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Original research article

Factors influencing the feeling of shame in individuals with incontinence: The INCOTEST study

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Abstract
Introduction: Shame is defined as a negative emotion associated with intense distress and self-blame. It strongly manifests in conditions such as urinary or fecal incontinence. This study aimed to explore the feeling of shame experienced by individuals with incontinence when discussing their condition with others. Additionally, the study sought to identify factors associated with this emotion.
Methods: A prospective observational study was conducted with 220 patients with incontinence who filled in a 17-item online survey. Multivariate linear regression analysis was used to identify factors related to shame.
Results: A significant sense of shame was reported by 39.1% of participants when discussing their incontinence. The highest levels of shame were observed among women with poorer health status who initially sought advice from general practitioners, had limited knowledge of incontinence, and relied primarily on the internet for information.
Conclusion: This study highlights the importance of adopting a comprehensive approach that includes incontinence's emotional and psychological aspects. Educational and awareness interventions are crucial to enhance understanding, provide reliable information, and reduce social stigma. Creating a trusting environment is essential to enable individuals with incontinence to feel comfortable discussing their condition with healthcare professionals, promoting open and supportive communication.

Keywords: Embarrassment; Incontinence; Shame; Stigma

Introduction

Shame is a complex and profound emotion that can emerge at various stages of life (Jaeb, 2022). Nihei et al. (2022) described shame as a negative emotion accompanied by intense distress and anxiety triggered by how others perceive an individual. Experiencing shame can challenge one's sense of identity and self-worth, resulting in feelings of humiliation, discomfort, and significant decreases in self-esteem (Jaeb, 2022; Nihei et al., 2022). Shame is often intensified when associated with physical or psychological vulnerability, such as chronic conditions or clinical situations that disrupt bodily functions or physical appearance (Berglund et al., 2024). Urinary and fecal incontinence are conditions that elicit particularly intense emotional responses of shame (Toye and Barker, 2020).

Addressing shame becomes especially relevant when considering global statistics on incontinence. Urinary incontinence is estimated to affect 700 million to 1.2 billion people in the ten most populous countries worldwide (Sadri et al., 2024). Meanwhile, fecal incontinence impacts over 71,800 individuals in the United States alone (Menees et al., 2018). Studies indicate that about one in twelve adults globally experiences fecal incontinence, predominantly affecting women and older adults. Urinary incontinence affects 5% to 70% of the global population, with increasing prevalence over recent decades (Mack et al., 2024; Milsom and Gyhagen, 2019).

Urinary and fecal incontinence can lead to both physical and psychological consequences. Physical effects include skin alterations, such as incontinence-associated dermatitis (commonly seen in older adults), mobility difficulties, and increased fall risks. Psychologically, individuals may experience depression and anxiety, significantly reducing their quality of life (Kuoch et al., 2019; Pizzol et al., 2021). Despite being common, the general population often does not recognize incontinence as a medical condition (Elenskaia et al., 2011). This underestimation is derived from social stigma, lack of information, and a tendency to minimize or conceal the problem. The misconception that incontinence is "normal" or unavoidable prevents individuals from perceiving it as treatable, leading to poor treatment-seeking behaviors and underuse of available interventions (Murphy et al., 2022).

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The fear of stigma or judgment can hinder social participation among individuals with incontinence. Interactions with healthcare professionals may sometimes exacerbate feelings of shame, as some patients blame themselves for their condition, believing they have failed to prevent it (Toye and Barker, 2020). Furthermore, managing a potentially embarrassing condition can negatively affect self-perception, lowering self-esteem and distorting one's body image and sense of self-worth (Pizzol et al., 2021; Rashidi Fakari et al., 2021).

Factors such as weak European patient rights frameworks and the slow implementation of specialized incontinence centers and outpatient clinics contribute to insecurity and mistrust among affected individuals.

Given the prevalence of incontinence, a significant portion of the population may experience hidden or inadequately addressed feelings of shame, embarrassment, and isolation. Exploring and understanding shame is critical to improving therapeutic and psychological support for individuals living with these conditions. Recognizing the concept of shame and how patients experience it can help nurses improve care delivery and build strong relationships with patients and their families (Nihei et al., 2022).

This study aims to explore the feelings of shame experienced by individuals with incontinence and identify the factors contributing to its manifestation.

