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Continence Promotion, Education & Primary Prevention

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Continence Promotion, Education & Primary Prevention

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I. INTRODUCTION

Continence promotion, education and primary prevention involves informing and educating the public and health care professionals that urinary incontinence and faecal incontinence are not inevitable, but are treatable or at least manageable. In addition, other bladder disorders such as bladder pain syndrome/painful bladder syndrome/interstitial cystitis and pelvic organ prolapse can be treated successfully. Taboos on mentioning disorders of the bladder and bowel are gradually lifting in most cultures. Two decades ago it was almost impossible to have urinary incontinence discussed in the media. Today, in most countries, consensus panels, government funding of continence initiatives and practice guidelines have been developed in the area of urinary and faecal incontinence, and many are referenced in this chapter. Around the world, expert panels have suggested that urinary and faecal incontinence be combined through a multidisciplinary approach to further research priorities.

Thus, there have been advances in promoting awareness of both urinary and faecal incontinence. Popular magazines, local and national papers, radio, and television, regularly cover topics on urinary incontinence in most developed countries. Many countries have run national or local public awareness campaigns, usually spearheaded by a national continence organisation. Many also have confidential help lines, which can be accessed anonymously. The World Wide Web provides a convenient source of health information for a growing number of consumers. Some experts believe that persons with incontinence might get valuable advice and comfort by using interactive services such as the chat rooms on the internet. However, in developing countries, public information and campaigns through these mediums is limited or non-existent.

This chapter updates previous International Consultation on Incontinence (ICI) chapters on three areas: continence promotion, education and primary prevention.

The majority of information available in these areas is on urinary and faecal incontinence which are the primary focus of this chapter. The first section reviews continence awareness by discussing health promotion and care-seeking behaviours for these conditions. It is evident that progress has been made in the promotion of continence on a worldwide basis but not much has changed in help-seeking behaviour for these disorders.

There is a lack of evidence on translating awareness into behavioural change and on what triggers help-seeking behaviour. Information is provided on continence promotion programs and advocacy through service delivery, models of care and worldwide organizations. Although there is a great deal of published information on building public and health care professional awareness of incontinence, there is minimal information on the effectiveness of changing public and professional attitudes and knowledge about it. Documentation of the success of campaigns is lacking and should be measured by behavioural changes and ultimately by improved patient outcomes.

A second topic reviewed in this chapter is the education of professionals in the areas of urinary incontinence, faecal incontinence, pelvic organ prolapse and bladder pain syndrome. The use of medical guidelines and care pathways will be discussed. Finally, as these conditions are prevalent but often ignored by sufferers and professional, the third topic addressed is primary prevention with identification of modifiable risk factors. There is a need for further research to substantiate the benefits of primary preventative strategies, including long term follow-up.

II. CONTINENCE AWARENESS

LITERATURE SEARCH

The online databases Medline, Embase, Biosis, Cinahl, Psycinfo, ERIC and Cochrane were searched, with focus on literatures published in and after 2003. The following search terms were used: awareness, consumer, education, urinary incontinence (UI), faecal incontinence (FI), incontinence, continence, continence awareness, continence promotion, health education, public education, public awareness, pelvic organ prolapse (POP), interstitial cystitis (IC), bladder pain syndrome (BPS), painful bladder syndrome (PBS) and outcome measures. Non-English language papers were noted but excluded from the review unless they contained English-language abstract providing sufficient information.

1. BACKGROUND

For a health-related issue like incontinence, the altruistic reason to educate consumers – referring mainly those with incontinence and their family members or informal caregivers, as well as individuals at risk – must be to increase awareness of incontinence and the benefits of prevention and management, with the noble goals of eliminating stigma, promoting disclosure and care-seeking, and reducing suffering [1]. Much of the health promotion efforts related to continence issues are undertaken by the many non-governmental continence organisations, professional and advocacy groups listed in Appendix I. Although in some countries, there is also strong governmental support, including a national advocacy on achieving an effective health literacy system. Components of such a system involving many levels of educational, health-care, and community service providers have been identified and include: (a) an information dissemination system providing materials that are readable, comprehensible, trustworthy, and culturally sensitive; (b) a coordinated health literacy learning system; (c) a measurement and assessment system; (d) a formal and informal health advice system, including a hotline, handbook, and online support; and (e) a health care professional educational system [2].

Consumer education in terms of having access to information about incontinence in this age of digital technology is a non-issue, especially for those internet users who tend to have a higher literacy level [2]. In light of the reluctance of those affected by stigmatized illnesses such as incontinence to seek treatment or to ask health care professionals for information, the internet may prove to be a useful tool for patient education and public health outreach. [3, 4].

The internet is widely accessible and frequently searched for health information. Recent estimates

indicate that around 20% of U.S.A. adults use the internet for health information [5]. Among those who do not use the internet, 60% are aware of publicly available internet access points within their community [6]. Also, the internet can be searched anonymously and informally. People with low levels of education and low socioeconomic status are less likely to use the internet [7]. Health care professionals can assist consumers to find reliable information sources by providing details of reputable web sites [8].

In a national survey of internet users in the U.S.A., [9] Berger 2005, found a trend among people with a stigmatized illness such as UI to more likely report that using the internet increased their health care utilization and communication with a health care provider.

A Google search for “urinary incontinence (UI)” and “faecal incontinence (FI)” yielded about 1.7 million and 62,800 websites respectively; “interstitial cystitis (IC)” - 828,000 sites, “painful bladder syndrome (PBS)” – 38,000 sites and “pelvic organ prolapse (POP)” – 120,000 sites. Many were repetitions. For “continence promotion”, the yield was about 6,450 sites, and for “continence awareness (CA)”, it was about 2,840. There was reference to 114 sites for “continence awareness” and “UI” or “FI”; 35 sites for “continence awareness” and “IC”, and 40 sites for “continence awareness” and “POP”. Many of the sites were related to non-government organisations such as the International Continence Society (ICS), the National Association for Continence (NAFC) and the Interstitial Cystitis Association (ICA), and the International Foundation for Functional Gastro-intestinal Disorders (IFFGD).

a) Health promotion

Efforts to promote continence may be enhanced by adopting evidence based theories and methods from the field of health promotion. Health promotion was defined by the Ottawa Charter for Health Promotion in 1986 as “the process of enabling people to increase control over and to improve their health” [10]. Hence, health promotion is an important factor in primary, secondary and tertiary prevention efforts directed at individuals, communities and populations with or at risk of developing incontinence.

Health promotion frameworks can be used to plan and evaluate the effectiveness of strategies and programs used to promote continence. When planning health promotion interventions consideration needs to be given to the demographic features of target groups including age, gender, culture, language and socioeconomic background. Health promotion strategies need to address issues such as accessibility, availability of transport and the cost of health promotion programs [11]. Other considerations include communication strategies. As noted above, there is an increasing trend for consumers to search and obtain information from the internet.

Palmer and Newman [12] reported on a U.S.A. health promotion project conducted in 2000 to determine the needs of senior citizens concerning bladder control issues. Focus groups of older adults attending health seminars in urban, community and church settings were conducted. The primary objective of the project was to determine the understanding of older adults in the areas of general health and their beliefs surrounding the problem of UI. The 82 participants were predominantly African-American women representing all socio-economic levels. Seniors expressed confusion when asked if “overactive bladder, bladder control issues and urinary incontinence” were the same condition. Most seniors said they felt comfortable about discussing bladder control issues, but most admitted that their physician had never asked them, nor had they raised the issue. However, they did discuss UI with family members and friends and they were aware that many persons with whom they socialize might have a problem with UI. The majority of seniors answered “no cure” when asked if treatments were successful.

b) Care-seeking (help-seeking) behaviour

Despite the considerable impact of incontinence on quality of life (QoL), many people never seek help for their incontinence and are thus uncounted [13]. Current research in the area of care-seeking (also referred to as “help-seeking” or health-seeking”) behaviour (seeking help from a health care provider or professional) in women with UI has determined that fewer than 38% sought help for their condition, and they waited more than a year to do so [14]. A European survey reported that patients wait from 2 to 11 or more years before seeking treatment [15]. Huang et. al.[16] reported that fewer than 50% of women in the U.S.A. with clinically significant UI reported seeking treatment. This was despite the fact that all women in this study had health insurance that would pay for services and had continuous access to a primary care provider. Women with stress UI are more likely to seek help when there is severe leakage that is having a significant impact on their QoL [17]. Shaw and colleagues [18] surveyed adult women attending primary care practices in UK and of those who noted UI symptoms (n=3273), only a total of 15.8% of women with stress UI, 32.3% of those with urge UI and 33.7% with mixed UI had sought help for urinary symptoms during the preceding 12 months. This study also found that when women sought help for UI, only one-third will receive appropriate treatment [17].

Men tend to be less proactive in health seeking behaviour. Gender specific strategies to address this should be considered [19]. Men with lower urinary tract symptoms (LUTS) have been found to seek help less frequently than women [20]. Conversely, a study into the prevalence of UI in men in the U.S.A. found that whilst only 50% of men with continence issues sought help, these men consulted their doctor within

12 months of the onset of symptoms [21]. This time period is much shorter than the length of time taken by women to seek help [21]. Men are more likely to seek help for LUTS if they have had advice from others or received information in the media, than seeking help as a result of their symptoms [22].

In a population-based study in Sweden (a supplement to a comprehensive survey of public health and general living conditions), a postal questionnaire comprising 12 questions on UI received a response rate of 64.5% from 15,360 randomly selected residents (aged 18–79 years) [23]. The prevalence of UI was 19% (when defined as “any leakage”) and most considered their problems to be minor. Only 18% of those with UI desired treatment. Of the 17% who had reported severe problems that interfered with daily life, 42% did not want treatment. The authors suspect that lack of knowledge, worries about different procedures and negative expectations may be important factors. They concluded that UI may not be an unrecognised major problem except for a limited group, and suggested that healthcare resources should be optimized to identify and meet the needs of those who are most afflicted.

Muller [24] reported on several epidemiologic surveys conducted over a 5 year period by the U.S.A. continence advocacy group, the NAFC. These surveys indicated that UI and overactive bladder (OAB) are prevalent problems and that most people do not understand these conditions. In one survey, conducted in 2000, only 26% of respondents (18% of men and 33% of women) reporting bladder control symptoms had discussed them with a doctor. This survey attempted to examine bathroom-related attitudes and behaviours and found that most feel the bathroom is a “haven” for refuge while others feel it represents a symbol of incarceration because of the preoccupation with the need to be near one frequently.

Bathroom privacy, cleanliness and ease of accessibility were voiced as concerns with only 20% of respondents noting that they are comfortable using a bathroom outside their home. A second survey by this group was conducted online (over the internet) and includes 1,025 interviews of U.S.A. adults (ages 30 to 70). This survey showed that women wait longer (average 6.5 years) than men (4.2 years) to seek out a diagnosis for their symptoms.

Barriers to seeking help for continence issues have been frequently identified in the literature and include embarrassment, social stigma and the mistaken belief that incontinence is either inevitable, untreatable and a normal part of aging [25]. Women with POP have also reported that fear and embarrassment are barriers to seeking help. Other barriers include the perception that incontinence and LUTS are not serious [26]. However symptoms such as nocturia have been linked with serious consequences such as falls and associated morbidity in older adults.

Bladder and bowel continence is an adjustment to the social norm, especially in Western cultures, which have developed acceptable rules and behaviour for bladder and bowel emptying. [27, 28]. If incontinence occurs in adulthood, persons revive those childhood beliefs and begin to internalize their condition causing a decrease in self-esteem and feelings of not being "normal" [29]. These barriers are shared by the public as well as by many health care providers [30]. Unfortunately, factors that promote health seeking behaviour for continence issues remain less well researched and the triggers for help-seeking behaviour are complex and multifactorial. With chronic problems like UI, FI, POP and BPS/IC/PBS, it is important to understand what triggers the patient to consult a health care provider [28]. Older people may be keen to seek help if they are concerned that a health issue such as incontinence impacts on their ability to remain independent and living in the community [31].

In certain parts of the world, the gender of the person with UI may be a factor in help-seeking behaviour and the gender of the health care provider may be a barrier. Doshani and colleagues [32] explored views and experiences of South Asian Indian women with UI and found that feelings of embarrassment were present, especially with male health care providers.

Rizk [33] identified reasons why women in the United Arab Emirates (UAE) were not seeking medical help for UI. Data from questionnaires was collected on 400 women (mean age 54.2) out of 448 enrolled subjects and noted that, 81 (20.3%) admitted UI and only 25 of these (30.9%) had sought medical advice. The reasons were embarrassment (38.2%), choice of self-treatment because of low expectations from medical care (38.2%), preferring to discuss the matter with friends, and assuming that UI is normal (23.3%). Women with UI were troubled by their inability to pray (90%) and to have sexual intercourse (33.3%). Saleh [34] found similar results when surveying women in Qatar who reported that UI interfered with their ability to pray (64%) because of lack of cleanliness and need to void and 47% reported that UI interfered with marital relationships.

Rizk and colleagues [35] also investigated the prevalence and help-seeking behaviour of women (n = 400, mean age 37.9) with FI using the same method. Fifty-one participants (11.3 %) admitted FI; 26 (5.8 %) were incontinent to liquid stool and 25 (5.5 %) to solid stool. Thirty-eight patients (8.4 %) had double (urinary and fecal) incontinence. Sixty-five patients (14.4 %) were incontinent to flatus only but not to stools. Only 21 incontinent patients (41 %) had sought medical advice. Women did not seek medical advice because they were embarrassed to consult their physician (64.7 %), they preferred to discuss the difficulty with friends, assuming that FI would resolve spontaneously (47.1 %) or was normal (31.3 %), and they chose self-treatment as a result of low expectations for

medical care (23.5 %). Women with FI were bothered by the inability to pray (92.2 %) and to have sexual intercourse (43.1 %). These studies note that both UI and FI are common yet underreported by UAE women because of cultural attitudes and inadequate public knowledge. These authors felt that male provider gender may also be a barrier to seeking health care in Middle Eastern women with UI. They were also surprised to find that women perceive their problem to be a neurological or "senile" disorder rather than related to childbirth or menopause.

