1988, p. 32).

2. Recommendation: Establishment of a nurse managed incontinence clinic that will accept public and professional referrals.

Mitteness and Wood (1986, p. 77) stress the need for the "development of continence clinics or similar programs at the local level so that service providers would have a place to refer incontinent clients where staff are trained and knowledgeable in the diagnosis and treatment of urinary incontinence." A number of incontinence clinics have been developed in the United States and Great Britain. Some are specialist medical clinics that accept referrals only from other physicians, but others are nurse-operated programs that provide assessment and intervention, starting with the least intrusive measures (Brink, Wells, & Diokno, 1983; Shepherd, Blannin, & Feneley, 1982) and referral services.

3. Recommendation: Nurses facilitate the organization of local chapters of existing self-help organizations or encourage of informal support networks.

Two organizations have been established to help incontinent people by providing information and organizing self-help chapters: the Simon Foundation of Canada, P.O. Box 3221, Tecumseh, Ontario, N8N 2M4 ("Millions live", 1988) and Help for Incontinent People, P.O. Box 544, Union, S.C. 29379 (Resnick, 1986). This type of organization would provide the social support that many informants said would be helpful.

Suggestions for future nursing research

The development of nursing knowledge leading to protocols for the assessment of bladder dysfunction and the development of effective interventions is dependent on clinical research. It is hypothesized that only when nurses have the skills and information to assist their clients to alleviate incontinence will they use those strategies and begin to routinely introduce the subject in a manner that demonstrates interest, knowledge and resources. Perhaps then, people who suffer with the problem will feel comfortable revealing their symptoms. It is therefore critical for nurses to conduct and support research on incontinence in order to utilize the findings in current and future practice.

Nursing research must examine the experience of incontinence for adults from other groups, such as, those who are unable to manage personal care independently, those who live in long-term care institutions, patients in acute care hospitals, other cultural groups, older adults with cognitive loss and family care givers.

Self-care practices must be explored in depth. Studies that identify interventions and develop products that are acceptable and practical based on clinical trials conducted in the community environment are needed. Although it is reported that the use of pads should be a last resort, the respondents in this study found, notwithstanding their dissatisfaction with the design, that the use of these products provided the security required for an active independent life. For some, surgery was considered a last resort.

Further investigation on the advice and support given by health care professionals is also needed. Participants in this study reported on their perspective of the advice or treatment given, but it is not known what the professional said or did. Health care teaching can only be more effective if communication gaps are identified.

The movement toward the implementation of nursing diagnosis is well underway in many practice settings including community health nursing (Rantz & Mass, 1987). The use of these diagnosis assist nurses to identify and classify observations and to plan effective interventions. The current nursing diagnosis on urinary incontinence names categories, such as "urge" and "stress" incontinence (Tunink, 1988). These labels are helpful to identify non-invasive measures for alleviating incontinence and to effectively communicate with other professionals. For example, the usefulness of increased fluid intake, bladder drill and pelvic floor exercises with biofeedback needs to be identified and established for different types of incontinence. Other nursing diagnosis on coping, self-perception or health management (Rantz & Mass, 1987) are needed to address the issues relative to the impact of incontinence on daily life.

Research is also required to address broader health issues: What conditions are deemed too trivial to seek advice or care? What attitudes need to be demonstrated by health care professionals to encourage clients to discuss their problems? What types of self-care practices do people use?

The list is not endless. It begins with the attitude that it is no longer enough to simply prescribe, and ends with research that is designed to understand the perspective of the client. Only then will interventions be developed that will achieve success with the client as a willing and active partner.

Summary and Conclusions

From this study, the major findings related to the day-to-day experience of incontinence are:

1. Older adults who suffered with urinary incontinence did so, to a large extent, in silence. The taboos against discussing excretion remain, and for many people, it was something "you just don't talk about."

2. Incontinence was a nuisance, a bother, something to just put up with or get used to, unless it was uncontrollable. Incontinence was also a constant concern; always "in mind." When large amounts of urine were unexpectedly lost, it was very distressing and uncomfortable.

3. Quality of life and independence were paramount to these respondents. Well older adults maintained an active social life through careful planning to avoid incontinence during social occasions.

4. People managed incontinence themselves using a variety of ingenious self-care methods that had been derived by trial-and-error. They were often unaware of measures that could promote continence.