Materials and methods

Study design

A prospective observational study was conducted in Italy among members of the Federation of Incontinence and Stomach Associations (F.A.I.S., 2024). F.A.I.S. is a volunteer-based organization, founded in 2002, that brings together regional associations committed to supporting individuals living with incontinence. The study will take place from June to October 2024, coinciding with several awareness campaigns promoted by F.A.I.S. The Federation was established in response to the expressed need from various regional associations to collaborate and increase awareness of incontinence. The Federation's efforts focus on multiple fronts: ensuring the rights of individuals and promoting uniform and adequate healthcare across Italy; encouraging the development of regional associations that can engage with local institutions; raising public awareness through social campaigns and advocacy initiatives; and fostering innovative projects while promoting studies and publications in the relevant fields.

Data collection

The sample was selected based on the following inclusion criteria: (a) being incontinent (reporting an involuntary loss of urine or stool in the past two weeks); (b) being a member of the F.A.I.S. association; (c) having the ability to understand and speak Italian; and (d) being an adult (≥18 years).

Data collection instrument

An online survey consisting of 17 questions was administered to the sample. Before administration, the questions were reviewed by 10 experts (5 health professionals and 5 individuals with incontinence) to assess the clarity of each section and ensure the content was consistent with the measurement objectives. Shame was evaluated using the question: "Do you generally feel ashamed or embarrassed to talk about your incontinence-related complaints and discomforts?" Participants responded using a four-point Likert scale. To identify factors influencing feelings of shame, a preliminary literature review was conducted to pinpoint variables previously studied concerning this phenomenon. Based on the findings, additional questions were included and organized into the following domains:

- Socio-Demographic Data: Gender, Age, Region of Residence, Employment Status
- Clinical and Social Data: Type of Incontinence, General Health Status, Frequency of Leakage, Need for Caregiver Support in Managing Incontinence
- Impact of Incontinence: Effects on Daily Life and Work Activities
- Access to Care: Challenges in Accepting One's Incontinence Condition and Involvement of Healthcare Professionals in Managing the Issue

Statistical analysis

We used the mean (M) and standard deviation (SD) to describe continuous variables and the distribution of Likert scale responses. Categorical variables were analyzed using frequencies and percentages. The question "Do you generally feel ashamed or embarrassed to talk about your incontinence-related complaints and discomforts?" served as the dependent variable for identifying predictors of shame among participants with incontinence. We performed a multivariate linear regression analysis using the backward method to select the optimal model. A significance level of $p = 0.05$ was set for all tests. Statistical analyses were conducted using SPSS version 29 software (IBM, Armonk, NY, USA).

Sample size

The minimum sample size required for performing multiple linear regression was calculated using G*Power software (version 3.1.9.7). The calculation was based on the following parameters: 11 independent variables included in the model, a medium effect size ($f^2 = 0.15$), a statistical significance level (α) set at 0.05, and a statistical power ($1 - \beta$) of 0.80. According to these specifications, the software estimated that a minimum of 88 participants would be necessary. This sample size ensures adequate statistical power to detect medium-sized effects, thereby reducing the risk of type II errors and enhancing the reliability of the conclusions drawn from the model.

Ethical aspects

The study was conducted in accordance with Italian privacy laws and the Declaration of Helsinki (Bibbins-Domingo et al., 2024). It received approval from the F.A.I.S. Board of Directors (C.D. 04/27/2023). Eligible participants were informed about the objectives of the research, and confidentiality regarding the data collected was ensured. Informed consent was obtained from all individuals who voluntarily participated in the survey.

Results

The sample comprised 220 patients experiencing incontinence, with a mean age of 64.5 ± 30.4 years. The characteristics of the sample are summarized in Table 1. Most participants were male (n = 111, 50.5%) and resided in northern Italy (n = 101, 45.9%). Additionally, a significant number were retired (n = 96, 43.6%). A large portion of the sample reported suffering from urinary incontinence, which they associated with perceived poor health (n = 101, 45.9%). Furthermore, many individuals experienced episodes of involuntary fecal

