

National Institutes of Health State-of-the-Science Statement: Prevention of Fecal and Urinary Incontinence in Adults

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Fecal incontinence and urinary incontinence—the inability to control bowel movements and urination, respectively—are conditions with ramifications that extend well beyond their physical manifestations. Many individuals find themselves withdrawing from their social lives and attempting to hide the problem from their families, friends, and even their doctors. The shame, embarrassment, and stigma associated with these conditions pose significant barriers to seeking professional treatment, resulting in many persons who suffer from these conditions without help. As baby boomers approach their sixties, the incidence and public health burden of incontinence are likely to increase.

Fecal incontinence is a syndrome that involves the unintentional loss of solid or liquid stool. It is serious and embarrassing. Fecal incontinence may affect individuals living at home as well as many living in nursing homes. Although fecal incontinence affects individuals of all ages, it is more common in women and older persons. Bowel function is controlled by 4 factors: rectal sensation, rectal storage capacity, anal sphincter pressure, and established bowel habits. If any of these is compromised, fecal incontinence can occur. Despite its serious effects on patients, families, and society, fecal incontinence is often ignored and has been studied less than have many other conditions.

Urinary incontinence can affect persons of all ages and is most common in child-bearing women and older men and women. Urinary incontinence is generally classified as urge incontinence (when a person has the sudden urge to urinate and cannot get to the bathroom in time); stress incontinence (when a person leaks urine after strains such as laughing, coughing, sneezing, or lifting); mixed incontinence (when a person has both urge and stress incontinence); and other incontinence (for example, when urine continues to leak after urination or leaks constantly). Urinary incontinence has been studied more extensively than fecal incontinence, but the magnitude of the problem of

urinary incontinence is disproportionate to the amount of research on its prevention and treatment.

It has been difficult to identify persons at risk for or affected by incontinence because it is often not reported or diagnosed. Prevention of fecal and urinary incontinence has been hindered by limited research and incomplete knowledge about the biological causes and interacting social and environmental factors.

To promote work that will reduce suffering from fecal and urinary incontinence, as well as their costs by preventing their occurrence, the National Institute of Diabetes and Digestive and Kidney Diseases and the Office of Medical Applications of Research of the National Institutes of Health convened a State-of-the-Science Conference from 10 to 12 December 2007 to assess the available scientific evidence relevant to the following questions: 1) What are the prevalence, incidence, and natural history of fecal and urinary incontinence in the community and long-term care settings? 2) What are the burden of illness and impact of fecal and urinary incontinence on the individual and society? 3) What are the risk factors for fecal and urinary incontinence? 4) What can be done to prevent fecal and urinary incontinence? 5) What are the strategies to improve the identification of persons at risk and patients who have fecal and urinary incontinence? 6) What are the re-

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search priorities in reducing the burden of illness in these conditions?

At the conference, invited speakers presented information pertinent to these questions, and a systematic literature review prepared under contract with the Agency for Healthcare Research and Quality (AHRQ) (www.ahrq.gov/clinic/tp/fuiadtp.htm) was summarized. Conference attendees provided both oral and written statements in response to the key questions. The panel members weighed all of this evidence as they addressed the conference questions.

This conference focused on preventing fecal and urinary incontinence and detecting persons at risk for and persons with untreated incontinence. The treatment of incontinence with surgery or drugs was beyond the scope of the conference.

1. WHAT ARE THE PREVALENCE, INCIDENCE, AND NATURAL HISTORY OF FECAL AND URINARY INCONTINENCE IN THE COMMUNITY AND LONG-TERM CARE SETTINGS?

The occurrence of fecal and urinary incontinence can be described in terms of prevalence (the number of individuals who have incontinence at a point in time), incidence (the number of individuals who newly develop incontinence in a period of time), and the natural history (whether incontinence improves, stays the same, or worsens over time). Each of these measures varies with factors such as whether the individual is living in the community or in a nursing home and the individual's sex, age, and racial or ethnic group.

Severity of incontinence varies in its frequency and amount. In addition, incontinence has many different causes. Little information describes incontinence rates due to each specific cause or by severity. Therefore, this section describes prevalence, incidence, and natural history for all causes of incontinence combined. To provide a sense of the impact of fecal and urinary incontinence, we provide estimates of incontinence rates derived from numerous studies. Because rates vary considerably across studies, we provide rates that are consistent with the largest body of data for each category of incontinence. Important limitations in this information include underreporting of symptoms, the lack of consistency in the definition of incontinence, and limited numbers of studies on specific topics.

