PROMOTING A COLLABORATIVE CONSUMER-FOCUSED APPROACH TO CONTINENCE CARE IN CANADA:

Background to the consensus guidelines for clinical practice and working models of continence care

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Promoting a Collaborative Consumer-Focused Approach to Continence Care in Canada

In March 1998 a national multidisciplinary workshop entitled "*Bringing INcontinence OUT of the Closet: Exploring Innovative Partnerships*" was organized by The Canadian Continence Foundation (TCCF) in Toronto, Ontario, with financial support from The Population Health Fund, Health Canada, Division of Aging and Seniors (The Canadian Continence Foundation, 1998). The goal was to explore partnerships that might increase awareness of incontinence and help sufferers and their caregivers to obtain help. A key issue identified at the workshop was the lack of a system in Canada to facilitate an individual's journey to appropriate assessment, treatment and follow-up of urinary incontinence.

A subsequent proposal was accepted by The Population Health Fund, to address this issue head-on through the development of standardized professional and consumer Canadian guidelines for urinary incontinence care, and through the development of recommendations for working models of incontinence care which would integrate the guidelines and facilitate individuals' access to care. The outcomes of that project, entitled *Promoting A Collaborative Consumer-Focused Approach to Continence Care in Canada,* include the first Canadian ***consensus*** guideline for the assessment, treatment and management of adult urinary incontinence, a recommendation for working models of continence care in typical Canadian settings, and a report on continence services worldwide that also formed the basis for the working models (Milne & Moore, 2000; see www.continence-fdn.ca). Other publications, including a version of the guidelines for consumers, follows.

Urinary incontinence

Urinary incontinence is "involuntary loss of urine that is objectively demonstrable and a social or hygienic problem" (International Continence Society, 1988). In studies of prevalence, objective demonstration is often not a realistic option, and so various arbitrary cut-offs in the frequency or amount of urine loss have been used. In spite of this, the data are quite consistent from study to study and country to country.

A national poll (Angus Reid group, 1997) suggested that 1.5 million of community-dwelling Canadians (7%) had suffered from an incontinence episode during the previous year. More women than men were affected (12% versus 2.5%). Prevalence increased with age, from 2% in those under 35 y to 12% of those 55 y and over. In other Canadian surveys, 16% of seniors over 64 y, living at home, needed help for urinary incontinence (Reid, 1991), and 24% of men and women over 84 years of age reported daily incontinence (Canadian Study of Health and Aging: Hunskaar et al, private communication).

The costs of urinary incontinence are high, even if indirect costs (e.g., for institutionalization triggered by incontinence) are excluded. For people in the community who receive assistance for incontinence products from provincial programs, the cost of these products is on average about $1000/year (Saltmarche, 1988; Alberta Aids to Daily Living Branch, private communication). Extrapolating from US figures (Wagner & Hu, 1998), the total direct and indirect costs of urinary incontinence in Canada are probably about $2.6 billion/year. Incontinence has a marked effect on the quality of life of those suffering from it. In 8-10% this results in social isolation (Angus Reid, 1997; Klag, 1999). Despite the negative effects of urinary incontinence, only about half have ever spoken to a physician about it (Angus Reid, 1997).

The barriers to effective delivery of services to people with incontinence include paucity of specialized centres, lack of knowledge and understanding by health professionals, and client embarrassment and fatalism about the problem (Saltmarche, 1988; Borrie et al, 1997). The guidelines and the accompanying models of continence care are intended to address some of these problems.

Consumers' and caregivers' perceptions of urinary incontinence

Incontinence has a negative impact on the lives of 44% of community-dwelling people with incontinence (Angus Reid, 1997). It affects the work and social life of 21%. Sixteen percent report some impact on their ability to work: it limits the ability to function normally in 10% and prevents 6% from working outside the home at all. Eight percent indicate that incontinence limits their ability to function normally in social settings and a further 8% are

prevented from socializing with friends at all. In a US survey of individuals with incontinence or their caregivers, 17% of over 10,000 respondents described their incontinence as a major problem with important social implications (Jeter & Wagner, 1990). Ten percent of incontinent individuals say that they deal with the problem by staying at home (Saltmarche, 1988). Ninety percent of Canadians experiencing incontinence report that it has an impact on their overall feeling of well-being, and over 80% report feelings of embarrassment and frustration (Klag, 1998).

Forty-five percent of seniors with incontinence report that it has a moderate or great impact on their emotional health. Thirty-four percent indicate that it has a moderate or great impact in their ability to participate in social activities and 45% state that it has a moderate or great impact on their ability to travel. More than half are moderately or greatly frustrated with their incontinence (Victorian Order of Nursing [VON] Canada, 1998; Skelly and Boblin-Cummings, 1999).

Between 53% (Daly, 1993) and 95% (Mohide et al, 1988) of caregivers living with people with incontinence view the incontinence as a problem. It may be the final reason for placing a loved one in an institution (Kirshen, 1983; Hart et al, 1999).

Consumers' information about incontinence

Nearly all consumers are aware of products such as diapers and sanitary pads and 51% use them. Seventy-one percent are aware of management techniques such as regular voiding or pelvic muscle exercises and 55% use these techniques. About half (45%) have heard of catheterization or other devices. In 1997, however, only 34% were aware that there were medications to help control urination; medications and devices were used by only 3% and 4% respectively (Angus Reid, 1997).

More than half of the respondents to a survey (The Canadian Continence Foundation, 2000) did not feel sufficiently informed about the issue of incontinence. Half said that there was not enough information available about it. The most frequently expressed needs were for reading materials and educational sessions on incontinence. The five information topics most frequently rated as useful were: 1) side effects and risks of treatment, 2) how to improve and/or manage the leakage, 3) how to choose products to manage the leakage, 4) where to find medical and other help, 5) costs and reimbursement/coverage for treatments and products.

Many consumers are influenced by common myths such as “urine leakage is normal at my age” or “nothing can be done about it” (Klag, 1998). Some think a doctor will say that nothing is wrong (8%), and some say they are too embarrassed to consult a physician (6%). Consequently, in spite of its impact on quality of life, urinary incontinence is a hidden problem that is under-reported by consumers (Angus Reid, 1997).

The need for better education of physicians and other health care professionals

There are differences between the perceptions of healthcare professionals and consumers. After treatment in a continence clinic, the staff perceived greater improvement than their patients did: the patients placed more emphasis on the psychological and social aspects of incontinence than the staff did (Lee et al, 1992).

Fifty percent of primary care physicians see more than one patient per week with incontinence. Yet 29% of them do not routinely ask about incontinence, and 85% underestimate the prevalence of incontinence in women (Flood and Drutz, 1995).

A critically important issue is the lack of training for family physicians in the area of incontinence. In a survey funded by Health Canada, Ontario Region, recent family practice graduates from Ontario were surveyed with respect to their training and knowledge on urinary incontinence (Schulz et al, 1999). Only 38% of respondents felt that they received adequate training about incontinence. Forty-four percent of respondents did not include urinary incontinence as part of the routine questioning for patient visits.

It is not only physicians who lack training and knowledge: a study of health care providers (mostly non-physicians) within the Victorian Order of Nurses of Canada identified the barriers to effective continence care as poor knowledge and attitudes, low priority, lack of support, and inadequate resources (Skelly & Boblin-Cummings, 1999). In the US survey referred to above (Jeter & Wagner, 1990) over half reported that their visit to a doctor or nurse was no help at all because the health care professional was not helpful, too busy, embarrassed, unsympathetic, not informative, or apparently not knowledgeable.

Access to effective services

According to 788 respondents to a survey of 5909 members in the database of TCCF, 66% of those who consult a health care professional consult the family practitioner first. In many cases (42%) however, the family practitioner does not ask about urinary incontinence (Klag, 1998), and this confirms the statement of practitioners themselves that many of them do not routinely ask about this problem. Thus, there is a need for interested and knowledgeable family practitioners as the first point of access to continence care. Survey participants also identified the pharmacist as an important professional, especially for those with less education or lower income.

Following the first contact with a health professional, the diagnostic tests, the treatments received, and - significantly - the levels of satisfaction vary greatly. Of those treated by pelvic floor muscle exercise instruction, medication, or surgery, at least 40% perceived no impact on the urine leakage (Klag, 1998).

Following a report to the Ontario Ministry of Health (Saltmarche, 1988), demonstration models of two delivery systems were proposed and tested: a continence clinic model in an

urban setting and a community model in a rural setting (Borrie et al, 1992; 1994). These two models showed that incontinence could be cured or substantially reduced in 70% of clients, at a one-time cost of about $500 per client, excluding savings on incontinence products (Saltmarche and Reid, 1992). In another Canadian study (Skelly and Kenny, 1998) nurse continence advisors reduced or cured incontinence in 42% of patients, at a cost of $95 per patient.

A training program for nurse continence advisors in Ontario (Borrie et al, 1992; 1994; 1997) showed that nurse continence advisors helped reduce incontinence events and pad use and improved quality of life. Yet recognition and acceptance of the service were hindered by lack of understanding of its nature and value among clients, caregivers and health professionals.

Milne & Moore (2000) surveyed specialty continence service providers in Canada (drawn primarily from the database of TCCF) and worldwide. The conclusion was that Canadian services are scattered and inconsistent, and there is often a fee for service once entry into the system has been established. A Canadian model for regional continence care services, that removes these barriers, facilitates help-seeking, and ensures appropriate care delivery through an organized care management model, is urgently needed.

It is indeed astonishing, given the high prevalence of incontinence, and the physical, social and financial burdens of this problem, that so many people experiencing incontinence cannot find appropriate treatment and/or management. It is clear that the public must be more informed of where they can find help, that health care professionals must be more educated and knowledgeable about this problem, and that more health care professionals across disciplines must be actively involved in proper assessment, treatment and management of urinary incontinence.

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CANADIAN CONSENSUS CONFERENCE ON URINARY INCONTINENCE:
CLINICAL PRACTICE GUIDELINES FOR ADULTS

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INTRODUCTION

Scope and objectives

These guidelines address urinary incontinence in community-dwelling adults. Pediatric incontinence and incontinence in institutions are excluded, not because they are unimportant, but because they involve different needs, and different professionals, organizations, and government departments.

The guidelines have been developed in response to needs identified both by consumers concerning their frustrations and lack of knowledge about incontinence and treatment options (Klag, 1999; The Canadian Continence Foundation, 1998), and by healthcare professionals, particularly those in the community, many of whom do not receive extensive training in the management of urinary incontinence (The Canadian Continence Foundation 1998; Schulz et al, 1999). The development team has tried, through a consensus process, to develop guidelines that are evidence-based, up-to-date, and easy to understand, and which can readily be implemented within the Canadian healthcare system. In a parallel consensus process we have developed models of continence care which demonstrate how the guidelines may be put into practice in typical Canadian settings. The guidelines are directed at physicians, nurses, physiotherapists, and other healthcare professionals who advise and care for people with incontinence. Consistent with the consumer focus of the project, a consumer-directed version of the guidelines will be produced to allow consumers to make informed decisions about their assessment and treatment and to encourage open discussion with the health professionals who are caring for them.

There has been recent discussion of the advantages and disadvantages of standardized guidelines (Multidisciplinary Summit, 1999; Woolf et al, 1999). Some see a danger in guidelines, that they imply that society has all the answers for a particular health issue. Thus, they may negate the judgment that is inevitably required between a professional and a patient in each unique situation, and may stifle the research necessary to improve the status quo (Multidisciplinary Summit, 1999). It is emphasized that these guidelines are intended to be an educational tool, to assist health professionals and people with incontinence and to help promote high quality continence care, by keeping consumers, healthcare professionals and other stakeholders up-to-date. Future updating and refinement are an essential part of the development process.

The Canadian Continence Foundation recognizes that health care professionals act within the boundaries of their professional standards of practice in collaboration with a physician. The guidelines are not legally binding in any way, nor are they intended to restrict the unique and irreplaceable professional-patient relationship. They are not the only possible approach to the

assessment and management of incontinence. However, they do reflect a wide consensus regarding assessment and treatment options and the order in which they should be considered.

Method: The Guidelines Development Process

A recent report referred to conclusions from the National Institutes of Health in the U.S.: "The institutes conclude that guideline development should be a multidisciplinary enterprise involving consultation with both patients and front-line health professionals, whose input is as essential as that of academics" (Multidisciplinary Summit, 1999). The method used in developing these guidelines was designed to ensure that, as far as possible, the judgments represent a consensus of those concerned with management and treatment of urinary incontinence in Canada, whether as professionals or as clients/consumers.

To arrive at a Canadian consensus, the guidelines were developed as follows:

- A core committee was convened by The Canadian Continence Foundation, to include clients/consumers and leading Canadian healthcare professionals from family practice, geriatrics, nursing, physiotherapy, gynecology, and urology, as well as a representative of the Division of Seniors and Aging of Health Canada, and an independent evaluator.
- The core committee decided on three broad classes of client/consumer for whom guidelines were needed. A small team of authors was selected for each class and asked to review the recent literature and draft evidence-based guidelines and a flow chart to represent them in visual form.
- The draft flow charts were reviewed by expert health professionals and consumers.
- The draft sets of guidelines were discussed by the whole committee and revised and edited for consistency.
- Participants were selected for a consensus conference, based primarily on nominations from national associations of health professionals and consumer groups, but bearing in mind also the need for geographic representation across Canada.
- The draft guidelines were circulated to the conference participants for review.
- The drafts were presented at the consensus conference, discussed in small groups, and further revised in the light of these discussions.
- Consensus was established by voting: over 80% representing consensus, 60-79% representing partial consensus.
- The resulting consensus guidelines were sent to community reactor panels across the country for review.

As a starting point, the core committee reviewed existing national and international guidelines for the management of incontinence. Two in particular form the basis of these Canadian guidelines:

- The guidelines of the U.S. Agency for Healthcare Policy and Research (AHCPR) were first published in 1992. The 1996 revision is based on reviews of the literature up to 1995. Our committee did not reanalyse this literature, which is referenced in the AHCPR

Guideline book, Edition 2, 1996. The recommendations arising from the AHCPR Guidelines 1996, became the starting point. The committee reviewed the recommendations and endorsed or modified them according to new literature (1995 onward) that either supported them or provided new evidence for new recommendations.

- The 1st International Consultation on Incontinence, held in Monaco in 1998, produced a series of algorithms or flow charts, and performed a further extensive review of the literature (Abrams, Khoury, et al, 1998). The core committee has taken this review into account but has not reanalyzed it. The committee has adapted the flow charts of the International Consultation to reflect the management of incontinence in men, women and the frail elderly.

The committee was also aware of the publication "Promoting Continence Care in Canada" (Skelly et al, 1998).

Description of the literature search

Core committee teams systematically searched the Cochrane Incontinence Group's trials register, Medline, Cinahl, Embase, PsychLit and ERIC and Ageline for the period January 1995 to January 2000. The following search terms were applied: incontinence, urinary, male, post prostatectomy, stimulation, electrical stimulation, biofeedback, pelvic muscle exercises, Kegel exercises, behavioural, behaviour, behaviour therapy, behaviour modification therapy, physiotherapy, surgery, continence, bladder control, quality of life, randomized controlled trial, evaluation, effectiveness, efficacy and outcomes. In addition we performed hand searching of abstracts and consulted with colleagues.

Levels of evidence for the recommendations

To develop recommendations for each assessment and treatment method, the core committee considered (1) the quality and amount of evidence, (2) the consistency of findings among studies, (3) the clinical applicability of the evidence to adult patients with urinary incontinence (UI), and (4) the evidence on harms or costs.

For all guideline statements taken over without revision from the AHCPR list, the original strengths of evidence are given, as defined in Table 1.

For all new or revised guideline statements, levels of evidence were assigned following a scheme recently used in the Canadian Medical Association Journal and in Canadian Clinical Practice Guidelines (Table 2) (Patterson et al, 1999)

We have used the customary terms "strength" or "level" of evidence, even though they may be misleading. On the one hand, the most convincing evidence for an intervention is a combination of expert opinion (level 3) with evidence from randomized controlled trials (level 1); on the other hand, interventions may be supported by expert opinion but not by randomized controlled trials, or vice versa. Thus different "levels" of evidence may reinforce or contradict one another.

Table 1. Strengths of evidence for recommendations taken over without modification from the AHCPR list

Strength	Criteria
A	The recommendation is supported by scientific evidence from properly designed and implemented controlled trials providing statistical results that consistently support the guideline statement.
B	The recommendation is supported by scientific evidence from properly designed and implemented clinical series that support the guideline statement.
C	The recommendation is supported by expert opinion.

"Please note that these ratings represent the strength of the supporting research evidence, not the strength of the recommendation itself. The strength of each recommendation is conveyed in the language describing it." (AHCPR p 12)

Table 2. Levels of evidence for new or revised recommendations, added to or modified from the AHCPR list

Level	Criteria for New Evidence
1	Evidence obtained from at least 1 properly randomized controlled trial.
2	Evidence obtained from well-designed controlled trials without randomization. Evidence obtained from well-designed cohort or case-control analytic studies, preferably from more than 1 centre or research group. Evidence obtained from comparisons between times or places without the intervention. Dramatic results in uncontrolled experiments are included in this category.
3	Opinions of respected authorities, based on clinical experience, descriptive studies or reports of expert committees

Authorship

This document represents a substantial consensus of all who contributed to its preparation. Although it reflects the generous participation of many individuals, The Canadian Continence Foundation, through the core committee, is the author of record of these guidelines and is wholly responsible for their content. The members of the core committee

are: Michael Borrie (geriatrician, co-chair), Luc Valiquette (urologist, co-chair), Claudia Brown (physical therapist), Harold Drutz (urogynecologist), Donna Fedorkow (gynecologist), Sender Herschorn (urologist), George Kuchel (geriatrician), Christianne Lepage (family practitioner), Grace Littler (consumer), Katherine Moore (nurse), Lisa Lacroix (ex-officio, Health Canada), Simone Powell (ex-officio, Health Canada), David Reid (ex-officio, Project Evaluator), Derek Griffiths (ex-officio, Consensus Conference Coordinator).

Publication date and revisions

These guidelines are based on literature published up to January 2000. They will need continuing, regular revision, which the core committee recommends should take place every 2 years. It is important for readers to check the publication date of any guideline they are reading. It is expected that use of the flow charts in practice will indicate desirable revisions and refinements.

Any feedback or suggestions for improvement of the guidelines or flow charts can be sent to: The Canadian Continence Foundation, P.O. Box 30, Victoria Branch, Westmount, Quebec H3Z 2V4, or e-mailed to help@continence-fdn.ca.