Table 1. Characteristics of the sample

Variable	M	DS (±)
Age	64.5	30.4
	n	%
Gender		
Male	111	50.5
Female	108	49.1
Non-responder	1	0.5
Macro-geographical area		
North	101	45.9
Center	61	27.7
South	36	16.4
Islands	22	10.0
Employment status		
Employee	51	23.2
Freelancer	26	11.8
Unemployed, looking for work	14	6.4
Unemployed, not looking for work	25	11.4
Retired	96	43.6
Student	5	2.3
Other	3	1.3
Type of incontinence		
Fecal	49	22.3
Mixed	13	5.9
Urinary	158	71.8
State of health		
Very bad	28	12.7
Poor	101	45.9
Good	85	38.6
Very good	6	2.7
Leak frequency		
Once a week	17	7.7
2/3 times a week	39	17.7
Once a day	57	25.9
Several times a day	105	47.7
Non-responder	2	0.9
Caregiver support		
Yes	106	48.2
No	97	44.10
Difficulty recognizing that you are incontinent		
Yes	165	75.0
No	55	25.0
How much does incontinence affect daily life?		
Little	32	14.5
Enough	147	66.9
A lot	41	18.6
How much does incontinence affect work?		
Little	30	13.6
Enough	32	14.5
A lot	49	22.3
I don't work	95	43.2
Non-responder	14	6.4
Shame to talk about incontinence-related disorders		
Not at alls	20	9.1
Little	29	13.2
Enough	85	38.6
A lot	86	39.1
Operator who first took charge of incontinence		
General practitioner	80	36.4
Urologist	39	17.7
Gynecologist	26	11.8
Psychologist	24	10.9
Nurse	24	10.9
Gastroenterologist	15	6.8
Surgeon	76	34.5
Pharmacist	24	10.9
Physiatrist	20	9.1
Physiotherapist	39	17.7
Nobody	4	1.8
Level of information on incontinence		
Very bad	36	16.4
Poor	99	45.0
Good	62	28.2
Very good	23	10.5
Source of information		
Physician/Specialist	97	44.1
Websites	124	56.4
Patient associations	41	18.6
Social media	57	25.9
TV Shows	31	14.1
Scientific articles	2	0.9
Nobody	26	11.8

or urinary leakage daily or more frequently (*n* = 105, 47.7%). A noteworthy percentage of participants (*n* = 106, 48.2%) relied on caregiver support for managing incontinence and reported initial difficulty in recognizing the issue (*n* = 165, 75%). Incontinence was perceived to significantly impact daily life (*n* = 147, 66.9%) and work activities (*n* = 49, 22.3%). The majority of patients discussed their incontinence for the first time with their general practitioner (*n* = 80, 36.4%). The level of awareness about incontinence was found to be predominantly low (*n* = 99, 45%). Among the various sources of information, the internet emerged as the most popular medium (*n* = 124, 56.4%).

The experience of shame and related factors

A significant portion of the participants reported feeling a strong sense of shame when discussing incontinence with others (*n* = 86, 39.1%).

As shown in Table 2, the regression analysis identified several key factors associated with higher levels of shame related to incontinence. Women who perceived their health status as poor reported greater feelings of shame. Additionally, those who initially consulted a general practitioner for diagnosis or treatment reported higher shame levels compared to those who sought specialized care directly. Furthermore, women who reported having limited knowledge about incontinence experienced greater shame. Finally, participants who primarily relied on internet sources for information also exhibited higher levels of shame.

To evaluate the overall significance of the regression model, an analysis of variance (ANOVA) was performed. The results of the ANOVA indicated that the regression model was statistically significant ($F(9, 210) = 7.518$; $p < 0.001$), meaning that at least one of the predictor variables contributed significantly to explaining variations in the dependent variable. Furthermore, the model demonstrated substantial explanatory power, accounting for 46% of the variance in the dependent variable. This suggests that nearly half of the variability in the dependent variable can be attributed to the predictor variables included in the model, reinforcing the robustness of the regression analysis.

Table 2. Factors influencing the feeling of shame

Variable	B*	Standard error	Beta	*t*-Test	Sign.
Gender: female	0.002	0.001	0.128	2.084	0.038
State of health: very bad	0.317	0.084	0.245	3.790	<0.001
First contact: GP	0.304	0.120	0.156	2.535	0.012
Level of information on incontinence: very bad	0.159	0.071	0.147	2.221	0.027
Media: websites	0.248	0.117	0.131	2.122	0.035

Note: B* – non-standardized coefficients

Discussion

This study explored the feeling of shame in individuals with incontinence. The novelty of this research lies in being the first to delineate the factors influencing the perception of shame using a quantitative approach, thus offering a deeper understanding of the multifaceted nature of this emotion.