Fecal Incontinence

Many definitions of fecal incontinence exist, some of which include flatus (passing gas), while others are confined to stool. The following data refer to incontinence of stool. Prevalence of fecal incontinence in women living in the community increases with age, from 6% in those younger than 40 years to 15% in older women. Among men living in the community, fecal incontinence is experienced by 6% to 10%, with the rate increasing slightly as

they age. Among both men and women who have fecal incontinence, approximately 50% will also have urinary incontinence. Severity of fecal incontinence increases with age. The few studies comparing racial or ethnic groups did not find differences.

In nursing homes, prevalence of fecal incontinence varies widely according to the physical and mental status of the residents. The overall prevalence is about 45%, with a rate as low as 10% to 15% in more independent residents and up to 70% in the most dependent. Combined fecal and urinary incontinence occurs in a large proportion of nursing home residents.

Data on incidence of fecal incontinence in the community are too sparse to permit estimates that can be generalized to the population. Similarly, the natural history of fecal incontinence is not well studied. Therefore, meaningful conclusions cannot be made regarding the rate of development of fecal incontinence and rates of improvement or worsening.

Urinary Incontinence

Prevalence of urinary incontinence in women living in the community increases with age, from 19% at age younger than 45 years to 29% in age 80 years and older; the rate levels off from age 50 to age 70 years, after which prevalence again increases. Current national estimates are that more than 20 million women have urinary incontinence or have experienced it at some point in their lives. For women, stress incontinence decreases with age, whereas urge incontinence increases with age. Information comparing prevalence in racial or ethnic groups suggests that urinary incontinence is prevalent in all ethnic groups, with some suggestion of higher rates among white women.

The epidemiology of urinary incontinence in men has not been studied to the same extent as in women. In men living in the community, the prevalence of urinary incontinence is 5% to 15% and exhibits a more steady increase with age than among women: 5% at younger than 45 years of age to 21% in men age 65 years and older. This increase primarily reflects urge incontinence and mixed urinary incontinence, with stress incontinence decreasing after age 65 years. Nationally, the prevalence of urinary incontinence during their lifetime in men is approximately 6 million. Few studies have examined racial or ethnic differences in prevalence of urinary incontinence among men, so reliable comparisons cannot be made.

Prevalence of urinary incontinence in nursing homes is much higher than in the community. Rates are 60% to 78% in women and 45% to 72% in men, respectively, and increase with age. This may be, in part, due to impaired mobility and difficulty getting to the toilet. Urinary incontinence can also be a reason for admission to a nursing home or a complication of other conditions that prompt admission. The few studies that have evaluated racial or ethnic differences suggest that such differences are minimal.

Data for incidence of urinary incontinence are consid-

erably more sparse than prevalence data. In the community, annual incidence in women increases with age, from less than 2% for age younger than age 45 years to 8% for age 80 years and older, with an overall annual rate of 6%. Only 4 studies have evaluated incidence in men; the overall annual rate of 4% and increases with age. Comparisons of incidence data by race or ethnicity, or by type of urinary incontinence, are very limited.

Little is known about how sex and age affect the natural history of urinary incontinence. Urinary incontinence resolves in some but not all individuals; it is unclear whether resolution resulted from any treatments. It is not known whether resolution is temporary or permanent and whether it differs by type of incontinence.

Other Populations To Consider

Case reports or smaller series may identify previously unrecognized behaviors and communities at risk for fecal or urinary incontinence. For example, injuries incurred during sports, work, and sexual activity may identify unique causes of incontinence. These causes could generate new hypotheses about how fecal or urinary incontinence occurs.

Strength of Evidence

With the exception of prevalence of urinary incontinence, most estimates of the incidence and prevalence of incontinence in adults are based on relatively small numbers of studies. Because these studies used varying definitions of incontinence and different methods of population sampling, the preceding statistics should be considered to be fairly crude estimates. Areas in particular need of further studies are incidence of both fecal and urinary incontinence, studies of type and severity of incontinence, comparisons of racial and ethnic groups with larger sample sizes and ability to evaluate cultural differences and risk factors, and studies of natural history.

2. WHAT ARE THE BURDEN OF ILLNESS AND IMPACT OF FECAL AND URINARY INCONTINENCE ON THE INDIVIDUAL AND SOCIETY?

The burdens of fecal and urinary incontinence fall into economic and noneconomic categories, and each is complex. We will use the term *costs* when referring to the economic dimension and *burden* when referring to the noneconomic dimension. The quality of evidence for both cost and burden is limited. Economic cost can be obscured by the often more life-threatening comorbid conditions, and current estimates are based on older data modified by estimates of inflation. Studies on burden are limited by the paucity of validated instruments measuring quality of life and the variability in personal response to the condition. Also, individuals who are incontinent live in a variety of situations—from independent community living to community living with home care to living in a nursing home, with different implications for both costs and personal

stresses. Interventions that reduce the burden of incontinence should address both costs and stresses.