There are several strategies that can be used to promote help-seeking behaviours and they need to include those that are culturally appropriate [36, 37]. Minority and disadvantaged groups have lower rates of health seeking behaviour for UI that may relate to a number of factors such as access to care and socioeconomic factors [38]. Understanding the reasons why people do or do not seek treatment for incontinence is hampered by the ethnic homogeneity of the existing data as most is derived primarily from white Caucasian populations and there is a lack of comparisons with ethnic minority populations.

Factors that enhance or enable people to change health behaviours include advice given by physicians [39]. Opportunities to promote continence can present themselves during other health screening activities such as cervical cancer screening [40]. Whilst health care professionals may enable people to seek help, those who have a lack of interest in incontinence can negatively affect health seeking behaviour in consumers [41, 12]. Other initiatives to promote health seeking behavior can include providing written information [42]. Continence health promotion information provided in a brochure [43] and in a computer based program [44] were found to improve health seeking behaviour.

Language, level of education and cultural factors may also be barriers to seeking help [45]. Consideration should be given to health literacy in target populations. Health literacy affects the ability to read and understand health information in written formats. Poor health literacy results in lower rates of health seeking behavior [46].

One of the most supportive government sponsored initiatives is from Australia. The National Continence Management Strategy (NCMS) was established in 1998 by the Australian Government Department of Health and Ageing. Funding of over \$33 million AUD has been allocated for the period from 1998 – 2010. More than 120 projects have received funding for research, public awareness activities, continence education, resource development and continence service development. The Strategy is now in its third phase of activity. A final evaluation report on Phase 1 and 2 of the NCMS was released in September 2006 [47, 48]. In the area of continence awareness,

the report noted that recognition of the barriers to help-seeking behaviour and identification of the most appropriate terminology and key messages would strengthen awareness raising strategies. The provision of an incontinence specific helpline (the National Continence Helpline) has been an important awareness raising initiative. **Table 1** reviews the specific programs developed and implemented by the NCMS.

2. CONTINENCE PROMOTION PROGRAMS

Continence promotion programs vary across countries and cultures, but the singular aim of creating awareness is similar. There is no standard model promotion program nor is there a standard outcome measure to determine the effectiveness of the program. While the current level of evidence for effectiveness of continence promotion program in raising awareness generally is level 4, there is a need for research to provide a higher level of evidence to affirm its effectiveness to generate higher interest and support.

Efforts to raise awareness of continence issues need to consider the following:

- **Target population** - Continence promotion programs need to consider age, gender and culture of target populations. It is necessary to consult with target groups when planning programs in order to meet the needs of these groups and to enhance help-seeking behaviour [49].

- **Target issues** - A continence promotion program needs to address risk factors and management options in different target groups.
- **Promotional material** – Newman [50] reported on a mail survey of 1,500 women, noting that most of the 422 respondents wanted more information regarding UI, and while they may not be equipped to fully understand the problem, they expect doctors, nurses, medical professionals, retail outlets, medical supply companies, and mail order houses to provide the information, including information through consumer advertising.
- **Channels of communication** – Health care professionals may launch campaigns or seminars to increase practice revenues. Commercial companies often fund public campaigns in order to sell their products. Continence organizations may be driven by missionary zeal or organizational growth. Regardless of motivation, care should be taken to avoid raising public expectations beyond what the services or products can deliver. Individualised “coaching” of the affected is one key channel that continence nurses use in the promotion of continence [51].

a) *Creating public awareness*

In the area of UI, building awareness among the general public is usually attempted via the media.

Table 1. NCMS Continence Awareness Programs

| Program | Description |
|--|---|
| Bladder and Bowel Health website www.bladderbowel.gov.au | Information and advice on the prevention and management of bladder control and bowel problems for consumers, carers, health professionals, service providers and researchers. It also contains information about the Continence Aids Assistance Scheme. |
| Continence Outcomes Measures (COMS) Dissemination Project | Development and delivery of a translation program of continence outcomes measures to national and international clinicians. Further work is being proposed to conduct field trials to establish the validity, reliability and suitability of the continence outcome measures in Australian treatment settings and then to translate these for use by health care professionals. The reports are: <ul style="list-style-type: none"> • Measuring Incontinence in Australia 2006 • Continence Outcomes Measurement Suite together with Review of Patient Satisfaction Measures 2006 • Framework for Economic and Cost Evaluation for Continence Conditions 2006 • Measuring Patient Satisfaction with Incontinence Treatment 2006 • Refining Continence Measurement Tools 2006 • Incontinence and Patient Satisfaction Tools and Instructions |
| National Men's Continence Awareness Project | Raise the awareness of the causes of poor bladder and bowel health, specifically targeting men. |
| Pharmacy Continence Care Project | Delivery of a training package to educate pharmacists and pharmacy assistants to enable them to better inform clients about continence care and management. |
| Daily Living Self Management Resources | Offers strategies for people with incontinence to help with their work life, family life and social life. <ul style="list-style-type: none"> • Live Better - for people with urinary incontinence |

Using the media to disseminate information in the form of Public Service Announcements (called PSAs) has been practised extensively in the U.S.A. to promote AIDS awareness and as anti-smoking campaigns. The U.S.A. National Institutes of Health, in partnership with the American Uro-Gynecologic Association, American Urological Association, American Foundation for Urologic Disease, National Association For Continence, Society of Urologic Nurses and Associates and the Simon Foundation for Continence, launched a national awareness campaign in 1997. The *Let's Talk About Bladder Control for Women* awareness campaign (http://kidney.niddk.nih.gov/kudiseases/pubs/bcw_ez/index.htm) offers easy-to-read booklets explaining the symptoms, types and causes of poor bladder control, as well as treatment options. The materials are designed to encourage and enhance communication between and among women and their health care providers. Free consumer and health care provider kits are available through a toll-free phone number. In 2001, the NAFC in the U.S.A. produced and disseminated continence awareness PSAs to 380 television media markets, including Hispanic outlets.

In many cultures, one of the best vehicles to reaching the public is through an informed journalist. Journalists often use a "media hook," an interesting story that will take priority over other news on the television, radio or newspaper. Having a spokesperson with the problem or finding a celebrity who is willing to speak for the cause can help [27]. These individuals can act as "influence leaders."

The Japan Continence Action Society held a "Toll Free Telephone Clinic" and callers were asked how they heard about the line. The responses in 2006 were: 30% from television, 16% from the web, 11% from a newspaper, 9% from a book, 6% from a friend, 5% from a brochure, 3% from a magazine and 20% others and/or unknown. In a UK campaign, Norton [52] found that newspapers were by far the most common source of information, followed by radio.

A media campaign should use multiple channels to ensure the broadest coverage [53]. An initial channel should include print media, television and radio. The Internet, phones, and other mobile devices are also effective outreach channels [54]. A second channel could be specialised age and health publications. A third channel could be the use of posters and brochures placed in medical offices, hospitals, senior's centre, pharmacies and churches. A final channel could be direct presentations to the public, such as at senior's centres [55].

Roe [56] suggested that local initiatives on the availability of services and how to access them, as well as health education information on UI, may be more effective in raising public awareness and should supplement national campaigns. Awareness raising

materials include pamphlets, self-care instructions, visual aids, pictographs, posters, banners, decals and advertisements in newspapers, magazines, newsletters, CD and films. Muller [57] believed that the change related to increased public awareness and help-seeking behaviour for continence care is likely to fuel the demand for innovation in technology and products. The Simon Foundation for Continence developed an innovative community education initiative *The Bladder Health Mobil*. This initiative provides education, increase public awareness, and promote early diagnosis and proper treatment of UI and other bladder control problems. It also facilitates dialogue between consumers and their health care professionals [58].

Terminology used when discussing urinary and bowel incontinence is important. The words "continence" or "incontinence", "interstitial cystitis" or "painful bladder syndrome" and "pelvic organ prolapse" are poorly understood and simpler terms may achieve greater public recognition in many languages and cultures. The use of "overactive bladder" in advertising has increased reporting of the condition to primary care professionals in the U.S.A. In the area of bowel disorders such as FI, it is felt that people find it difficult to find the right words to discuss their symptoms [27]. The International Foundation for Functional Gastrointestinal Disorder (IFFGD) in the U.S.A. has found that people will often report having diarrhea to their physician. If the physician or nurse does not question the patient any further regarding the ability to control gas, liquid or solid stool, the incontinence may not be discovered.

b) Program evaluation

Evaluation methods need to be established prior to developing the continence promotion program. Evaluation should include quantitative measurements and qualitative measures. Open-ended questions may be more sensitive than "direct satisfaction" questions [59, 60].

Health promotion evaluation methods include process evaluation, impact evaluation and outcome evaluation. Evaluation measures can include the number of media responses to a media release, or numbers of people who sought help.

In the evaluation report of the Australian NCMS, a total of 16 projects were undertaken for raising continence awareness, with focus on the development and distribution of information resources for use by the general community and specific target groups [47, 48, 61]. As of June 2006, a market survey found that 9 of the completed projects with measurable outcomes had generally shown favorable outcome.

Evaluation of the effectiveness of leaflets or brochures is gathering better evidence. An Australian study found that provision of a continence education package, which included a *Continence Educational Brochure*

helped to improve the health-seeking behaviours of participants who were bothered by UI symptoms [62]. Within 3 months following the education, of the 111 participants who were bothered by UI symptoms, 49 participants (44.1%) indicated that they had discussed the issue of bladder or bowel problems with someone directly because of the study or the information contained in the brochure. More than 94% of participants who remembered the brochure indicated that they believed it would be helpful if given to other people. In a study of 1175 participants, Wagg et al [63] reported that a self-help standard treatment leaflet is as effective as structured help from a continence nurse in reducing bothersome urinary symptoms in women. Similarly, a Swedish population-based study found that the distribution of a brochure on UI to the general public was well received and can be an efficient method to spread knowledge and encourage self-management [64].

The interventions that are most effective in reaching the public and triggering the desired behaviour seem to vary between countries and cultures. Television and newspapers work best in Singapore, with a “cured” patient bearing testimony to former suffering and its alleviation having the most impact. In the U.S.A., television advertising targeting OAB, funded primarily by pharmaceutical companies, has yielded a significant response. Nationwide television reaches more people than the circulation of any single newspaper or the distribution of a booklet through physician offices. In March 2008, Japanese National Television broadcast a program about UI during “golden time” (2000 to 2045 hours). The audience rating was 15.6%, the highest in a year (usual rating 12%), and more than 500 calls were received in one night, requesting repeat broadcast and more details about treatment. There are also cultural differences in the online health information is used, as well as the types of sites users prefer to surf [54].

In France, the effect of health education was evaluated in a randomized study in sheltered accommodations for the elderly [65]. Twenty centers were randomized to either a single one-hour health information meeting or control group. During a 30-minute talk, a nurse encouraged people to visit a physician if they had urinary problems. A questionnaire three months later found that the experimental group was much more likely to have had treatment if they were incontinent (41% vs. 13% controls) and 82% said that they had received some information about UI in the previous 3 months (compared to 22% controls).

A health promotion project called ‘Dry Expectations’ was developed and implemented in six ethnically diverse, predominantly minority, and inner city senior centres in the U.S.A. in 1996 [55]. The program was designed to address an older population. The project consisted of three phases: orientation and training of key staff members/peer educators at the centres (train-the-trainer model); educating seniors through four

one-hour weekly sessions involving visual aids and completion of bladder records and quizzes; and follow up sessions with senior staff/peer educators to reinforce the previous training. The program was very well received by the participants, and approximately 80% felt they had more control over their bladder by the end of the last session.

The impact and success of any continence promotion program must surely be its sustained effectiveness many years down the road, be it for primary prevention or treatment. A randomized controlled study of 359 community-dwelling older women showed that group instruction supplemented with brief individual instruction as needed is an effective teaching method for the acquisition of knowledge and motor skill in bladder training (BT) and pelvic floor muscle training (PFMT). The 1 year adherence following a behavioural modification program ranged from 63 to 82% for PFMT and 58 to 67% for BT [66]. Adherence is reduced over time and the marked benefit of intensive PFMT seen short-term may not be maintained and the long-term adherence to training can be low [67].

c) Recommendations for Continence Awareness and Promotion

Based on the literature reviewed in this section, the following recommendations can be made:

- Continence awareness should be included in any national advocacy program that is working towards an effective health literacy system, as it is consistent with and requires the involvement of many levels of educational, health-care, and community service providers, namely a(n):
 - Information dissemination system providing materials that are readable, comprehensible, trustworthy, and culturally sensitive;
 - Coordinated health literacy learning system;
 - Measurement and assessment system;
 - Formal and informal health advice system, including a helpline, handbook, and online support; and
 - Professional health care provider learning system. **(Grade D)**
- Continence awareness should be part of the main stream and on-going health education and advocacy programs with emphasis on eliminating stigma, promoting disclosure and help-seeking behaviour and improving quality of life. **(Grade D)**
- There is a need for research to provide higher level of evidence on the effectiveness of continence promotion programs to increase awareness, be it for primary prevention, treatment or management. **(Grade D)**

- There is a need for research on the most effective means to educate the public and professional groups on continence issues. Specifically, there is need for research on:
 - Identification and understanding of barriers to health-seeking behaviours
 - Translation of research into improved clinical practice and identification of methods by which this happens.
 - Effectiveness and impact of consumer education initiatives.
- (Grade D)**

3. CONTINENCE ADVOCACY

Advocacy is defined as act or process of defending or maintaining a cause or proposal. Advocacy, as it pertains to incontinence, involves assisting individuals in finding necessary health care and treatment. Organisations consisting of professional and public members promote continence advocacy as a core mission.

a) Service delivery

The provision of continence care and services in each country will depend on the organisation and infrastructure of its health services. It is difficult to make recommendations that will apply in such a variety of contexts. In addition, UI is so widespread and affects so many different types of people that they can present for help to literally any health care professional. This means that there will seldom be one portal of entry to a continence service.

