Reducing the Stigma: Social and Emotional Challenges of Living with Incontinence

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Capital Nursing Education
Objectives

1. Discuss how “stigma” relates to incontinent patients.
2. Discuss the prevalence of UI and fecal incontinence.
3. Briefly review the types of incontinence.
4. Understand the types of Stigma associated with incontinence.
5. Understand the psychosocial effects of incontinence.
6. Explore the changes in the quality of life of people with incontinence.
7. Explore the methods of decreasing the stigma related to incontinence.
What is Stigma?

**Noun:** stigma, **Plural noun:** stigmas, **Plural noun:** stigmata

A mark of disgrace associated with a particular circumstance, quality, or person.

*Example:* “The stigma of having gone to prison will always be with me”  
*Synonyms:* shame, disgrace, dishonor.

What does this mean to a person who is incontinent?
Stigmatization

Social phenomenon:
Insiders (have the trait)
Outsiders (don’t have the trait)

Stigma is fundamentally a threat to one’s self-identity
Individuals are stigmatized when they possess, or are thought to possess, an attribute or characteristic that conveys a social identity that is devalued in a particular social context.¹⁰
About 17% of women over 18 years old have overactive bladder (OAB) and an estimated 12.2 million adults have urge incontinence.

One in five adults over 40 are affected by OAB or recurring symptoms of urgency and frequency.

OAB and UI occur about twice as frequently in women as in men and become more prevalent with age.

An estimated 17 million adults in the United States have daily UI and a further 33 million suffer from the overlapping condition, OAB.

In women between the ages of 20 and 45, the prevalence of overactive bladder was found to be 36.8%.

Stress urinary incontinence, the most prevalent form of incontinence among women, affects an estimated 15 million adult women in the U.S.

29% of individuals ages 60-70 experience leakage when coughing, sneezing, or laughing compared to 17% of men and women ages 30-39. A portion of these individuals also experience urge incontinence.

Approximately 1 out of 3 women over the age of 45 – and 1 out of every 2 women over 65 – have stress urinary incontinence.¹
Prevalence of Fecal Incontinence

- The estimated prevalence of FI in noninstitutionalized US adults is 8.3% and consists of liquid stool in 6.2%, solid stool in 1.6%, and mucus in 3.1%.
- It occurs at least weekly in 2.7%.
- Prevalence is similar in women (8.9%) and men (7.7%) and increases with age from 2.6% in 20 to 29 year olds up to 15.3% in participants aged 70 years and older.
- FI is not significantly associated with race/ethnicity, education, income, or marital status after adjusting for age.
- Independent risk factors in women are advancing age, loose or watery stools, more than 21 stools per week, multiple chronic illnesses, and urinary incontinence.
- Independent risk factors in men are age, loose or watery stools, poor self-rated health, and urinary incontinence.²
Types of Urinary Incontinence

- Stress incontinence
- Urge incontinence
- Mixed incontinence
- Functional incontinence
- Overflow incontinence
- Overactive Bladder
- Total incontinence
Persistent Incontinence

- Sphincter weakness-following prostate surgery in men or vaginal surgery in women
- Pelvic prolapse
- Nervous system impairment-MS, Parkinson’s, strokes, spinal cord injury
- Mental or psychological changes

- Bladder Cancer
- Pelvic muscle weakness
- Enlarged prostate
- Nerve or muscle damage after radiation
- Developmental problems of bladder
- Pelvic, prostate or rectal surgery
- Bladder spasms

*Studies done by DevoreEE, Minassian VA,l and Grodstein F show that older age, white race, and obesity were particularly strongly related to persistent UI.*
Transient Causes

• Delirium
• Infection
• Atrophic vaginitis
• Pharmaceuticals
• Psychological
• Endocrine disorder
• Restricted mobility
• Stool impaction

Acute Incontinence

➢ Inflammation of urinary tract
➢ Stool impaction
➢ Medication side effects
➢ Polyuria
➢ Psychological factors
Causes of Urinary Incontinence in Women