For some individuals, costs can be reduced absolutely, even with the current state of knowledge; for many others, however, there is a tradeoff between reductions in burden and increased costs. Although the total costs to society are great, on an individual level, costs and burden range widely, as does the spectrum of incontinence itself.

Burden to Individuals Who Are Incontinent

Individuals who are incontinent may have an emotional burden of shame and embarrassment as well as the physical discomfort and disruption of their lives that occur with episodes of incontinence. The impact of incontinence on individuals varies by age, sex, type of incontinence, individual differences in coping skills, and the quality of social support. The emotional and social burdens are not easily measured. For example, some persons may experience stresses in relationships, low productivity at work, job difficulties, arranging daily activities by bathroom location, and avoiding activities that provoke incontinence.

Individuals who are incontinent may experience anxiety about “accidents,” depression, social isolation, and social exclusion. The management of incontinence itself is burdensome. Quality of life is a subjective measure and difficult to associate with physiologic measures of urinary incontinence. This bears further investigation for both urinary and fecal incontinence. Few objective data exist on the effect of incontinence on quality of relationships: sexual, parent–child, sibling, employer–employee. Stress may result when these relationships involve caregiving.

Caregiver Burden

Incontinence requires greater amounts of informal and formal caregiving. Informal caregivers are usually family members or friends who give unpaid assistance. Formal caregivers are those paid to provide that assistance. Caregiver responsibilities range from helping to stock the refrigerator and preparing food to supervising the taking of medicine or helping with toileting. A major source of stress for caregivers is the physical and mental effort needed for some of their tasks and the unpleasantness of dealing with incontinence. Despite large numbers of informal caregivers, research examining the impact of incontinence on caregiver burden is limited. The dramatic increase in baby boomers faced with caring for their elderly parents now will affect how they choose to get care for themselves when they are the elders. Efforts to avoid nursing home placement are generating many creative ways to “age in place.” The need for caregivers, informal or formal, will have to be factored into these efforts.

After adjustment for comorbid illness, socioeconomic status, and living situation, older individuals who have urinary incontinence require more informal care than those who are continent. Although women have a higher prevalence of incontinence, men receive more hours of informal caregiving than women in each incontinence category.

When informal caregivers can no longer cope with the additional burden imposed by incontinence, the likelihood of transfer to a nursing home increases. This is especially true when fecal incontinence accompanies urinary incontinence.

Separating the burden of incontinence from the burden of other conditions that coexist, especially dementia, is difficult. Studies are needed to show whether it is advantageous for nurse continence advisers to coach both informal and formal caregivers, which may not only improve quality of care but also decrease caregiver burden. We need to measure quality of life for both the care recipient and the caregivers.

Most studies of formal caregiver burden have been done only in nursing homes and show that incontinence care may contribute to job stress. The workload of toileting programs, in which nursing home staff assist residents in visiting the toilet at regular intervals, may be a barrier to their implementation, especially given the current staffing ratios in these facilities.

Economic Costs

Direct costs fall into categories of costs of management by the individual or caregivers, supplies, treatments (ranging from education and exercise to drugs and surgery), and costs related to dealing with complications of incontinence. Indirect costs are costs related to lost wages by affected individuals and their caregivers. Estimates of total costs of incontinence have a high degree of uncertainty because of imprecise prevalence estimates. Current estimates of the costs of fecal incontinence in the United States are not available. Incidence itself is even less precisely estimated, and studies are few. The total cost of urinary incontinence for individuals in the community in the United States has been estimated as exceeding \$14 billion in the year 2000. For the institutional population, a much smaller group, the estimated costs were more than \$5 billion. Other varying estimates have been made but are in the same range. Most nursing home residents are 65 years of age or older. The projected population growth for this group in the next 10 years is about 35%, with an associated increase in costs. The total of about \$20 billion for urinary incontinence is not an insignificant sum and is comparable to the estimated direct costs of other highly prevalent conditions, such as arthritis, and is somewhat greater than the cost of care for pneumonia, influenza, or even breast cancer.

The variation of costs at an individual level is great. For many of those in the community, a major out-of-pocket cost is for absorbent pads, diapers, or briefs. For others, the costs of behavior training, drugs, or surgery are factors. Nongeneric drug costs may exceed \$1300 per year, and surgeries are more expensive. Entry to a nursing home may not be related solely to incontinence but may be triggered by it. The contribution of incontinence to the likelihood of admission requires further study.

Estimated costs are total costs irrespective of the direct payer. Most costs related to incontinence that are not med-

ical are borne directly by the individual or the individual's family. Absorbent materials, and even behavioral training, might not be reimbursed. Other costs are paid by private or government insurers. All the costs transfer back to the individual or the public as insurance premiums and taxes. Payers may play a part in determining treatment patterns; however, the type of insurance and benefit structure may be more or less permissive in determining coverage.