When new services are created, there is a temptation to focus on the high technology investigation and medical treatment elements without considering the infrastructure needed to support that service [68]. However, there has never been a comprehensive examination of an optimal service. It is not known whether academic, specialist-led centres will achieve better and more cost-effective results than primary care clinics, domiciliary services or any other model. However, most experts believe that female UI is initially most effectively diagnosed and managed by primary care providers compared to specialist services.

In 2000, the UK's Department of Health issued guidance on continence services that outlined a good practice model to achieve more responsive, equitable, effective continence services [69]. In the U.S.A., the primary sources of care for the majority of Medicare patients (primarily an elderly population) are family physicians and primary care physicians [70]. Less than 1 person in 1000 is admitted to an academic, medical centre hospital [71]. Thus, in the U.S.A., elderly persons with UI and FI will probably be seen by primary care physicians for initial assessment. This

is unlikely to address the needs of developing countries (such as the Asia Pacific area or in Africa) where dissemination of expertise to rural communities and isolated community health care workers is more logical. They are being implemented in several countries using shared teaching and educational resources through co-operative arrangements of the respective Continence Foundations. Thus, the general practitioner or family physician plays an important role in the first line treatment of UI that may be treated successfully with conservative treatments in the majority of patients [72, 73].

In some health systems, both UI and FI have traditionally been seen solely as a nursing problem, with little interest or input from other members of a multidisciplinary medical team. Except for a few isolated areas, the main intervention has been trying to help the individual and caregivers cope with symptoms rather than attempting to treat the underlying cause of the UI. For example, in the UK, it is common for an elderly person presenting with UI to be referred directly to the district nurse "for assessment for pads and pants," with no physical examination or further investigation considered.

In fact, UI is often a complex and multi-faceted problem, particularly in frail or dependent individuals, and it may require input from a wide variety of disciplines to tackle it effectively. Symptoms typically associated with incontinence may also be indicative of other conditions as evidenced by the urgency and frequency symptoms of BPS, also referred to as IC and PBS, a chronic inflammatory condition of the bladder [74, 75]. The ICI Committee 19, addresses bladder pain syndrome. While it may not be practical for all specialities to work in close proximity, there is a need to consider carefully who does what, with protocols to guide appropriate referral and ensure good liaison. It is important that there are neither gaps, nor overlaps, in the service.

In countries such as Australia, New Zealand and the UK, where there is a national network of Continence Nurse Advisors (CNAs) or Continence Nurses. These nurses liaise, integrate services, and guide individuals through the referral route most appropriate to their individual needs.

The efficacy of Continence Nurse Practitioners (CNP) in the UK was reported by Matharu and associates [76] who studied four hundred and fifty (450) women over 40 years of age who underwent urodynamic studies in the UK after seeing a trained CNP. In patients diagnosed with detrusor overactivity, the CNP had prescribed 79% to have drug therapy and 64.8% to have PFMT. In those with urodynamic stress UI, 88% had appropriately been assigned to have PFMT. Nursing assessment has the potential to assign patients to the correct conservative treatment thereby shortening waiting times for urodynamics and specialist assessment.

Shaw, Williams, and Assassa [77] conducted a postal survey of people in the UK receiving services for UI by CNPs. Participants expressed satisfaction with nurse-led services because of the interpersonal skills, technical skills, and communication and information-giving abilities of the nurses. There is more evidence that treatment of incontinent community-dwelling individuals by a “continence nurse” is beneficial in terms of clinical outcomes [78].

Although some might see multidisciplinary working as the ideal, the reality is not always smooth. In some situations, rivalries and competition between disciplines and medical specialities is evident. This may be because of competition for patients and revenue, or because of disputes over the demarcation of the scope of different disciplines (such as the boundary between urology and gynaecology, or between nursing and physiotherapy).

There are no studies directly comparing the effectiveness of specific delivery systems for continence care. In certain cases, enthusiasts have conducted research and results may not generalize to the wider setting. Others have combined the expertise of multidisciplinary teams to maximize service delivery. The level of evidence on service delivery models is 4.

j) The need for service

As discussed at the beginning of this chapter, the majority of people (60-70%) who admit to UI in prevalence surveys do not seek professional help [13, 71, 79]. Not all incontinent people want or need help, and this may vary considerably between different cultures. For example, a postal questionnaire asking about urinary symptoms found that nocturnal problems caused the most bother (69% were bothered by nocturnal enuresis, 63% by nocturia). Only 50% found stress UI a bother and only 56% were bothered by urge UI [80]. A community based study found that only 15% of severely incontinent women (daily incontinence requiring protective pads most of the time) were worried about it, 15% felt that their activities were restricted and the majority seemed able to cope [81]. Overall, 78% were not worried by their incontinence and the authors suggested that services should be targeted towards the minority who do find it a problem. In Japan, it has been found that 55% of elderly incontinent people do not consider incontinence a bother, but 15% did not leave home, 10% found it difficult to leave home, and 10% felt that they caused bother to family and neighbours [82]. However it is pertinent to note that, there is significant underreporting by patients of UI and the severity of symptoms [83]. It is also evident from this data that the burden of incontinence, is responsible for 20% of healthy life lost for 75 year olds and older [84] and has the third highest impact on QoL of major chronic conditions [85].

A Japanese survey of over 1,000 caregivers of elderly incontinent people in the community found that more than 80% of caregivers are female and over half were more than 60 years old [82]. The caregivers felt that incontinence caused problems with the home getting dirty (10%); extra laundry (9%), need to wake at night (7%), and not being able to go out because of incontinence (9%). When asked what kind of government service they wanted, caregivers replied “health training” (10%), “knowledge about incontinence” (10%), and “supply of a portable toilet” (3%). Only 6% wanted the government to send them professional caregivers and only 4% desired referral to a specialist physician.

Incontinence is responsible for up to 30 - 50% of admissions into nursing homes, often precipitated by the burden of care on caregivers who spend half of their care-giving time providing personal care such as toileting assistance [86].

Some people seem to cope better than others with symptoms, and some had coping strategies, which were easily undermined by any suggestion that professional help was required [87]. Few people seem prepared to take action to prevent UI.

This can create a dilemma and raises many questions. Should health care professionals attempt to persuade or educate people who do not see UI as a problem that it is an abnormal condition? Should a patient who is “not bothered” by symptoms be treated because the partner or caregiver requests the physician’s assistance? This may be of concern, as Rodriquez, et al. [88] found that physicians underestimated the degree to which patients were bothered by their symptoms 25% to 37% of the time. Is lack of bother genuine or simply a defense against having to tackle an unpleasant problem? Does early intervention prevent later deterioration in symptoms? Does delay in treatment mean that success rates are lowered? There is scant evidence on any of these issues, or on the most acceptable way of providing help.

It is the impression of all members of this committee that, specifically for the field of UI, due to the high percentage of people not seeking help (for all the above mentioned reasons), that health care professionals must develop a concept of a “reaching-out” service and to actively provide service for incontinence care, meaning promoting awareness, openly discussing and actively detecting UI and providing simple and efficient therapy.

b) Models of continence care

Continence care was defined by the Canadian Continence Foundation as “all measures directed toward the prevention, improvement and or management of urinary incontinence” [89]. In this chapter, anal and faecal incontinence will be included within the concept of continence care.

As noted above continence care is well suited to management in the primary care setting. A range of models are described below.

1. SINGLE SPECIALIST MODEL - This is a service led by a consultant or specialist physician (urologist, gynaecologist or urogynaecologist), often focused around an “urodynamic unit” providing medical or surgical treatment. This is the most common model in developed countries; the best of them have a nurse continence advisor or continence nurse specialist as an integrated part of the service.

In some countries, physiotherapists (PTs) have also developed a specialized practice with incontinent patients. In France, all women, after childbirth, are entitled to a maximum of 10 sessions of pelvic floor muscle physiotherapy, paid for by the government. In Australia, Scandinavia and the UK, research on PFMT has been led by PTs. However, there is a lack of consensus as to best practices for UI. In a postal survey of British PTs, many were providing specialized service. Gynaecologists were the most common source of referral. The majority said physiotherapy was the first line of treatment. Pelvic floor muscle exercises and electrical stimulation were the most used modalities. However, there was little consensus about optimum treatment regimes amidst a wide variety in the details of therapies used [90].

2. NURSE CONTINENCE ADVISOR MODEL - The nurse continence advisor (NCA) may be independent but is usually associated with community/area health centres, where they may have variable professional support from general practitioners (GP) and family physicians. Continence nurses often work in both hospital and community, and the service is focused on primary care, particularly district nurses. Key roles include patient assessment and implementation of conservative management strategies where appropriate and facilitating patient access to incontinence product subsidies or schemes.

The Department of Health in the UK has commissioned an evaluation of different models of nursing services, with and without specialist NCAs. It was found that where there is a continence nurse, incontinent people are more likely to receive targeted referral to specialists such as an urologist, and are more likely to have had investigations such as urodynamic testing and to receive more appropriate treatment and care for their UI. These patients were also more likely to report satisfaction with the service. In contrast there is still concerns that general nurses continue to “contain the problem” instead of promoting continence despite acknowledging its importance [91].

In a series of studies performed in Leicestershire UK, the short and long-term outcomes of a new CNP-led service for urinary symptoms (3 and 6 months after implementing the program) were examined and evaluated [87, 92, 93]. Williams, et al. [93] reported

on a randomized, controlled study of 3,746 community-dwelling individuals greater than 40 years of age (61% women) who had incontinence, frequency, urgency, and nocturia all impacting QoL. The experimental group was comprised of 2,958 patients. The standard care was the control group (n=788) who accessed GP services and existing continence services in the area. The experimental group received an 8-week primary intervention package by the CNP (21 generalist nurses who trained as CNPs), delivered evidence-based behavioural interventions using predetermined care pathways in four visits over an 8-week period. Interventions included advice on diet, fluids, BT, pelvic floor muscle awareness and healthy eating. Individuals whose symptoms persisted after primary intervention were offered urodynamic testing. The CNP led service had a 10% higher cure rate than standard care with statistically and clinically significant reductions in urgency, frequency, nocturia and UI. In addition, QoL improvements were greater in users of the CNP led service and higher levels of patient satisfaction were achieved. This is the first study to show the effectiveness of nursing services on urinary storage symptoms (rather than simply incontinence) and associated QoL. The authors noted that the public health value of a 10% reduction in symptoms is substantial when applied to such a common problem.

A similar RCT in Australia compared outcomes in 145 women presenting with stress UI, with or without urge UI, randomly allocated to a standardised regimen with the NCA or treatment by an urogynaecologist [94]. After 12 weeks, 110 women were evaluated. Sixty-four percent (n=58) of the NCA group and 52% (n=52) of the urogynaecologist group were asymptomatic with a dry pad test. There were no significant differences between the groups for incontinence scores, pad test changes, voids/day or scores on Urogenital Distress Inventory or Incontinence Impact Questionnaire. The treatment by the NCA took a median of 160 minutes, but cost AUD59.20 compared with 90 minutes of gynaecologist time at a cost of AUD189.70. At 2.5 years, 29% of the NCA group and 41% of the other group were dry. The authors concluded that similar results were achieved at lower cost using the NCA.

An additional number of studies support the efficacy of specialist NCA in the delivery of community continence care [72, 95, 96]. In the U.S.A., urology nurses have been trained as “teachers” to successfully implement behavior modification program to groups [97].

In the U.S.A., there has also been an increase in nurses who specialize in dealing with patients with pelvic floor disorders including UI, FI, POP and BPS/IC/PBS, although there are no academic or clinical proficiency requirements in order to be considered a CNP or “continence nurse specialist.” Those nurses who do specialize in continence care have obtained their knowledge and skills through self-

motivated activities [98]. Masters prepared or educated “advanced practice nurses” (APNs) have become increasingly interested in and knowledgeable about the assessment, diagnosis, and treatment of people suffering with UI. These nurses are developing a nursing subspecialty in the care of individuals with UI and related pelvic floor dysfunction and provide comprehensive assessment and treatment (drug and conservative therapy) and act as educators and researchers [25].

A 2000 study in the U.S.A. demonstrated significantly improved outcomes for three clinical problems: UI, depression, and pressure ulcers when advanced practice gerontological nurses (APNs) worked with nursing home (NH) staff to implement scientifically based protocols [99]. In addition to working with NHs to provide resident evaluation as physician extenders, this research indicates that this service model using an APN can be an effective link between current research based knowledge about clinical problems and NH staff. This study also showed that consistent educational efforts with staff and NH residents demonstrated that interventions could improve or stabilize the level of UI in these individuals.

In some countries the NCA is attached to a district nursing service providing expert advice and support for non-specialist nurses with patients who have continence problems.

3. MULTIDISCIPLINARY RESOURCE AND REFERRAL CENTRE MODEL - Multidisciplinary clinics, as service models, have been shown to provide comprehensive continence care. In multidisciplinary clinics, such as a “Pelvic Floor Clinic”, gynaecologist, urologist, colorectal surgeon, and continence nurse work together [100]. Some pelvic floor clinic staffing models also include physical therapists and registered dietitians.

An Australian study took all community referrals of those who had been incontinent for at least two months and had at least one episode in the preceding 2 weeks to a continence clinic. [101]. Patients were randomised to conservative treatment or control, with a crossover design. Patients were asked subjective questions about embarrassment, odour, depression, family relationships, isolation and laundry on a 4-point scale ranging from no effect to major effect upon life. The questionnaire was completed at the start, and at 2, 4, 8, and 12 months. Seventy-eight patients entered the study: 87% improved with treatment (vs. 41% controls). Fifty-two percent were moderately or severely embarrassed at the start of the study period, but at 4 months, only 17% were. Depression decreased from 49% to 22% and isolation from 28% to 12%. Odour and the use of extra laundry also decreased. All benefits were maintained at 12 months. Controls did not improve on these items until crossed over to active treatment, despite feeling better. The authors conclude

that conservative treatment in a multidisciplinary community clinic improves continence and well being.