• Stress incontinence: Leakage when sneezing, exercising, or coughing
• Side effects of medications
• Certain foods
• Weakened pelvic floor muscles
• Pregnancy & child birth
• Aging
• Severe constipation
• Changes in the body from childbirth or surgery
Causes of Urinary Incontinence in Men

• It's often a side effect after surgery for
  – Prostate cancer
  – Benign prostatic hypertrophy

• It can be a symptom or a result of many different health conditions
  – Diabetes
  – Strokes
  – MS
  – Sometimes it can develop for less clear reasons, such as an overactive bladder
Causes of Fecal Incontinence

The list of medical conditions that can cause bowel incontinence includes:

- Anorectal surgery
- Diabetic peripheral neuropathy
- Rectal inflammation
- Forceps delivery
- Reduced anal sensation
Three Types of Stigma

**Perceived-Stigma**
Fear and worry of being subjected to a stigmatizing event.

**Self-stigma**
Directing prejudicial attitudes inwards toward oneself.

**Enacted-stigma**
Episodes of discrimination based on a stigmatizing attribute.
It’s a “private” matter.....

• We are socialized to understand that elimination of bodily waste is a private matter and should be done in a tidy way

• Failure to do so risks being stigmatized
Incontinent Patients

• Perceived as “different”
• Stereotyped as frail, dependent, incompetent or old
• Threatens one’s adult status
• May be both embarrassed and shamed
• Frequency, urgency and nocturia are stigmatizing as they are socially disruptive and indicate loss of control over bodily functions¹¹
## The Six Stigma Dimensions

<table>
<thead>
<tr>
<th>Dimension</th>
<th>Distinguishing characteristic</th>
</tr>
</thead>
<tbody>
<tr>
<td>Concealability</td>
<td>Is the trait apparent to others?</td>
</tr>
<tr>
<td>The course of the mark</td>
<td>Does the trait become more prominent over time?</td>
</tr>
<tr>
<td>Disruptiveness</td>
<td>Does the trait impede social interactions?</td>
</tr>
<tr>
<td>Aesthetics</td>
<td>Is the trait unattractive to others?</td>
</tr>
<tr>
<td>Origin</td>
<td>Is the trait individual perceived to be responsible in acquiring or creating the trait?</td>
</tr>
<tr>
<td>Peril</td>
<td>Is the trait perceived to be dangerous to others in the social settings?</td>
</tr>
</tbody>
</table>
Available Questionnaires Concerning Stigmatization

Goal of the study was to evaluate the efficacy of available questionnaires for assessing the outcomes of “continence difficulty” interventions and to assess the selected questionnaires concerning aspects of stigmatization.

- Literature search done yielding 194 references
- 11 questionnaires fit the inclusion criteria
- 6 of the 11 did not have any stigma content
- The remaining five had very limited content regarding stigma

**Conclusion:** Further studies are required to examine how the stigma associated with continence difficulty impacts upon health care interventions.

*Study by K.Southall, J Tuason, et.al*
Psychosocial Issues

H umiliation
E mbarrassment
L oss of dignity
P sychological damage
L onely
E nclosed
S hame
S elf conscious

A ggravated
F rustrated
R estrained
A lone
I solated
D ependent

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Effect on Incontinent Patient’s Self Esteem

- Nearly one out of every five men over the age of 60 is dealing with male urinary incontinence.
- Most men will not even discuss UI with anybody.
- Men can feel very humiliated.
- A healthy active adult male can feel like an invalid.
- Fecal incontinent men will not tell anyone.
- Women do handle having incontinence better than most men.
- Women over 65 are used to wearing pads due to their periods in the past.
- Younger women have more of an issue with decreased self esteem.
Quality of Life with Incontinence

UI and FI greatly diminish the quality of life. Therefore, it is important to:

• Diagnose the three main types of urinary incontinence correctly: stress, urge or mixed incontinence.

• Evaluate the impact of incontinence on quality of life.

• After a detailed history, a bladder diary and questionnaires are the most useful tools with which to determine what aspects of quality of life are most impaired (i.e., daily, work-related, recreational or sexual activities).