Although the research into costs and potential for cost reduction is not on firm ground, there is reason to believe that reducing the noneconomic burden may be possible. It has been proposed that some practices could reduce this burden with changes in the way care is delivered. It is likely that there would be a tradeoff between costs and other forms of burden.

3. WHAT ARE THE RISK FACTORS FOR FECAL AND URINARY INCONTINENCE?

Predictors of Incontinence

Very few studies have dealt with fecal incontinence, while many studies have examined patient and clinical characteristics associated with urinary incontinence. However, the wide range of patients populations, outcomes, and risk factors makes it impossible to present all of the detailed findings in this statement. We can, however, summarize several general results. A statistically significant association exists between both female sex and older age and greater prevalence of fecal and urinary incontinence. These findings, seen previously in studies of prevalence, have been confirmed through numerous risk factor analyses. In addition, both increased body mass index and limited physical activity are associated with an increased prevalence of incontinence, although the relationship between physical activity and fecal incontinence is less well established. Statistically significant relationships have been found for race and ethnicity (white women have higher rates of incontinence) and for family history in women.

There is also an association between the general category of neurologic diseases and incontinence, as well as between the specific conditions of depression and urinary incontinence, stroke and incontinence, and diabetes and incontinence. Several studies have found an association between number of births and incontinence (with some evidence for greater risk for incontinence with more births) but also a weakening of the relationship with number of births among older women (with almost no relationship between number of births and incontinence in women > age 65 years). Episiotomy also has been found to increase the risk for fecal incontinence. Surgery or radiation that damage sphincter function also are associated with fecal and urinary incontinence. Finally, diarrhea, inflammatory bowel disease, and the irritable bowel syndrome have been associated with fecal incontinence, while smoking and constipation have weaker links to incontinence. Although hundreds of studies have reported on many risk factors for

incontinence, the studies' measures and methods vary so much that only the preceding findings are credible. Other potential risk factors that bear further study are childhood abuse and adult sexual abuse.

Limitations

Our ability to find risk factors is limited by the ways that studies were designed and analyzed. The most important limitation is the fact that most existing studies of fecal and urinary incontinence use a cross-sectional design. Such studies let us examine associations with incontinence but not cause. We cannot be sure that the associated factor comes before the occurrence of incontinence or determine whether it is the cause of the incontinence and therefore whether changing the associated factor will reduce or eliminate the incontinence. Studies in which individuals are followed and measured repeatedly over long periods would be necessary to identify true risk factors. Such studies are much more difficult to carry out and appear rarely in the incontinence literature.

Also of critical importance is the lack of commonly accepted and validated definitions of occurrence for both fecal and urinary incontinence. Because current studies of urinary incontinence use definitions of occurrence that range from minor (a few drops of urine) to major (frequent incontinence that limits daily function) impairment, the size of a risk factor's effect, and even the investigator's ability to establish an effect, varies greatly from study to study. Similar inconsistency exists in the definitions of fecal incontinence, which can range from incontinence of flatus alone to the combination of both fecal and urinary incontinence. The field of incontinence research needs to develop standardized questionnaires and accepted definitions for both fecal and urinary incontinence that include 5 features: frequency, severity, volume, bother to the patient, and desire for treatment. Other questions specific to the type of incontinence will be necessary. For example, type of stool will be specific to fecal incontinence. These questionnaires need to be developed so that they may be given to all types of individuals, even those with limited educational background, so that they can be filled out as confidential self-reports and provide more accurate reporting.

In addition to standardizing the outcome variables, possible risk factors need to be measured and examined in similar ways across studies, and multivariable regression models must be used to adjust for alternative risk factors, which can hide true results and render many existing unadjusted analyses uninterpretable. For example, as individuals get older, they develop not only more incontinence but also other medical conditions and limitations in their daily living activities. A multivariable regression analysis can attempt to disentangle the effects of age, medical conditions, and limitations in daily living activities on the occurrence of incontinence. Other aspects of incontinence research that make it difficult to know the importance of risk factors are the number of patient subgroups (commu-

nity-dwelling women, community-dwelling men, pregnant women, and elderly individuals in long-term care facilities) and the number of different types of fecal and urinary incontinence that must be considered separately, each potentially with its own set of unique risk factors.