RECOMMENDED STEPS IN ASSESSMENT AND MANAGEMENT

Description of the flow charts

The flow charts provide a visual representation of the recommended steps in the assessment and management of urinary incontinence, and the order in which they should be considered. They are not algorithms mandating decisions, but allow the health professional and client to make their own decisions in a logical way. After feedback from the reactor panels it was decided that a single flow chart for the initial management of incontinence, and 3 separate flowcharts for specialized management in men, women, and the frail elderly respectively, could best guide professionals and clients through these steps. By the frail elderly we do not mean the fit older person, and in the absence of evidence of frailty the same approach should be used in older and younger people. The definition of frail elderly persons is "those in whom the assets maintaining health and the deficits threatening it are in precarious balance." In practical terms, this definition takes in those who depend on others for the activities of daily living or who are at high risk of becoming dependent (Rockwood et al, 1994). Examples include people with impaired mobility, who do not leave their residence without assistance of others, or with cognitive impairment. Most such people will be over 75 years of age, although some younger people with disabilities may respond to similar management.

An essential part of initial management is assessment, to establish a presumed etiology and to identify complex cases or serious conditions. It includes conservative methods using lifestyle

modifications and behavioural interventions. They can be (but do not have to be) taught and implemented by primary-care professionals, as suggested in the recommended models of continence care developed in parallel with the guidelines. Conservative measures can be taught to and implemented by most people with incontinence. Time for thorough education in lifestyle modification and behavioural techniques is essential if they are to have any impact on the symptoms. These measures alone may completely resolve urinary incontinence or significantly improve it and the person's quality of life. Consistent with the non-prescriptive nature of the guidelines, however, the measures actually implemented will depend on the wishes of the client/consumer and the opinion of the health-care professional consulted. Specialized management is usually offered by a continence specialist from one of a number of disciplines. It may include more invasive urologic and urodynamic investigations. Management options include further trials of medication, devices, bulking agents such as periurethral collagen, or surgery.

As shown at the top of the flow chart for initial management, most patients or clients present with one of three or four common types of symptoms. A focused history is taken, and as one of the first steps it is important that the health professional discusses with the patient or client their expectations, to determine whether they want treatment, and what realistic outcomes would reflect a meaningful improvement in their quality of life. In some there may be a complex history, and they should be referred for specialized management. In the majority, the history, a physical examination, and simple tests lead to a presumed etiology. These steps (history, physical and listed tests) should be followed whether the professional is a physician or is acting under the guidance of a physician, because they may suggest the presence of serious conditions which require onward referral. Based on the presumed etiology, the professional should discuss with the patient the possible steps in management, beginning with conservative lifestyle and behavioural interventions (AHCPR, 1996; Abrams, Khoury, et al, 1998). These are reversible and do not have side effects. If indicated (and respecting the boundaries of professional standards of practice), drug therapy or various devices may be considered. They may cause side effects but are reversible. The use of incontinence products, which includes a large variety of pads and devices for effective containment of urine, may be implemented at any point in the management.

Throughout the process and follow-up, it is important for the professional to continue to review with the individual their expectations, levels of improvement or worsening of symptoms, and their quality of life.

After thorough evaluation of the results of initial management, failure to satisfy expectations may lead to specialized management. Specialized clinical assessment provides a diagnosis of the etiology and the underlying pathophysiology. On the basis of this new diagnosis, the possible efficacy of first-line management options is re-evaluated. Incontinence containment products may be considered again. Surgical interventions - which may cause side effects and are not reversible - may be instituted. After treatment, expectations, improvement, and quality of life are again evaluated.

Flow Charts

The flow chart for initial management and the 3 flow charts for specialized management of men, women and frail elderly are shown in Figures 1 - 4. Their general structure is based on the recommendations of the 1st International Consultation on Incontinence (Abrams, Khoury, et al, 1998), together with statements II-1, II-2, II-4, II-5, II-5a, II-5b, and II-5c in the list of guidelines below.

GUIDELINES

PART I INTRODUCTION

The following is the list of guideline statements on which the flow charts are based. The list is divided into 4 parts, numbered II to V in accordance with the AHCPR handbook (1996). Part II (Identifying and evaluating urinary incontinence) is mainly relevant to the initial clinical assessment and the re-evaluation of treatment/management. Part III (Treatment of urinary incontinence) provides the scientific basis for the treatments suggested in the flowcharts. Part IV (Chronic intractable urinary incontinence) states or reiterates some of the issues relevant to this type of incontinence. Part V (Education) contains statements that are particularly relevant to the proposed models of continence care.

The guideline statements extracted from the AHCPR handbook (1996) are shown in regular type, and throughout the document the statement numbers and page numbers refer to that handbook.

Revisions, additions, and references to new evidence, based on the core committee's review of the recent literature, are shown in bold type. Levels of evidence 1-3 are approximately equivalent to AHCPR strengths of evidence A-C (see Tables 1 and 2).

The guideline statements are followed by a list of the new literature references (1995 - January 2000) identified by the core committee. For the literature references on which the unchanged AHCPR guideline statements are based, the AHCPR handbook (1996) should be consulted. Finally, in an appendix two issues particularly relevant to the elderly are discussed.

PART II IDENTIFYING AND EVALUATING URINARY INCONTINENCE

1. General Principles of Diagnostic Evaluation

Health care providers are encouraged to be knowledgeable about and initiate the basic evaluation of patients with UI. (Strength of Evidence = C) AHCPR p 18

2. Basic Evaluation

All patients with UI should undergo a basic evaluation that includes a history, physical examination, measurement of post void residual volume, and urinalysis.

(Strength of Evidence = B) AHCPR p 19

Risk factors that are associated with UI should be identified and attempts made to modify them.
(Strength of Evidence = B) AHCPR p 19

2.a. Quality of Life

A number of quality of life measures are available and can measure subjective and objective improvement. These measurements reflect outcomes that are important to the person with UI and should be established at baseline. (Level of Evidence = 1) (Fonda et al, 1995)

2.b. Assessment of Residual Urine in the Bladder

A bladder ultrasound scan is a non-invasive alternative to in/out catheterization to rule out clinically significant urinary retention. (Level of Evidence = 2) (Resnick, 1995; Simforoosh et al, 1997)

3. Supplementary Assessments

Blood testing (Blood, urea, nitrogen (BUN), creatinine, glucose, and calcium) is recommended if compromised renal function is suspected or if polyuria (in the absence of diuretics) is present.
(Strength of Evidence = C) AHCPR p 23

Urine cytology is not recommended in the routine evaluation of the incontinent patient.
(Strength of Evidence = B) AHCPR p 23

4. Further Evaluation

After the basic evaluation, treatment for the presumed type of urinary incontinence should be initiated unless there is an indication for further evaluation. (Strength of Evidence = B) AHCPR p 23

After the basic evaluation and initial treatment, patients who fail or those who are not appropriate for treatment based on presumptive diagnosis should undergo further evaluation. (Strength of Evidence = C) AHCPR p 24

5. Specialized Tests

Specialized tests are not intended to be part of the basic evaluation of UI. (Strength of Evidence = B) AHCPR p 24

5.a. Urodynamic Tests

In the further evaluation of UI, simple cystometry is appropriate for detecting abnormalities of detrusor compliance and contractility, measuring post void residual (PVR), and determining capacity. (Strength of Evidence = A) AHCPR p 27

In some instances of complicated diagnostic situations or involved therapeutic plans, multichannel cystometric tests are appropriate. (Strength of Evidence = B) AHCPR p 27

When performing urodynamic studies, the health care provider should attempt to reproduce the patient's symptoms. (Strength of Evidence = C) AHCPR p 27

5.b. Endoscopic Tests

Cystoscopy is not recommended in the basic evaluation of UI. (Strength of Evidence = B), AHCPR p 28. However, cystoscopy may be indicated in the further evaluation when the following situations are present:

(a) sterile pyuria or hematuria (Strength of Evidence = B) AHCPR p 28

(b) when urodynamics fail to duplicate symptoms (Strength of Evidence = C) AHCPR p28

(c) new onset of irritative voiding symptoms, bladder pain, recurrent cystitis, or suspected foreign body. (Strength of Evidence = B) AHCPR p 29

5.c. Imaging Tests

Radiographic, ultrasonographic, and other imaging tests should be used for the evaluation of anatomic conditions associated with UI when clinically needed. (Strength of Evidence = C) AHCPR p 29

PART III TREATMENT OF URINARY INCONTINENCE

Behavioural Technique

1a. Lifestyle Adjustment:

Fluid increase/decrease - intake of adequate fluid (approximately 30 ml/kg or 1.5 to 2 litres a day) may improve symptoms of urinary incontinence (Level of Evidence = 3) (Griffiths et al, 1996; Dowd et al, 1996)

Caffeine reduction or elimination may improve lower urinary tract symptoms (Level of Evidence = 1) (Tomlinson et al, 1999)

Smoking - not engaging in smoking or quitting smoking may prevent or reduce the onset of lower urinary symptoms (Level of Evidence = 2) (Koskimaki et al, 1998)

Weight loss may reduce urine loss in obese women (Level of Evidence = 3) (Bump et al, 1992)
Moderate physical activity - exercise may prevent or reduce lower urinary symptoms (Level of Evidence = 3) (Platz et al, 1998)

Constipation - bowel regularity may improve continence (Level of Evidence = 3) (MacDonald et al, 1991)

Women with stress, urge or mixed urinary incontinence may have long term persisting improvement from conservative measures (Level of Evidence = 2) (Seim et al, 1998; Weinberger et al, 1999; Bear et al, 1997)

1. Toileting Assistance

Routine or scheduled toileting should be offered to incontinent patients on a consistent schedule. This technique is recommended for patients who cannot participate in independent toileting.
(Strength of Evidence = C) AHCPR p 33

Habit training is recommended for patients for whom a natural voiding pattern can be determined. (Strength of Evidence = B) AHCPR p 33

Prompted voiding is recommended in patients who can learn to recognize some degree of bladder fullness or the need to void, or who can ask for assistance or respond when prompted to toilet. Patients who are appropriate for prompted voiding may not have sufficient cognitive ability to participate in other, more complex behavioural therapies. (Strength of Evidence = A) AHCPR p 34

2. Bladder Training

Bladder training is recommended for management of urge (DI) and mixed incontinence.
(Strength of Evidence = A) AHCPR p 35. (Level of Evidence = 1) (Roe, Williams, Palmer, 1999)

3. Pelvic Muscle Rehabilitation

3.a. Pelvic Muscle Exercise (PME)

Teaching women PMEs may prevent UI. (Strength of Evidence = C) AHCPR p 36

Teaching exercises to strengthen pelvic muscles may decrease the incidence of UI. (Strength of Evidence = C) AHCPR p 36

PMEs are strongly recommended for women with SUI. (Strength of Evidence = A) AHCPR p 36 (Level of Evidence = 1) (Bø, 1999)

PMEs are recommended in conjunction with bladder training for urge incontinence. (Strength of Evidence = B) AHCPR p 36

PMEs may benefit men who develop urinary incontinence following prostatectomy. (Strength of Evidence = C) AHCPR p 36

PMEs in combination with electrical stimulation, biofeedback, or bladder retraining may improve incontinence following radical prostatectomy (Level of Evidence = 2) (Van Kampen, 2000)

Bulbous urethral massage or PMEs are useful for post micturition dribble. (Level of Evidence = 2) (Paterson et al, 1997)

3.b. PME and Bladder Inhibition Augmented by Biofeedback Therapy

Pelvic muscle rehabilitation and bladder inhibition using biofeedback therapy are recommended for patients with stress UI, urge UI, and mixed UI.
(Strength of Evidence = A) AHCPR p 39

Biofeedback-assisted behavioural treatment is safe and more effective than oxybutynin or placebo in women with urge and mixed incontinence. (Level of Evidence = 1) (Burgio et al, 1998)

Biofeedback-assisted pelvic floor muscle training in homebound older women can reduce urine loss. (Level of Evidence = 1) (McDowell et al, 1999)

Electrical stimulation may reduce the symptoms of urgency and frequency (Level of Evidence = 2) (Bower et al, 1998; Hasan et al, 1996)

3.c. Pelvic Muscle Exercises Augmented with Vaginal Weight Training

Vaginal weight training may be recommended for SUI in premenopausal women, but is no more effective than pelvic muscle exercises. (Level of evidence = 2) (Bø 1999)

3.d. Pelvic Floor Electrical Stimulation

Pelvic floor electrical stimulation may decrease incontinence in women with SUI. (Strength of Evidence = B) AHCPR p 42

Pelvic floor electrical stimulation may be useful for urge and mixed incontinence. (Strength of Evidence = B) AHCPR p 42

Pelvic floor exercises, electrical stimulation and estrogen may reduce urinary incontinence in older women with stress, urge, or mixed UI. (Level of Evidence = 1) (Holtedahl et al, 1998)

4. Pharmacologic Treatment

4.a. Urge Incontinence: Detrusor Instability (DI)

The following pharmacologic agents are reported to be useful in DI as observed in clinical practice. (Strength of Evidence = B) AHCPR p 44

- Anticholinergic agents: oxybutynin, dicyclomine hydrochloride, propantheline, tolterodine.
- Tricyclic antidepressants: imipramine, doxepin, desipramine, and nortriptyline.
- Direct smooth muscle relaxant: flavoxate.

4.b. Anticholinergic Agents

Anticholinergic agents are the first-line pharmacologic therapy for patients with DI. (Strength of Evidence = A) AHCPR p 44

When pharmacologic therapy is to be used for patients with DI, oxybutynin is the anticholinergic agent of choice. The recommended dosage is 2.5-5mg taken orally two to four times per day. (Strength of Evidence = A) AHCPR p 44

Once a day controlled release oxybutynin is as efficacious as immediate release oxybutynin. Higher doses may be better tolerated using controlled release. (Level of Evidence = 1) (Anderson et al, 1999) (Level of Evidence = 2) (Gleason et al, 1999)

Low dose oxybutynin combined with bladder retraining may reduce urinary frequency in elderly women with detrusor instability. (Level of Evidence = 2) (Szonyi et al, 1995)

Tolterodine is an anticholinergic agent with selectivity for urinary bladder receptors over salivary receptors. It has comparable efficacy to oxybutynin. It is the drug of choice if oxybutynin use is limited by excessive dry mouth. The optimum dose is 2 mg BID. (Level of Evidence = 1) (Drutz et al, 1999; Abrams and Wein, 1997)

Propantheline is the second-line anticholinergic agent in the treatment of patients with DI who can tolerate the full dosage. The recommended dosages are 7.5-30mg administered three to five times per day; higher dosages (15-60mg qid) may be required. (Strength of Evidence = B) AHCPR p 44

Flavoxate at higher doses (800 mg-1200 mg) in divided dose 3 times/day may be of benefit in people with urinary urgency or urge incontinence (Level of Evidence = 2) (Fehrmann-Zumpe et al, 1999; Guarneri et al, 1994).

4.c. Tricyclic Agents

The use of tricyclic agents (TCAs) should be reserved for carefully evaluated patients. The usual oral dosages are 10-25mg, initially one to three times per day, but less frequent administration is usually possible because of the long half-life. The daily total dosage is usually 25-100mg. (Strength of Evidence = B) AHCPR p 46

Strongly anticholinergic TCAs including Amitriptyline and Doxepin are contra-indicated in the frail elderly. (Level of evidence = 3) (McLeod et al 1997; Pollock BG 1999)

4.d. Nonsteroidal Anti-Inflammatory Drugs

Nonsteroidal anti-inflammatory drugs (NSAIDs) are not recommended for the primary treatment of DI. (Strength of Evidence = C) AHCPR p 47

5. Stress Urinary Incontinence (SUI): Urethral Sphincter Insufficiency

5.a. Estrogen Therapy

Estrogen (oral or vaginal) may be considered as an adjunctive pharmacologic agent for postmenopausal women with SUI or mixed incontinence. Conjugated estrogen is usually administered either orally (0.3-1.25mg/day) or vaginally (2g or fraction/day). Progestin (e.g., medroxyprogesterone 2.5-10 mg/day) may be given continuously or intermittently. (Strength of Evidence = B) AHCPR p 49 (Level of Evidence = 2) (Fantl et al, 1996) Results from existing randomized controlled trials are disparate. The best study (Fantl et al, 1996) showed no effect of estrogen on continence status. There are potentially other reasons to consider estrogen in post-menopausal women with stress incontinence.

5.b. Other Drugs of Possible Benefit

Imipramine (10-75 mg qhs) is recommended as an alternative pharmacologic therapy for SUI when first-line agents have proven unsatisfactory. Although there are no studies regarding the safety of the long term use of imipramine for stress urinary incontinence, inferences from the psychiatric literature are reassuring. (Strength of Evidence = C) AHCPR p 51

The use of propranolol or other beta-blockers cannot be recommended for treatment of SUI because of lack of clinical experience and clinical studies.
(Strength of Evidence = C) AHCPR p 51

6. Surgical Treatment

Surgery is recommended for treatment of stress incontinence in men and women and may be recommended as first-line treatment for appropriately selected patients who are unable to

comply with other lifestyle modifications and behavioural interventions. (Strength of Evidence = B) AHCPR p 52

7. Stress Incontinence in Women

Hypermobility or Intrinsic Sphincter Deficiency (ISD)

7.a. Procedures for Hypermobility

Retropubic suspension is recommended for women with hypermobility when SUI is the primary indication for surgery. On the basis of greater efficacy, this procedure is recommended over anterior vaginal repair for hypermobility. (Strength of Evidence = B) AHCPR p 54. All retropubic suspension techniques have equal efficacy short and long term. Long-term results of needle suspensions are not as good. (Level of evidence = 2) (Leach et al, 1997)

7.b. Procedure for Intrinsic Sphincter Deficiency (ISD)

Sling procedures are recommended for women who have ISD with coexisting hypermobility or as first-line treatment for ISD. (Strength of Evidence = B) AHCPR p 57

Urethral bulking injections are recommended as first-line treatment for women with ISD. (Strength of Evidence = B) AHCPR p 57. Coexisting hypermobility is not necessarily a contra-indication (Level of evidence = 2) (Herschorn et al 1996)

Tension-free vaginal tape is a new minimally invasive technique for treating genuine stress urinary incontinence in women. This procedure by trained operators is an alternative to sling procedures. Its short- to medium-term success rate is comparable and the incidence of post-operative complications may be lower. Further longer term follow-up data (more than 3 years) are needed for a complete comparison. (Level of evidence = 2) (Ulmsten et al, 1995, 1998, 1999; Wang & Lo, 1998; Olsson & Kroon, 1999).