• In general, urgency and urge incontinence have a worse effect on quality of life than stress urinary incontinence; however, fecal incontinence affects the quality of life considerably more.

• Measures of quality of life have become essential in developing management plans and in follow-up.
Quality of Life Questionnaire (Fecal Incontinence)

Q 1: In general, would you say your health is:

1 [ ] Excellent
2 [ ] Very Good
3 [ ] Good
4 [ ] Fair
5 [ ] Poor
Q2: For each of the following items, please indicate how much of the time the issue is a concern for you due to accidental bowel leakage (ABL).

*If it is a concern for you for reasons other than accidental bowel leakage then check the box under Not Applicable, (N/A).*
**Quality of Life Questionnaire (Fecal Incontinence)**

<table>
<thead>
<tr>
<th>Q2. Due to accidental bowel leakage:</th>
<th>Most of the time</th>
<th>Some of the time</th>
<th>A little of the time</th>
<th>None of the time</th>
<th>NA</th>
</tr>
</thead>
<tbody>
<tr>
<td>a. I am afraid to go out</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>[]</td>
</tr>
<tr>
<td>b. I avoid visiting friends</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>[]</td>
</tr>
<tr>
<td>c. I avoid staying overnight away from home</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>[]</td>
</tr>
<tr>
<td>d. It is difficult for me to get out and do things like going to a movie or to church</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>[]</td>
</tr>
<tr>
<td>e. I cut down on how much I eat before I go out</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>[]</td>
</tr>
<tr>
<td>f. Whenever I am away from home I try to stay near a restroom as much as possible</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>[]</td>
</tr>
<tr>
<td>g. It is important to plan my schedule around my bowel pattern</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>[]</td>
</tr>
<tr>
<td>h. I avoid traveling</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>[]</td>
</tr>
<tr>
<td>i. I worry about not being able to get to the toilet in time</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>[]</td>
</tr>
<tr>
<td>j. I feel I have no control over my bowels</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>[]</td>
</tr>
<tr>
<td>k. I can't hold my bowel movement long enough to get to the bathroom</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>[]</td>
</tr>
<tr>
<td>l. I leak stool without even knowing it</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>[]</td>
</tr>
<tr>
<td>m. I try to prevent bowel accidents by staying very near a bathroom</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>[]</td>
</tr>
</tbody>
</table>

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Quality of Life Questionnaire  (Example 2)

1. If you were to spend the rest of your life with your urinary condition just the way it is now, how would you feel about that?

   □ Delighted  □ Pleased  □ Mostly satisfied  □ Mixed (about equally satisfied & dissatisfied)

2. Over the past month, how much of the time has any urinary problem kept you from doing the kinds of things you would usually do:

   □ None of the time  □ A little of the time  □ Some of the time  □ Most of the time  □ All of the time
A study was done by Coyne KS, et al. They examined the impact of each type of UI on health related quality of life (HRQL):

- 919 participants
- 82.5% female
- 85.4% Caucasian
- Average age was 55.9 years.

Coyne KS, et al. BJU Int. 2003
CONCLUSION of the study:

Compared with stress incontinence, respondents with urge incontinence and mixed incontinence reported not only significantly greater ratings of urinary urge intensity and more incontinence episodes, but also significantly worse HRQL.

These results are consistent with previous findings which indicated a greater impact on HRQL for the urge component of mixed incontinence than for the stress component.

Coyne KS, et al. BJU Int. 2003
Overcoming the Stigma

Incontinence can be associated with a great deal of embarrassment and shame:

- Due to the feeling of helplessness in hospital
- Due to the lack of control over one’s bladder in the hospital or at home

There are a number of ways to help restore their sense of independence:

- Educate both patients and the public
- Recommend discreet products and simple exercises
- Provide personal, compassionate support
Educate Patients and the Public

Demystify the situation.

Empower the patient with knowledge.

Explain causes, how the bladder should work, and how common it is.