A Classification System for Risk Factors

To move forward in finding risk factors, more effort must be made to work from a unified classification system that can suggest sensible predictors based on pathophysiology (the basic processes in the body that cause incontinence, such as nerve or muscle damage). We believe that a more organized method of classification of risk factors would make it easier to find common causes of incontinence, identify subgroups of patients with common risk factors, identify types of incontinence with common risk factors, and, ultimately, identify specific treatments. As a first suggestion, we have found that the risk factors in many existing studies can be categorized as 1) physical status (for example, age, sex, obesity, limited physical activity), 2) genetic factors (for example, family history), 3) neuropsychiatric conditions (for example, multiple sclerosis, spinal cord injury, dementia, depression, stroke, diabetic neuropathy), 4) trauma (for example, childbirth, prostatectomy, radiation), and 5) associated causalities (for example, diarrhea, inflammatory bowel disease, the irritable bowel syndrome, menopause, smoking, constipation). The risk factors can be further classified according to their suspected cause: for example, through the muscles in the pelvic floor, through the nerves in the pelvic floor, or through the inability of the individual to reach a bathroom. With this additional detail, it may be possible to develop treatments for specific conditions causing incontinence.

We know that this classification system has limitations and includes overlaps between categories. For example, stroke can reasonably fall into multiple categories and cause incontinence through many paths. Nevertheless, even as we make this first suggestion, we expect that researchers and experts in the field of incontinence will change this classification system and expand it to make it as useful as possible. The creation of an organized conceptual model is our primary goal—a goal that may allow the identification of new risk factors and potential treatments to proceed at a quicker pace.

Suggestions for Analysis of Risk Factors

In addition to the lack of clarity in studies of risk factors that has been caused by the wide range of possible predictors, a separation often exists between studies of different types of urinary incontinence and between studies of fecal and urinary incontinence. This separation may not be the most efficient approach. Current studies already suggest that some risk factors (such as age) apply to all types of incontinence, while others (such as neurologic disorders) have stronger effects for urge incontinence than for stress incontinence. When comparing fecal and urinary incontinence, we see that they share many common features. An-

atomically, both depend on the levator musculature and the pelvic floor. They are both susceptible to some of the same diseases: neurologic diseases and systemic diseases such as diabetes. Both fecal and urinary incontinence are described with the same terms, such as sphincter dyssynergia, compliance, and storage. Fecal and urinary incontinence have many of the same risk factors (see above) and, as many studies have shown, both fecal and urinary incontinence often occur at the same time in the individual. We recommend that future studies of incontinence include methods to measure all outcomes: the different types of urinary incontinence as well as isolated fecal incontinence. Although each outcome would be analyzed separately, the consistency or inconsistency of risk factors would be valuable in helping researchers decide whether common or different causes exist for the different types of fecal and urinary incontinence and, therefore, which types of prevention programs or treatments may be beneficial for specific types of incontinence.

We also emphasize that a more organized approach is needed to address the area of risk factor identification. On the basis of what we have learned from current studies, we would recommend that future studies use longitudinal designs and sufficient numbers of individuals to increase precision and adjust by using multivariable models for known or suspected risk factors: age, sex, body mass index, race or ethnicity, level of physical activity, neurologic conditions, number of births, method of delivery, surgical trauma, diarrhea, and bowel conditions.

4. WHAT CAN BE DONE TO PREVENT FECAL AND URINARY INCONTINENCE?

Fecal and urinary incontinence are each associated with a range of risk factors. In a few instances, there is a single clear cause. In most, however, the pathways are much more complex, involve multiple factors, and are still not well understood. At this point, the evidence is insufficient to recommend preventive interventions for incontinence, other than for a few specific causes. There is good evidence that some risks for fecal and urinary incontinence are modifiable, and the likelihood of developing incontinence can be reduced through preventive measures. However, the evidence is not strong, is inconsistent, and is insufficiently targeted to specific types of incontinence.

Behavioral and Lifestyle Issues

Behavioral and lifestyle changes can reduce the risk for both fecal and urinary incontinence. Behavioral and lifestyle issues with a known relationship to incontinence include obesity, limited physical activity or exercise, poor diet, and smoking. Workers in some occupations and participants in high-impact recreational activities are at increased risk for incontinence and provide an opportunity for testing interventions that reduce risk for these groups. Promotion of early interventions in community settings, or public health initiatives, might encourage lifestyle changes.

Although education, support-group, and self-management strategies are being used in clinical settings, little research into the effectiveness of these interventions in both clinical and nonclinical settings and in the use of multidisciplinary models has been done. Research into the effectiveness and cost-effectiveness of these strategies would improve the ability to appropriately prioritize, reimburse, and promote the most effective interventions.

The pelvic floor consists of muscles and ligaments that maintain fecal and urinary continence. Pelvic floor muscle training and biofeedback are effective in preventing and reversing some pregnancy-related fecal and urinary incontinence for the first year after delivery. Some evidence shows that pelvic floor muscle training has short-term effectiveness in preventing and reversing urinary incontinence in older women. Some evidence suggests short-term benefit of pelvic floor muscle training in preventing fecal and urinary incontinence following pelvic surgery. There is insufficient research on the sustained long-term benefits of pelvic floor muscle training or biofeedback on preventing fecal or urinary incontinence. Other interventions that increase muscle strength and mobility are needed. There is also a need to standardize protocols for pelvic floor muscle training.