Artificial sphincter is recommended for ISD patients who have severe SUI that is unresponsive to other surgical treatments. Because of the high complication rate, this treatment is rarely used as primary therapy. (Strength of Evidence = B) AHCPR p 57

8. Stress Incontinence in Men

Intrinsic Sphincter Deficiency

Lifestyle adjustments may improve lower urinary tract symptoms. (Level of Evidence = 3) (Kondo et al, 1999).

8.a. Periurethral Bulking Injections

Periurethral bulking injections may be recommended as a first-line surgical treatment for men with ISD. (Strength of Evidence = B) AHCPR p 59

8.b. Placement of an Artificial Sphincter

Artificial sphincter may be elected for ISD 6 months after prostatectomy. Behavioural intervention should also be tried during this period.
(Strength of Evidence = B) AHCPR p 60 (Level of Evidence = 2) (Schettini et al, 1998)

9. Urge Incontinence: Overactive Bladder

Neuromodulation is a minimally invasive surgical treatment for detrusor instability offered in specialized centres and may be considered after failure of non-invasive treatments. (Level of evidence = 2) (Weil et al, 1998; Shaker and Hassouna, 1998).

Augmentation intestinocystoplasty is recommended for individuals with intractable, severe bladder instability or poor bladder compliance that is unresponsive to nonsurgical therapies (Strength of Evidence = B) AHCPR p 61

Urinary diversion is recommended in severe intractable cases of detrusor instability or poor bladder compliance that is unresponsive to other therapies.
(Strength of Evidence = B) AHCPR p 61

10. Incomplete Emptying

10.a Bladder Neck or Urethral Obstruction or Poorly Contractile Bladder

Symptoms of overflow or incontinence secondary to bladder neck obstruction, prostatic enlargement or urethral stricture can be addressed with surgical procedure(s) to relieve the obstruction. (Strength of Evidence = B) AHCPR p 63

Intermittent catheterization or an indwelling catheter may be considered as a temporary or permanent measure for individuals who have urinary incontinence due to incomplete emptying secondary to underactive or obstructed bladder, and who are not candidates for surgery or who are awaiting surgery. (Strength of Evidence = C) AHCPR p 63
There is no evidence to support the use of urethral dilation for the treatment of incontinence in women, although it may be useful in the extremely rare cases of primary obstruction. (Strength of Evidence = C) AHCPR p 64

Internal urethrotomy is not recommended for treating urethral obstruction in women. (Strength of Evidence = C) AHCPR p 64

Bladder neck electrical stimulation in men and women with acontractile or hypocontractile bladder may enhance bladder emptying. (Level of Evidence = 3) (Primus et al, 1996)

Surgical management

In cases of anatomic obstruction in men, surgery can be selected when other forms of therapies have failed. Benign prostatic hyperplasia (BPH) is the most common cause of infravesical obstruction in males. The treatment of BPH is multifaceted and is addressed in other published clinical practice guidelines. (Level of Evidence = 3) (Jepsen and Bruskewitz, 1998)

11. Other Measures and Supportive Devices

Protective garments and external collecting devices have a major part in the management of chronic incontinence. The most absorbent and skin-friendly products should always be utilized. However, no scientific literature is available to guide selection of the most effective product. (Strength of Evidence = C) AHCPR p 83

11.a. Intermittent Catheterization (IC)

IC is recommended as a supportive measure for patients with spinal cord injury, persistent UI, or chronic urinary retention secondary to underactive or partially obstructed bladder. (Strength of Evidence = B) AHCPR p 65

Clean technique for IC is recommended for all except immunocompromised individuals. (Strength of Evidence = B) AHCPR p 65

Sterile technique for IC is recommended for elderly patients and patients with compromised immune system. (Strength of Evidence = C) AHCPR p 65

Routine use of long-term suppressive therapy with antibiotics in patients with chronic, clean IC is not recommended. (Strength of Evidence = B) AHCPR p 66

In high-risk populations, for example, those with an internal prosthesis or those who are immunosuppressed because of age or disease, the use of antibiotic therapy for asymptomatic bacteriuria must be individually reviewed. (Strength of Evidence = C)
AHCPR p 66

11.b. Indwelling Urethral Catheters

Indwelling catheters are recommended for selected incontinent patients who are terminally ill or for patients with pressure ulcers as short-term treatment.
(Strength of Evidence = B) AHCPR p 67

Indwelling catheters are recommended in severely impaired individuals in whom alternative interventions are not an option and when a patient lives alone and a caregiver is unavailable to provide other supportive measures. (Strength of Evidence = C) AHCPR p 67

11.c. Suprapubic Catheters

Suprapubic catheters are for short-term use following gynecologic, urologic, and other surgery, or as an alternative to long-term catheter use. Suprapubic catheterization is contraindicated as a long-term management option in persons with chronic unstable bladder (detrusor instability, detrusor hyperactivity) and ISD. (Strength of Evidence = B) AHCPR p 69

11.d. External Collection Systems

External collection systems are recommended for incontinent men and women who have adequate bladder emptying, who have intact genital skin, and in whom other therapies have failed or are not appropriate. (Strength of Evidence = C) AHCPR p 70

11.e. Penile Compression Devices

Penile compression devices are known to be used in clinical practice in the treatment of UI. No scientific literature was found to support the use of these devices. The panel recognizes the temporary use of penile compression devices in males in selected circumstances under the supervision of a health care provider.
(Strength of Evidence = C) AHCPR p 71

11.f. Pelvic Organ Support Devices

There are no comparison studies with other treatments to recommend or discourage the use of pessaries for the treatment of UI in women. (Level of Evidence = 3)

Pessaries are recommended for women who have symptomatic pelvic organ prolapse. (Strength of Evidence = C) AHCPR p 71

11.g. Vaginal Devices for Urge Incontinence

Vaginal devices for urge incontinence may reduce urine loss. (Level of Evidence = 2) (Thyssen et al, 1999, Versi et al, 1997)

PART IV CHRONIC INTRACTABLE URINARY INCONTINENCE

1. Prevalence and Incidence

1.a. Interventions for Chronic UI

Care of people with chronic UI should include attention to toileting schedules, fluid and dietary intake, strategies to decrease urine loss at night, use of the most absorbent and skin-friendly protective garments possible, and prevention and early treatment of skin breakdown. (Strength of Evidence = B) AHCPR p 76 - 77

1.b. Physical and Environmental Alterations

All caregivers for elderly or disabled individuals must assess the environment in which the patient resides. Simple alterations, or the addition of toileting or ambulation devices, can often eliminate or reduce episodes of involuntary urine loss.
(Strength of Evidence = C) AHCPR p 80

Strategies that maintain or improve mobility are likely to prevent or reduce incontinent episodes in the frail elderly. (Strength of Evidence = B) AHCPR p 80

1.c. Fluid and Dietary Management

Constipation is a common problem for patients with chronic UI. Establishing a bowel regimen based on adequate fibre and fluid intake is often helpful. Elimination of bowel impaction and consequent pressure on the bladder and urethra are often necessary first steps in the treatment of chronic UI. (Strength of Evidence = C) AHCPR p 81

1.d. Management of Nocturia

Night-time voiding and incontinence are major problems for adults of all ages. Prevention measures to decrease night-time voids are recommended. The use of simple electronic urine detection devices should be encouraged for more efficient and effective patient monitoring of night-time urine loss. (Strength of Evidence = B) AHCPR p 81

2. Other Measures and Supportive Care

2.a. Absorbent products

Absorbent products are recommended during evaluation, as an adjunct to other therapy, and for long-term care of patients with chronic, intractable urinary incontinence. (Strength of Evidence = C) AHCPR p 72. There is limited information on the relative merit of the many different products available. (Level of Evidence = 3) (Baker and Norton, 1996; McClish et al, 1999)

2.b. Suprapubic Catheters

Suprapubic catheters may be an acceptable alternative for indwelling urethral catheters when patient choice or circumstances require the use of a bladder drainage device. (Strength of Evidence = B) AHCPR p 85

2.c. Skin Care

Recommended measures of cleansing the skin before and immediately after urine loss are helpful in preserving skin integrity. (Strength of Evidence = B) AHCPR p 85

Some pads and garments may provide some protection from skin damage.
(Strength of Evidence = C) AHCPR p 85

PART V EDUCATION

1. Public Education

Urinary incontinence has the stigma of a socially unacceptable condition because of public lack of knowledge, misconceptions and intolerance. This leads to personal isolation, social embarrassment, and delays in seeking medical advice. The public needs to know that many therapy and management problems surround urinary incontinence. Since the 1998 NIH Consensus Conference, public knowledge has increased somewhat through publication of the 1992 AHCPR Guideline document and efforts of the two self-help groups in the United States, the Simon Foundation for Continence and the National Association for Continence (NAFC, formerly Help for Incontinent People, HIP). In Canada, The Canadian Continence Foundation has raised public awareness through its many publications, surveys and Incontinence Awareness Month (November).

Increased efforts to inform and educate the public about incontinence are essential. (Strength of Evidence = C) AHCPR p 89

The public should be aware that incontinence is not inevitable or shameful but is treatable or at least manageable. (Strength of Evidence = C) AHCPR p 89

Patient education needs to be comprehensive and multidisciplinary so as to explain all management alternatives. (Strength of Evidence = C) AHCPR p 89

More research is needed to test the effectiveness of patient education activities.
(Strength of Evidence = C) AHCPR p 89

2. Professional Education

Education about urinary incontinence for professionals, paraprofessionals and survey teams continues to be urgently needed. Information about urinary incontinence should be included and enhanced in the curricula of undergraduate and graduate health care professional schools. Schools of nursing and physiotherapy should consider educating professionals on incontinence care who can then serve as expert advisors (continence advisors) to other health care providers, regionally, on the provincial level in academic health sciences, community care access centres/home care and in long term care facilities.

Nurse continence advisor training has been formalized with the lead being taken at McMaster University, spearheaded by Jennifer Skelly, RN, PhD.. Distance education for nurses is available through this program. There are opportunities for similar programs to develop across the country for nurses. Formalized physiotherapy programs are evolving and would likewise be offered across Canada. In Canada, identifying sites that can provide the clinical component of education in a wide variety of settings, acute care hospitals, long term care

facilities and the community will be important for nurses and physiotherapists and other health professionals seeking higher levels of training.

Education about UI evaluation and treatment should be included in the basic curricula of undergraduate and graduate training programs of all health care providers. Continuing education programs on UI should be offered to all health care providers.
(Strength of Evidence = C) AHCPR p 91

Continuing education programs on UI should be offered to all health care providers. Training programs that provide didactic and broad clinical experience need to be available for nurses , physiotherapists and other health care professionals to become experts within their discipline for the management of continence in adults.

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APPENDIX: Urinary Incontinence in the Frail Elderly—Specific Issues

1. Physiological Changes Associated With Aging That May Influence Continence

Lower Urinary Tract :
Although the precise impact of normal aging on bladder function remains to be defined, a number of physiologic changes have been described. Bladder capacity, urethral compliance, maximal urethral closing pressure and flow rates, all appear to decline in healthy continent women (Resnick, 1995, 1996). Post-void residuals and involuntary detrusor contractions increase in both genders, while urethral resistance increases in older men (Resnick, 1996).

None of these factors alone or even in combination result in incontinence. Nevertheless, any of these may contribute towards the loss of continence in an otherwise vulnerable individual.

Other Systems :
The vast majority of older individuals remain fully mobile even at an advanced age. Nevertheless, speed, range and functional flexibility of locomotion are all reduced even in ostensibly healthy older individuals. Such changes may, for example, impact upon the individual's ability to reach the bathroom following onset of urgency. Moreover, even relatively minor changes in visual perception and fine motor coordination may influence the removal of clothes and positioning in the bathroom.

Diurnal pattern of fluid excretion also changes, with older individuals excreting a much larger proportion of their ingested fluid at night (Kirkland et al, 1983). Sleep patterns are altered in aging, with increased episodes of nocturnal awakening (Martin et al, 1999). Together these changes result in increased nocturia. The risk of incontinence and falls at night is particularly great due to changes in lighting. As well, neuropsychologic and perceptual changes associated with transition from sleep to an awake state may also be problematic.

Finally, response to medication changes in old age. This also occurs in healthy older individuals showing altered responsiveness to some medications and a greater risk of adverse reactions (Tumer et al, 1992). Anticholinergic medications represent a particular risk with a much greater risk of xerostomia, constipation, urinary retention and impaired cognition. The percentage of body composition which is fat tends to increase, while lean body mass decreases. Thus, the volume of distribution of lipid soluble drugs tends to increase, while that of water soluble compounds tends to decrease. Decreased renal clearance of the latter category medications requires dose adjustments in many, if not all, older individuals.

For all these reasons, the initial dose of any medication prescribed for an older individual requires careful consideration and should nearly always be lower than that used in younger adults.

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2. Incomplete Bladder Emptying/Urinary Retention

Urinary retention (UR) in the elderly has been associated with poor outcomes including urinary tract infections, bladder overdistension, and higher hospital fatalities (Simforoosh et al, 1997; Smith and Albazzaz, 1996). Overdistension following surgery under general anesthesia is probably the most common cause of acute urinary retention (Jacobsen et al, 1997; Waterhouse et al, 1987). UR can be silent and lower abdominal symptoms of acute UR may be masked in the elderly by analgesics or may not be perceived due to cognitive impairment. Clinical examination of the abdomen is a notoriously unreliable method of detecting UR. The definition of UR based on the volume of a post void residual urine (PVR) is somewhat arbitrary. It depends on the population being studied or the clinically relevant condition. Smith and Albazzaz (1996) defined PVR greater than 300 ml in a study of outcomes in elderly women undergoing surgery for proximal hip fracture. Mainprize and Drutz (1989) in studying women with chronic persistent urinary tract symptoms used >30 ml as being abnormal in this population. Grosshans et al (1993) used 50 ml PVR to report a prevalence of 34% UR in elderly patients on an acute care ward. A literature review revealed 16 papers with a range of "normal" post void residual urine from 0 to less than 250 ml. Diokno (1990) maintains one cannot establish a "normal" or "pathologic" value, while most authors accept a figure of between 100 150 ml as being within the normal range. Clinically significant volumes may vary between a lower limit of 50 ml and an upper limit of 300 ml (Grosshans et al 1993; Marks et al, 1997; Smith and Albazzaz 1996). The post void residual urine may vary in the elderly and may reflect lower urinary tract obstruction, poor contractility or detrusor hyperactivity with impaired contractility (DHIC) (Resnick et al, 1987, 1989) or a combination of these entities.

In the elderly, as part of investigation of incontinence, Ouslander has listed criteria for referral of elderly incontinent patients for urologic/gynecological urodynamic evaluation. A post void residual urine of greater than 100 ml is one suggested indication for referral (Ouslander et al. 1989).

Before the ready availability of the portable bladder ultrasound, the AHCPR Practice Guidelines for Urinary Incontinence suggested in/out catheterization to rule out urinary retention in any person with urinary incontinence (AHCPR, 1992).

In/out catheterization remains the gold standard for precise measurement of PVR volumes. Catheterization, especially after hip fracture, post stroke, or in the presence of cognitive impairment, can be very challenging for nursing staff and uncomfortable for elderly people with these conditions. Portable bladder ultrasound offers a non invasive painless method of estimating the post void residual urine and eliminates the risk of introducing urinary infection or causing urethral trauma by catheterization. Previous research, in various settings, has supported portable hand held ultrasound scanners as non invasive, cost effective, reliable and accurate tools for measuring PVR urine (Chan, 1993; Grosshans et al, 1993; Lewis, 1995; Mainprize and Drutz, 1989; Marks et al, 1997; Ouslander et al, 1994; Resnick 1995, Revord et al, 1993; Simforoosh et al, 1997; Smith and Albazzaz, 1996; Wagner and Schmid, 1997).

Portable ultrasound has been evaluated in a nursing home population (Ouslander et al, 1994) and in a younger population (mean age 58) undergoing urodynamics (Coombes and Millard, 1994). It has been found to have an acceptable level of accuracy. Portable ultrasound is an acceptable alternative to in/out catheterization.

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CANADIAN CONSENSUS CONFERENCE ON URINARY INCONTINENCE:
WORKING MODELS OF CONTINENCE CARE

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INTRODUCTION

Objectives

At the Canadian consensus conference on urinary incontinence (Toronto, May 2000), realistic, working models for continence care were approved. Unlike development of guidelines for clinical practice, development of consensus on models of continence care is a relatively new activity for which there are no established rules.

The main aim of the models is to show how the guidelines can be put into practice in various representative settings, taking into account medical, organizational, funding, and educational issues. Guidelines alone cannot change continence care if the infrastructures to implement them are not present. These models suggest concrete solutions for continence care in various settings across Canada.

A next step will be to pilot the models in appropriate settings. Although pilot testing is outside the scope of the current project, actual sites will be identified for follow-up implementation of models and guidelines. In some locations, these models may be most easily implemented as part of broader health service issues, such as geriatrics or women's health.

Method

To arrive at a consensus, the working models were developed as follows.

- A researcher (Jill Milne, supervised by Dr Katherine Moore) was commissioned to produce an environmental scan of the models of continence care in use both in Canada and worldwide. In her report the specialty continence services in The Canadian Continence Foundation's database are well represented, but family physicians and specialists practising alone may be underrepresented, resulting in some bias. The report (Milne & Moore, 2000) can be consulted on the web site of the foundation (www.continence-fdn.ca)
- A core working models committee was convened by The Canadian Continence Foundation, to include clients/consumers and leading Canadian multidisciplinary health care professionals from urology, gynecology and urogynecology, family practice, nursing and physiotherapy, as well as a representative of the Division of Seniors and Aging of Health Canada, and an independent evaluator
- The core committee decided on three broad settings for which working models should be prepared: rural/remote, small-city, and urban/academic
- A team of experts was selected for each setting and asked to review the environmental scan
- Each team drafted a working model of continence care and a flow chart to represent it in visual form, drawing on the environmental scan, any other relevant reports, personal experience, consultations with colleagues, and input from current or former clients with incontinence
- Teams drafted reports on the definition of continence care, the concept of a working model, and on issues associated with the regionalization of health care

- The draft reports and working models were discussed by the whole committee in the light of the draft guidelines, and edited for consistency
- Participants were selected for a consensus conference, based primarily on nominations from national associations of health professionals and consumer groups, but considering also the need for geographic representation across Canada
- The draft working models were circulated to the conference participants for review
- The drafts were presented at the consensus conference, discussed in small groups, and further revised in the light of these discussions
- Consensus was established by voting: over 80% representing consensus, 60-79% representing partial consensus
- The resulting proposals for working models were sent to community reactor panels across the country for review before finalization.