5. It was expected that the future would hold little change, although many wanted more control, better protection and access to acceptable treatment.

6. Consistent with other research, few obtained help from health care professionals, and often, if first attempts were not successful, they did not pursue treatment options.

7. Nurses were under utilized for resolving the problem of incontinence. Furthermore, those nurses who were aware of these problems in older clients did not provide nursing resources or corrective advice, but rather only provided access to incontinence products. Opportunities to provide health teaching and to develop strategies to assist clients in managing, minimizing or eliminating incontinence were lost.

The respondents in this study all initiated contact with the researcher and were not reticent about reporting their experiences because they believed the researcher was interested in the topic. Despite the fact that they often managed their problem independently, they were still seeking information and wanted to know if there was anything else that they could do to remedy the problem. It is clear that, given opportunities, these individuals would also avail themselves of specialized nursing service.

In this study incontinence was not a catastrophe for most individuals. But neither was it a trivial matter. With an attitude committed to research and education, future nursing services will reflect well informed professionals in a relationship that fosters understanding of the clients perspective. This is a client and health professional partnership; a joint approach to the management and control of individual health problems and issues, such as incontinence. The challenge for the professional is to be able to provide help, promoting, rather than threatening, the independence of the client.

REFERENCES

Barker, J. C., & Mitteness, L. S. (1988). Nocturia in the elderly. The Gerontologist, 28, 99-104.

Blume, E. (1983). Palliation may block cure of incontinence in the elderly. Journal of the American Medical Association, 250, 1371.

Bogdan, R. C., & Biklen, S. K. (1982). Qualitative research for education: An introduction to theory and methods. Boston: Allyn and Bacon.

Breakwell, S. L., & Walker, S. N. (1988). Differences in physical health, social interaction, and personal adjustment between continent and incontinent homebound aged women. Journal of Community Health Nursing, 5, 19-31.

Brink, C. (1980). Assessing the problem. Geriatric Nursing, 1, 241-245, 275.

Brink, C., Wells, T., & Diokno, A. (1983). A continence clinic for the aged. Journal of Gerontological Nursing, 9, 651-655.

Brocklehurst, J. C. (1973). Genito-urinary system: The bladder. In J. C. Brocklehurst (Ed.), Textbook of geriatric medicine and gerontology (pp. 298-320). Edinburgh: Churchill Livingstone.

Brocklehurst, J. C. (1978). Differential diagnosis of urinary incontinence. Geriatrics, 33(4), 36-39.

Brocklehurst, J. C. (1984). Ageing, bladder function and incontinence. In J. C. Brocklehurst (Ed.), Urology in the elderly (pp. 1-18). Edinburgh: Churchill Livingstone.

Castleden, C. M., Duffin, H. M., Asher, M. J., & Yeomanson, C. W. (1985). Factors influencing outcome in elderly patients with urinary incontinence and detrusor instability. Age and Aging, 14, 303-307.

Castleden, C. M., Duffin, H. M., & Mitchell E. P. (1984). The effect of physiotherapy on stress incontinence. Age and Ageing, 13, 235-237.

Chalifoux, P. (1980). Recognizing warning time. Geriatric Nursing, 1, 254-255.

Champion, V. L. (1976). Clean technique for intermittent self catheterization. Nursing Research, 25, 13-18.

Colombotos, J. (1969). Personal versus telephone interviews: Effect on responses. Public Health Reports, 84, 773-782.

Ebersole, P., & Hess, P. (1985). Toward Healthy Aging (2nd ed.). St. Louis: C. V. Mosby Company.

Falconer, P. A. (1979). The effect of aging on the time between the urge to void and need to void in elderly, self-ambulant, continent, institutionalized women. Unpublished master's thesis. University of Rochester, New York.

Feneley, R. C. L. (1986a). Normal micturition and its control. In D. Mandelstam (Ed.), Incontinence and its management (2nd ed.) (pp. 16-34). London: Croom Helm.

Feneley, R. C. 1. (1986b). Urological aspects of incontinence. In D. Mandestam (Ed.), Incontinence and its management (2nd ed.) (pp. 35-54). London: Croom Helm.

Field, P. A., & Morse, J. M. (1985). Nursing research: Application of qualitative approaches. London: Croom Helm.