Most individuals who have fecal and urinary incontinence live at home and function in society. Individuals of all ages are faced with physical, emotional, sexual, and financial challenges while maintaining employment, community interactions, sexual activity, and family relationships. Research is needed on ways to support individuals who have incontinence and are living at home and to encourage aging in place. Strategies for screening and educating caregivers that can delay or deter institutionalization may improve quality of life for both individuals and caregivers and reduce health care costs.

Management of Comorbid Conditions

Effective management of diabetes, the irritable bowel syndrome, inflammatory bowel disease, neurologic conditions, impaired mobility, depression, diarrhea, constipation, and fecal and urinary urgency may reduce the prevalence of incontinence because these conditions have a known association with the development of incontinence. Effective treatment of depression may relieve incontinence as well as depressive symptoms. More research is needed into the mechanisms by which these conditions lead to incontinence and the strategies to reduce the risk. Research is needed related to treatments that are known to increase the risks for incontinence (for example, anorectal surgery, prostatectomy, pelvic radiation therapy, oral estrogen therapy). Although many treatments, including medications and surgical procedures, are known to adversely affect continence, it is unclear that clinicians consider or patients understand these risks when selecting treatments. Research, education, and policy should be directed at disseminating effective interventions for preventing incontinence into the

practice setting. Some interventions need to be eliminated (for example, routine use of episiotomy, which is not associated with maternal or fetal benefits and is associated with sphincter injury and fecal incontinence).

Long-Term Care

Factors known to influence fecal and urinary incontinence include staffing levels and care processes in long-term care settings. Effective preventive interventions need to target residents who can benefit. Further research should explore the effect of organizational factors and care delivery models on the prevalence and management of incontinence.

Reimbursement

Currently, such interventions as biofeedback and pelvic floor exercises, with at least short-term demonstrated effectiveness in preventing or decreasing incontinence, are not covered by third-party reimbursement, thus limiting access to effective interventions. Research describing when these interventions are effective and how access to preventive interventions for incontinence influences the incidence, severity, and duration of incontinence is important to inform public policy and third-party practices.

5. WHAT ARE THE STRATEGIES TO IMPROVE THE IDENTIFICATION OF PERSONS AT RISK AND PATIENTS WHO HAVE FECAL AND URINARY INCONTINENCE?

Fewer than half of incontinent individuals spontaneously report their symptoms during health care visits. Clinical recognition of fecal and urinary incontinence is hindered by multiple factors. These include social stigma, discomfort with disclosing symptoms, limited knowledge about potential benefits of intervention, use of nonspecific language by patients to describe their concerns to care providers, competing demands during care encounters, time limitations of health care visits, poor continuity of care, and lack of consistency and directness when care providers seek to determine continence status. Because behavioral, medical, and surgical interventions are available for selected conditions, identifying individuals who have incontinence is important.

Detection of those who have involuntary loss of urine or stool is the first step in a process of evaluation and care that includes determining frequency, severity, and related symptoms; establishing cause and type of incontinence; assessing influence of symptoms on quality of life; providing education about the condition; and initiating discussion of treatment options. Providing appropriate care and referral depends on a systematic approach to the first step—asking. Little evidence informs the practical matter of what brief questions a provider can ask to detect incontinence most efficiently. An example of a simple question to ask could be “How often do you leak urine or stool?” Follow-up questions will be required, such as “Do you use pads or protective garments?” Refining these initial questions to maxi-

mize detection warrants research and validation. Most patients will report their condition when asked.

Health care provider education alone is insufficient to improve detection and treatment. Successfully improving detection depends on key elements in the practice setting, specifically, that 1) care providers must value identifying the condition; 2) care teams must develop protocols that clarify who will ask, what questions will be asked, when in the care encounter the questions will be asked, how the answers will be gathered (written survey, direct query, computer-assisted tools, conversation with caregiver or family), and which patients will be asked systematically; 3) practices must explicitly identify resources for patient education materials and referral; and 4) providers must have confidence in the availability of treatments that work.