The Continence Foundation of Australia is funded by the Australian Government to employ continence nurse advisors in the National Continence Helpline to provide advice to consumers and health professionals, including referral advice. Evaluation of the helpline by Deakin University showed the majority of callers took action to improve the incontinence issues they enquired about and, the most common course of action following the phone call was to change how they dealt with incontinence [48].

An expansion of this service provision is exemplified by the National Centre for Continence in Israel, which aimed to provide an integrated service [102]. The Center’s professional team not only treats incontinent patients but also educates GPs and nurses who come from pre-selected peripheral/outlying clinics, and provides ongoing support and advice as well as a pathway for tertiary referral. A local team (GP and nurse) are also selected to be in charge of promotion, detection and treatment of incontinence at the clinic. They later become “in charge” of incontinence in their region. This model allows national distribution of continence services with support from the resource centre and provides interdisciplinary exchange, as well as, maximum co-operation between Medical Centres and community health services. The national centre is funded by government and industry to provide a “Hotline” for the public, to promote education programmes in nursing and medical schools, hospitals and nursing homes, and to develop guidelines for diagnosis and management of incontinence by primary healthcare staff.

A report on continence care services worldwide noted that services were scattered, inconsistent and considerable discrepancies exist in their funding. It was concluded that there is a need for accessible (and affordable) continence care and multidisciplinary teamwork [103].

4. PRIMARY CARE MODEL - There are many factors that can persuade health care planners about the importance of adequate investment in community continence services: the prevalence and the number of incontinent people is likely to increase with an aging and increasingly dependent population and many frail, disabled or elderly people are incontinent for reasons extraneous to the urinary system (such as poor mobility, an inappropriate physical environment or lack of an individualised care regime). It is often best to provide an initial assessment for such individuals in their usual surroundings and to reserve hospital or clinic (specialist or academic) referral for those who do not respond to simple measures such as treatment of constipation, modifying a diuretic medication, or provision of accessible toilet facilities. A number of guidelines have suggested an algorithmic, step-wise

approach to assessment and treatment of urinary incontinent patients and many conservative treatments have a good success rate in primary care [104, 105, 106, 107, 108].

A New Zealand study of 600 family physicians found that most respondents provided continence care and 2.6% offered special clinics for continence promotion [109]. Fewer than half felt confident to diagnose the causes of incontinence. Confidence in managing incontinence in children was consistently lower than for other childhood problems. There was no difference by sex in confidence, although female respondents were more likely to consider management of continence care as part of a practice nurse's role and to routinely ask women about UI during a "well" visit. Most respondents (71.9%) could not remember having had any formal training in the management of incontinence either at the undergraduate or postgraduate level. Recall of postgraduate education was associated with greater levels of confidence in management of incontinence problems.

Family physicians have been shown to be successful in treating UI. A UK study examined assessment and treatment of 65 women, who were treated according to their type of UI [110]. Those with stress UI were treated by PFMT, those with urge UI by BT and medication, and those with mixed UI by both. Patients with stress UI or urge UI, but not mixed, improved compared to controls at 12 weeks. A Dutch study of 110 women reporting UI to a family physician was randomly assigned to the treatment or control group. Treatment was PFMT for stress UI and bladder training for urge UI [81]. Patients were interviewed at 3 and 12 months, with crossover at 3 months for controls. At 3 months, 60% were dry or only slightly incontinent. Mean wet episodes were down from 27 to 7 per week. Seventy-four percent felt improved or cured and there was further slight improvement at 1 year.

A study in a community clinic in Israel showed that after training, family physicians detected 98 patients with UI during a period of 19 months [111]. Mean age of the 94 females and 4 males was 71 years (range 56-89). Most patients (53) were detected by the physicians on direct questioning, some by nurses (29) and only 18 by self-referral. After a mean follow up of 10 months, 35 were dry and 32 significantly improved. Cure or improvement was achieved at the clinic with no involvement of an urologist or gynaecologist.

5. OTHER SERVICE MODELS - Acute or sub acute care to community- Patients with UI who receive care in acute care hospitals have been shown to lack appropriate care because of the lack of knowledge amongst acute care nurses about assessment or management of UI [112] Nursing education will have to change to affect this situation. The value of tackling this is shown in a retrospective review of 6,773 episodes of care in 54 medical facilities [113]. The

discharge destination was altered by the presence or absence of UI – 57% vs. 82% being discharged home, respectively, and 29% vs. 12% being discharged to a nursing home or other health care venue. In addition, the time in rehabilitation was 185.6 days with UI compared with 156.8 days without UI, and geriatric costs in evaluation and management were higher in the UI group. The level of functional independence and motor function also impacted outcome.

Elder services (e.g long term care or nursing homes) There is growth worldwide in the use of APN "continence" specialists practicing in home care and LTC settings, providing expert consultation in UI and related disorders [25, 98]. Many have developed innovative approaches to management of UI in nursing homes. Bucci [114] developed the CHAMMP (Continence, History, Assessment, Medications, Mobility, Plan) tool to educate nursing home staff in the U.S.A. on a comprehensive continence assessment and to assist in implementation of individualized plans of care. The CHAMMP program improved one facility's Quality Measure Indicator Report. ICI Committee 11 discusses services for frail elders.

Services in developing nations - The potential demand for UI services in developing nations far outstrips the resources that are available. The provision of services will depend on dedicated healthcare professionals with support by government or industry and by a local continence organisation to educate a new generation of service providers who will carry the services to remote communities. In some instances, consideration will have to be given to cultural, social mores and taboos.

For example Ethiopia's Health Minister has stressed the need to develop rural health services to reduce the incidence of fistula and to have first time mothers examined by Traditional Birth Attendants (TBAs). The ICI Committee 18, Vesico vaginal fistula in the developing world addresses service for this specific condition. It is planned that TBAs will be trained to identify high-risk women, and thereby divert expenditure from high cost physicians and urban health services to training community health workers and health education. Attitudes on female circumcision, contraception and women's health, which are often decided by their husbands, obviously have much wider implications than just continence care.

Continence services are a relative luxury, to which countries with a low per capita income are unlikely to devote scarce resources whilst other population health issues have precedence. For example, in Brazil, priorities for their health budget are childhood immunizations, AIDS/STDs, basic sanitation, healthy environment and literacy to help with the problem of street children.

c) Worldwide organisations

The stigma associated with incontinence is similar to other conditions and is associated with public ignorance and lack of awareness [114]. Despite all this, it is important to understand how attitudes and stigma have changed for these conditions. An important component is breaking the cycle of public and personal ignorance through education and public awareness programs. Patient advocacy organisations for UI have been formed worldwide to promote awareness. But for any advocacy group to be successful, there needs to be a partnership between health care professionals, governments, and industry groups with a vested interest to work together to break the cycle of ignorance and negative attitude.

Professionals (e.g. urologists, urogynecologists, gynaecologists, primary care practitioners, physiotherapists, nurses) and professional organizations have been instrumental in promoting awareness of continence in all care settings. The International Continence Society (ICS) established the Continence Promotion Committee (CPC) to promote education, services and public awareness about incontinence throughout the world, and to facilitate communication, exchange of information and partnerships between continence organizations, health care professionals, governments, and industry. The CPC's multinational and multidisciplinary representation aims to identify broad issues through an international forum that can facilitate translation at the local and national level. Each year at the ICS's annual meeting, the CPC has held workshops around various themes that have a broad national focus such as prevention; general practitioner education; and promotional strategies. Its relevance, as is the case with each of the national organizations, is to recognize the interface between continence management and continence awareness and promotion. The CPC is increasing continence awareness through the hosting of Public Forums in conjunction with the ICS annual meeting. In 2009, it will sponsor *World Continence Week*.

Although it may not be practical to develop global and uniform strategies for continence promotion and public awareness, much can be learned from the positive and negative experiences of other organisations in other countries.

Continence promotion is a most challenging endeavour. Although the ratio between affected patient populations and continence organisations funding has not been formally studied, anecdotal information suggests that fund-raising for continence programmes is among the most difficult of medical problems for which to obtain funding. In view of all these challenges, the proliferation of new continence organisations, especially in the Far East and in South America, is a validation of both the need for continence promotion and the dedication of those who have recognized and are addressing this need.

1. CONTINENCE ORGANISATIONS In the past fifteen years, several national organizations have been formed under various auspices to tackle issues to do with incontinence awareness, education and promotion. Organizations which promote continence are as diverse as the cultures they serve. They represent a wide diversity of models, including consumer-led, company sponsored, patient-only, professionals only, and organizations which have deliberately set about trying to bring together all relevant stakeholders in a relatively democratic model. In every part of the world, these organizations play a dynamic role in building both public and professional awareness of this underserved and underreported condition.

Most continence organizations are poorly capitalized, being either under- or unfunded (i.e. run by volunteers) and are held together initially by either a dedicated patient advocate or an energized healthcare professional. In most cases, this professional is an urologist or nurse whose patient population includes persons with UI.

As of 2008, there are 47 Continence Organisations in 34 countries world wide with an additional 2 international patient-based organisations. Appendix 1 is a directory and provides the contact details of various national continence organisations. Most of them function as multi-disciplinary bodies. The previous ICI chapter published results of a survey conducted on these organizations [117] Findings include:

- More than 50% of these organizations have been in existence for more than 10 years and that membership includes both professionals and the public.
- Organizations have oversight from advisory boards consisting of consumers (lay public) and health care professional members.
- Most have developed medical guidelines for continence care which represent solo efforts by the organization or in collaboration with the medical community and the government.
- Funding is an ongoing challenge for most of these organizations. Very few receive government funds, and most rely on support from industry or manufacturers of drugs and products for specific projects.
- Continence awareness is being provided generally to a public that has 'very little' to 'no understanding' of incontinence.
- There is now an increase in media interest in continence

Education about incontinence has been identified as the most important method to decrease the perceived stigma associated with the disease. A successful method to educate has been through public awareness campaigns, health promotion projects, or health fairs.

Information is provided on the internet through websites developed by each continence organization. These websites provide useful information on incontinence, what it is, and how it can be managed, treated, and cured. They provide frequently asked questions (FAQs) as well as useful links to other continence related websites.

A needed service identified by several organizations concerns the management or containment of urine leakage through the use of products and devices. A guide to continence products has been developed by many organizations and is available to the members as well as health care professionals. This is aimed at providing useful information about the range of different products available.

Most have developed a directory of health care professionals who have expertise in the area of incontinence and its management. Certain organizations have this directory available through their website.

Organisations that primarily target the general public typically do not participate in educating professionals. Those countries where a consumer-based organisation does not exist do engage in educating professionals as well as raising the awareness of incontinence to the population in general. In those countries that have consumer-based continence organisations, there are national public awareness campaigns (e.g. the U.S.A. has a designated *Bladder Health Week* every fall and November is *Bladder Health Awareness Month*). It is generally felt that media coverage is inadequate. However, in a recent article, the NAFC (U.S.A.) strongly advocates enlisting the help of the media as one of the 3 main strategies that will help to improve the quality of life for many incontinence sufferers in future [57].

There is a paucity of published work on the formation of national organisations that target consumers or the general public. The level of evidence on the impact of national organisations increasing continence awareness is Level 3.

2. NETWORKING OF CONTINENCE ORGANISATIONS While there is little data on the outcomes of the use of organisations to change consumers' views and awareness of incontinence, sharing of experience and collaboration amongst countries could lead to more efficient use of resources. For instance, in 1998, the Asia Pacific Continence Advisory Board (APCAB) was established with a mission to develop *Continence Promotion* programmes that work together with health care professionals and the general public to develop strategies to increase awareness and reduce the social burden of UI in the Asia Pacific Rim.

The APCAB member countries are Thailand, Korea, China, Hong Kong, Taiwan, Malaysia, Indonesia, India, Philippines, Singapore and Pakistan.

d) Recommendations for Continence Advocacy

Based on the literature reviewed in this section, the following recommendations can be made:

- Government support and co-operation are needed to develop services, and responsibility for this should be identified at a high level in each Health Ministry. Incontinence should be identified as a separate issue on the health care agenda. There is a need for funding as a discrete item and for funding, not to be linked to any one patient group (e.g. elderly or disabled), and should be mandatory. **(Grade D)**
- No single model for Continence services can be recommended. In all health care systems, much will depend on the local health care structure. Because of the magnitude of UI, prevalence, detection and basic assessment will need to be performed by primary care providers. Specialist consultation should generally be reserved for those patients where appropriate conservative treatments have failed, or for specified indications. **(Grade D)**
- There is a need for research on outcomes, not just the process of service delivery. This research should have patient-focused outcomes, evaluate the outcomes for all sufferers who present for care, use validated audit tools/outcome measures and longitudinal studies of the outcomes of services provided. **(Grade D)**
- There is a need for cost-effectiveness studies of services currently being provided. **(Grade D)**

III. PROFESSIONAL EDUCATION

LITERATURE SEARCH

The online databases Medline, Embase, Biosis, Science Citation index, Web of science and Cinahl were used to obtain the literature, additional databases of ERIC (an education database) and psychlit were also searched. The focuses of the searches were between 2004-2008, although literature from the preceding 10 years was also scanned to ensure thorough coverage. The objective was to obtain relevant literature relating to incontinence education. The following search terms were used: incontinence, overactive bladder, health education, education, allied health care professionals, doctors, nurses, consumer, and public education. There was significant overlap between the searches made on different databases as would be expected. The search largely identified the literature already used for the chapter in 2002/2004. Additional references from the preceding 4 years were included and references found which had not been previously identified were also incorporated.

1. BACKGROUND

With the continued advances in health care, increasing public pressure to provide high quality evidence based care, limited time for health professionals to update their knowledge and the recognised ineffectiveness of passive 'lecture style' education provision, the need for new models to change health care providers behaviour is essential. Nowhere is this more relevant than in the provision of care for those with UI and FI where traditionally educational provision has been inconsistent at best.

Professional education is a key component in the provision and care of individuals with UI and FI. In their state-of-the-science statement on the prevention of faecal and urinary incontinence, Landfeld et al [1] identified that education of health care providers alone is insufficient to improve detection and treatment of UI and FI. However they recognise that in order to appropriately detect and evaluate incontinence, professional education is required along with outreach and practice based resources. To date, the education and training of those involved in the provision of continence care has been poor.