Fine, M. (1988). Incontinence: the importance of being earnest. The Australian Nurses Journal, 17(6), 31-34.

Freeman, R. M., McPherson, F. M., & Baxby, K. (1985). Psychological features of women with idiopathic detrusor instability. Urology, 40, 257-259.

Freed, S. Z. (1982). Urinary incontinence in the elderly. Hospital Practice, 17(3), 81-94.

Greengold, B. A., & Ouslander, J. G. (1986). Bladder retraining. Journal of Gerontological Nursing, 12, 31-35.

Gregory, J. G., & Purcell, M. H. (1986). Urinary incontinence in the elderly. Postgraduate Medicine, 80(2), 253-262.

Griffin, D. J. (1983). Urinary incontinence in the elderly. Postgraduate Medicine, 73(2), 143-156.

Haber, P. A. L. (1986). Urinary incontinence. *Annals of Internal Medicine*, *104*, 429-430.

Hadley, E. C. (1986). Bladder training and related therapies for urinary incontinence in older people. *Journal of the American Medical Association*, *256*, 372-379.

Hamilton, B. H., Badger, F. J., Drummond, M. J., & Issacs, B. (1985). The work of a nurse adviser on incontinence. *Geriatric Nursing*, *6*, 100-102.

Hargreave, T. B., & Galloway, N. T. M. (1983). Incontinence. *British Medical Journal*, *287*, 1002-1003.

Harris, T. (1986, Aug. 27). Aging in the eighties, prevalence and impact of urinary problems in individuals age 65 years and over. Preliminary Data from the Supplement on Aging to the National Health Interview Survey, United States, January - June 1984. *Advance data from vital and health statistics* No. 121. DHHS Pub. No. (PHS) 86-1250 Public Service, Hyattsville, Md.

Harris, J. (1984). A positive step. *Nursing Mirror*, *158* (7), 16-17.

International Continence Society Committee for Standardization of Terminology. (1979). The standardization of terminology of lower urinary tract function. *The Journal of Urology*. *121*, 551-554.

International Continence Society Committee on Standardization of Terminology. (1981). Standardization of terminology of the lower urinary tract function. Fourth report: neuromuscular dysfunction. Urology. 17, 618- 620.

Janofsky, A. I. (1971). Affective self-disclosure in telephone versus face to face interviews. Journal of Humanistic Psychology, 11, 93-103.

Jeter, K. F. (1986). Eliminating incontinence ignorance. Journal of Gerontological Nursing, 12, 5.

Keegan, G. T., & McNichols, D. W. (1982). The evaluation and treatment of urinary incontinence in the elderly. Surgical Clinics of North America, 62(2), 261-273.

Kegel, A. H. (1951). Physiologic therapy for urinary stress incontinence. Journal of the American Medical Association, 146, 915-917.

Kendall, A. R., & Stein, B. S. (1983). Practical approach to stress urinary incontinence. Geriatrics, 38(5), 69-79.

Kennedy, A. P. (1984). Nursing the incontinent patient. In J. C. Brocklehurst (Ed.) Urology in the elderly (pp. 127-143). Edinburgh: Churchill Livingstone.

Kenney, R. A. (1982). Physiology of aging. Chicago: Year Book Medical Publishers.

King, M. (1984). Aids for incontinence. Nursing Mirror, 158(7), 30.

Kirshen, A. J., & Cape, R. D. T. (1984). A history of urinary incontinence: Or, 400 years of incontinence – are we any drier? Journal of the American Geriatrics Society, 32(9), 686-688.

Leininger, M. M. (1985). Ethnography and ethnonursing: models and modes of qualitative data analysis. In M. M. Leininger (Ed.), Qualitative Research Methods in Nursing (pp. 33-71). Orlando: Grune & Stratton. Inc.

Mandelstam, D. (1980). Strengthening pelvic floor muscles. Geriatric Nursing, 1, 251-252.

Maney, J. Y. (1976). A behavioral therapy approach to bladder retraining. Nursing Clinics of North America, 11(1), 179-188.

Manley, R. (1984). Containing the problem. Nursing Mirror, 158(7), 37-38.

Marchant, D. J. (1983). Urinary incontinence in the female. Hospital Medicine, 19(6), 49-64.

McCormick, K. A., & Burgio, K. L. (1984). Incontinence: an update on nursing care measures. Journal of Gerontological Nursing, 10 16-23.