Authorship

This document represents a substantial consensus of all who contributed to its preparation. Although it reflects the generous participation of many individuals, The Canadian Continence Foundation, through the core committee, is the author of record of these working models and is wholly responsible for their content. The members of the core committee are: Sonya Lytwynec (nurse, co-chair), Shirley McSavaney (nurse, co-chair), Gordon Brock (family physician), Mary Egan (physiotherapist), Jerzy Gajewski (urologist), Gail McAlpine (nurse), Jill Milne (Master of Nursing candidate), Fran Monkman (nurse), Anita Saltmarche (nurse), Jane Schulz (gynecologist), Ron Schurman (consumer), Sharon Sholzberg-Gray (Canadian Healthcare Association), Malvina Klag (ex officio, The Canadian Continence Foundation), Ruth Pelletier (ex officio, The Canadian Continence Foundation), Cathy Bennett (ex officio, Health Canada), David Reid (ex officio, project evaluator), Derek Griffiths (ex officio, Consensus Conference coordinator).

The meaning of continence care

What is continence care? Answers to this question from health care professionals would focus on assessment and treatment. To individuals with incontinence, however, research indicates that continence care means something different. The need for knowledge is foremost – knowledge about incontinence, about health care professionals, testing, treatment and management. For the purposes of the environmental scan referred to above (Milne & Moore, 2000), continence care includes "all measures directed toward the prevention, improvement and/or management of urinary incontinence."

The definition of continence care used in this document stresses the importance of access. It is defined as any information, assessment, treatment and/or support that may be perceived to be needed by an individual experiencing incontinence and/or his/her caregiver (s). Consequently, it includes:

1) Access to information about:
- the urinary tract system, healthy bladder habits, healthy aging, risk factors, prevention
- the signs & symptoms of incontinence, types of incontinence
- the wide variety of treatments and containment products available
- how to express and articulate symptoms to a health care provider

2) Access to timely and appropriate assessment, diagnostic testing and treatment by knowledgeable health care professionals, including:
- basic level assessment through a health centre, clinic, home care, family physician, or long term care
- easy access to specialists
- access to treatments such as biofeedback, electrical stimulation.
- access to bladder scanning, uroflow testing and urodynamics when needed

3) Access to a wide variety of management methods in convenient locations, such as:
- home care
- community centres
- continence clinics or centres for relevant medical/surgical specialisms
- local home health supply stores

Currently, the provision of continence care is unsystematic and varies both locally and regionally (Griffiths, 1997). Many individuals with incontinence do not receive any care at all. For those who do, the type of care received, the information provided, the referrals involved, and ultimately the treatment received, differ in a haphazard way, even within the same city or town and for individuals with the same condition.

Adequate funding is required to provide education, assessment, treatment and management of incontinence and to address the current inconsistencies in continence care.

What is meant by a model of continence care?

In accordance with the mission of The Canadian Continence Foundation, the core committee developed models of continence care from the perspective of an individual who experiences the problem. A model is a pathway to and through continence care seen from this individual's viewpoint. It is not just an individual clinic or even a series of clinics. An ideal model will ensure that:

1. any person experiencing incontinence, whether male, female, young or old, is able to consult an interested and knowledgeable healthcare professional within a reasonable timeframe for an initial assessment, followed by either a treatment/management plan carried out by this professional or a referral;
2. the consultation is at a convenient place (i.e. within reasonable driving distance, or easily accessible via public transit, or at home if necessary);

3. if referral to the next level of care or for testing is necessary, it too is accessible and timely;
4. the assessment and care received are comprehensive, centralized, and include not only a treatment plan but also the necessary psychosocial and occupational-therapy support, together with information that allows the individual to be an integral part of the development and implementation of the plan;
5. once the treatment plan is initiated, the individual is able to ask questions when needed, know who to ask, and receive timely follow-up;
6. continence care is determined in collaboration between the individual and the health care team, and is coordinated with the individual's overall health care.

Entry on to the pathway of continence care is a critical step, and deserves elaboration as an additional level of continence care (the screening level). At present many people with incontinence do not make this step because of embarrassment, myths about incontinence, and lack of access to knowledgeable professionals and facilities (VON Canada, 1998; Skelly, Boblin-Cummings, 1999)

Finally, the ideal model is flexible and will be realized in various ways depending on a number of factors, including:

1. the age and sex of the individual;
2. whether or not there are neurological or other diseases or conditions affecting continence, directly or indirectly;
3. whether the individual lives in or near an urban/academic center, a small city or a rural/remote area;
4. the availability of health care professionals with the needed expertise in the area;
5. the existing structures and systems in place in the particular area.

The core committee has addressed point 3 by developing different models of continence care for different settings. Points 1 and 2 are addressed in the guidelines for clinical practice which the models are intended to implement.

With regard to point 4, The Canadian Continence Foundation recognizes that health care professionals act within the boundaries of their professional standards of practice in collaboration with a physician. Clearly no single health care discipline working in isolation can deliver ideal continence care. In many rural areas, however, there will not be more than one family physician, nurse or physiotherapist with expertise and interest in incontinence. For example, a physiotherapist in independent practice must have clear relationships with local physicians and with professionals from nearby urban centres. In these circumstances there may be an increased need for telephone support, and this one professional may have to be highly trained in incontinence management. A telehealth network may be particularly useful.

With regard to point 5, it is essential that the models of continence care that are proposed are realistic and build on existing structures and resources.

The settings in which continence care needs to be provided

Canadians live in diverse settings with very different available resources, from remote, rural areas to large cities with academic medical schools. As it is unlikely that continence care can be provided in the same way in every setting, the core committee has chosen 3 representative settings and has considered what models of care may be most suited to each. The chosen settings are: rural/remote, small city, and urban/academic. The urban/academic setting is a city with a university and a school of medicine and other health sciences. In the small-city setting there is no medical school (as a rough guide, the committee envisions that the population of the "small" city exceeds about 10,000, although this number may differ from part to part of the country). The rural/remote setting includes towns, villages or hamlets with population smaller than about 10,000.

Close to one-third of the Canadian population lives in a rural/remote setting (Health Canada, 1999), with a relatively low population, usually concentrated in one small town that is surrounded by a geographically large, sparsely-populated, "catchment area".

Most cities in Canada fit the small-city model since, with the exception of Ontario, most provinces have only one or two urban/academic centres. In small cities, the special challenges are shortage of specialists despite patients' desire for them, lack of specialized resources, and under-utilization of health care professionals such as nurse continence advisors and physiotherapists. In some provinces regionalization of health care delivery may govern whether referrals can be accepted from practitioners in rural/remote areas, and from which areas they are accepted.

The urban/academic setting includes 16 Canadian metropolitan regions with medical schools. In this setting, there is a dense population of clients who have the opportunity to access health care professionals with expert knowledge of continence care. Continence care is provided at primary, secondary, and tertiary care levels. Referrals to secondary- and tertiary-level care are accepted from rural/remote areas and from small cities.

The levels of continence care

In any model of care the concept of level of care is central.

Primary health care –The World Health Organization (1978) defines primary care as "essential health care based on practical, scientifically sound and socially acceptable methods and technology ... made universally accessible to individuals and families. It is the first contact of the individual, the family and the community with the national health system, ...

constituting the first element of a continuing health care process.". (World Health Organization, 1978). Included in the definition are education concerning prevailing health problems, methods of prevention and control, as well as appropriate treatment.

In the case of continence care, primary health care should provide:
1) Access to educators with interest in and knowledge of incontinence, ranging from family physician, community health nurse, to pharmacist
2) Access to basic level assessment through a health centre, clinic, long term care facility or family physician
3) Access to simple diagnostics such as bladder diary, urine testing and residual urine
4) Access to basic treatment strategies such as lifestyle changes and behavioural therapies.

Secondary health care is generally understood to be the next step in the continuing health process referred to by the WHO. It is care provided on referral from primary care providers, by specialists who do not necessarily work in an academic setting. It should provide:
1) Expert care by a team of multidisciplinary professionals with specialized continence training
2) Quick access to diagnostic procedures such as bladder scanning, uroflow testing and simple cystometry
3) Availability and ease of access to treatment such as biofeedback, electrical stimulation, pessaries

Tertiary health care is a further step in the continuing care process. It is highly specialized care, usually provided in an academic setting on referral from the secondary level. It should provide:
1) Access to urodynamic testing when required
2) Availability of specialized surgical and medical treatments
3) Advances in continence assessment, treatment and management

Relation to initial and specialized management described in the Canadian clinical practice guidelines

The 3 levels of care are defined organizationally, as steps on a referral pathway. The initial management and specialized management described in the clinical practice guidelines are defined by the types of procedures used for assessment and treatment. Generally speaking, initial management will be performed at primary or secondary level, and subsequent specialized management at secondary or tertiary level.

Models from other countries

The report "Continence Care Services Worldwide: An Environmental Scan" (Milne & Moore, 2000) describes many models of continence care. The Australian experience is among the longest and most highly developed, and the problems faced - sparse population, great distances, and interprovincial or interstate differences - are similar to those in Canada.

Nevertheless, the comprehensive national or regional continence services implemented in Israel and Somerset (UK) are especially relevant to the Canadian models we are aiming to develop. Since the report was completed, the National Health Service in the UK has issued a guidance recommending the establishment of integrated, multidisciplinary continence services, similar to those we are proposing for Canada (Department of Health, UK, 2000).

Israel

In Israel the continence service includes:

1. A National Centre for Continence, providing -
- training and education of primary health care providers
- a central clinic with advanced diagnostic tools and a variety of treatment options, including surgery
- selection of regional clinics staffed by family practitioners and nurses, to provide regional continence care
- educational training for nursing home staff

2. Regional Leading Teams
- one physician and one nurse leading all the continence clinics in a region
- provision of telephone advisory services

3. Peripheral Clinic Leading Teams
- one physician and one nurse leading the continence services at each clinic.

Somerset, UK

The Somerset Health Authority in the United Kingdom has set up a three-tiered regional continence service.

Tier 1:
- continence service at primary care level (simple assessment and treatment by caregiver)
- open access (no referral required)
- setting is community and institutional, both urban and rural
- primary caregivers are nurses in the community and in physician practices.

Tier 2:
- domiciliary and clinic-based continence nurse advisory services, multidisciplinary clinic-based services, and enuresis clinics
- access is by referral from primary caregiver
- setting is clinic-based with outreach to the community in urban and rural areas

- caregivers are continence nurse advisors, physical therapists

Tier 3:
- medical clinics and complex urodynamic services
- access by referral from continence nurse advisor or physical therapist
- setting is institutional and urban
- caregivers are medical consultants: urologists/urogynecologists

Both the Israeli and the Somerset model include:
- a primary level evaluation and treatment by a physician and/or nurse
- a tertiary level featuring urodynamic studies and (sub)specialist opinion.
- an intermediate secondary level

The models of continence care proposed at the consensus conference also include these three levels, which are provided or accessed in different ways in the different settings.

At the primary level, care is provided by a family physician, nurse (including home care nurse or long term care nurse), or physical therapist. They are able to perform a basic evaluation and simple lab tests. Whoever is providing the primary care, it is important that these evaluations and tests are carried out as set down in the guidelines, so that complicating factors and serious disease are recognized and referred on to an appropriate level of care. They have some familiarity with the principles of incontinence treatment and management, including behavioural therapy such as pelvic muscle exercises and bladder retraining, drug therapy, and incontinence products.

At the secondary level, which is almost inevitably sited in a small or large city, care is provided by a urologist or gynecologist, or by a specially trained continence nurse working in a multidisciplinary continence clinic in cooperation with a physician. They are able to provide diagnostic facilities such as simple urodynamics (e.g. uroflow and cystometrogram), cystoscopy and more complex imaging. Treatment options will be based on expertise and experience in non-surgical therapies, including possibly biofeedback, and may include some basic surgical options for treatment such as urethrovaginal suspension.

At the tertiary level, care is provided by a specialist urologist or urogynecologist in an urban/academic centre. There is state-of-the art diagnosis and treatment. Full urodynamics is available as well as surgical expertise in such procedures as fascial sling, collagen injections, nerve stimulation, cystoplasty and urinary diversion.

To deal with the problem of entry on to the path of continence care, the core committee proposes a new screening level of care, intended to facilitate access, which is identified above as the single most critical part of continence care. The screening level has several aspects:
1. The most basic aspect is education of all front-line professionals associated with health care, including pharmacists, home support workers, nursing aides, social workers, occupational therapists, physiotherapists, nurses, family physicians, and others, about the prevalence of incontinence, the fact that it can be treated, and the routes to help. The aim is to

stimulate front-line professionals to become proactive in asking about incontinence, noticing it in their clients, and directing people to primary care if they wish it.
2. A second aspect is to provide suitable front-line workers with the tools to give direct help to some people with incontinence, so stimulating their enthusiasm. Experience in both London, Ontario and Edmonton, Alberta, has shown that simple tools (check lists) can be used by front-line workers such as community nurses -- after a small amount of specific incontinence training -- to screen for incontinence, suggest simple "healthy bladder habits," reassure people that treatment is available if they need it, and recognize risk factors which might suggest that further assessment is advisable. They can refer clients to further care if desired, but experience shows that care at the screening level may sometimes be sufficient, enabling the problems of a large number of people who at present do not get any help with their incontinence to be addressed. Preparation of a model screening tool, based on the London and Edmonton models, will therefore be a priority in piloting the proposed models of continence care.
3. A third aspect is community outreach: education of the public about incontinence, especially caregivers and those in groups at high risk for incontinence; establishment of consumer support groups; telephone support (especially in rural areas); advocacy.

Estimated numbers requiring care

The numbers requiring continence care at each level and in each setting depend not only on the numbers of individuals with incontinence but on the referral pathways. The models proposed for the 3 settings differ in the care available. In urban/academic centres screening, primary, secondary and tertiary levels of care are all present; in small cities the tertiary level is absent, while in rural and remote areas only the screening and primary levels are present. Consequently, if patients are referred to higher levels of care they may also move from one setting to another, as shown in Figure 5. The numbers of patients seeking help in urban centres thus are affected by the situation in the surrounding rural and small-city areas. The numbers in small cities are similarly affected by the surrounding rural areas.

Figure 5 provides an example of the main referral pathways and the numbers seeking help in a typical region comprising one urban centre (an academic centre in a city) and its surrounding small cities and rural catchment area. Since there are about 16 such regions in Canada, each serves an average population of about 2,000,000 people, as indicated at the top of the figure. Approximately 100,000 of these people (5%) suffer from incontinence. According to a survey of members of The Canadian Continence Foundation (Klag, 1998), the average duration of the problem among those affected is about 6 y. Assuming that this figure can be generalized, there are about 16,000 new cases per year in the region. About half of these would like professional advice (O'Brien et al, 1991). Thus, after any backlog has been dealt with, 8000 people, about 2700 in each of the three settings, might reach the screening level of care each year. In the first few years, because of a backlog of untreated cases, the numbers might be higher.

As an illustration for the purposes of Figure 5, the following estimates have been made on the basis of informal surveys of informed opinion and the literature (Jeter and Wagner, 1990): 50% are satisfied or adequately reassured at the screening level; the other 50% go on to primary continence care; 35% of these are referred on to a higher level of care; those referred from rural/remote regions go to secondary care in small cities or in the urban center in equal numbers; at the secondary level 80% can be treated adequately; the remaining 20% are referred to the urban/academic centre for tertiary care. It is noteworthy that, of the 8000 per year seeking help at the screening level, only about 270 ultimately require tertiary care. Obviously these figures are open to debate, but they provide a working basis for a discussion of numbers at each level.

The numbers of health care professionals needed to provide this care can be estimated as follows. Experience shows that each full-time health care professional in a primary or secondary level multidisciplinary clinic can care for about 250 new patients per year (Griffiths, 1997). A specialist (urologist, gynecologist or urogynecologist) can probably care for about the same number of new incontinent patients per year. Based on these estimates, the necessary numbers of specialists and other health professionals are shown in Figure 5. These numbers are full-time equivalents. Thus for example the figure shows that 2 fte specialists are required in the region, serving 2 million people. In actual practice probably only 10-30% of a specialist's practice relates to incontinence, so that a somewhat larger number would be involved in total. For comparison, there would currently be about 40 urologists in a region serving 2 million people, in addition to gynecologists and geriatricians.

Regional models of continence care and their relation to the regionalization of health care in general

It is important to understand the issues surrounding the establishment of regional continence care models in Canada. These issues differ from province to province but must be addressed because regionalization currently plays such a prominent role in determining the changing structure of health care.

After screening, most clients will be seen at the primary level, where they will be evaluated and treated by family physicians, nurses, or physical therapists. Some can be adequately evaluated and managed at this level, but some will be referred to a higher level of care, in accordance with the Canadian consensus guidelines for clinical practice. In most provinces, the approval of a family physician will need to be obtained before referral can be made, since this is essential both for a formal diagnosis and for payment to the specialist involved. In some provinces, referral can be made only along predefined pathways within the region.

The proposed three-level model of continence care (plus a screening level) is flexible enough to adapt to different local conditions, but there are still some issues to be addressed.

1. At the primary level, not every family physician or nurse has a particular interest in incontinence. We hope that all health care professionals would be able to provide the screening level of education and care; however, even this stage requires some minimal

training. For family physicians, funding of incontinence screening as a specific procedure would encourage its adoption.

2. At the secondary level, not every urologist or gynecologist has a special interest in incontinence or is able to devote the required time to managing referred patients with incontinence. Funding and payment may be a problem as assessment and treatment are often time-intensive. The role of health professionals, such as advanced practice nurses or nurse continence advisors, may be critical. These individuals will need to be trained in quite large numbers.

3. At the tertiary level, assessment of the patient is resource-intensive and costly. Therefore, issues of payment and funding may again be important. A limited number of clinics are available in Canada and only a relatively limited number of patients can be seen. Of course, the decision of whether to refer a patient to the secondary level or direct to the tertiary level should be based on the guidelines, but it has to be individualized. If the primary-level physician has the final decision, how much time will tertiary level clinics be willing to devote to patients referred from this level, as opposed to patients referred from the secondary level by specialist physicians?