Use a straightforward manner of discussion.
Recommend Discreet Products and Simple Exercises

- There can be positive results without having surgery.
- Kegel exercises can be beneficial for women especially.
- Educate the patient on the variety of affordable incontinence products on the market.
- When surgery is the best option, explain the current technology that is designed to provide outstanding cure rates from simple procedures.
Provide Personal, Compassionate Support

Remember to consider the quality-of-life effects of urinary incontinence rather than just its medical aspects.

Some patients miss work, skip social events, and experience sexual dysfunction.

Have empathy throughout the treatment process with the additional emotional support.
Example of Initial Assessment of Patient with UI
Goals for Treatment

- Improve ability to suppress bladder urgency and delay voiding
- Reduce urinary frequency
- Increase bladder capacity
- Reduce urinary incontinence
- Restore confidence in bladder control

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Patient Education

- Normal bladder function
- Types of incontinence that relate to the patient
- Normal pelvic floor musculature
- Deviations as related to the patient’s condition
- Exercises that may prove effective in re-educating the patient’s pelvic floor
- Dietary issues
- Suppression techniques
- Voiding protocol
- Daily diary
- Time allowed for questions
Plan

Two weeks to practice exercises and behavior modification

Return for further therapy utilizing the biofeedback equipment
Behavior Modification

- **Dietary issues:**
  - Cut out caffeine completely
  - No fluids after 6pm
  - Drinking eight 8oz cups of plain water

- **Suppression techniques:**
  - Squeeze before you sneeze (stress)
  - Mind over bladder
  - Stop – quick flicks – walk to toilet

- **Voiding protocol:**
  - Every two hours
  - Finish, wipe, stand, then go again (double voiding to empty)

- **Daily diary:**
  - Record each voiding
  - Record food and fluid

*Time allowed for questions*
Motivation Is Important

- Imagine you are going to succeed
- Aim to restore muscle strength and tone
- Motivation is your most important tool
- Devote time each day to exercise
- Remember, it will take time to regain control
- You are the key to your success
Reinforcement and Encouragement

You are not alone
Continence Support Group: Others share stories

You can be helped
Share success stories

This does not define you
It does not change your personality

You can succeed
Point out any small milestone, i.e., even one pad less per day!!
In a survey of 36,000 Americans with incontinence, Jeter and Wagner reported that 17% described their incontinence as a major problem with important social implications but the rest described it as a relatively minor problem with limited impact on their respective lifestyles.
References

1. **Assessing the stigma content of urinary incontinence intervention outcome measures.** Kenneth Southall 1,2, Joshua R Tuazon 3, Abdul H Djokhdem 3,4, Eleanor A van den Heuvel 5, Walter Wittich 6,7 and Jeffrey W Jutai 3,4. First Published November 1, 2017, Sage Journals

2. The National Association for Continence: [http://www.nafc.org](http://www.nafc.org), Prevalence and incidence of UI


7. Health-related quality of life (HRQoL) is a multi-dimensional concept that includes domains related to physical, mental, emotional, and social functioning. It goes beyond direct measures of population health, life expectancy, and causes of death, and focuses on the impact health status has on quality of life. https://www.google.com/search?q=hrql


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Accidents Happen
What To Do After An Incontinence Episode
For the most part, the human body is a wonder of nature, a... Aaron Baker

Pull-ups Vs. Briefs
We recently had a comment on our site asking what the difference was between adult pull-ups and... Annee Sharp

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Types of Incontinence
Free Incontinence Guide
How Common is Incontinence?
Famous People with Incontinence
Common Incontinence Terms
Products for Incontinence Care
How To Prevent Diaper Leakage
Ways to Reduce Urine Odor
Parent with Incontinence? Here Are Some Helpful Tips
How to Apply/Remove an Adult Diaper
AFL: Accidental Bowel Leakage
Bladder Retraining for Bladder Control
How Diet Affects Bladder Control
For Women
Common Questions About Stress Incontinence
Pregnancy and Incontinence
For Men
Alternatives to Briefs: Male External Collectors
Prostate Cancer: Signs, Symptoms and Treatment

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