McGrother, C. W., Castleden, C. M., Duffin, H., & Clarke, M. (1986). Provision of services for incontinent elderly people at home. Journal of Epidemiology and Community Health, 40, 134-138.

Millard, P. H. (1981). The prevention of incontinence. The Practitioner, 225, 1739-1751.

Millions live with humiliation as bladder, bowel control goes. (1988, February 26). The Edmonton Journal, H2.

Mitteness, L. S. (1987a, November). Folk beliefs about urinary incontinence in late life. In B. Powers (Chair), Aging, culture, and health. Symposium conducted at the annual meeting of the American Anthropological Association, Chicago.

Mitteness, L. S. (1987b). The management of urinary incontinence by community-dwelling elderly. The Gerontologist. 27, 185-193.

Mitteness, L. S., & Wood, S. J. (1986). Social workers' responses to incontinence, confusion and mobility impairments in frail elderly clients. Journal of Gerontological Social Work, 9, 63-78.

Morse, J. M. (1986). Quantitative and qualitative research: Issues in sampling. In P. L. Chinn (Ed.) Nursing research methodology (pp. 181-193). Rockville, Maryland: Aspen Publishers.

Muir Gray, J. A. (1986). Incontinence in the elderly. In D. Mandelstam (Ed.), Incontinence and its management (2nd ed.) (pp. 135-160). London: Croom Helm.

Norton, C. (1985). Incontinence aids. Nursing Times, 81(5), 17-20.

Ouslander, J. G., Hepps, K., Raz, S., & Su, H. (1986). Genito-urinary dysfunction in a geriatric outpatient population. Journal of the American Geriatric Society, 34(7), 507-514.

Ouslander, J. G., & Elhilali, M. M. (1987). The Diagnosis and Management of Urinary Incontinence. New York: Clinical Medical Research Institute.

Overstall, P. W., Rounce, K., & Palmer, J. H. (1980). Experience with an incontinence clinic. Journal of the American Geriatrics Society. 28(12), 535-538.

Palmer, M. H. (1985). Urinary Incontinence. Thorofare, New Jersey: Slack Inc.

Perston, Y. (1981). Ways to help solve a sensitive problem. Nursing Mirror, 153(17), 38-42.

Rantz, M. J., & Maas, M. (Eds.). (1987). Nursing Diagnosis: Implementation. The Nursing Clinics of North America. 22(4).

Reid, J. S. (1985). Estrogen-depletion urethritis. Geriatric Nursing, 6, 42-43.

Resnick, N. (1986, November). Incontinence: managing involuntary urination (you can!). McCalls, 97.

Resnick, N. M., & Yalla, S. B. (1987). Detrusor hyperactivity with impaired contractile function. Journal of the American Medical Association. 257, 3076-3081.

Robinson, J. M. (1984). Evaluation of methods for assessment of bladder and urethral function. In J. C. Brocklehurst (Ed.), Urology and the elderly (pp. 19-54). Edinburgh: Churchill Livingstone.

Rogers, T. F. (1976). Interviews by telephone and in person: Quality of responses and field performance. Public Opinion Quarterly, 40, 51-63.

Sandelowski, M. (1986). The problem of rigor in qualitative research. Advances in Nursing Science, 8(3), 27-37.

Shepherd, A. M., Blannin, J. P.,& Feneley, R. C. L. (1982). Changing attitudes in the management of urinary incontinence-the need for specialist nursing. British Medical Journal, 284, 645-646.

Shepherd, A. M., & Blannin, J. P. (1986). The role of the nurse. In D. Mandelstam (Ed.), Incontinence and its management (2nd ed., pp. 160-183). London: Croom Helm.

Shepherd, A. M., Blannin, J. P., & Smart, M. E. (1980). The role of the nurse. In D. Mandelstam (Ed.), Incontinence and its management (pp. 135-156). London: Croom Helm.

Simmons-Tropea, D., Osborn, R. W., & Schwenger, C. W. (1986). Health status and health services for elderly Canadians (Research Report No. 8). Toronto: University of Toronto, The Programme in Gerontology, Information Centre.

Simons, J. (1983). Self-concept in elderly females: The impact of urinary incontinence. Unpublished master's thesis, The University of Arizona.