4. Travel to tertiary level units for people in outlying rural areas is expensive. Their expenses for accommodation and travel need to be covered. (Some provinces do have plans that address travel costs.)

5. Referral pathways need to be defined so that each primary level clinic knows who to refer to, and the different levels are developed to work together.

These issues indicate that, apart from adequate funding, training/education of consumers and health care professionals at all levels is also an integral part of continence care, to ensure that there is satisfactory access and that there are enough interested primary health care providers and specialists to allow a satisfactory referral pathway. The importance in actual practice of some of the issues can be tested by piloting the models we propose. Other issues, for example the work load at the tertiary level, can only be roughly extrapolated from a pilot study.

WORKING MODELS OF CONTINENCE CARE

Before describing in detail the 3 models of care in the chosen settings it is helpful to refer back to Figure 5. As shown, the main differences between the settings are in the levels of care available locally. The typical level of care in the rural/remote setting is primary; rural patients requiring secondary level care have to be referred elsewhere. The highest level of care in most small cities is secondary; small-city patients needing tertiary care have to be referred to an urban/academic center. Consequently, in the following descriptions, primary level care is described most fully in the rural/remote setting (remembering that primary care in the other settings is similar); secondary level care in the small-city setting; and tertiary level care in the urban/academic setting. The screening level is described in detail in the urban/academic setting, but is similar in the other settings.

1. Continence Care in the Rural/Remote Setting

Introduction

In rural or remote regions, distances between caregivers, and between caregiver and patient, are often large. There is typically a general shortage of health-care personnel and a lack of specialist care. Most of the care will be given by a diverse mix of health-care professionals, often self-taught in incontinence management. Specialized equipment and knowledge may not be locally available. Federal government policy is specifically directed at improving health care in these areas (Health Canada, 1999).

Given these limitations, the emphasis must be on simple therapies that do not require special equipment and carry little risk of side effects or contraindications (i.e. behavioral therapies, such as pelvic muscle exercises and bladder retraining). Thus, primary care may be the only level of care that can be provided, relying on referral for higher levels of care.

To minimize staff time, treatment of patients in a dedicated unit might be the ideal, allowing one therapist to supervise several patients at the same time. However, it is more realistic to suppose that the continence care is provided by a team dispersed over several locations. Use of telehealth technology may be critical to facilitate communication within the team and with professionals outside the area.

To ensure that rural teams share a common philosophy and meet a minimum standard of practice, a rural-friendly educational program for health-care providers must be put in place. Training may eventually be standardized by an accepted certification program for practitioners. Individuals who may not have the formal education may be grandfathered, as it is essential to encourage practitioners who are currently providing continence care to continue to do so. There should be a mechanism to insure that all team professionals have a basic level of knowledge and technical skill in incontinence assessment and care, and for certifying that the team is able to meet an acceptable standard. This mechanism must satisfy the legal requirements relating to professional practice in each individual province.

The proposed model most closely resembles the primary level in the Israeli national continence service, the peripheral clinic staffed by a physician and a nurse (Milne & Moore, 2000). Its structure is shown in Figure 6.

Description

Screening level:
Continence care at the screening level is critical. It is intended to facilitate access without overloading the limited number of professionals who are expert in continence care. A detailed description is provided in the urban/academic model.

Primary level:
Continence care at the primary level is provided by multidisciplinary teams, to consist of at least two of the following:
A) Registered nurse
B) Physical therapist
C) Occupational therapist
D) Family physician

If there is no family physician in the team, the team should develop a working relationship with a motivated family physician, and from a legal point of view it may be essential to enter into a formal agreement. The family physician provides the following services as required:
a) Formal diagnosis as to type of incontinence and the role of other medical diseases or factors in the incontinence.
b) Help in elaboration of a treatment plan, including :
i) Identification of patient/family expectations and establishment of measurable and individual goals
ii) Suggestions for appropriate therapies
iii) Referral to specialized non-physician services (e.g. physiotherapist - required in some provinces, and as per local practice).
iv) Help in deciding who to refer to secondary or tertiary levels of care and signing of referrals (required in most provinces)
v) Recommendations for pharmacotherapy, as indicated. The physician may provide authorization for therapy over the telephone or via a telehealth network, if he/she is satisfied with this approach.

If possible, a social worker should be associated with the team and participate in the evaluation of the patients. His/her work will include :

a) Ensuring patients use government plans, etc to pay for services and appliances
b) Helping with travel arrangements
c) Support of care-givers and people being cared for at home
d) Liaison with other bodies and organizations

Although in practice the team may be dispersed over several locations, ideally the members would be situated in one reasonably accessible building, e.g. a rural hospital, outpatient health center, community center, or free-standing clinic, depending on the local situation. This would provide an opportunity for clients to see all health-care providers in the team at the same visit and to view educational material and incontinence products. The aim should be "one-stop shopping" as far as practicable. To this end, the individual members of the team may operate as a team on days and times selected according to demand and availability, for example one afternoon/month. For specific therapy and monitoring, e.g. for biofeedback, patients may meet with their individual therapist on an individualized, more frequent, basis.

Relation to Other Levels of Care

The team will receive self-referrals from patients/clients and referrals from other health-care professionals in its own area. As it is not practical to provide teams in all population centers of a catchment area, the screening level of care will be of special importance in attracting clients from outlying areas. The team should provide a consulting service in these areas, resources permitting, including telephone/email consultation for health-care professionals, educational material and support, and a telephone information/email advice service for patients/clients. It should receive referrals from this source, and provide assessment, treatment and telephone/email follow-up if the problem cannot be resolved locally. Distances and resources permitting, visits to outlying areas to meet with local health-care personnel and patients may be important.

The relation of these primary-care continence teams to the screening, secondary and tertiary levels of care is shown in Figure 6.

Assessment Process

All teams should offer the following as part of the assessment process, on an "as indicated" basis in each individual client. Decisions about the division of labour (i.e. who does what) are subject to local availability, individual levels of training and experience and general preferences :

Basic Urological, Medical and Surgical History, including Social History and "Burden of Illness"
FP or RN or PT

Focused Physical/Neurologic /ADL
FP or RN or PT or OT

"Pelvic Floor" Examination (not "full pelvic" exam) FP or RN or PT

Bladder Diary
RN or PT or OT

Dipstick Urinalysis
FP or RN or Lab

Residual Urine (With Medical Order)
FP or RN

FP = family physician RN = registered nurse PT = physiotherapist OT = occupational therapist. Note that all of the above diagnostic modalities are part of initial management as defined in the flow charts that form part of the Canadian clinical practice guidelines for continence care.

Following this basic work-up, establishment of the presumed etiology and elaboration of a treatment/management plan should be multidisciplinary, involving all members of the team including the family physician.

A standardized questionnaire/ examination form would help to insure uniform standards. Similarly, a standardized and validated method of assessing the severity of the incontinence is desirable. A possible role for The Canadian Continence Foundation is to provide such forms to all teams who desire them.

The Canadian consensus guidelines on management of urinary incontinence should be the standard reference.

Treatment/management

As a minimum, the following should be offered by all teams, on an "as indicated" basis:

Lifestyle Changes, “Non-specific Advice”
RN or PT or OT or FP

Behavioural Therapy (e.g. timed voiding)
RN or PT or FP

Bladder Retraining/Urge Suppression
PT or RN or FP

Pelvic Floor Muscle Exercises
PT or RN or FP

Appliances (i.e. Pads) and Devices
FP or PT or OT or RN

Pharmacotherapy
FP (or Advanced Practice Nurse if available)

Social Support
Social Worker or RN or FP or PT

Home adaptation suggestions
OT or RN or PT

Referral to secondary or tertiary level
FP (or as per local practice)

All the above treatment/management modalities are included in initial management, as defined in the Canadian clinical practice guidelines for continence care.

Other treatments or management such as electrical stimulation, biofeedback, or vaginal weight training, may be offered as per local expertise, preference, and equipment availability.

Other services

The teams should offer a home-care ("outreach") service for evaluation and treatment of patients who are house-confined, provided distance and other factors permit.

General role of the multidisciplinary teams at the primary level in rural/remote settings

The teams evaluate and treat only urinary incontinence and do not function as urological or gynecological clinics. They should not take on an ongoing health-care role from the client's regular family physician. The team provides an evaluation and treatment or management, plus specific follow-up as required.

With the client's consent, the team should send a letter to the family physician, informing him or her of the diagnosis or presumed etiology, the results of any relevant tests and their recommendations for a treatment plan, as well as what has already been done, e.g. "Pelvic muscle exercise instruction given."

The final decision on drug prescriptions is the responsibility of the regular physician. Although it may make recommendations, the team in most cases will not prescribe medications, as this decision, and the monitoring of any drugs given, are best left to the regular physician.

Consent of the client's regular family physician should be sought before referral to a higher level of care.

The team may provide periodic re-assessments of clients at reasonable intervals after the first evaluation/treatment. Again, a letter will be sent to the patient's regular physician.

Funding and payment issues concerning primary-level care

One of the major barriers to continence care is funding. Without supportive funding, proactive, rational continence care is unlikely. Payment has varied from province to province, and this issue is especially important for non-physician health professionals, who traditionally have either been on either an hourly or a weekly salary from an institution, or else on a fee-for-service from either the patient or a third party. Physicians have traditionally been on a fee-for-service. It is questionable whether the traditional fee-for-service mode is the most effective for treating a complex problem such as urinary incontinence, since it may not permit taking the time needed to perform a thorough continence assessment.

The following payment modalities may be considered:
a) “Global fees” - the team is paid a set fee for initial evaluation of the incontinent patient, including all diagnostic tests; and then set fees for each service, e.g. a fixed fee for pelvic muscle exercise instruction (no matter whether this requires 15 minutes or one hour).
b) “Sessional fees” - the team is paid a set fee for a three-hour block of time
c) “Salary” - the team members are on a salary
d) “Fee-for-service” - e.g. a set fee for the initial evaluation (history and physical examination), a set fee for a residual urine determination, and a set fee for a 10-minute pelvic muscle exercise session.

Implementation

The barriers to implementation include the need to identify and train the many health professionals needed to establish continence teams wherever they are needed. The present limited education available - which is aimed primarily at nurses - needs to be developed into an accepted certification program for all primary-level practitioners.

Professionals could be attracted to participate in and set up continence teams by properly structured payment, but arranging a satisfactory payment schedule requires negotiation with different provincial jurisdictions as well as adequate funding.

Consistency with Canadian clinical practice guidelines for continence care

The main aim of the model is to put the Canadian continence care guidelines into practice in the rural/remote setting. In the guidelines, initial management includes the simpler assessment, therapeutic and management procedures that can be carried out safely on the basis of a presumed etiology. The multidisciplinary teams proposed here carry out initial management, leaving specialized management, for patients who fail or are unsuitable, to be carried at the secondary or tertiary level on referral, exactly as proposed in the guidelines. Compliance with the guidelines for initial management will ensure that patients with complicated problems receive adequate assessment, so that the problems are recognized and referred to an appropriate physician.

SUMMARY: The rural/remote setting

The characteristic level of care in the rural/remote setting is primary care, providing initial management as defined in the clinical practice guidelines. In many respects this level of care will be similar in the other settings, but there are characteristic problems of distance and scarce resources that need to be overcome in the rural/remote setting. Telehealth techniques and a well-developed screening (community outreach) level of care may be helpful. Patients requiring specialized management will normally need to be referred to secondary or tertiary care in a city.

2. Continence Care in Small Cities

Introduction

Canada is a country of "small" cities. For continence care, the lack of large urban centres creates special challenges:

1) Shortage of specialists (urologists, urogynecologists) in some areas;
2) Lack of resources (urodynamics labs, endoscopy facilities, and operating rooms);
3) Insufficient availability and utilization of health care personnel such as nurse continence advisors and physical therapists;
4) The trend to regionalization in some provinces

The model suggested for a small city is adapted from the three-tiered multidisciplinary services in Israel and Somerset (UK) (Milne and Moore, 2000), taking into account that in small cities there are independent specialists and often referrals will go from the primary level to the specialist. Because the number of health care professionals with advanced training is limited, a multidisciplinary secondary level may not always be available. However, the multidisciplinary clinic is emphasized to encourage the adoption of this concept. One of its advantages is that clients may prefer to speak directly with a continence nurse rather than a physician regarding an issue as sensitive as incontinence. Another is that it promotes help-seeking by limiting the steps required at a time when many primary caregivers are not adequately informed regarding continence care (although we intend to change this situation).

Description

Screening level:

This level of care is just as important in the small city as in the other settings. It is described under the urban/academic model.

Primary Level:

This level of care, the relation of non-MD health care professionals to a physician, and funding issues, are discussed extensively in the rural/remote setting. A few points require emphasis in the small-city setting. The entry point to this level is self-referral. Continence care is typically given by a sole provider, preferably working as a member of a team, and usually a family practitioner, physiotherapist, or community nurse. Initial management is provided in accordance with the Canadian clinical practice guidelines. Basic assessment includes establishment of goals and expectations of treatment, history and focused physical exam, bladder diary, urinalysis (lab or dipstick), and if possible a pelvic exam and post-void residual urine. Treatments include life style changes, behavioural therapies, pelvic floor muscle exercises, and containment measures. The family physician might suggest medication. The community nurse would have the opportunity to suggest environmental changes.

Secondary Level:

The point of entry to this level can be either self-referral or through the primary care system. Continence care is provided by a mix of specialists and one or more multidisciplinary continence clinics. The ideal setting for a continence clinic would be a community health centre. To run such an operation, a multidisciplinary team is needed, as shown on the chart below. Depending on the size of the city and the number of independent specialists, more than one clinic may be required (see estimated numbers, Figure 5).

In addition to initial management similar to that at the primary level, the secondary centre should offer assessment and treatment as shown on the chart below, and should provide advice on containment products and keep up-to-date on new products and devices. It should offer outreach and educational resources. Further description is provided below.

As shown in the flow chart (Figure 7), at the secondary level a significant role is played by independent specialists (urologists and gynecologists) and geriatricians, working outside the multidisciplinary clinics. They will receive direct referrals from primary care physicians in the city, and also from multidisciplinary clinics, thus providing an alternative to immediate referral to tertiary care outside the city.

Tertiary Level:

In most small cities the tertiary level does not exist. In the past, urologists and gynecologists in small-city practice have treated the majority of patients referred from family physicians. However, the situation has slowly changed, so that clients who need specialized management are frequently referred to a large tertiary-care facility. For example, in Manitoba, most cases requiring urodynamics will be referred to Winnipeg.

The need for referral should be based on the Canadian clinical practice guidelines. The tertiary level provides more advanced diagnostic testing such as urodynamics and urinary tract imaging, and advanced or complex treatments such as neuromodulation. It is discussed more extensively in the urban/academic setting.

The structure of the small cities model is shown in the flow chart (Figure 7).

Characteristics of the secondary-level, multidisciplinary continence clinic in small cities

Service:

Initial management of incontinence is delivered via a continence clinic or clinics; it may also be delivered by independent specialists. The multidisciplinary clinics provide specialized management by urologists, gynecologists or geriatricians attached to the clinic or via well-

established lines of referral to specialists in the same city. These independent specialists may provide specialized management without involvement of the clinics.

Clinic staff may include 2 or more of: 1. Nurse with expertise in continence care:
nurse continence advisor
enterostomal therapy nurse
advanced practice nurse
2. Physiotherapist with expertise in continence care
3. Family physician

With lines of referral to: Home care nurse
Social worker
Occupational therapist
Urologist or urogynecologist

The clinic provides outreach: Domiciliary
to Long-term care facilities
to Community Health Clinics (possibly via a satellite clinic)

Location Continence clinic in outpatient hospital or community clinic

Incoming referral pathways Open
From home care/VON
From a physician

Assessment/treatment Bladder scanner (ultrasound)
Uroflowmetry
Simple cystometry
Referral for urodynamic testing

In detail, the treatments provided depend on which health care professionals are available. They may include:

Behavioural strategies: Pelvic muscle exercises
Biofeedback
Electrical stimulation
Devices such as vaginal cones
Pessaries
Education

Other: Pharmacological intervention
Straightforward surgical procedures

Funding of secondary-level care

Experience in small cities suggests that programs paid for by the client on a fee-for-service basis encounter difficulties with fee collection. Clients feel that the service should be covered through Medicare. Since most of the staff in continence clinics situated in health care facilities are salaried employees, Medicare should cover the salaries and other services. The exception might be devices used in treatment, such as probes, pessaries and vaginal cones, which ideally might be (but rarely are) covered by third party insurance.

Funding via Medicare might be feasible if it could be shown, in pilot studies, that continence services help reduce overall costs of incontinence to government, by keeping people at home longer, reducing the need for absorbent supplies, and reducing time out of the work force. With limited funding, other resources may need to be looked at, including peer-manned telephone lines, support groups and volunteer educators, for example retired health care professionals.

Implementation

Apart from funding, the main obstacle to implementing this model is lack of knowledge about incontinence and its management. The screening level requires wide dissemination of basic knowledge about incontinence. At the primary level, the sole providers would require additional training as little is normally taught about continence in any health professional's formal training. At the secondary level, further education again is required. For example, in Manitoba there is only one nurse continence advisor and five physical therapists with advanced training.

SUMMARY: The small-cities setting

The characteristic level of care in a small city is the secondary level, providing initial management and some aspects of specialized management of urinary incontinence. Initial management can be well provided by multidisciplinary clinics, but in small cities in the past the bulk of the management has been provided by independent specialists. The multidisciplinary clinic works in cooperation and in parallel with these specialists, and this is reflected in the complexity of the flow chart (Figure 7). Patients requiring full specialized management will be referred out of the small city to an urban/academic centre. The screening (community outreach) level of care is again critical in the small city.

3. Urban/academic model of continence care

Introduction

In an urban centre there is a dense population of several different groups of clients who in principle have the opportunity to access a large number of health care professionals with knowledge of continence care. At present, however, there is no easy self-referral access that

allows initial incontinence assessment, with the potential to refer on to a specialist if needed. The current structure of continence care means that many clients do not receive a basic continence assessment from their initial contact with a primary health professional, and must wait until they are seen by a tertiary care specialist, such as a urologist, urogynecologist or gynecologist. This often creates a lengthy waiting period for clients who are experiencing mild to moderate incontinence and who could benefit from behavioural interventions at an earlier stage. In Edmonton, Alberta for example the present waiting list to see a urogynecologist is 18 months.