It is well recognised internationally, that continence care provision in the area of UI has developed at different rates within differing care models, resulting in scattered and inconsistent services [103]. There are wide variations in health care professional input and a lack of continuity of care between primary and secondary care providers [117]. Central to the provision of high quality continence care is the education of the individuals providing care, including physicians, nurses, and allied health care professionals. There is limited literature on the educational preparation and ongoing training of those health care professionals engaged in continence promotion, care, and referral and even less on the evaluation of education programmes in terms of educational or practice outcomes. It has long been recognised that professional education with reference to UI and FI remains only a small part of the basic training of physicians, nurses, or allied health professionals and on-going training is largely 'ad-hoc' with huge variations in the types, content and quality of such training. An early survey in the UK found minimal attention given to incontinence in both medical and nurse training, and a key recommendation for improving continence care was an increase in quality and quantity of professional education [117]. This has clearly not occurred. While educational initiatives have been undertaken, they remain fragmented and inconsistent internationally. Most notable is the absence of evidence demonstrating an impact of professional or public education on the burden of suffering posed by OAB and UI. The ICS has established an Education Committee to promote, organise and co-ordinate all educational advances undertaken under the auspices of the ICS. This promises to be a step forward in defining core

competencies and educational goals and objectives for trainers and trainee alike. Subcommittees in medical student and resident education, nurse education, physiotherapy education have been established. Though to date, educational initiatives are broadly medical. Details are available on the ICS website (www.icsoffice.org).

There is a paucity of published work on professional education on UI or FI. Similarly, there are few studies addressing the effectiveness of education in improving the knowledge of learners, or on whether improved knowledge impacts on patient outcomes. Since the publication of the ICI chapter in 2005 [116], the evidence has been building but the level of evidence on the effectiveness of professional education remains 4.

This section will examine the available evidence on the effectiveness of professional education on incontinence for different groups of health care professionals.

2. PHYSICIANS (FAMILY PHYSICIANS/ GENERAL PRACTITIONERS/PRIMARY CARE PHYSICIANS)

Physicians (general, primary care, and family physicians) often have a gate-keeping role in continence provision as they are often the most likely first point of contact when patients seek formal help for their incontinence [118]. They may refer their patients to other health care professionals in primary care, such as a continence advisor (nurse or other allied health care provider), or, to a specialist in secondary care. Physicians provide this service without having undergone essential training in the management of patients with urinary symptoms, as this is largely unavailable.

a) Medical education

Most physicians have received little education about incontinence, fail to screen for it, and view the likelihood of successful treatment as low [119]. At the same time, there are no data confirming the benefits of screening as a method to reduce the burden of suffering from UI. A postal survey noted that only 18% of respondents said providers asked them to complete a questionnaire about bladder control during routine office visits and a majority (69%) felt it would be very helpful in prompting discussion if their physician or health care professional provided a form for them to check off symptoms of incontinence [50].

Traditionally, UI and FI have formed only a very small part of the undergraduate medical curriculum. Education on UI has usually been fragmented across different organ systems, with training scattered between gynaecology, urology, and geriatric medicine. Bladder and pelvic floor anatomy is poorly covered in preclinical training and relevant physiology is rarely

mentioned. A survey of urology residency directors, medical student educators in urology, and urology applicants identified UI as one of the 8 most commonly cited topics to be included in a core urology curriculum [120]. Co-ordination between the disciplines is rare, although there are some international examples of joint seminars/modules on urinary and faecal incontinence (University of New South Wales) and inter-disciplinary input into curriculum (University of Newcastle). Minimal training is provided on paediatric continence issues.

There is a clear history of inadequacies in continence care which have been acknowledged for some time. In 1983, the Incontinence Action Group published a report [121] which identified 'the huge gap which exists between available knowledge of the causes and methods of management and that which is actually known to practising nurse and doctors.' In their review of the evaluation and treatment of women with UI in the primary care setting, Walters and Realini [122] found that UI can be diagnosed accurately by family physicians using basic tests.

A later study found that outpatient geriatric assessment units were better than physicians in community based practices at identifying patients with both mild and severe incontinence [123]. There is clear evidence that there is a need for further education of health care professionals. Brocklehurst [118] found that less than 25% of patients with UI were given a full examination by their GPs. Deficits in the knowledge of GPs about UI were found by Jolleys and Wilson [124] in a survey of 1284 GPs. They also found that GPs lacked confidence in their abilities to diagnose and manage UI, although this lack of confidence was not related to length of practice as a GP. In an analysis of incontinence in the community, the action taken by many GPs was found to be suboptimal, with considerable geographical variation [125]. Fewer than 5% of those who consulted a doctor in this survey were referred to a nurse or incontinence clinic. It also suggested that medication was often prescribed without clinical examination and probably without a diagnosis being made. In a study by Briggs and Williams [126], 42 of 101 general practitioners surveyed never used the service of a continence advisor for older patients although the service was available to them.

There have been efforts to educate family physicians in Australia; in 1989, the New South Wales state government gave AUD 25000 to the Continence Foundation of Australia to develop an educational package (15000 copies) on incontinence to be distributed to all family physicians in the country [127]. An evaluation of the package was undertaken to determine whether the package significantly improved knowledge of incontinence. There was no difference in initial knowledge between the intervention and

control groups, but there was a significant difference in post-pack scores between the groups with no difference in scores on questions not in the pack. Sixty-three percent continued to use components of the package later in clinical practice. However, response rate from the 510 family physicians contacted was only 16%.

Two studies have reported that family physicians can be effective in treating UI by using conservative treatments when educated and motivated [95,128] with cure or improvement rates reported at 60 - 70%. Education can also increase referral rates to specialist practitioners [129]. However, the best format for education initiatives to all professionals needs further delineation. The use of road shows (e.g. continuing medical education [CME] seminars), teleconferences, guidelines, booklets and face-to-face teaching are commonly used but rarely evaluated.

There is very little available literature on knowledge amongst family doctors on faecal incontinence. A study has recently been undertaken to explore GPs awareness of surgical treatment options for FI. [130]. A postal questionnaire was mailed to 1,100 GP's in Yorkshire region in the UK, a response rate of 48.5% was achieved. The questionnaire assessed basic knowledge of FI and treatment options. Overall knowledge was poor, with the majority unaware of available investigations, treatments and specialist centres. The authors recommend better communication between specialist centres and GPs, as well as CME programme implementation.

There is growing evidence to suggest that traditional 'lecture style' medical education is ineffective in changing physician behaviour and ultimately patient outcomes [131]. More innovative teaching methods are clearly required. Levine and colleagues [132] used a train-the-trainer model to evaluate the management of a number of common geriatric conditions including incontinence. This model involved training, by an expert faculty, a team of non-expert peer educators. These peer educators used a toolkit, to conduct small group learning sessions.

These sessions were evaluated immediately after and 6 months after the education sessions. The model used principles of knowledge translation and active teaching using tool kits based on guidelines to train geriatricians. Results showed statistically significant improvements in self reported knowledge, attitudes and office based practices. The study concluded that modest changes in practice in relation to geriatric conditions were achieved using this peer led approach. Whilst such evaluations are promising, such models are difficult to sustain and costly. Perhaps most importantly they point to the need to use innovative teaching methods to ensure that educational efforts actually make a difference.

b) Medical specialists

There is little new published evidence on medical specialist training in the form of effective training interventions. Specialist training in incontinence is not always adequate. A survey of urological trainees between 1988 and 1994 in Australia showed many felt their training in the management of incontinence had not been adequate [133]. The Colleges of Obstetrics and Gynaecology in the United Kingdom and Australia and the American Board of Obstetrics and Gynaecology have developed courses and credentialing of specially trained urogynaecologists with separate examinations. Similarly, both the American Urologic Association and the European Board of Urology conduct courses, CME programmes and set standards in UI management. However, both UI and FI still may be perceived as exclusive to “super-specialists,” potentially alienating colleagues.

A survey of 163 urodynamic services in the UK found that half the respondents felt their training in urodynamics was inadequate [134]. This led Ellis-Jones and colleagues [135] to explore whether a recognised education and training programme for urodynamics led to changes in urodynamic practice. They asked programme delegates to complete a questionnaire (n=84) pre and post education programme and found that 79% reported a change in practice following completion of the course. This type of evaluation of an education programme is essential to determine the value of such courses, however the evaluation of programmes are often undertaken by those delivering the programme and the need for independent evaluation should not be underestimated. Committee 7, Dynamic Testing, of the ICI recommends that invasive urodynamic studies should be performed in accredited urodynamic laboratories, by trained and certified staff, with formal control of the quality of the results. This committee highly recommends the establishment of national accreditation, training, certification and quality-control programmes.

3. NURSING PROFESSIONALS

Nurses have a significant role to play in the area of incontinence as they are the largest single group of health care professionals around the world and are often the first to become aware that the patient is experiencing incontinence. Cheater and colleagues [136] found that in the UK, an average community nurse case load will comprise approximately one-third of patients with UI. There have been a number of recent studies which explore the use of new innovative methods of education provision for nurses. Rogalski [137] reports persistence in the lack of educational emphasis on common symptoms like UI and recommends a curriculum model based on existing guidelines and the best available evidence which could address this shortfall and would increase the quality of continence service provision.

A common theme that runs through the international nursing literature over the past two decades is that nursing staff recognise a lack of knowledge of UI and indicate that they would like further training [138, 139, 140]. There are significant gaps in knowledge and clinical practice adoption related to both UI and FI although nurses worldwide have played a major role in developing new information and testing interventions [141]. Although nurses can provide effective interventions in the area of UI, there is limited research on effective interventions for FI.

Innovative methods of improving knowledge amongst nurses have undergone recent evaluation. An important study undertaken by Cheater and colleagues [142] adds to the debate by examining the value of audit and feedback and educational outreach which in the past has often focused on doctors' behaviours rather than nurses. In this study, the researchers undertook a cluster randomised trial to evaluate 194 nurses in 157 family practices with 1078 patients with a diagnosis of UI. They found that when compared to educational materials alone, there were no improvements in care for either educational outreach or audit and feedback (all groups did improve but differences between groups were not significant). McConnell et al [41] describes how advanced practice nurses learned evidence based approaches to managing complex cases including incontinence in nursing home residents. Advanced practice skills included assessment and diagnosis appraisal of evidence for management. The authors suggest that such practices can enhance both student and facility outcomes, although no systematic evaluation was undertaken.

Ostaszkiwski [143] describes a nursing leadership model to enhance continence care in older adults. Evaluation of the programme suggests improved management and assessment of incontinence for individuals sustained after a two year period. Leadership programmes have proved effective in a number of areas in nursing provision.

Within these more recent studies, the use of innovative methods of knowledge transfer and education are beginning to be adopted, such methods, used in other areas of professional education may be well suited to UI and FI.

Some self-study materials have been developed which link issues on continence care with other regulatory and policy content such as recognition and reporting of elder abuse and neglect [144].

a) Specialist nurses

Educational courses on incontinence are available for nurses in the UK, U.S.A., Europe and Australia and are beginning to appear in Asia, notably Hong Kong and Singapore. These courses vary from 2 to 4 weeks of face to face didactic courses to distance learning

courses lasting 4 to 6 months that lead to a post-basic nursing certificate.

In the UK, education programmes are documented at the Association for Continence advice website (http://www.aca.uk.com/education_modules.php) and comprise information on 1 day courses as well as diploma courses, degree modules and masters level study. Such databases of courses offer an excellent overview for students and providers.

Williams et al [145] conducted a small study in the UK that showed improvements in both knowledge and attitudes of nurses who undertook a specially designed full time, 3 month programme that included a continence module.

Internationally, there is inconsistency in the provision of specialist education to prepare nurses to practice as experts in the field of incontinence. Programmes of study are developed, but rarely fully evaluated. The need for innovative web-based learning programmes incorporating modern information and communication technology (e-learning) may offer one way of providing standardised programmes of study to practitioners.

Beitz and Snarponis [146] describe their innovative on-line learning programme which includes continence nursing. They feel that such teaching strategies are acceptable to nurses.

As with physicians, it is unlikely that improving nursing knowledge alone will translate into improved clinical practice, or into the ultimate goal of improved patient outcomes. A review of hospital policies and community nursing practice in an area with a well-established continence service and education program demonstrated very little evidence that improved education had a tangible effect on practice [147]. The authors concluded that nurse specialists are most usefully employed providing a clinical service to individual patients rather than spending their time educating other nurses.

There is a lack of consensus on what should be taught to different nursing groups at each educational level. It is not clear how educational needs can be met or who will pay for the time and expertise required to provide educational initiatives. Governments, as primary payer of nursing home care, have a vested interest in promoting continence in order to minimise costs. It is likely that the continent nursing home resident requires less nursing time than an incontinent resident. It therefore falls to the payer to underwrite the education that is needed to promote continence. In the U.S.A., the Centers for Medicare and Medicaid Services has developed a "guidance" for UI care in nursing homes and provided web-based education to staff. (www.cms.internetstreaming.com)

More emphasis on incontinence care and the nurses' role in continence promotion should be encompassed in basic nurse training courses. Specialist continence

nurse practitioners and nurse continence advisors are likely to be the best instructors to provide this education.

Standard Setting, care pathways and level of continence knowledge - Standard setting has been one method by which general nurses can acquire skills to meet set standards of practice. But a more effective method may be care pathways which map out a timed process of patient-focused care which specifies key events, tests and assessments to produce the best-prescribed outcomes, within the limits of the resources available, for an appropriate episode of care [148].

The use of Continence Care Pathways has been evaluated amongst generalist nurses. It was found that the use of such pathways has aided in the identification of reversible causes of incontinence (e.g., UTI, medication, fluid intake, constipation, dexterity and mobility issues), and addressed poor quality of life and bothersomeness issues [149]. In a recent audit of 144 continence care providers in the UK, this group found that nearly half of them were using the guidelines and found them to be effective in helping with assessment and management of patients [150]. By using care pathways, patients could be referred to specialist nursing care more appropriately for specific treatment beyond the scope of the generalist nurse, or when they failed to respond to first line therapy. The care pathway identified the needs of the patient, directed simple investigation and primary therapy, but also identified the resources needed by the nurses (e.g., urine testing dipsticks, lists of drugs, frequency/volume charts). The pathway could be modified according to the equipment and expertise locally available. Educating large numbers of general nurses to follow a simple pathway with basic continence-care competencies [151] may allow better use of specialist nursing time and specialized skills [152].