Smith, J. P. (1982). The problem of promoting continence: An account of 16 regional study days convened by the Royal College of Nursing of the United Kingdom in association with Squibb Surgicare Ltd. London, England: Squibb Surgicare.

Smith, P. S., & Smith, L. J. (1987). Continence and incontinence. London: Croom Helm.

Statistics Canada. (May, 1987) Population projections for Canada, Provinces and Territories 1984 - 2006. (Catalogue No. 91-520). Ottawa.

Stewart, M. (1986). Incontinence and the team in geriatric medicine. In D. Mandelstam (Ed.), Incontinence and its Management (2nd ed.) (pp. 103-109) London: Billings and Sons.

Tallis, R., & Norton, C. (1985). Incontinence in the elderly: Summary and conclusions. Nursing Times, 81(13), 21-24.

Taylor, K., & Henderson, J. (1986). Effects of biofeedback and urinary stress incontinence in older women. Journal of Gerontological Nursing, 12 (9), 25-30.

Thomas, B. (1980). Problem solving: urinary incontinence in the elderly. Journal of Gerontological Nursing. 6, 533-536.

Toufexis, A. (1986, October 6). "The last of the closet issues." Time, p. 83.

Tunink, P. M. (1988). Alteration in urinary elimination. Journal of Gerontological Nursing, 14(4), 25-30.

Vetter, N. J., Jones, D. A., & Victor, C. R. (1981). Urinary incontinence in the elderly at home. The Lancet, 11, 1275-1277.

Voith, A. M., & Smith, D. A. (1985). Validation of the nursing diagnosis of urinary retention. Nursing Clinics of North America, 20(4), 723-729.

Webster's New Collegiate Dictionary (1981). Springfield, Mass: G. and C. Merriam.

Weiss, B. D. (1983). Intractable urinary incontinence in geriatric patients. Postgraduate Medicine, 73(4), 115-123.

Wells, T. (1975). Promoting urinary continence in the elderly in hospital. Nursing Times, 71, 1908-1909.

Wells, T. (1980). Scope of the problem. Geriatric Nursing, 1, 236-240, 275.

Wells, T. (1984). Social and psychological implications of incontinence. In J. C. Brocklehurst (Ed.), Urology in the elderly. (pp. 107-126). Edinburgh: Churchill Livingstone.

Wells, T. (1987). Diagnosing incontinence type. Nursing Times, 83(15), 89-91.

Wells, T., & Brink, C. A. (1988). Elimination: Urinary. In I. M. Burnside (Ed.), Nursing and the aged (3rd ed.) (pp. 485-520). New York, NY: McGraw-Hill.

Williams, M. E. (1983). A critical evaluation of the assessment technology for urinary continence in older persons. Journal of the American Geriatrics Society, 31(11), 657-664.

Williams, M. E., & Pannill, F. C. (1982). Urinary incontinence in the elderly. Annals of Internal Medicine, 97, 895-907.

Willington, F. L. (1975). Incontinence: the nursing component in diagnosis and treatment. Nursing Times, 71, 464-467.

Wolin, L. H. (1969). Stress incontinence in young, healthy nulliparous female subjects. The Journal of Urology, 101, 545-549.

Yarnell, J. W. G., & St Leger, A. S. (1979). The prevalence, severity and factors associated with urinary incontinence in a random sample of the elderly. Age and Aging, 8, 81-85.

Yarnell, J. W. G., Voyle, G. J., Richards, C. J., & Stephenson, T. P. (1981). The prevalence and severity of urinary incontinence in women. Journal of Epidemiology and Community Health, 35, 71-74.

Yu, L. C. (1987). Incontinence stress index: measuring psychological impact. Journal of Gerontological Nursing, 13, 18-25.

Zawada, E. T. (1985). Voiding problems in the elderly: Functional disorders of the lower urinary tract. In E. T. Zawada & D. A. Sica (Editors), Geriatric Nephrology and Urology (pp. 317-333). Littleton, Massachusetts: PSG Publishing Company.

APPENDIX A

Semi-Structured Guided Interview

SEMI-STRUCTURED GUIDED INTERVIEW

INTRODUCTION

Thank you for calling. My name is Anita Thomas. I am a nurse studying at the University of Alberta. I would like to ask you questions about any problems you may have with bladder control as part of a nursing research project on incontinence. I am doing this project as part of a Master in Nursing degree.