The available evidence is insufficient to define what prevalence is high enough to warrant screening for all members of a group (for example, men, obese individuals, and people older than a specific age). Determining a prevalence threshold requires additional research, including better studies of diagnostic test characteristics, improved population-based prevalence studies, modeling studies, and, eventually, randomized trials of the influence of detection on related health outcomes. Focusing detection in groups likely to have severe symptoms might also be considered. Current knowledge suggests that traumatic or surgical sphincter injury and disordered bowel habits are primary markers for fecal incontinence; female sex and urogenital surgery are clear risk markers for urinary incontinence; and increasing age and dementia are markers for both. Furthermore, identification strategies will have higher yield among groups with increased risk, including those with obstetric injury or functional bowel disorders or those who live in long-term care settings. Identifying individuals who are at risk but do not currently have fecal or urinary incontinence could form the basis for targeting preventive interventions. Weight reduction and physical activity are promising. However, the benefits of preventive strategies directed at high-risk groups are unknown.

Tools To Assist Diagnosis

After initial detection, health care practitioners need to characterize symptoms, refine the diagnosis, and assess the impact on an individual's day-to-day function. Some questionnaires have shown moderately improved detection of fecal or urinary incontinence as defined by formal physiologic testing. However, these physiologic “gold standards” may not always serve as the appropriate point of reference for the outcomes that the patient aims to address. Several questionnaires focus explicitly on features of impairment of function and quality of life. Some of these tools have yielded preliminary evidence showing a connection to treatment-related improvements and to patient satisfaction with outcomes and can thus also be used to monitor success of intervention and as potential tools in further research.

Education To Promote Risk Awareness and Self-Referral

Detection and evaluation of incontinence are essential and will require professional education, outreach, and practice-based resources. Raising the awareness of the general public is a parallel need. In many cases, individuals who have symptoms may be troubled by embarrassment and anxiety about their incontinence, resulting in isolation and hopelessness.

Communicating the message via popular culture that fecal and urinary incontinence are common and can be addressed could help break down barriers and promote care seeking. Examples of appropriate educational messages, based in science and respectful of the issues of health literacy, include the following: 1) You are not alone; 2) some medical conditions that cause fecal and urinary incontinence can be treated; 3) incontinence does not have to be a part of aging; 4) lifestyle changes, behavioral interventions, medical treatment, and surgery can provide benefit in many cases; 5) you should tell your care provider.

Filling these and other knowledge gaps by coverage in popular media, advocacy from consumer groups, and reliable Internet and print material educational resources will bring fecal and urinary incontinence into focus, establish it as no longer being a taboo topic, promote understanding of the isolation and impairment of daily life experienced by those affected, and encourage care seeking. Individuals who have conditions associated with greater risk also may benefit from anticipatory guidance about risk and from encouragement to review prevention and treatment options with their health care providers.

In summary, the knowledge base to support strategies for identification of those at risk and those who have incontinence is limited. Specific recommendations for research in these areas are addressed in the next section.

6. WHAT ARE THE RESEARCH PRIORITIES IN REDUCING THE BURDEN OF ILLNESS IN THESE CONDITIONS?

The goals of future research on fecal and urinary incontinence are more effective prevention and reducing the suffering of and burden on affected persons, their families, and society. To achieve these goals, research informed by past contributions should establish underlying mechanisms of fecal and urinary incontinence, describe a classification system, design interventions targeted to specific population groups, determine the effects of these interventions, and guide public policy. Novel approaches in each of these areas should be sought. The broadest possible range of stakeholders, from basic scientists to health care providers, affected persons, and other interested individuals, should be included to achieve effective research strategies.

Conceptual

Recognizing that incontinence often involves abnormalities on the structural, physiologic, and environmental levels, conceptual models need refinement on at least 2

aspects. First, a conceptual model of the causes of abnormalities of bowel or bladder function that can lead to incontinence at the cellular, structural, and physiologic levels would inform research to understand underlying causes. Second, a conceptual model for the experience of incontinence should describe the relationships between the characteristics of incontinence (for example, frequency, amount, predictability), other personal characteristics (for example, mobility, weight, mood, cognition), quality of life, personal preferences, and characteristics of the social and physical environment. Conceptual models and classifications should be revised as new information on causes becomes available.

Methodologic

Consensus is needed on uniform definitions for fecal and urinary incontinence with regard to severity, condition-specific quality of life, patient burden, economic considerations, and patient preferences, and efforts should be made to standardize these definitions and use them systematically across studies. This consensus could be supported by a systematic evaluation of the validity of existing measures; such an evaluation could identify areas in which existing measures are inadequate. A systematic evaluation of current knowledge of the anatomic structure and physiology of the pelvic floor in continent and incontinent individuals also is needed, with the goals of achieving standardization, stratification, and identification of gaps in understanding. Imaging and bioengineering may be promising approaches.

Measures of Burden

Studies are needed to estimate the direct and indirect economic and societal costs of fecal and urinary incontinence and the potential benefits that might derive from successful prevention and treatment interventions. More research is needed to quantify the effects of chronic fecal and urinary incontinence on patients, caregivers, families, and friends and their quality of life. A particular need exists to determine how often fecal or urinary incontinence leads a person to move to a nursing home and how persons who are incontinent continue to live in the community.