Jha, Moran, Blackwell, and Greenham [153] conducted a small study of women attending gynaecology outpatient departments with incontinence problems. Thirty-five percent (7/20) patients did not need to see a doctor as they were symptom free following treatment recommendations by continence nurses using an integrated care pathway. The authors felt this process facilitated earlier diagnosis, improved access to specialist services and discharge from secondary care.

The level of knowledge about UI within the general nursing community appears to be less than ideal in both the U.S.A. [151, 154] and Sweden [139]. Many non-specialist nurses (referred to as general nurses) desire, and have a need for, more education about what they can do to better manage incontinent patients. Moreover, the quality of life of the incontinent nursing home resident is often more dependent upon the skill,

education, and attitudes of the nursing aide than of the qualified nursing staff.

In an older UK study of learner and qualified nurses' knowledge, only 12% of qualified nurses had received any education on incontinence in the previous 12 months, and for those who had, most was on products [155]. Forty-four percent of charge nurses and 81% of staff nurses had received no additional training on incontinence since qualifying. Further work on attitudes via a questionnaire to qualified nurses on hospital wards found predominantly therapeutic, rehabilitative attitudes, but also a number of misconceptions. Twenty one percent thought their primary role with incontinent patients should be supplying products and 11% saw incontinence as an inevitable part of aging. Sixteen percent agreed that incontinence was often due to laziness and 28% thought that incontinence was more distressing for a younger than for an older adult [156]. In a further survey of trained nurses, the author found that nurses still focus primarily on palliative rather than therapeutic care and lacked knowledge on which to base care [157]. However, nurses with a post-basic qualification or in-service education were more likely to have positive attitudes, although it was not clear whether this was as a result of the education, or whether these nurses already had a positive attitude and had therefore self-selected to receive further education.

More recently, Rigby [158] explored whether increased continence knowledge amongst general nurses resulted in changes in clinical practice using an opportunistic sample of 130 general nurses achieving a 54% response rate to all stages of the study. The results demonstrated a significant change in knowledge score for nurses following a continence study day, but showed that application in clinical practice of this knowledge posed significant problems. This study had a number of limitations using a small opportunistic sample with poor response, however the real challenge remains of not simply increasing knowledge, but translating that knowledge into improvements in clinical practice.

In the U.S.A., although there are a growing number of nurses who are developing expertise caring for incontinent patients, there are no academic or clinical proficiency requirements to be considered a "continence nurse practitioner or specialist." In 1993, the Wound, Ostomy, and Continence Nurses Society developed the first certification program for continence care nurses in the U.S.A. The Society of Urologic Nurses and Associates certifies different levels of nurses in the area of urology and in urodynamic testing. The norm is that most "continence" nurses in the U.S.A. obtain their knowledge and skill through self-motivated activities. A survey of nurses attending a national nursing conference on UI asked about educational preparation related to this condition [159].

Respondents reported that less than half (40%) received academic education including course work in accredited post-baccalaureate or graduate programmes related to UI. However, most nurses (76%) obtained instruction at professional conferences, continence clinics supervised by nurse practitioners or physicians, "on-the-job" training, self-study, or in-service programmes.

In another UK study of general nurses' knowledge of UI, a clinical handbook was evaluated using a pre- and post-test design with an experimental and control group [112]. This study showed that the use of the handbook, which consisted of a decanted, user-friendly, research-based resource on continence care, improved nurses' knowledge of incontinence. A significant improvement in reported clinical practice was found for 86% of variables in the experimental group compared to a 59% improvement in controls. However, only 54% of those approached agreed to enter the study, suggesting a general lack of interest and motivation.

4. PHYSIOTHERAPY AND OTHER ALLIED HEALTH PROFESSIONALS

Physiotherapists or physical therapists (PT) have long played a part in continence care and the management of UI. In some countries, patient self-referral to specializing physiotherapists has become commonplace. Physiotherapists' involvement in UI appears to be either on the basis of individual interest or through association with women's hospitals or obstetric departments, rather than as part of a general physiotherapy practice [160]. As such, they tend to be highly motivated and enthusiastic.

Pharmacists have a variety of roles to play in continence care. In Australia, they have been avid consumers of continence education programmes. In 2004, the Pharmacy Guild launched an educational and promotional program for their members with appropriate outcome evaluation measures. The public sees pharmacists as important and approachable sources of health information, especially information on medicines that may cause or exacerbate UI and FI. Many retail pharmacies display health promotion literature on a range of subjects including UI. Pharmacists may also advise the consumer on appropriate continence products. Educational seminars for pharmacists are generally well received. There are a growing number of CME programmes for pharmacists on the Internet either through new products or through sites such as www.worldwidelearn.com which aims for on-line CME for pharmacists and technicians.

There is also a need to address the training needs of nursing assistants and aides, particularly in the nursing home setting. In the U.S.A. and many other countries, one concern is the high turnover rate among first-line

caregivers in institutional and home care settings, making it difficult to maintain desired training levels. Nursing assistants are often the people providing 'hands-on' incontinence care and yet, often with the least training. Certainly, in terms of published evidence there are few reports of efforts to train nursing assistants.

Regulatory issues are often linked not only to quality of care, but also to reimbursement for clinical care and services. Reimbursement policies for services often determine which professionals are able to provide continence care. In the Netherlands, for example, the government pays for up to 14 visits to a physiotherapist for incontinence therapy. In the U.S.A., patient's visits to a physiotherapist are restricted.

5. IMPACT OF UI GUIDELINES

The development of guidelines, primarily on UI and more recently FI, has increased significantly in recent years throughout the world [104,161,162,163,164,165,166,167,168]. In 1992 and 1996 (revised), the U.S.A. Agency for Healthcare Research and Quality (AHRQ) (formerly known as the Agency for Health Care Policy Research (AHCPR), sponsored the development of clinical practice guidelines that were produced to help standardize the assessment and management of urinary incontinence in adults [104,161]. Aimed at health care professionals, the guidelines are widely quoted, but they have failed to impact the practice of physicians or trainees [169]. A more recent study in North Carolina, U.S.A. used a multifaceted educational intervention based on the 1996 AHCPR guideline in 20 of 41 primary care practices and failed to show an effect in increasing screening or management of UI by PCPs [170]. They concluded the guidelines may not be the best approach to treating UI in this setting. Similar disappointing results have been reported in Europe [107]. However, nurses have used the AHCPR recommendations more effectively than physicians, incorporating them into curricula, evidence-based clinical practice, and care pathways [171, 172, 173].

More recently, Penning-van Beest et al [174] report on the impact of the Dutch College of General Practitioners, treatment guidelines for incontinence. They identified a cohort of women with newly identified incontinence (n=1663), they found that the majority of women did not receive active treatment within 1 year of identification, many received no active treatment and use of pads was high. They recommend that this lack of active treatment could be addressed through better physician education.

Many of the published guidelines focus on younger, healthy, community dwelling adults. Guidelines for evaluation and treatment of UI and FI in children and the elderly population or those with significant comorbidity need to be developed. These will need to

take into account issues such as cognitive impairment which can influence continence status in older adults [175].

Fung [176], in a small study in a large academic Veterans Affairs medical centre in the U.S.A., used guidelines to develop condition-specific computerized templates to serve as guides for clinicians to ask questions and perform elements of a physical examination for two specific medical conditions UI and falls. This study demonstrated that a set of templates can be developed within an existing electronic health record system and can be used to prompt a clinician to obtain elements of a history and to perform physical exam elements in relation to falls and UI.

Changing the current patterns of medical care with respect to detection and management of incontinence through education is a difficult task [177]. Guidelines for medical practice can contribute to improved care only if they succeed in moving practice closer to the guideline recommendations [178]. Unless there are other incentives or the removal of disincentives, guidelines are unlikely to effect rapid changes in actual practice. It is recognized that other tools or strategies are needed to augment and build on educational endeavours [179]. Strategies that aid in implementation of a guideline include reminder systems to remember when to implement guidelines, tracking systems to identify patients who need follow-up and continuous quality improvement monitoring and regulations. Educational programmes alone may change knowledge and attitude, but rarely change behaviours. Guidelines combined with continuing medical education programmes may be more successful [105].

Even evidence-derived guidelines may not always result in better practice or outcomes. The implementation and evaluation of such a guideline in one primary care practice in the UK from which 1503 patients were randomly selected has been reported [171]. Thirty-five percent of women and 9.9% of men suffered from incontinence in the previous two months, but 61% had never sought help. Of those who did, 63% were referred to specialists, 53% had a urine test, 1 in 4 women had a vaginal examination, and 4 of 206 persons with UI were asked to complete a frequency/volume chart. After implementing the guideline, two abdominal examinations and one new rectal examination were performed, but no new vaginal examinations were performed. Frequency/volume charts were given to three people. Two patients used fewer drugs. The severity of incontinence was unchanged following the intervention. Family physicians did not effectively implement the guideline. It remains to be tested whether, properly used, guidelines can improve incontinence in practice.

In 2006, a national UK guideline was produced on UI in women [165]. Within the document the area of

surgeons competence is discussed however there is no mention of other care providers education and training (including GPs, nurses, physiotherapists etc). In order for services to be delivered effectively, primacy needs to be given to practitioners education and training in such documents.

In a 1999 repeat of a 1996 survey, among 6481 patients older than 50 years, it was found that after numerous UI awareness and education campaigns, German physicians were even less likely to address incontinence than 3 years earlier [180]. The “don’t ask, don’t tell” attitude between physicians and patients, has significant fiscal implications for health care. The consequence of not treating the condition may increase the annual cost of care by an estimated USD 3941 per individual [181]. Funding for conservative management of UI, or better-informed public demand, may stimulate more interest and improved performance among this important group. It remains critically important that PCPs have an understanding of how to manage UI effectively [182].

DuBeau et al [183] assessed the knowledge and attitudes of nursing home staff (including directors of nursing and nursing home surveyors) following revised U.S. government guidelines on continence care (Tag F315- <http://www.cms.hhs.gov/transmittals/downloads/R8SOM.pdf>).

They used a questionnaire in a convenience sample of 558 staff attending workshops. The authors report striking deficiencies in knowledge amongst staff, and identified managerial structures as barriers to guideline implementation. They suggest such barriers need to be overcome in order to improve the quality of care.

A number of CME programmes for PCPs on UI are now available through Internet sites. One by the American Geriatrics Society covers screening for UI, history taking, ruling out other factors, urinalysis, behavioural therapy and challenges in impaired people. Pharmacy Times site offers a free Temple University program with 2 CME credits on medical management of UI.

It covers differentiation between transient and established incontinence, identification of medications which can contribute to UI and agents which can be used to manage the various types of UI, how to assess, choose appropriate pharmacotherapy and identifying which agents should not be used.

In 1998 the Japan Continence Action Society compiled a Continence Educational set (CE-set) for professionals to use in the community. The CE-set comprised text books, lantern slides, and a CD-ROM based on current evidence. Fifty five CE-sets were distributed to Health Education centres in each prefecture. In 2008, only 11 of the CE-sets had been used, whilst 44(80%) remained unused. The single factor that

encouraged use was whether a continence course had been provided in the region or not.

Realistically the likelihood of obtaining adequate independent funding for effective professional education on UI and FI is unlikely in the current economic climate.

6. RECOMMENDATIONS FOR PROFESSIONAL EDUCATION

Based on the literature reviewed in this section, the following recommendations can be made:

- There remains a need for rigorously evaluated continence education programmes which adhere to defined minimum standards for continence specialists and, generalists, utilizing web-based and distance learning techniques alongside audit and feedback, train-the-trainer models and leadership models as well as traditional methods. The following should be considered:
 - Compulsory inclusion of a specified number of hours of incontinence education in the basic curriculum (physicians, nurses, physiotherapists and other allied health professionals). Ideally incontinence should be identified, planned and taught as a separate topic.
 - Specific education programmes adhering to approved standards should be reported to a recognized central body linked to appropriate evidence and guidance.
 - Where possible, education programmes should be independently evaluated using appropriate research methods.
(Grade D)
- There is a need for research on the most effective means to educate professional groups on continence issues. Specifically, there is need for research on:
 - The effectiveness of innovative teaching methods in improving knowledge and practice
 - Translation of research into improved clinical practice and identification of methods by which this happens.
 - Mechanisms for increasing professional motivation to acquire education and improve performance.
(Grade D)

IV. PRIMARY PREVENTION

LITERATURE SEARCH

The following key words were used in the literature search: prevention + primary/secondary/tertiary, prevention + incontinence /urinary incontinence/ fecal/anal incontinence, prevention + population, continence + promotion, health promotion, health promotion + continence, risk (factors) + incontinence, urinary /faecal incontinence + BMI/obesity, incontinence + diabetes, urinary incontinence , diet/ caffeine/fluid intake, physical activity + incontinence, mental health + incontinence/ painful bladder syndrome, urinary /faecal incontinence + (cigarette) smoking, pregnancy/ childbirth/antenatal/ postnatal/ postpartum + incontinence, occupation + incontinence, pelvic floor muscle exercises + pregnancy/childbirth/ antenatal/postnatal/postpartum + incontinence, pregnancy/childbirth/antenatal/postnatal/ postpartum + incontinence + prevention, pelvic floor muscle exercises + prostatectomy, post prostatectomy + incontinence + prevention, conservative management + incontinence, risk factors + urinary incontinence, risk factors + faecal incontinence/ anal incontinence, occupation + risk + incontinence, painful bladder syndrome + prevention, painful bladder syndrome + risk, pelvic organ prolapse, prevention, pelvic organ prolapse + risk, older adults, urinary incontinence + prevention, self-efficacy + incontinence, falls + risk + incontinence. Search strategy included a range of electronic databases as follows: Ageline, AMI: Australasian Medical Index, AMED Allied and Complementary Medicine, Australian Institute of Health and Welfare: Publications, Blackwell Scientific now joined with Wiley Interscience, BMJ Journals online, Cambridge Journals on line, Cinahl, Cochrane Library EBSCO Host, Google, Health and Medical Complete, Meditext, Medline, Ovid, Oxford Journals

Pedro, Proquest, Pubmed, Springer, Wiley Interscience, Wilson

1. BACKGROUND

Urinary incontinence is a highly prevalent and chronic condition that can be prevented by addressing modifiable risk factors through primary prevention. Although the evidence base for FI and POP is more limited than that for UI, the conditions share many similarities with respect to risk and treatment, suggesting that similar benefits may derive from population-based strategies [116]. These strategies may also be relevant to people with bladder pain syndrome (also referred to as interstitial cystitis, painful bladder syndrome and urologic chronic pelvic pain), although there is no research on primary prevention for this condition.