TELEPHONE CONSENT

The purpose of this study is to learn more about urinary incontinence from individuals over the age of 50 who experience this type of problem.

I would like to spend 20 or 30 minutes talking to you on the telephone. I will be asking you some questions. The conversation will be tape recorded.

You do not have to answer any question that you do not wish to, and you can stop the conversation at any time.

You do not have to give me your name, and I will not identify you on the tape recording.

All of the information you give me will be kept anonymous.

Do you have any questions?

INTERVIEW SCHEDULE

Subject....................

Date......................

1. Tell me in your own words about your problem with bladder control.
2. What happens day to day?

3. Does urine ever come away unexpectedly and without your being able to stop it and you get wet?

4. How many times a day do you go? How often are you incontinent of urine?

5. What happens at night?

6. Do you have any other symptoms (i.e. burning, pain)?

7. Does your skin (groin) get sore or infected?

8. Have you seen a doctor about the problem with bladder control?

9. What did the doctor tell you?

10. Have you had any treatment or medication? Did it help?

11. Have you talked to any other health care professional (i.e. a nurse or physiotherapist) about this?

12. What did this person tell you? Did that help?

13. How is your health otherwise?

14. Do you take any medication?

15. When did this problem first start?

16. Why do you think it started? (What do you think caused it?)

17. Has there been a change since it started? (Is it worse or better?) Why do you think that happened?

18. What do you do about this problem? (How do you cope?)

    (a) What do you do to control the loss of urine?

    (b) Do you wear anything special?

    (c) Where do you get the supplies?

    (d) Do you have to pay for the supplies?

    (e) How much do you spend?

    (f) Do you have extra laundry?

    (g) How do you manage?

19. How much fluid do you drink? Do you cut down?

20. Have you told anyone about your incontinence? Has anyone given you any advice? What has this person said about it?

21. How does this problem make you feel?

22. Has anything embarrassing happened? Can you tell me about the most embarrassing time?

23. Do you get out much? How often? Do you stay home because of your difficulty with urine control?

24. How has your daily life changed since the problem started?

25. What do you think will happen about this in the future? What you like to happen?

26. Do you know anyone else with this kind of problem?

27. What is your age?

28. Do you live in your own home, or apartment or a lodge?

29. Do you live alone? Who lives in the house with you? Does he (she) know about your problem?

30. Is there anything you would like to ask me about your incontinence?

APPENDIX B

Handout and Poster

SENIORS

TELL ME —

WHAT IS IT LIKE TO HAVE PROBLEMS WITH BLADDER CONTROL?

The involuntary loss of urine is something people seldom talk about. It is a very private matter but it often has far reaching effects on daily life. At present little is known about how people manage. If nurses understood the feelings people have and their ways of managing incontinence, then more help could be given to those who suffer from this type of problem.

Can you help?

My name is Anita Thomas and I am a graduate student at the University of Alberta in the Faculty of Nursing. I would like seniors who have difficulties with bladder control to telephone me. I ask them to describe their experiences and tell me how they manage this type of problem on a day to day basis. All interviews are anonymous.

Please call if you can share your experiences and help me learn more about this problem.

Call Anita Thomas at the Faculty of Nursing
432-8233 Monday to Friday
481-3315 evenings and weekends.

SENIORS

WHAT IS IT LIKE TO HAVE PROBLEMS WITH BLADDER CONTROL?

The involuntary loss of urine is something people seldom talk about. It is a very private matter but it often has far reaching effects on daily life. At present little is known about how many people have this type of problem or how they manage with it.

Anita Thomas is a graduate student at the University of Alberta in the Faculty of Nursing. She would like seniors who have difficulties with bladder control to telephone her. She asks people to describe their experiences and tell her how they manage this on a day to day basis. All interviews are anonymous.

" Urinary Incontinence is a hidden problem. Many people never ask for help because of the mistaken belief that the loss of bladder control is just the result of aging, and nothing can be done. It is important for nurses to understand the feelings people have and their ways of managing involuntary urine loss so that more help can be given to those who suffer. Please call me if you can share your experiences and help me learn more about this problem."

Please call Anita Thomas at the Faculty of Nursing
432-8233 Monday to Friday
or call
481-3315 evenings and weekends.