Currently, there is often duplication of services due to a lack of interaction between continence specialists in the urban centre. The goal of the model is to expedite access and referral of clients to continence care, create a logical flow chart and enhance communication with health care providers across the sites. The continuity of continence care will require the participation of the client's family physician.

The urban/academic model provides accessible continence care at primary, secondary, and tertiary care levels. As shown in the flow chart (Figure 8), there is a web of connections between the tertiary level of care, and sites for screening and primary care, as well as secondary level clinics operated by independent specialists. The tertiary and secondary levels receive referrals from their own urban community (for complex cases), but also from small cities and rural/remote areas in the region. Continence care services in this model have to augment the care that is provided at the primary and secondary levels in rural areas and small cities, where there are fewer available resources and multidisciplinary specialists.

Because the tertiary level is the distinguishing feature of the urban/academic model, it receives most attention here, together with the screening level, but the secondary and primary levels of care are just as important, because many patients never require tertiary-level care. (See estimated numbers in Figure 5). The proposed model resembles the National Continence Centre of the Israeli model of care (Milne & Moore, 2000). The structure is shown in Figure 8.

Overview

The urban/academic centre model for continence care in Canada functions in five major areas:

- clinical service and consultation
- a referral centre for the region
- education
- community care development
- research

Some of these involve all levels of care. Some are specific to secondary or tertiary care.

Clinical service and consultation

How and to whom care is provided at the screening, primary, secondary and tertiary levels is explained below and illustrated in the flow chart (Figure 8).

The staff required for this task are specified below, but to deal with the large numbers of potential clients at the screening and primary levels, it is only realistic to suppose that many different types of professionals will be involved. They will require some training, and this is one reason why the education function is important.

Outreach is an important part of the service for patients who cannot reach clinics. Multidisciplinary outreach teams, home visits, or monthly clinics in outlying areas by visiting specialists, may have to be arranged.

The urban centre provides consultative services to professionals requiring information or assistance in remote areas and small cities as well as in urban areas. Ideally a support network would be established for the health care professional with limited resources, providing discussion of problems during conferences and rounds via phone or computer. A 1-800 help line similar to that currently available through The Canadian Continence Foundation might provide information to clients, families and professionals.

A referral centre for the region

The tertiary and secondary levels accept referrals from small cities and rural/remote areas in the region, as described above and also in the detailed description below.

The baseline assessment conducted at primary level before referral should have included the goals and expectations of the client or caregiver. This enables clients to be evaluated for success/improvement at each level. Follow up, including further evaluation, is managed by the initial referral site, in consultation with the specialist as needed.

Education

Education in the city and its surrounding region is a critical function of the urban/academic model. Patient and caregiver education will occur at all care levels. The secondary and tertiary care levels will provide education and training of health care professionals, including education about basic screening and assessment, as well as more advanced education. It may be provided in collaboration with professional organizations, universities, and/or The Canadian Continence Foundation.

The tertiary level of the urban/academic model thus provides comprehensive multidisciplinary clinical expertise for clients; and consultation, support and education (formal and informal) for professionals, clients and caregivers.

Research and community care development

The tertiary level is the setting where research and community development occur in partnership with organizations such as The Canadian Continence Foundation. The development of support groups for clients and their caregivers can be initiated at this point.

The urban/academic centre fulfils a leadership role, working in partnership with others to initiate and conduct continence research studies. Recent information and findings would be disseminated to outlying areas, small cities, and urban communities.

The urban/academic centre should be actively involved in promoting continence awareness by interacting with the media and by acting as advocate for the clients and their families. This can be facilitated in association with The Canadian Continence Foundation at a local and national level through participation in Continence Awareness Month, and by hosting conferences and educational presentations.

Consistency with environmental scan and Canadian guidelines for continence care

The role of proposed model for continence care in an urban/academic centre resembles that of the National Centre in the Israeli model, described in the environmental scan of existing continence services (Milne & Moore, 2000). We believe that it reflects a logical, client-focussed approach to continence care in urban Canada.

The model provides for initial management, mainly at the primary and community-outreach levels of care (letters B and C on the flow chart, Figure 8), and for referral to specialized management at secondary or tertiary levels (letters D, E, and F) when appropriate, as suggested in the guidelines.

Detailed description of the levels of care provided in the urban/academic model

Screening level/Community outreach

The aim of this level is to greatly improve access to the pathway of continence care by ensuring that front-line professionals (e.g. family physicians, nurses, physiotherapists, pharmacists, and social workers), even though not highly trained in incontinence, nevertheless encourage discussion of it with their clients, screen for it, suggest simple lifestyle measures if appropriate, and refer appropriately to the primary level of care. Principles and practice will be similar in the surrounding small cities and rural/remote areas but will of course be addressed to the residents of these areas.

ServiceIdentification, screening or assessment of clients in the community at a basic level
Community , institutional (including long-term care) and domiciliary outreach.

Clients Urban-residing individuals with urinary incontinence who are unable to visit the clinic location(s) or who have not yet accessed available resources

Health Care Professionals (as available) Nurse continence advisor
Home care nurse 1
Physiotherapist 1
Long term care nurse 1
Licensed practical nurse 1
Occupational therapists 1
Enterostomy nurse 1
Pharmacist 1

1 These health care professionals may be seeing the client for other reasons. Other para professionals and disciplines as well as trained volunteers may be able to complete basic screening questions and continence information in collaboration with a continence professional.

Referral Pathway Self-referral by client, family or caregiver; referral encouraged, particularly from institution if client discharged

Assessment/Treatment Basic identification and screening
Provision of knowledge of available resources, by nurse or physiotherapist with basic continence training
History: standardized check list available to obtain a brief history
Initial assessment and treatment as per clinical practice guidelines, with recognition of limitations imposed by home environment
(No physical examination will be done at this basic level)
Referral for further testing in clinic environment if able to attend

Important Considerations/rationale:

I. An important part of outreach services will be the involvement, through teaching and open communication, of community health personnel, particularly the family physicians, health nurses, and pharmacists.

II. Domiciliary professionals will be an integral part of the team and information will be reviewed in team meetings, as possible.

III. Clients will be referred to clinic if mobility increases.

Primary care level

This level of care is fully described in the context of the rural/remote model. The following points are important in the urban/academic setting.

ServiceInitial assessment and management/ treatment of urinary incontinence at primary care level by health care professionals with generalist focus

Clients All individuals residing within urban area with perceived need, their families and their caregivers

Location All sites for primary care, including:

- Domiciliary (homes/community)
- Long term care facilities
- Rehabilitation facilities
- Doctor's offices
- Community health clinics

Health care professionals Health care professionals providing generalized care:

- General practitioners
- Community health nurses
- Physical therapists

Referral pathway

Open access, as currently exists.

Clients may be referred to secondary or tertiary care level at any point if more advanced assessment or treatment is required (refer to clinical practice guidelines), or if treatment at the primary level was unsuccessful and the client requests further care

Assessment/Treatment

Initial assessment as per Canadian clinical practice guidelines Goals and expectations of treatment

- History
- Focused physical examination
- Bladder diary
- Urinalysis
- Post-void residual

Conservative treatment measures Behavioural and lifestyle modifications

- Pelvic floor exercises
- Medication
- Pessaries
- Devices

Important considerations/rationale:

I. It is important that primary health professionals are educated in the basic assessment and treatment strategies. Preference for referrals from primary caregivers at the secondary level should promote this as well as open lines of communication that will enhance follow-up once the client is discharged from the program.

II. An open referral pathway is important at the secondary level to ensure those who are not in regular contact with primary caregivers, or who prefer to speak directly to a continence nurse advisor, can do so. The public will need to be educated about the levels of care and their options, with emphasis on the role of the primary caregiver.

Secondary care level

Secondary-level care in the urban centre is based on multidisciplinary clinics similar to those described as part of the small-cities model. However, the urban setting implies some differences in implementation.

To promote accessibility and meet the need in large urban areas there would ideally be community-based continence clinics (satellite centers) as well as a clinic within a teaching hospital in the city. Communication and team-building between all health care professionals will be a key component, with the various clinics acting as a unit with close communication for consultation and easy referral pathway to tertiary care services.

Clients may have been assessed, and treatment initiated, at primary care level, but require further assessment, treatment, and/or management by continence specialist; OR they may choose to directly access care by continence specialist.

Health Care Professionals

1. Hospital-Based Clinic Primary personnel (full time presence):
   Continence nurse advisor or nurse with special continence training 1
   Physiotherapist specializing in continence care 1

1 Client assigned to either continence nurse or physiotherapist as case manager to follow client through system and ensure smooth flow. Also family physician involved at this level

   Secondary personnel - pre-determined referral pathway/available for consultation:
   Urologist
   Gynecologist
   Social worker
   Occupational therapist
   Dietician
   Pharmacist
   Behavioral specialist
   Pelvic pain specialist

2. Satellite Centers/Large Community Health Clinics Continence nurse advisor or nurse with continence care training
   Physiotherapist with continence care training
   Family physician with a special interest in continence care (on site at least part-time)
   Secondary personnel available by phone for consultation

Referral Pathway Referrals from primary caregivers specifying care to date
   Self-referrals to maintain accessibility

Assessment/Treatment As per clinical practice guidelines. Attention to avoid duplicating assessments already completed at primary care level

Tertiary care level

Service Hospital-based assessment and treatment by multi disciplinary health care team with specialized expertise in urinary incontinence

Clients Individuals from urban, small cities and rural/remote areas who have been referred based on need for specialized care

Location Urban teaching hospital

Health Care Professionals include: Medical specialists with interest in urinary incontinence (depending on interest and availability):

Urogynecologist
Gynecologist
Urologist
Internist
Geriatrician
Colorectal surgeon
Nurse continence advisor or nurse with continence care training:
special teaching role, on-going follow-up of behavioral therapies, coordination of flow of care
Physiotherapist:
reinforcement of teaching to date, further biofeedback and electrical stimulation available for complex cases
Other allied health professionals:
Occupational therapist
Social worker
Dietician
Psychologist
Pharmacist
Pelvic pain specialist

Referral Pathway Referral required from health care professionals at primary or secondary care level

Assessment/Treatment Goals and expectations reviewed
Specialized with easy access to urodynamics, medical and surgical interventions

Important considerations/rationale:

I. Care management will continue to be an important role for the continence nurse/physiotherapist as clients initiate treatment at this level and are referred back to the primary or secondary levels following treatment.
II. The other important components include consultation, education, community development that would be accessed available to the referral sites, professional and the client.

SUMMARY: The urban/academic setting

The characteristic level of care in this setting is the tertiary level, providing specialized management of incontinence on referral from specialists (urologists, gynecologists, and geriatricians) in the urban centre and its surrounding region. Equally important functions are to provide screening, primary, and secondary care within the urban centre, and to ensure excellence of care at all levels through a strong educational and research component. As in the other settings, a multidisciplinary team is proposed, led in this case by specialist(s) with subspecialization in an incontinence-related field.

CONCLUSION: The next step

Three models for continence care have been proposed, suitable for three different settings typical of Canada. All offer a practical implementation of the Canadian clinical practice guidelines for continence care. The following stage of the working models process is to suggest locations where they might be piloted. This will be done partly on the basis of suggestions from reactor panels across the country. Because not all settings can provide both initial and specialized management, and because of the resulting flow of patients/clients from one setting to another (Figure 5), the three models are in reality interdependent. To enable the critical links between the various settings to be studied, it may be appropriate to pilot all three models in one urban/academic centre and its surrounding small-city region and rural hinterland (as represented in Figure 5).

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LEGENDS

Figure 5. Levels of care, referral pathways, numbers seeking help, and required numbers of health care professionals in a typical region. The arrows show referral and return pathways within and between the different levels of care and settings. For simplicity, all clients/patients have been shown as first coming to screening care, but some may self-refer directly to the primary level. Estimated numbers of new clients/patients requiring care at each level every year are shown. Estimated numbers of full-time health care professionals (HCP) and surgical specialists (SP) are indicated. The types of HCP required are described in the text.

Figure 6. Rural/remote model of continence care. The arrows show possible referral pathways within and out of the rural/remote area. Two different primary-level teams are shown. One includes a family physician. The other has a formal cooperation with a family physician who works independently, but is responsible for the work of the team.

Key to letter symbols. The letters show the types of care that should be available (but not every HCP may be able to offer every type):

A Basic education about bladder function, good bladder, bowel and fluid habits; goals and expectations of treatment; provision of knowledge about access to care; provision of knowledge about absorbent and other products,* and skin care; bladder diary; urine dipstick
B Basic assessment (including goals and expectations, history, focused physical exam, PVR, urinalysis, and bladder diary)
C Goals and expectations; lifestyle modifications; education on fluid habits; environmental changes; behavioural strategies/bladder retraining; pelvic floor exercises; education regarding pads/products* (types & selection); with or without pessaries, devices, medications, clean intermittent catheterization
D Goals and expectations; lifestyle modifications; education on fluid habits; environmental changes; behavioural strategies/bladder retraining; pelvic floor exercises; education regarding pads/products* (types & selection); pessaries, devices, medications, clean intermittent catheterization; simple cystometry; cystoscopy
E Goals and expectations; simple surgical management (including retropubic urethropexies, slings, straightforward prolapse repair, bulking agents)
F Goals and expectations; advanced investigation, imaging, and management; videourodynamics; all surgical procedures (including retropubic urethropexies, slings, all prolapse repair, bulking agents, urinary diversion, bladder augmentation, artificial sphincter); neuromodulation

* Pads/products are not an ideal treatment for incontinence, but it is important to provide information on availability and use, at least while assessment and management are ongoing

Figure 7. Small cities model of continence care. The arrows show possible referral pathways within, into, and out of the small city area. The secondary level includes independent physicians, who accept referrals directly from family practitioners. They may refer to the multidisciplinary secondary-level team, or directly to the tertiary level.
Key to letter symbols: as for Figure 6.

Figure 8. Urban/academic model of continence care. The arrows show possible referral pathways within and from outside the urban/academic centre.
Key to letter symbols: as for Figure 6.
HCP = health care professional (usually non-MD); SP = surgical specialist, PT = physiotherapist, NCA = nurse continence advisor

PROMOTING A COLLABORATIVE CONSUMER-FOCUSSED APPROACH TO CONTINENCE CARE IN CANADA

A REPORT ON

THE SURVEY OF "REACTOR PANELS"

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Summary

Seven Reactor Panels, located in varied regions/communities across Canada, held meetings for two main reasons. These reasons were (1) to discuss the new Canadian Clinical Practice Guidelines for the Assessment and Treatment of Incontinence and the accompanying Continence Care Delivery Models and (2) to express their views, in light of the Guidelines and Models, on how best to implement continence care delivery in their setting. The information from these meetings makes it clear that: (1) all the stakeholders see the guidelines as viable (2) there is a perceived need for improving Continence Services despite existing barriers and (3) there is an interest in implementing these guidelines in ways that optimize service delivery. This report presents the results of a detailed analysis of information gathered across these meetings to gain insights into how effective continence care can be provided. Recommendations derived from the survey are provided.

Brief History

The survey of Reactor Panels is the fourth and final part of a three-year project titled "Promoting a Collaborative Consumer-Focused Approach to Continence Care in Canada". This project is funded by a grant awarded by Health Canada, Population Health Fund, Division of Aging and Seniors to The Canadian Continence Foundation (TCCF) in 1998. The first part of the project was a critical review of Canadian and worldwide continence services called the Environmental Scan. This review formed a backdrop to the second part that was the job of two multidisciplinary committees called the Guidelines Committee and the Working Models Committee. These committees worked in tandem to (a) draft up-to-date assessment and treatment guidelines (Guidelines Committee) and (b) to outline models of continence care delivery that would follow the guidelines and work in Canada (Working Models Committee). The third part was a Consensus Conference held in May 2000 at which consumers and delegates from across Canada discussed and debated the proposed guidelines and working models. Then, following formal voting procedures, they adopted these guidelines. It is important to emphasise that from the outset this project paid careful attention to both the scientific integrity and the practical application of the guidelines. This is the reason for the development of the Working Models alongside the Guidelines with the collaboration of the various professional disciplines and consumers. However, there remains the question of whether those operating in varied communities across Canada would find the Guidelines and their application 'workable'. The survey of Reactor Panels, therefore, was a test case to ascertain the perceived viability of the Guidelines and their application.

Method

Sample. The seven centres, listed in Table 1 below, participated in the survey. In the initial proposal (section on Phase 4) the goal for the survey of Reactor Panels was to survey 3 key sites composed of a large urban site, one small community and one rural/remote site. Subsequently it was decided in discussions with Health Canada to expand this survey to include, if possible, a survey of 13 sites so as to improve the sample size. In order to undertake this survey it was necessary for continence care professionals located in centres across Canada to volunteer to establish a Reactor Panel that would meet at a convenient time/location and host a survey of their discussions. The Executive Director of TCCF negotiated with the seven hosts and provided support for the meeting.

Table 1
Locations of the Seven Reactor Panels and their Designation by Population Size

Urban/Metropolitan (Includes University)	Small City	Rural/Remote
Winnipeg (Oct. 13, 2000)	Red Deer (March 30, 2001)	Kirkland Lake (Feb 8 & 9, 2001)
Halifax (Feb. 18, 2001)	Oshawa (April 11, 2001)	[2 Rural/Remote locations were cancelled as explained in the text]
Hamilton (March 16, 2001)	Sudbury (April 27, 2001)	

Note: Reactor Panel meeting dates are in Parentheses

Procedure. Copies of the 4-page handout titled "Description of Survey and Terms of Reference" along with copies of the Guidelines and the Working Models were sent to each Reactor Panel host for distribution. A copy is appended. The purpose of this handout was to provide clear instructions and objectives for each Reactor Panel and to provide a common structure that allowed comparison of results across the Reactor Panels. More specifically, this handout provided the Reactor Panel members with a list of goals, questions, and a format to follow. This handout was distributed (along with copies of the Guidelines and Working Models) to the stakeholders prior to their meeting so as to allow them to prepare for the ensuing discussions.

The Executive Director of the Canadian Continence Foundation, Ms. Ruth Pelletier, and the Project Evaluator, Dr. David Reid, attended each Reactor Panel. The evening before the meeting, the host(s) met with Ms. Pelletier and Dr. Reid to overview the agenda so as to affirm the stated objectives/procedures of the Reactor Panel. Although timing varied from location to location in order to optimize participation of stakeholders (e.g. one site met on a Friday evening during a blizzard and Saturday morning), the meetings were similar in length and typically ran from 8:30am to 3-4 p.m.