In the past few years, substantive work has examined

the evidence base for preventative strategies for incontinence. This work included a Cochrane Review of conservative management for post prostatectomy urinary incontinence [184], an extensive Evidence Report conducted for the U.S.A. AHRQ on prevention of urinary and fecal incontinence in adults, [167], and a state of the science conference also on the prevention of urinary and fecal incontinence in adults, sponsored by the National Institutes of Health in the U.S.A. [166].

Primary prevention refers to efforts directed at a community or population level to promote protective health behaviors [185] in order to reduce the incidence of UI, FI and POP. Other preventative measures include secondary prevention (where screening of asymptomatic people occurs in order to detect symptoms early and provide treatment) and tertiary prevention (where efforts are directed at curing, rehabilitating, restoring function and preventing of future relapse of symptoms) [186]. This section will focus on primary prevention of UI and POP. Additional and more in-depth information is presented by the ICI Committee 4, Pathophysiology of Urinary Incontinence, Fecal Incontinence and Pelvic Organ Prolapse; Committee 12, Conservative management of urinary incontinence (men and women), and pelvic organ prolapse. Primary prevention of FI is addressed by Committee 16, Conservative and Pharmacological Management of Faecal Incontinence in Adults. There is no evidence concerning addressing secondary and tertiary prevention of bladder pain syndrome.

2. POPULATION-BASED PREVENTION

Prevention should include education about behavioural changes that increase the probability of incontinence, the normal functioning of the urogenital and gastrointestinal tracts, expected age related and developmental changes, and how to find the appropriate treatment providers. Raising awareness of health problems and providing information on terms used to describe symptoms assists in promoting help-seeking behaviour [187].

The 3rd ICI stressed the importance of all healthcare professionals promoting primary prevention of incontinence [116]. It was acknowledged that this would require raising the level of community awareness, providing public education as well as addressing healthcare professionals' education. Whilst some advances have been made, these strategies remain a priority. The challenges of dealing with an ageing population are likely to result in urological symptoms including incontinence being as prevalent as cardiovascular disease in the U.S.A. by 2025 [188, 189] and is likely to result in an increased demand for hospital and long term care [190]. As noted above, incontinence is responsible for up to 30 - 50% of admissions into nursing homes, often precipitated by the burden of care on care givers who spend half of

their care-giving time providing personal care such as toileting assistance [84]. Caregivers of people with dementia living in the community have been shown to benefit from learning strategies to assist in preventing and managing FI [191]. This study highlights the need to include carers in primary and secondary prevention strategies.

Programs developed to raise awareness of continence issues should consider targeting a range of groups including people of different ages and genders [47]. Consideration should be given to the setting in which the health promotion program is to be delivered such as schools, work places, community groups and health care institutions [192]. It is acknowledged that whilst some nations are successfully implementing primary prevention strategies, others are yet to effectively implement secondary prevention measures such as assessment and management of continence conditions [193]. In Australia, the UK and the U.S.A, continence organizations have received additional support from national governmental departments and agencies resulting in greater resources being applied to preventative and continence promotion programs.

The evidence for population-based prevention strategies remains at **Level 4, Grade C**.

3. RISK FACTORS

There is an increasing body of evidence linking incontinence with other conditions. These links provide opportunities to benefit from cooperative efforts with other health promotion initiatives. Identification of individuals who have the potential for becoming incontinent is an important primary prevention activity.

Level 3 Grade B evidence exists for general risk factors of age, pregnancy, parity, [194, 195, 196]. Earlier studies reported Level 3 evidence regarding the risk of overweight and obesity in women [92, 197]. More recently a systematic review has found Level 2 and Level 3 evidence that establishes overweight and obesity as independent risk factors for the development of UI in women [198]. Women with obesity and diabetes have a greater risk of developing pelvic floor disorders, including UI, FI and pelvic organ prolapse [199]. There is a 91% prevalence of these pelvic floor disorders in morbidly obese women [200].

Higher body mass index (BMI) and greater weight are independent risk factors for stress and mixed UI in middle-aged and menopausal women [198, 201]. There is Level 3 evidence to recommend that women with a BMI over 30 should be advised to lose weight to reduce their UI [165]. Randomised control trials have found that women who are overweight or obese can reduce the frequency of urine loss by losing between 3 - 5% of body weight [202] and 7% of body weight [203]. Bariatric surgery for morbidly obese women has resulted in "significant improvement" of UI and has reduced the prevalence of FI from 19%

to 9 % [204]. A weight reduction program focusing on avoiding weight gain and maintaining a waist circumference within a normal range may lower the risk of UI in women [205].

Diabetes - Lower urinary tract symptoms and changes in bladder function occur in over 50% of men and women with diabetes [206; 207]. In middle-aged women, diabetes is the strongest risk associated with the development of UI [197] and the increase in severity of UI [208, 209]. The risk of pathological bladder changes and incontinence may be reversed if diabetes can be prevented by lifestyle interventions including weight loss [206; 209] and physical activity [206]. Providing this information to patients may be a strategy to motivate people to take positive action to improve their health.

Fluid intake - Urinary symptoms may be adversely affected by extremes of fluid intake. Amending high or low fluid intake improves UI and OAB [165]. Patients who decrease an excessive fluid intake experience decreased urinary frequency and urgency to statistically significant levels [165; 210]

Diet - The effect of diet on urinary function is not well studied, however it has been reported that eating a diet containing vitamin D, potassium, chicken, vegetables, bread and protein may lead to a reduction in the risk of stress UI and OAB [165]. Diets containing carbonated drinks, high fat levels, cholesterol, vitamin B12, zinc [166] and spicy foods and artificial sweeteners were associated with an increased risk of UI or an increase in the severity of OAB. There are mixed results on the effects of caffeine upon nocturia and OAB, with one study of normal volunteers reporting no change in nocturia [211] and others that showed an association with caffeine ingestion and nocturia but not urinary urgency [212, 213]. A recent study with normal volunteers found that artificial sweeteners had a significant effect upon increasing urinary frequency and urgency [212].

Diet is also implicated in the exacerbation of urinary symptoms in BPS/IC/PBS. The types of food and drink reported to aggravate these symptoms include chocolate, citrus fruits, and tomatoes, carbonated drinks, [214], alcohol, coffee, and tea, [214, 215, 216].

Physical activity - Low impact physical activity in younger women appears to assist in promoting continence [217]. Conversely high impact, strenuous physical activity can aggravate symptoms of PBS [218]. Older women who engage in regular physical activity such as walking have significantly lower levels of UI [219] and are less likely to have urgency if they exercise at least weekly. It is not clear if commencing exercise could reduce urgency [165]. Severity of UI in women is related to the perception of UI being a barrier to exercise, and women with severe UI are less likely to achieve recommended amounts of

physical activity required for good health. Women with less severe incontinence are more likely to wear a pad or restrict their fluid intake in an attempt to minimize UI when exercising [220].

Depression and mental health - Incontinence has been linked with mental health issues, including depression and self-harm. This may be due to a common underlying causality rather than incontinence causing depression or risk of self-harm [218]. Severity of incontinence is strongly associated with major depression in women [222] and screening for depression should be considered when a woman presents with severe UI. The World Health Organization (WHO) predicts that by 2020 depression will be the second highest cause of disability for all ages and genders [223]. It is likely that the prevalence of incontinence will rise as a consequence of this. IC is also associated with a higher risk of depression [218, 224]. Symptoms are exacerbated by psychological stress [215]. This syndrome is frequently associated with fibromyalgia and irritable bowel syndrome [215, 224]. A recent study however has found that women with fibromyalgia have a pattern of urinary symptoms that are distinct from those experienced by women with PBS/IC [225].

Cigarette smoking Whilst cigarette smoking has previously been shown to exacerbate OAB and has been linked with UI and FI [167], research has not yet demonstrated that smoking cessation results in changes to UI or FI [164, 165].

Occupational risk factors Increasing voiding intervals have been reported in workers who have limited access to toilet facilities (such as teachers, nurses and production workers). This is thought to result in reducing bladder sensation and lead to UI [167]. An earlier study found that women in the military and the occupations described above deliberately restricted their fluid intake in order to control their UI [226]. A recent study of teachers in Taipei found that UI occurred more often in those who had a higher BMI, poor bladder habits and lack of access to toilets [213]. Heavy lifting was shown to increase the risk of urgency in teachers [213]. Women living in rural Thailand performing laboring duties had a higher risk of UI [227]. There are still no intervention studies that have been reported in these at-risk populations.

4. PREVENTION OF CHILDBIRTH-RELATED INCONTINENCE

Recent studies suggest that the percentage of women experiencing UI prior to pregnancy ranges from 15% [228] to 39% [217]. Women who engaged in high impact physical activity during pregnancy were at greater risk of UI, whereas a protective effect for UI was noted in women who undertook low impact physical activity prior to and during pregnancy [217].

During pregnancy, approximately 50% of primiparous women experience UI [229]. UI during pregnancy has been reported as a risk factor for UI later on in life [228, 230]. Pelvic floor disorders, particularly POP have been associated with women who delay pregnancy and childbirth until they are older [231].

A systematic review conducted in 2005 found that whilst PFMT is associated with reduction or amelioration of UI in pregnancy and postpartum, there is no evidence to support PFMT as a strategy to prevent UI from occurring. [232]. It has also been found that self-reported PFMT does not affect the onset of UI during pregnancy [233]. There is some suggestion that PFMT appears to be effective in preventing UI in the post partum period in those women who do not experience UI during pregnancy [230]. A recent randomised control trial of women with UI during pregnancy who were given three PFMT sessions for a period during pregnancy, and one session post partum found no effect upon UI six months post partum compared with controls who received standard advice [234].

Management of the second stage of labour may also affect continence. Pelvic floor muscle trauma may be reduced by allowing the woman to bear down when she has an urge to push and avoiding instrumental delivery when possible [235].

When clinical guidelines have provided an indication for the use of an episiotomy, debate has ensued as to whether a midline or mediolateral episiotomy will provide the best protection to the perineum. A case-control study found that a mediolateral incision reduced the risk of third degree tearing of the perineum. The angle of the episiotomy resulted in a 50% relative reduction of sustaining a third degree perineal tear for each 6° away from the midline [43].

Previously Level 2 and Level 3 evidence suggested that elective caesarean delivery could be considered as a UI prevention strategy. Women who had a caesarean section have less UI at three months post partum [233], however the risk of UI is not completely eliminated as 14% of women still report UI [236]. More research is required into UI occurring before and during pregnancy due to the strong link to UI occurring postpartum [237]. In addition, antenatal UI has been found to be an independent risk for postpartum FI [167; 229].

Despite a significant body of evidence that advocates PFMT before, during and after pregnancy to prevent and treat UI during pregnancy and in the postnatal period, [204]; [167], the actual number of women performing regular PFMT during pregnancy varies from 17% in Norway, 69 % in the UK and 54.5 % in Australia [238]. Poor adherence to PFMT is also an issue [239]. The effectiveness of PFMT in preventing

childbirth related UI, in conjunction with the non-invasive nature of this self-care strategy, makes it a logical focus for UI prevention efforts among women during the period of childbearing. [240]. Due to the lack of research, there is only Level 4 evidence to support the use of PFMT to prevent incontinence during pregnancy and in the post natal period.

5. PREVENTION OF PROSTATECTOMY-RELATED URINARY INCONTINENCE

Prostatectomy remains an established risk factor for UI in men [241], resulting in postoperative pad use [242] and decreased quality of life [243]. Despite advances in surgical techniques that have reduced the risk of UI, it remains a distressing post-operative complication for many men [244]. It is of concern that over 40% of men in one study claimed not to have received preoperative information that they may develop UI following prostate surgery [245].

Pre-operative UI is a significant risk for UI following a radical prostatectomy [246].

A Cochrane Review published in 2008 found few studies on the effect of PFMT undertaken prior to radical prostatectomy on the development of UI post-operatively [247].

One RCT compared subjects given biofeedback and daily home exercise to controls given usual post-operative instruction to cut off the flow of urine when urinating [285]. The intervention group achieved continence faster and suffered less severe UI than controls.

Secondary prevention of UI with men undergoing PFMT following radical prostatectomy also shows conflicting results, with some showing no change on UI [249] and others showing improvement in men who underwent PFMT compared to men who did not [250]. The Cochrane Review concluded that the evidence was inconclusive and that there was a paucity of quality research in this area, [247].

Whilst there is a focus on UI and erectile dysfunction after radical prostatectomy, a number of men experience fecal urgency and FI post-operatively, with a small percentage of men developing FI two years post-operatively. It is suggested that there may be a higher number of men with FI post-operatively than currently reported [245].

Researchers are urged to investigate preventative strategies for FI and faecal urgency following radical prostatectomy [166] as currently there appears to be no research into this area.

In regards to prostatectomy, there remains mixed Level 2 evidence to support the use of PFMT pre and post-operatively for UI. There is no evidence to either support or refute the use of PFMT pre and post operatively to prevent FI.