Biological and Environmental Bases of Fecal and Urinary Incontinence

Studies are needed to test specific hypotheses derived from the conceptual model of the causes of abnormalities of bowel or bladder function that can lead to incontinence, recognizing that incontinence is often multifactorial. Novel hypotheses might involve the function of cells (for example, smooth muscle), organs (for example, bladder and bowel), structures (for example, sphincters and peripheral nerves), and biological systems (for example, neurologic and endocrine). Further studies are needed to test specific hypotheses derived from the conceptual model of the experience of incontinence. These hypotheses might involve the characteristics of individuals who are incontinent (for example, age, cognitive function, mood, mobility, comor-

bid conditions), their social supports, and their environments (for example, resources and management of nursing homes).

Research also is needed to elucidate the existence and causes of differences in rates and impact of fecal and urinary incontinence among different risk groups.

Natural History

Natural history studies are needed to identify factors affecting the incidence and, importantly, progression and remission of fecal and urinary incontinence. Longitudinal observational studies could be accomplished by adding standardized questions on fecal and urinary incontinence to ongoing observational studies in both currently identified at-risk populations (such as persons with dementia, persons with diabetes, and child-bearing women) and in general populations, as well as by assembling new cohorts. Other issues of interest include the relationships between different aspects of incontinence (such as that among the amount, frequency, and predictability of incontinence, quality of life, burden on patients and family, and patient preferences for management), and the interrelationships between fecal and urinary incontinence and anxiety, depression, and coping strategies.

Risk Factors

Although risk factors are incompletely understood, the identification of risk factors is important for targeting of interventions and identifying possible causes. Study populations enriched for problems related to fecal and urinary incontinence may provide special opportunities for studies of the causes, prevention, detection, and management of fecal and urinary incontinence.

Research is needed on medical and surgical treatments that may secondarily cause incontinence (for example, anorectal surgery, prostatectomy, pelvic radiation, and commonly prescribed drugs). Additional studies might explore novel risk factors, such as occupational hazards and childhood abuse and sexual abuse.

Detection, Prevention, and Education

Attention is needed on prevention of bowel and bladder conditions that cause fecal and urinary incontinence. Preventive strategies can be informed by a specific framework of the etiology of fecal and urinary incontinence, and targeted to specific populations or clinical groups. Research should examine the impact of public health initiatives, increased public and provider awareness, changes in reimbursement mechanisms, and health delivery redesign. Research should examine the potential value of such approaches as education and support models on quality of life, coping strategies, prevention of disease progression, self-management, resilience, and social support.

Studies are needed that will compare different brief instruments for screening, evaluate brief questionnaire-based classification tools, determine optimal detection approaches, and determine the comparative efficacy of pre-

ventive strategies. Screening and detection interventions should be tested in studies that incorporate efficacious preventive measures to learn whether screening and detection can improve patient outcomes. When efficacious interventions are identified, methods for knowledge dissemination (such as educational programs and guidelines development) should be studied to ensure the greatest possible impact. Education strategies need to address the appropriate settings, manner, and timing for distribution.

CONCLUSIONS

Fecal incontinence and urinary incontinence will affect more than one fourth of all U.S. adults during their lives. The natural history of fecal incontinence is unknown, and the natural history of urinary incontinence over several years is not well described.

Fecal incontinence and urinary incontinence often have serious effects on the lives of the many individuals who suffer physical discomfort, embarrassment, stigma, and social isolation, and on family members, caregivers, and society. Financial costs are substantial and may be underestimated because of underreporting.

Routine episiotomy is the most easily preventable risk factor for fecal incontinence. Risk factors for both fecal and urinary incontinence include female sex, older age, and neurologic disease (including stroke). Increased body mass, decreased physical activity, depression, and diabetes may also increase risk.

Pelvic floor muscle training and biofeedback are effective in preventing and reversing fecal and urinary incontinence in women for the first year after giving birth, and these approaches may also prevent or reduce urinary incontinence in older women and in men undergoing prostate surgery. Fecal and urinary incontinence may be prevented by lifestyle changes, such as weight loss and exercise.

Efforts to raise public awareness of incontinence and the benefits of prevention and management should aim to eliminate stigma, promote disclosure and care-seeking, and reduce suffering. Organized approaches to improving clinical detection of fecal and urinary incontinence are needed and require rigorous evaluation.

To reduce the suffering and burden of fecal and urinary incontinence, research is needed to establish underlying mechanisms, describe a classification system, determine natural history, classify persons according to their future risk for fecal or urinary incontinence, design interventions targeted to specific population groups, determine the effects of these interventions, and guide public policy.

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APPENDIX

State-of-the-Science Panel

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