Results/Discussion

Participation

The success of the Reactor Panels depended, in part, on the participation of a wide variety of professionals and consumers. Table 2 presents the distribution of the professionals and the consumers for each Reactor Panel. The data in Table 2 indicate that in general, the participants across the Reactor Panels represented a wide sampling of stakeholders expected to both play a key role and/or to have considerable interest in the provision of Continence Care in their location. With the exception of Kirkland Lake, there was a consumer representation at all the meetings. Also, the number of participants in each Reactor Panel, compared to each host's knowledge of the total number of stakeholders in the location, was large. It needs to be pointed out that while Kirkland Lake had the lowest number of participants, Kirkland Lake is also the smallest community that participated and it was also that Reactor Panel meeting that took place during blizzard conditions. It is important to emphasise, however, that all the hosts expressed disappointment at the lack of participation of General Practitioners (GPs) even though they had made special efforts to invite them and to arrange times to suit their normally busy schedules. The issue of participation by GPs is raised later in this report.

Viability of the Guidelines

The Guidelines had gone through several iterations in their development culminating in the multidisciplinary endorsement at the Consensus Conference. There remained, however, an interest in the extent to which the stakeholders in various regions of Canada would find the Guidelines to be "workable", "usable" and of "value" for both educational and applied reasons. This determination is done best by having the Guidelines carefully reviewed, on site, in light of the challenges of utilising the Guidelines in specific locations. The word "viable" means "practical", "workable" and "capable of growing and developing" (Random House Dictionary of the English Language). At each of the Reactor Panels, and nearing the end of the day's discussions, the participants were asked to vote on whether or not they viewed the Guidelines as "viable". The meaning of that word was explained before the vote was taken. Across the seven Reactor Panels there was consistently a consensus on the viability of the Guidelines with the following exception. At three of the Reactor Panels one consumer in each case chose to abstain from voting, indicating that she/he felt that only the professionals should judge the adequacy of the detail in the Guidelines.

THEMES: Common Suggestions, Concerns, and Directions Raised by the Reactor Panels

A key part of this survey was to garner the wisdom and insights of Reactor Panels as they discussed both the guidelines and their application in their respective setting. This information was gathered in the form of notes, often verbatim, that were taken while the participants were exchanging pertinent points of view. These notes are qualitative data that represent the essence of the discourse among the Reactor Panel stakeholders. These data have been submitted to a form of qualitative analysis in order to discern the underlying themes that were raised across the Reactor Panels. Table 3 contains each of the themes. Underneath each theme are the "notes" or data that were interpreted as being consistent with the identified theme. Typically the themes as written in Table 3 reflect the actual words of the speaker(s).

It is important that the reader realise the following, when reviewing Table 3. First, each Reactor Panel engaged in open discussion and was not cued to discuss the themes identified. The one exception is that following the strong suggestion for a single-sheet flow-chart of the Initial Assessment guidelines from the first two Reactor Panels, the subsequent panels were informed of the suggestion if they did not automatically make the suggestion on their own. Thus, the identification of which Reactor Panel discussed the implicit 'theme' is provided in Table 3 so as to demonstrate how common the theme was across the Reactor Panels. If the theme was not discussed at a particular Reactor Panel it means the idea was not apparent from the notes taken; it does not mean they do not endorse the "theme". Second, it is important to keep the extensive detail in Table 3, rather than merely include a smaller sample/example of the "data", so as to underscore the integrity of the data analyses and to provide the reader with the advantage of reviewing the "data" for her/his consideration. The continuity of the themes across the samples of stakeholder/consumers is quite notable.

Interpretation of the Themes

The 15 themes in Table 3 are interpreted through sorting them into four categories with each category having an overarching emphasis. These four emphases form the basis for recommendations presented at the end of this report.

 Suggestions for Optimizing the Efficacy of Guidelines. Themes 1 – 6 fall into this category. They reflect the common opinion that the Guideline flow-charts and the Working Models were ideal for focusing on factors and assumptions critical for applying the guidelines to the individual client. The first was the importance of having the flowchart in a form that was easily available (e.g., coated card – Theme 2) and on a single sheet for initial assessment (Theme 1). The latter provision has already been made. The second was the strong emphasis placed on the difficulty some consumers and health care providers have in effectively and sensitively broaching the topic of incontinence. Thus some GPs, for example, expressed a desire for empirically validated questions that are worded so as to effectively elicit the pertinent information during the screening for potential incontinence symptoms and associated complications/concerns such as the impact on sexuality (Theme 3). The third factor was a strong emphasis placed on how critical it was that attention be placed on both clarifying and respecting the goals/expectations of the consumer as well as for the health care provider to communicate with the consumer, their expected outcome in light of the consumer's goal(s). The treatment process to be taken towards achieving that goal(s) needs to be clearly understood (Theme 4). The goals (consumer and professional) that will be used to

assess treatment outcome should also be set within a treatment plan and then re-evaluated when determining the outcome and documented. The latter could, in an ideal world, be forwarded with the patient should further treatment by a specialist be recommended/requested.(Theme 6). Finally, many health care professionals advised that the application of the guidelines would benefit from the health professionals having access to appropriate instruments and procedures such as ultrasound bladder scanner, urodynamic testing facility, knowledge of a standardised voiding-diary method (Theme 5).

- Training of Health Care Professionals in Assessment and Treatment (Upgrading). The application of the Guidelines assumes the practitioner has the appropriate level of skills to assess/address incontinence. There was a common view among the Reactor Panel participants that in light of advances in continence care; there is a great need for education/upgrading of health professionals in utilising the Guidelines (Theme 7). Furthermore, it was felt that there is variation in how well specific parts of the Guidelines may be applied, a variation that could be reduced by setting "standards of care" to accompany the Guidelines. Although "standards of practice" are normally set within professional disciplines, it would be useful to have common standards of care as they apply to continence assessment and management (theme 8). Finally, since the prevalence of incontinence symptoms is relatively high and commonplace among those seeking treatment from GPs and other professionals, the Reactor Panels felt that education and training in Continence Care should be a regular part of Medical School, Nursing education, and possibly, Physiotherapy training (Theme 9).
- It is Imperative to Focus on Educating Citizens on Continence Care. All of the Reactor Panels placed great emphasis on how critical it is that knowledge about Continence including the incontinence symptoms, management, services available, impact on quality of life and the importance of early treatment be commonplace. It was felt that there is a great deal of ignorance about Continence, that some citizens don't even realise they have correctable symptoms of incontinence. Considerable time was placed on this broad topic. Theme 10 lists the many comments and suggestions. A central emphasis was on the importance of Self-Referral by the public. It is felt that there are a large number of citizens who would not only benefit from education and cost-effective treatment (e.g. reduction in use of containment devices), but that early treatment could save on subsequent costs. These costs include unnecessary referral to specialists (due to ignorance of more conservative approaches), surgery, or pre-mature entry into Nursing Home or Home Care due to difficulties in managing incontinence at home. With the advent of increasing use of the Internet, by the public, it may be useful for health professionals to have a Web Page in which there are "links" to locations providing useful information on Continence. A Urologist reported he is already doing this. His Web Page not only briefed the patient about what to expect and bring in anticipation of seeing the specialist, it also provided the patient with a means to confirm his/her understanding of what was learned at the meeting with the specialist (and the originating referral source as well). Patient knowledge increases the likelihood of cost-effective health delivery and consumer satisfaction.
- Barriers, Challenges and Some Solutions. Three barriers are identified. The greatest barrier to addressing the Continence Care issues is the lack of funding for the assessment and treatment services (Theme 11). This lack of funding has created a circular problem. At the moment consumers must pay for any services that go beyond a brief assessment by their GP. This cost acts as a critical disincentive to seek appropriate treatment. Conversely, because

there is insufficient payment for a GP to undertake a comprehensive assessment and management of Incontinence Symptoms, there is a lack of incentive for the GP to attend to issues of incontinence. As one participant said, when a person wets herself when she coughs, the GP will be more inclined to treat the cough, than the symptom of incontinence. Furthermore, several health professionals indicate that their continence care services are so insufficiently funded that they must subsidise their services through other professional activities (thus taking their services away from treating incontinence) because there is insufficient revenue from paying patients (Theme 11 again). A second barrier is either the scarcity or difficulty in accessing medical specialists with the training/interest in treating the more complicated cases of incontinence (Theme 12). Many specialists have very long waiting lists. The specialists such as Urologists report that many of these referrals ought to have been better screened or treated at the Primary Care stage of treatment. A third barrier is the almost chronic lack of involvement of GPs in Continence Care (Theme 13). GPs who participated in the Reactor Panels corroborated the common impression that GPs are typically not involved, yet their services were seen as highly important to good comprehensive Continence Care. Factors contributing to the lack of GP involvement include the following. (1) Many GPs do not see incontinence as sufficiently important alongside what they perceive as more critical complaints. (2) GPs are generally overworked and too busy to spend the necessary time to undertake Continence Care. (3) Many GPs do not have the training to undertake the assessment and treatment of Incontinence. (4) Either GPs do not know about Continence Care efficacy or do not know a primary care professional they are confident in referring a patient with symptoms of Incontinence. (5) The Billing Practices normally neither remunerate GPs directly nor adequately for the comprehensive assessment and treatment of incontinence. Two Solutions Proposed. The Reactor Panels did suggest two approaches that, with the availability of funding, could be next steps in the improvement of Continence Care. These steps are in addition to the highly important enterprise of educating citizens and agencies about Continence Care. The first approach is to encourage the establishment of Continence Clinics and/or Virtual Continence Clinics, particularly in places where demand is high and there are the resources and the will be create such a systematic, multidisciplinary approach to continence care. Theme 14 includes a list of benefits from having a Clinic. A main benefit of the Clinic is to create a kind of one-stop comprehensive service that begins with a thorough assessment and triaging that focuses on conservative treatment. The assumption is that this is the most cost-effective way to address the problems presented by consumers. Among the benefits are assuring that only the most appropriate cases are referred to a medical specialists, that the GP's have a resource to refer patients presenting with continence problems, and that the consumer receives the kind of care that is both empowering and beneficial in the long term. The second approach is to encourage the establishment of working alliances (Theme 15) between one or more referring GPs and a health professional with special training in Continence assessment and treatment. This approach may be particularly advantageous in locations where there is neither sufficient resources nor demand to set up a Clinic. It is also the kind of arrangement that can augment (continence care within) solo practices such as GPs preferring to work independently (other than join in such a alliance). A working alliance is thought to be beneficial because in light of the Guidelines, medical involvement or consultation is highly desirable, yet much of the assessment and treatment outlined in the guidelines can be done more readily (largely due to

greater availability and specialized training) by a health professional. Continence Care could, in the future, be offered as a specialized and remunerated service such as Nurse Practitioners.

Recommendations

The following recommendations are based on information received from the Reactor Panels. The reader's appreciation of the intent of each recommendation relies on having reviewed the preceding section on Interpretation of the Themes.

 Recommendation 1. First, develop, empirically test, and standardize a set of relatively brief questions (with or without probes) that can be used by front-line health care professionals in eliciting information about potential Incontinence Symptoms. Second (likely related to the preceding suggestion), develop and field test a screening instrument that could be used to both streamline and standardize the initial assessment of consumers seeking Assessment and Treatment for Incontinence symptoms. This questionnaire could take the form where the patient self-reports information that speeds up the assessment process and then the health care professional can use the information on that sheet to ask for further information. Ideally, the information gathered with this form would be used in treatment planning and educational feedback to the patient.

 Recommendation 2. Make a concerted effort to have Continence Care taught to health care professionals including nursing and medical students (as part of their regular education) and also practicing GPs. Recommendations were made during the Reactor Panel discussions for training in Continence Care to be given Continuing Education Credits for professionals such as GPs. Thus efforts might be made to engage those who provide mandatory Continuing Education to GPs to include instruction modules on comprehensive Continence Care.

 Recommendation 3. Facilitate the development of one or more "Demonstration Model(s)" of Continence Care Clinics. Such Demonstrations would require extra funding only for the evaluation of the Clinic. However, such an evaluation would not only look at the efficacy in terms of various Outcome criteria, but also provide feedback as to the systemic efficiencies of the Clinic. Thus, the information ought to be gathered in such a way as to determine not only the success of the Clinic, but also ways in which that information can be used towards establishing similarly effective Clinics elsewhere in Canada. Included in the assessment would be close examination of the Cost-Effectiveness and the Economics of the service and how the service would complement the larger objectives of the appropriate Health Funding agencies such as the provincial governments.

 Recommendation 4. Test the viability of establishing Working Alliances as described in Theme 15. These would be a series of mini "Demonstration Models" undertaken to both facilitate the development of such alliances and then testing them according to quantitative and qualitative indices. Adequate evaluation of these models would determine whether they work well, are self-sustaining professionally and economically, complement the larger mosaic of health care delivery services, and in light of their success, can be promulgated as an efficient and relatively inexpensive means for providing initial primary care for Incontinence.

 Recommendation 5. NOTE: The wording of this "recommendation" is decidedly presumptuous and the implicit assumptions may be false. If the answer to either of the following two questions is "No", then please omit this so-called "recommendation". The first question is "are there places in the Guidelines where professionals realize that there is amongst practitioners a lack of a common understanding of what constitutes the appropriate application of a procedure or assessment? Examples may be (?) the reliable assessment of voiding residual or what constitutes a "Pelvic examination". If the answer to the latter question is "Yes", do you think that it would be beneficial to provide a 'statement of standard' or criteria that clarifies what the appropriate application of a procedure or assessment is? Rational: The Guidelines Committee together with TCCF executive and its members have provided the leadership necessary to establish up-to-date Guidelines for Continence Care. These are to be used not only for Continence Care delivery, but will likely be used for educational purposes as well. The value of the Guidelines and especially their application clinically and educationally would be augmented if they were accompanied by brief descriptions of those procedures that may otherwise be at risk of incomplete application or misinterpretation. It is recommended that TCCF initiate either drafting statements on "Standards of Care" or else provide a reference to sources that present "standards of care" that could be appended to the current Guidelines at a later date or included in an updated draft.

 Comment & Query. It was apparent from the Reactor Panels discussions that there is a lack of "hands on" education among health care professionals in what constitutes front line assessment and initial conservative treatment procedures. If such "hands on" education were provided to GPs, Nurses, Physiotherapists, etc. it would appear that kind of education would provide a more substantive grasp of Continence Care and its value among health care professionals (than would a lecture, teleconference discussion or advertisement). Indeed, some professionals liked the idea of, for example, a one-day workshop on Continence Care being provided in places such as Kirkland Lake. This raises the question about the adequacy of a one-day workshop and its benefits. If the TCCF members saw this kind of education of health care professionals as an effective way of promoting better awareness of Continence Care, then maybe it would be worth investing/promoting establishing such "workshops" and testing them. Once in place, they might also be evaluated as to their success and longer-term benefit. What is questioned here are (a) "how much education" can be had in one or two workshops (?) and (b) what value is that education for improving Continence Care (?). These are empirical questions that need to be researched in order to facilitate improved education and training among health professionals.

Table 2
Total Number and Professional Distribution of Participants at each Reactor Panel

HealthCare Profession	Seven Reactor Panels							
	Winnipeg	Kirkland Lake	Halifax	Hamilton	Red Deer	Oshawa	Sudbury	TOTALS
Nurses	17	4	9	6	4	9	7	56
Consumers	1	0	2	1	2	4	1	11
GPs	2	3	3	3	0	0	0	11
Physiotherapy	5	0	1	1	0	0	1	8
Pharmacy	1	0	1	1	0	1	1	5
Urology	1	1	1	1	1	1	1	7
OBS/GYN	0	0	0	0	1	0	0	1
URO/GYN	0	0	1	1	1	0	0	3
Gerontologist	1	0	0	1	0	0	0	2
Industry (as observers)	1	0	0	0	1	0	0	2
Centre on Ageing	0	0	2	0	0	0	0	2
Rehab/Geriatric	1	0	0	0	0	0	0	1
Enterostomal Therapists	0	0	0	0	0	0	2	2
TOTALS	30	8	20	15	10	15	13	111

Table 3
Themes Emanating From Reactor Panel Deliberations

THEME(S)	Winnipeg	Kirkland Lake	Halifax	Hamilton	Red Deer	Oshawa	Sudbury
(1) SINGLE SHEET GUIDELINE FLOW-CHART FOR INITIAL MANAGEMENT OF ALL ADULT CONSUMERS • reduces redundancy across 3-sheets. • easier use for the GP's and other professionals • single sheet more readily available.	X	X	X	X	X	X	X
(2) PROVIDE HEALTH PROFESSIONALS WITH A COATED FOLD-OUT CARD OR 'CHECK-LIST' THAT PARALLELS THE GUIDELINES. MAKING THIS EASILY ACCESSIBLE INCREASES UTILITY. • current guidelines are highly useful for education and training, but abbreviated 'crib-sheet' or portable/durable outline could maximize utility.[There were many redundant statements consistent with this theme.]	__	X	__	X	X	X	X
(3) NEED FOR EFFICIENT, YET SENSITIVE TOOL FOR SCREENING OF CLIENTS FOR POTENTIAL CONTINENCE ISSUES. KEY QUESTIONS TO ELICIT INFORMATION. • for introducing/eliciting info about existence and extent of incontinence symptoms • Some wanted such questions to fit within an algorithm that goes from initial history to 'presumed	X	X	__	__	X	X	X

aetiology.

- several settings stressed that discussing continence issues is difficult for many consumers and there needs to be effective/sensitive ways to facilitate such discussion as some consumers highly sensitive to the topic.
- some consumers do not think of their symptoms as being either incontinence or treatable.
- impact on sexuality and hygiene and comfort.

THEME(S)	Winnipeg	Kirkland Lake	Halifax	Hamilton	Red Deer	Oshawa	Sudbury
(4) SET GOALS/EXPECTATIONS:	X	__	X	__	X	__	X
(5) AVAILABILITY OF APPROPRIATE INSTRUMENTS:	X	__	X	X	__	__	X

- important to do early & clearly in the assessment-treatment process.
- optimises working alliance between Consumer & Health Professional.
- mitigates misunderstandings and promotes appropriate education.
- streamlines assessment-treatment process = efficiency @ thoroughness
- allows for post-treatment evaluation and feedback.
- takes into consideration consumer's preferences as well as the health-care providers' professional opinion.