6. PREVENTION OF URINARY INCONTINENCE IN OLDER ADULTS

It is predicted that the number of people aged over 60 will increase from 650 million in 2005 to over 2 billion in 2050 [223]. Whilst ageing does not cause incontinence it is acknowledged that the risk of incontinence increases with advancing age and is associated with a concomitant increase in a range of co-morbid conditions.

Older adults are a heterogeneous group, and therefore preventative strategies for older adults need to take into consideration the well aged as well as the frail aged. It is important to involve older people and upcoming generations in health promotion research and health promotion intervention programs targeted at older people [251].

Due to the association of diabetes and UI, gerontologists have an important role to play in screening older women with diabetes for UI so that they can receive treatment [206].

Well older adults - There is Level 2 evidence to support the use of preventative strategies in well older adults. These strategies include promoting self-efficacy such that the individual has a belief that they have the capacity and skills to improve their own health. In addition, self-efficacy improves the ability to cope better with symptoms and is linked to motivation, knowledge of the benefits of making changes, and adherence to behavior change [252; 253]. Self-efficacy over UI may be enhanced if women are taught self monitoring techniques such as adjusting fluid and caffeine intake, resolving constipation, pelvic floor muscle training in "Quick Kegel" contractions and monitoring voiding intervals [254]. These self-monitoring techniques resulted in decreased volumes of urine loss and improved quality of life [254]. Promoting self-efficacy results in good adherence to PFMT in older, well educated women [255]. Self-efficacy measures such as the Geriatric Self-Efficacy Index for Urinary Incontinence can be used to determine adherence to behavioural programs developed for the prevention and management of UI [253].

A behavioural modification program delivered to women aged over 55 years reported the preventative effects of increasing pelvic floor muscle strength and increasing time between voids upon continence status, suggesting that preventative strategies are effective in older women [66, 256;]. A recent systematic review concluded that there was "moderate evidence" to support the use of PFMT and bladder training in resolving UI in women [257]. An older study reported that these interventions were "very successful" in treating UI in elderly community dwelling people [258].

Frail older people Correlations have been found between poor general health and severe urinary and/or

fecal incontinence in frail older people [259]. Incontinence is the second main reason for frail aged people to seek admission into nursing homes in the UK and the U.S.A., and is the third main reason in Australia [86]. Incontinence in nursing home residents has negative effects upon the morale of residents, families and staff. Conversely the time and effort spent in promoting continence through toileting programs and other strategies is labour intensive and also places strain upon staff [129].

A recent study has found that there is a greater risk of functional disabilities in men and women who are obese, specifically those with higher waist circumference measurements [260]. These disabilities are associated with a range of chronic health conditions, including incontinence. Prevention of obesity may prevent the development of functional disabilities, chronic health problems and incontinence in the frail aged [260].

Treatment of poor mobility and communication difficulties [259], UTI, environmental barriers and removing physical restraints [261], could reverse or ameliorate urinary and/or fecal incontinence. Despite this, a UK survey of continence practices in care homes there were few mobility programs in place to promote continence [88].

Falls have been associated with a range of factors, including UI and taking medicines such as diuretics [262, 263]. Falls have also been associated with OAB, urge UI and nocturia [264]. Opportunities exist to link with other health promotion programs targeted at older adults such as falls prevention programs [262]. However opportunities to promote continence are not currently being adopted in these programs, despite incontinence being a known risk for falls

[264]. A number of factors have been identified linking the risk of incontinence to chronic health conditions in the frail aged. Screening is recommended to identify risk factors for incontinence in the early stages when it may be easier to adopt preventative strategies [167]. Whilst strategies to address these factors have been recommended there is a lack of studies to show the efficacy of these interventions. Due to the paucity of research in this area there is Level 4 evidence to recommend the use of preventative strategies described above to prevent incontinence and promote continence in frail aged adults.

7. PREVENTION OF PELVIC ORGAN PROLAPSE

Some degree of POP is reported in 51% of women aged over 50 years who have had children [265]. Whilst clinical assessment of POP has revealed higher prevalence, mild degrees of prolapse may be asymptomatic. There is mixed evidence related to risk factors associated with developing POP. Smoking, increased waist circumference and higher BMI were not associated with POP in one study [266]. Another

study reported that grand multiparity (defined as five or more vaginal deliveries) and raised BMI are risk factors for POP [267]. It was also found that in older women that POP worsened and resolved over time [267]. Irritable bowel syndrome was found to be associated with POP [268].

A systematic review of POP conducted in 2007 concluded that whilst there is currently no research to demonstrate effective prevention, conservative strategies such as weight loss, avoiding heavy lifting, resolving constipation, pelvic floor physiotherapy and addressing obstetric risk factors should be considered [269]. One report presents Level II-3 evidence that symptoms of POP are relieved by the use of a vaginal pessary. This is of relevance to women who choose or are not able to have surgery and those who are awaiting surgery [265].

Pelvic organ prolapse in women may be decreased following the long term use of a vaginal pessary [265]. The use of a pessary may also assist in improving bladder, bowel and sexual functioning but there is mixed evidence for improvement of stress urinary incontinence and urge urinary incontinence [265].

A Cochrane Review of pessary use in 2004 was unable to find any randomised control trials assessing the efficacy of pessary use [269]. These authors also note that despite this lack of evidence, pessaries have been used for centuries and are currently used in clinical practice by the vast majority of gynaecologists, urogynaecologists and nurse specialists.

8. PREVENTION OF FAECAL INCONTINENCE

Whilst it appears that people are seeking help more readily for UI, the problem of FI remains under-reported [130] especially in older people [270] and few physicians ask patients about it [271]. Analysis of studies on FI is hampered by a lack of standardised terminology with regards to stool consistency, gas leakage and frequency of incontinent episodes [166, 272, 273]. Whilst acknowledging that prevention of FI is important, it is recognized that more research is needed to determine the risk factors and interventions to prevent FI [274]. An extensive systematic review of risk factors associated with FI is reported by Committee 4, Pathophysiology of Urinary Incontinence, Fecal Incontinence and Pelvic Organ Prolapse and hence only a brief summary is provided below. Risk factors for developing FI include diarrhoea [274], irritable bowel syndrome (IBS), UI [271], [272], and obesity, particularly for people with a BMI more than 40 [272, 274]. Morbidly obese women may have rates of FI as high as 63% [271]. Chronic obstructive pulmonary disease, diabetes, colectomy and cholecystectomy are also associated with an increased risk of FI [275]. An association with FI has been found in postmenopausal women [275]. Conversely it was also found that the use of hormone replacement therapy in women increased the risk of FI [275].

9. RECOMMENDATIONS FOR PRIMARY PREVENTION

Health promotion strategies aimed at individual, interpersonal, community and population levels are needed in order to promote urinary and fecal continence [192]. Educating people about continence issues and ways in which they can improve their bladder and bowel health will also assist in removing some of the stigma that surrounds continence issues [167]. Conversely, care needs to be taken to ensure that incontinence is not “normalised” as this can have the unintended consequence of people not seeking help for a condition deemed to be “normal” [276]. For moderately overweight women, the Third International Consultation on Incontinence recommended programs such Weight Watchers® to encourage moderate weight loss as first line therapy in overweight women. There is little evidence at this stage to demonstrate that these recommendations have been followed. The acceptance of public health programs to reduce obesity, increase physical activity and promote eating fruits and vegetables can be built upon to promote good bladder and bowel habits, including PFMT and BT for the primary prevention of UI.

Based on the literature reviewed in this section, the following recommendations can be made:

- Primary prevention studies should not be limited to individual interventions, but also test the impact of population-based public health strategies (**Grade C**)
- PFMT should be a standard component of prenatal and postpartum care. Due to the number of women who experience incontinence prior to pregnancy, measures need to be taken to instruct women in PFMT prior to pregnancy (**Grade C**)
- Randomised controlled trials (RCTs) should be conducted to test the preventative effect of PFMT for men post-prostatectomy surgery (**Grade B**)
- Further investigation is warranted to assess the efficacy of PFMT and BT for primary prevention of UI in well older adults (**Grade B**)

Primary prevention efforts should be aimed at interventions to promote a healthy body weight to assist in the prevention of incontinence (**Grade A**).

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**APPENDIX 1 –
 DIRECTORY OF CONTINENCE ORGANIZATIONS**

AUSTRALIA

***Continence Foundation of Australia Ltd**
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 Tel: 03 9347 2522
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AUSTRIA

***Medizinische Geseellschaft fur
 Inkontinenzlife Osterreich**
 Speckbacherstrasse 1 A-6020, Innsbruck
 Tel: (43) 512 58 38 03
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 Website: www.inkontinenz.at
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BELGIUM

***U-Control vzw,
 (Belgian Association for Incontinence)**
 Leopoldstraat 24
 B-30000 Leuven
 Tel: 32 8161 6455/32 38213047
 Fax: 32 816 16270/32 382 14475
 Email: jean-jaques.wyndaele@uza.be

BRAZIL

***Urobel Belgian association for urological
 nurses and associates**
 De Pintelaan 185, BE-9000, Gent
 Tel.: 09/240.27.65
 Fax: 09/240.38.89
 Website: www.urobel.be

***Brazilian Foundation for Continence Promotion**
 Email: seabrarios@uol.com.br

CANADA

***The Canadian Continence Foundation**
 PO Box 417, Peterborough, Ontario, K9J6Z3
 Tel: (1) 705-750-4600
 Fax: (1) 705-750-1770
 Website: www.canadiancontinence.ca

CZECH REPUBLIC

***Inco Forum**
 Tel: (420) 02-61-082135
 Fax: (420) 02-61-082135
 Website: www.incoforum.cz/

DENMARK

***Kontinensoreningen-
 Danish Continence Association**
 (The Danish Association of Incontinent People)
 Vesterbrogade 64, 1620 Copenhagen V
 Website: www.kontinens.dk/

FRANCE

***Feemes pour Toujours**
 Nicole Kremer, President
 17 rue des Nanettes, Paris 75011
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GERMANY

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HONG KONG

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HUNGARY

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INDIA

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 Rajajinagar, Bangalore 560 010 India
 Tel: 91 80 3131833 / 3424728
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INDONESIA

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KOREA

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ITALY

***Fondazione Italiana Continenza
(The Italian Continence Foundation)**
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201 33 Milano
Website: www.continenza-italia.org
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***Associazione Italiana Donne Medico (AIDM)**
Tel: 39 335 282045/39 065 811390
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***The Federazione Italiana INCOntinenti (FINCO)**
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JAPAN

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MALAYSIA

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MEXICO

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ACI Mexuci AC
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NETHERLANDS

***Pelvic Floor Netherlands**
PO Box 23594, 1100EB
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***Pelvic Floor Patients Foundation (SBP)**
Stichting Bekkenbodern Patienten
Stationspleing
3818 LE Amersfoort
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Website: www.bekkenbodern.net

***Vereniging Nederlandse Incontinentie,
Verpleegkundigen (V N I V)**
Postbus 1206, 3434 CA Nieuwegein
Tel: (31) 30 606 0053
Fax: (31) 30 608 1312
Website: www.cvnc.nl/

NORWAY

***NOFUS (Norwegian Society for Patients with
Urologic Diseases)**
Oyjordsveien 71, 5038 Bergen
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PHILIPPINES

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POLAND

***NTM (INCO) Forum
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SINGAPORE

***Society for Continence (Singapore)**
Gleneagles Medical Center
6 Napier Road #06-02
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NEW ZEALAND

***New Zealand Continence Assn Inc**
PO Box 270
Drury, Auckland 1730
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SOUTH AFRICA

***Continenence Association of South Africa (CASA)**

Affiliated to Association of Continence Advice
PO Box 6479, Westgate 1734
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SPAIN

***Association National de Ostomizados e Incontinentes (ANOI)**

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SWEDEN

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SWITZERLAND

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THAILAND

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SLOVAKIA

***Slovakia Inco Forum**

Website: www.incoforum.sk

TAIWAN

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UNITED KINGDOM

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***The Bladder and Bowel Foundation (F&BF)**

Nurse helpline: 0845 345 0165
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General Enquiries: 01536 533255
www.bladderandbowelfoundation.org

***Enuresis Resource and Information Centre (ERIC)**

34 Old School House, Britannia Road
Kingswood, Bristol BS15 2DB
Tel: (44) 117 960 3060
Fax: (44) 117 960 0401
Website: www.eric.org.uk

***Royal College of Nursing Continence Care Forum**

(Royal College of Nursing)
20 Cavendish Square, London, WIM OAB
Tel: 44 020 7409 3333
Website: <http://www.rcn.org.uk/>

UNITED STATES

*** American Urological Association Foundation (AUAF)**

1000 Corporate Boulevard
Linthicum, MD 21090
Tel: 866-746-4282
Fax: 410-689-3800
Website: <http://www.auafoundation.org/>

***International Foundation for Functional Gastrointestinal Disorders (IFFGD)**

P O Box 170864
Milwaukee WI 53217-8076
Tel: 414 964 1799
Fax: 414 964 7176
Website: www.iffgd.org www.aboutincontinence.org
Email: iffgd@iffgd.org

***Interstitial Cystitis Association (ICA)**

110 North Washington Street
Rockville, MD 20850
Website: www.ichelp.org
Email: ICAmail@ichelp.org

***National Association For Continence (NAFC)**

P O Box 1019, 62 Columbus Street
Charleston, SC 29402
Tel: 843 377 0900
Fax: 843 377 0905
Website: www.nafc.org

***Simon Foundation for Continence**

P O Box 815, Wilmette Illinois 60091

Tel: (1) 847 864 3913

Fax: (1) 847 864 9758

Website: www.simonfoundation.org

***Society of Urologic Nurses & Associates (SUNA)**

East Holly Avenue, Box 56, Pitman, NJ 08071-0056

Tel: 888-827-7862

Website: www.suna.org

Email: suna@ajj.com

OTHER ADVOCACY ORGANIZATIONS

***International Painful Bladder Foundation (IPBF)**

Email: info@painful-bladder.org

Website: www.painful-bladder.org

***World Federation of Incontinent Patients (WPIF)**

Email: presidency@wfip.org

Website: www.wfip.org