- trained health care professionals should have available the instruments and knowledge of their proper application. -e.g. Bladder Scanner Ultrasound to assess, manage urinary retention; voiding-diary method; updated list of medications known to aggravate incontinence symptoms, updated list of medication known to benefit

continence, quality of life measure(s).

(6) USING THE GUIDELINES, X __ X __ X __ X
ESTABLISH FOR EACH PATIENT DOCUMENTATION AND TREATMENT PLAN THAT CAN BE FORWARDED WITH THE PATIENT (to specialist).

- helps facilitate a continuity of care.
- reduces redundancy of assessment across health professionals and thus
- increases efficiency (e.g., timely progress).
- allows for establishing/using benchmarks of treatment progress
- improves communication.
- assumes a future where exchange of medical information more readily undertaken. Perhaps workable only where health professionals work within the same clinic or health care system.
- keep in mind each profession responsible for information used/but corroboration good

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- use guidelines to create a 'check-list' form to follow when recording notes and assessment/treatment results summary.
- use of such a completed form can expedite the work of specialist when referral received.
- such a 'check-list' can enhance identifying "focal questions" that the health care provider and specialist could be sure to ask in light of preceding answers. E.g. Pharmacological or life-style exacerbation of symptoms or inadequacy of past treatment follow-up

(7) EDUCATION OF HEALTH X X X X X X X
PROFESSIONALS ON PRIMARY

HEALTH CARE OF CONTINENCE IS NEEDED.

- utility of guidelines requires appropriate skills.
- the administration of the guidelines for assessment and treatment assumes a knowledge of how to undertake these procedures, particularly as they apply to continence issues.
- establish means for educating/upgrading health professionals, especially GP's, on the assessment and treatment of continence is needed.
- comprehensive screening not happening.
- depending on location, educational forums are needed through telehealth link-up and on-site workshops. In-service training. In London they have established professional Discussion meetings (3x/year) regarding continence care advances and problem solve special cases.
- presentations at Women's' Health meetings.
- include in CME credits for MD's. Inform hospitals and universities that provide CME training of the need for continence care education.
- include Occupation Therapists/Social Workers as they will come across Incontinence.

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(8) STANDARDIZATION OF ASSESSMENT & TREATMENT PROCEDURES. "STANDARDS OF PRACTICE"	X	__	X	X	X	X	X

- With multidisciplinary involvement it would be beneficial to standardise some of the key assessments.
- important for service delivery person to know when and where to refer based on assessment & treatment standards.

- establish a common form to be completed by patient.
- establish 'standards of practice' for key assessment/treatment methods. E.G., establish a common/equivalent procedure(s) for measuring voiding.
- As the utilization of guidelines evolve it would be progressive to have reference to established definitions of "standards of care". These may have to be discipline based, but would increase assurance guidelines applied adequately across disciplines.

(9) EDUCATION AND TRAINING IN CONTINENCE CARE SHOULD BE PART OF MEDICAL SCHOOL, NURSING AND PHYSIOTHERAPY TRAINING (AND PHARMACY AS WELL). X X X X __ __ X

- lack of education/training is a barrier.
- given the prevalence of continence problems, professionals should be educated in how to assess/treat.
- making Continence part of regular education will culminate in better co-ordination of services and ultimately better care for consumers

(10) IT IS IMPERATIVE TO FOCUS ON SELF-REFERRAL BY CONSUMERS. THIS REQUIRES EDUCATION OF CONSUMERS ABOUT CONTINENCE AND ACCESSING SERVICES. CRITICAL TO EDUCATE CITIZENS ABOUT WHAT INCONTINENCE SYMPTOMS ARE, THEIR TREATMENT, AND SERVICES AVAILABLE X X X X X X X

- many potential consumers do not realise their symptoms treatable.
- distribute general information with guidance to sources of greater detail, answers, direction.
- informed consumers are empowered

and as a result work more co-operatively

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with health professionals. • important to keep in mind the variation in literacy levels when drafting advertisement/education. • advertising is important through: media posters in MD waiting rooms (co-ordinate with CMA poster system), establishing 'catchy' acronym, advising other health groups of prevalence and treatment for incontinence symptoms. • concerted advertising requires funding. • [see later theme about funding for Continence Care services.] • need to educate the government agencies. • Develop strategies: opinion leaders, workshops, utilize public relations friends, 'grand rounds' in hospitals, conference-presentations, arrange group 'education' meetings with potential consumers, magazines, seniors organizations. • Vocabulary = consumers need the words, phrases to communicate their symptoms. E.g.. If consumer says she 'wets' when she coughs the GP may see the coughing as problem and not the 'wetting'. • be repetitious so, like osteoporosis, public retains consciousness of Continence issues. • inform public and government that a few hundred dollars for assessment and follow-up is highly cost-effective compared to ongoing cost of containment devices and frivolous luxury expenditures such as 'hair styles'. • utilize talents of Media Education programs such as those at Durham College (Oshawa) where students can produce information on "Continence Awareness" for public.							
(11) BOTH THE PROVISION OF CARE	X	X	X	X	X	X	X

AND ACCESS TO CONTINENCE CARE SERVICES NEED FUNDING.

- currently consumers seeking services from specially trained nurse continence advisors, physiotherapists, etc., must pay for such services.
- funding costs are a barrier to accessing services.
- GP's lack sufficient funding for comprehensive assessment and in particular, providing comprehensive treatment with follow-up. Billing practices operate as disincentive.
- private insurance does not fund the appropriate services or professionals.

THEME(S)	Winnipeg	Kirkland Lake	Halifax	Hamilton	Red Deer	Oshawa	Sudbury
(12) THERE IS A SCARCITY OF MEDICAL SPECIALISTS, & GPs PARTICULARLY IN RURAL-REMOTE & SMALL CITIES. THIS CREATES A BOTTLE-NECK IN THE TREATMENT OF MORE COMPLICATED CASES. IT WOULD BE A GREAT ASSISTANCE TO PROVIDE BETTER INITIAL ASSESSMENT AND TREATMENT	X	X	X	__	X	__	X

- Kirkland Lake, for example, has only a consulting urologist who visits monthly. Sudbury = 4.5hrs away, North Bay = 3.5hrs. There are 9 GPs When gov't feels 15-18 needed.
- Sudbury has 40 GP's, 3.5 gynaecologists, 3 urologists for 160,000. Sudbury urologist working on incontinence reports waiting list = 1 year referrals;18-24 mos. Surgery.
- Red Deer has 16 family MDs;

2 urologists, 4 gynaecologists for 70,000.

- thorough training of health professionals to competently undertake Initial Management of incontinence symptoms will provide a screening so only those clients who are appropriate for specialist services are referred. This should reduce wait-lists for specialist services and also utilize their services more effectively.
- When specialists see only those consumers who have already undergone the initial management and bring with them the results of the initial assessment/treatment = better initial workup = better health care.

THEME(S)	Winnipeg	Kirkland Lake	Halifax	Hamilton	Red Deer	Oshawa	Sudbury
(13) CONCERNS ABOUT WHETHER GP'S WOULD BECOME INVOLVED IN CONTINENCE CARE SERVICES. LACK OF PARTICIPATION OF GP'S IN REACTOR PANELS SUPPORTS CONCERN. THERE IS NEED TO FACILITATE GREATER INVOLVEMENT OF GPs IN CONTINENCE CARE	X	X	X	X	X	X	X

- GPs are currently overwhelmed with heavy patient loads, addressing other needs of patients, such that they do not have the time to assess/treat Incontinence.
- Current fee-for-service structure doesn't reward undertaking Continence care.
- Continence Care may be seen as non-life

threatening suggesting lack of GP understanding of the importance and cost-effectiveness of treating incontinence symptoms to benefit health/wellness status and reduce long term costs.

- despite extra effort by Reactor Panel hosts to invite GPs there was a very low, often nil participation by GP's in the Reactor Panels.
- it is possible that many GP's do not know that assessment and treatment of incontinence are efficacious and beneficial

(14) IN PLACES WHERE RESOURCES ARE SCARCE IT IS BEST TO BRING THESE TOGETHER (AS IN A CLINIC OR VIRTUAL CLINIC CO-ORDINATION) AND BUILD FROM THERE.

- provides accessible place for patients to self-refer.
- provides a place for MD's to refer because they lack the time or specialized training to assess/treat.
- much of primary care will be done appropriately before referral to specialists; improves efficient use of specialist skills/services.
- status of the clinic will encourage greater involvement of Family Physicians and other clinics (e.g. women's health clinic) in eradicating prevalence of continence problems.
- in rural areas, especially, there is a shortage of MD's such that follow-up and comprehensive assessment is difficult or not available..
- fee-for-service billing disincentive against more comprehensive evaluation and time intensive treatment by a physician.
- availability of clinic may help reduce

THEME(S)	Winnipeg	Kirkland Lake	Halifax	Hamilton	Red Deer	Oshawa	Sudbury
(14)	X	__	X	X	X	X	X

demand of GP's time.

- clinic becomes a catalyst for providing, advising, educating, advancing continence care.
- direct involvement of GP or urologist in the clinic required. Medical-legal standards must be met.
- include data collection to demonstrate cost-savings of clinic services.
- clinic benefits neurology, obstetrics, gynaecology, geriatrics, rehab., as well as urology.
- standardised referral form to screen and streamline, but clinic must be open to citizen self-referral as well.
- ***payment for clinic services remains a major barrier.

(15) ESTABLISH WORKING ALLIANCE BETWEEN M.D. AND HEALTH-CARE PROFESSIONAL(S) TRAINED IN CONTINENCE CARE. X X __ X X __ __

- GP's often do not know where to refer consumers for competent, reliable assessment/treatment.
- GP's have neither the time nor incentive in a busy practise to undertake full-scale assessment and treatment implementation.
- GP's are not used to referring to nurses and physiotherapists, likely because they do not know the assessment/initial treatment of continence is within the "scope of practice" of specially trained nurse, physiotherapist.
- Collaboration between nurse and GP essential because (a) internal assessment cannot be done without physician's permission and (b) co-ordination with GP contributes to comprehensive assessment/treatment.
- instead of saying "nothing can be done" the GP or medical specialist can turn to their associated continence care professional for second opinion as to what else could be done.

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- because this arrangement requires only two professionals (MD & Health Professional), administration is lean and responsive.
- **assumes funding for the services of the health professional
- Specialist Referrals expedited. For cases where a Health Care Professional such as a Nurse Continence Adviser feels that referral to a specialist is necessary, the existing alliance with the GP can expedite the GP's involvement in making the appropriate referral.

Note: The designation of an "X" signifies that the theme was clearly discussed according to the notes taken at that Reactor Panel location.

APPENDIX

TERMS OF REFERENCE THAT WERE DISTRIBUTED

TO PARTICIPANTS

AT EACH REACTOR PANEL MEETING

PROMOTING A COLLABORATIVE CONSUMER-FOCUSSED APPROACH TO CONTINENCE CARE IN CANADA

Survey of "Reactor Panels" :

Ascertaining how Stakeholders across Canada would implement Continence Care services in their setting that would follow the Canadian Clinical Practice Guidelines for the Assessment and Treatment of Incontinence.

DESCRIPTION OF SURVEY AND TERMS OF REFERENCE

Purpose

Meetings will be held with seven reactor panels, located in various regions/ communities across Canada. The purpose of these meetings is to introduce the stakeholders to the new guidelines and the accompanying continence care delivery models, and to seek their views on how best to implement continence care delivery in their setting. Information obtained from these meetings will be used to determine whether the guidelines are viable and can be implemented in practical ways throughout Canada. The meetings will also serve to increase awareness of incontinence and its appropriate treatment. The terms of reference are designed to insure that all 7 meetings follow a similar protocol and achieve the goals listed below. It is also important to gather information from different settings, to allow comparison between them and to gain insight into how effective continence care can be provided in each setting.

Brief History of the Project

In 1998 The Canadian Continence Foundation (TCCF) received a contribution from Health Canada, Population Health Fund to carry out a three (3) year project titled "Promoting a Collaborative Consumer-Focused Approach to Continence Care in Canada". TCCF is endeavoring throughout this project to make it highly participatory so that consumers and various health professionals all have an opportunity to contribute. From the outset the project has had input from multidisciplinary committees and consumers. The project is following a strategic plan that began with a critical review of information on continence services worldwide and particularly in Canada. A multidisciplinary committee, benefiting from this review, subsequently undertook its own review of the research literature and drafted assessment and treatment guidelines. A second multidisciplinary committee, working in tandem, drafted models of continence care delivery that may be followed in a variety of Canadian settings (e.g., rural versus small city versus large metropolitan centers). Developing the guidelines and working models was an iterative process involving a succession of reviews and revisions prior to distributing the potentially final drafts to delegates to a multidisciplinary consensus conference. The delegates, using formal voting procedures, adopted these guidelines and working models subsequent to minor revisions.

The next step, and a very important step, is having reactor panels review the guidelines and working models and consider how they would implement them in a coordinated way in their own location.
In the future, TCCF hopes to pilot models of continence care delivery in a number of locations. The aims will be to prove feasibility, refine the guidelines and models, and demonstrate cost-effective improvements in continence care. The choice of pilot sites will be based partly on the reports of the reactor panels.

2

Primary goals

- Introduce guidelines and continence care delivery models
- Seek views of stakeholders on how best to implement continence care delivery in their own setting
- Determine the viability of the guidelines as to whether they can be implemented in practical ways throughout Canada
- Increase awareness of incontinence and its appropriate treatment
- Gather information from different settings, enabling comparison and providing insight into provision of effective continence care in each setting

Secondary goals

- Increase number of people (professionals and consumers) consulted
- Broaden the spectrum of inter-professional and consumer consultation
- Assure regional representation across Canada
- Confirm clarity of the text and ease of use of the guidelines
- Increase knowledge and comfort level for consumers
- Test openness of professionals to treatment and management of incontinence
- Find / diagnose “gaps” in the Health Care system for continence care, i.e. funding, billing, etc. What is the next step for TCCF?
- Increase awareness of TCCF in institutions across the country.
- Attract new members for TCCF.

Terms of Reference for Reactor Panel (i.e., what is proposed to be done)

The following are specifics of this general term of reference:

- Facilitate a discussion among the reactor panel members of how they could implement the guidelines through a proposed continence care delivery model (of their design) in their community. The "working models" report should be used as a guideline. The proposed model does not have to be definitive, for creating a final model in one meeting is not objective; rather a preliminary sketch would suffice.

- Determine how "workable" the reactor panel thinks their proposed model would be. This determination would help identify "barriers" and enable the panel to discuss how to surmount or avoid them. This would require the reactor panel members, including consumers, to conduct "thought experiments": i.e., to create a continence treatment scenario or case and to think through how well the proposed continence care model would work while also following the guidelines.

- Establish commitment from the reactor panel to actively disseminate and promote the use of the guidelines. It would be useful to gain the reactor panels permission for TCCF to contact them later to determine their success in disseminating this information. Such information would be useful to TCCF for reporting on the success of this project and for making future plans for promoting effective continence services.

3

Format

- A host at the meeting site will compile a list of the stakeholders in her/his community who are normally involved in the assessment and treatment of urinary incontinence in adults . This list is critical in that it provides a basis for knowing whether all potential stakeholders take part as Reactor Panel members. Unless someone else is nominated, the host will be considered the Chair.

- The stakeholders will be invited to attend a meeting at a time and location suitable for an optimal attendance.

- Each stakeholder will receive copies of the guidelines and the working models along with a worksheet containing questions and directions to follow when reviewing the guidelines and working models.

- Before the meeting a note-taker will be identified. This person will take notes that capture the key information pertaining to the questions/directions on the attached "work sheet".

- OVERVIEW OF GUIDELINES & WORKING MODEL. At the beginning of the meeting, the Chair (or her/his nominee) will provide a cursory overview of the guidelines and the working model that seems most appropriate to their setting. This overview would be followed by (or include) discussion with the participants about the guidelines. Invariably such discussion will include consideration of the application of the guidelines and such

discussion will overlap with the review of the working models. This portion of the meeting should follow an agreed time limit that is sufficient to insure that all participants understand the general thrust of the guidelines. It is important that as a result of this overview that all participants share a common general understanding of the guidelines and a working model before proceeding to the next portion of the meeting. A suggested time length is 1 to 1.5 hours, but this could be shorter if the delegates arrive having already reviewed the guidelines and working model(s). This overview will prime the participants for the next portion of the meeting that will take the form of a workshop discussion.

 DETERMINING THE MOST EFFECTIVE AND REALISTIC WAY OF PROVIDING CONTINENCE CARE IN THIS SETTING. A time limit ought to be set a minimum of three (3) hours is suggested and an individual identified to monitor the progress of the discussions in light of the time available. It is critical that the note taker capture the information requested in the worksheet. The more detail in the notes, the better, for the TCCF will use this detail in subsequent reports about this project and Continence Care in Canada. The Chair (or her/his nominee) would lead a discussion to outline a proposed continence care model that would (a) follow the guidelines and appropriate working model (b) be adaptable to the realities of the setting (e.g. Consumers, availability of various professionals, geographic parameters, etc.) The product of this workshop will not be the definitive model but rather an outline that could be used to develop a definitive model in the future. To this end, the discussions ought to be constructive, creative, affirmative and undertaken in a proactive and collaborative spirit to determine what is possible in the light of current regional resources.

4
WORKSHEET FOR REACTOR PANEL DISCUSSIONS

Date, time and location of Reactor Panel discussions:

Names (please print) of delegates with professional specialization:
Name Profession E-mail / Telephone

1.

2.

3.

4.

5.

6.

7.

8.

9.

10.

11.

12.

Questions:

1. Can you work with these guidelines? Are they useable? Will they be used? When answering this question please realize that the guidelines are not restrictive algorithms mandating the decisions that the professional must make, rather they are a logical sequencing to facilitate thorough assessment and treatment decisions. They are also designed to help standardize quality care among healthcare professionals.

2. If there are obstacles to utilizing these guidelines, please identify these and indicate what can realistically be done to overcome these obstacles.

3. Please append an outline of a proposed model of continence care delivery in your setting. Please attach notes that explain the working of the proposed model and in particular indicate whether one of the "working models" was adapted and in what ways.

4. Having outlined a proposed model, please indicate how "workable" this model is in your setting and list some of the assumptions, potential barriers, etc. that are necessary to consider in making the model "workable".

5. A LOOK TO THE FUTURE. What "action plans" are necessary in order to put the Reactor Panel's proposed Continence Care delivery model in place, to get it underway? Please provide as much detail as possible. Treat this like a mock business plan. Point form notation will suffice.