The majority of the study sample was composed of older adults, often retired, with urinary incontinence and frequent daily episodes of leakage. The participants' strong dependence on caregivers and initial difficulties in recognizing the condition confirm the complexity of managing incontinence and its significant impact on quality of life (Bartlett et al., 2009; Pizzol et al., 2021).

Over a third of participants (39.1%) reported feelings of shame associated with incontinence. This finding highlights the emotional and social relevance of incontinence and underscores the significant psychological and relational implications of shame (Elenskaia et al., 2011; Jaeb, 2022; Olsson and Berterö, 2015; Peroni et al., 2022; Pizzol et al., 2021). Previous studies emphasize that shame can lead to negative consequences, including diminished self-esteem, reduced self-efficacy, intense distress, anxiety, and self-rejection (Nihei et al., 2022). Additionally, shame can trigger defensive mechanisms, such as increased social anxiety due to perceived negative judgment by others, resulting in avoidance behaviors and depressive states (Pizzol et al., 2021; Pradeep and Anand, 2023).

Our results revealed that shame was particularly pronounced among women. This aligns with previous findings showing that women are more susceptible to intense shame due to societal and cultural factors that expose them to greater scrutiny and judgment than men (Furuyama et al., 2025; Pradeep and Anand, 2023).

This study revealed that poor perceived health was also associated with higher levels of shame. This relationship may reflect the compounding effect of incontinence on other debilitating health conditions, which amplifies feelings of vulnerability and loss of autonomy (Peroni et al., 2022; Scime et al., 2022).

An important and novel finding of our study is the association between elevated shame levels and discussing incontinence for the first time with a general practitioner. While this relationship has not been explored in previous studies, it may indicate that sharing the issue with a familiar yet professional figure intensifies feelings of shame. The pre-existing relationship with the general practitioner might make it harder for individuals to feel discomfort and fear of judgment, contributing to greater emotional vulnerability.

Our results highlighted that low levels of knowledge about incontinence amplify feelings of shame. This finding is consistent with previous literature, which suggests that a lack of information can generate insecurities and fears, leading individuals to perceive their condition as abnormal or embarrassing (Mendes et al., 2017; Shearon and Alexander, 2025). This finding reinforces the urgency for healthcare professionals to provide comprehensive and accurate information about incontinence when the issue arises. Supportive and well-prepared healthcare interactions are essential to reducing shame, as inadequate information and insufficient preparation can exacerbate feelings of shame and isolation (Olsson and Berterö, 2015). Conversely, empathetic and supportive interactions can alleviate these emotions.

Furthermore, the study highlighted that individuals experiencing higher levels of shame tended to rely primarily on online sources for information. This is not surprising, as the digital environment provides a degree of anonymity that reduces the fear of external judgment (Brainard et al., 2024). However, exclusive reliance on online resources may expose individuals to inaccurate or unverified information, potentially exacerbating confusion and distress regarding their condition.

Our findings provide a comprehensive understanding of the shame experienced by individuals with incontinence and the factors that contribute to it. This study also offers valuable insights for targeted interventions to reduce stigma. Notably, the need to normalize incontinence by dispelling misconceptions and fostering a more supportive societal environment emerged as a key priority. This can be achieved through well-organized health campaigns and integrating incontinence education into primary care settings (Pradeep and Anand, 2023). Additionally, improving communication between patients and healthcare providers is essential, as it can empower individuals to seek medical advice without fear of judgment (Toye and Barker, 2020). Finally, ensuring access to high-quality educational resources and facilitating peer support networks may equip individuals with the knowledge and coping strategies necessary to regain confidence and autonomy (Siddiqui et al., 2014).

Limitations

Despite offering a comprehensive overview of factors influencing shame in individuals with incontinence, the study has limitations that affect its generalizability. First, the research only involved members of the F.A.I.S. association, which, while national, is not representative of the entire population of individuals with incontinence. Furthermore, the sociocultural and healthcare characteristics of the sample, primarily from northern Italy, may not adequately reflect the diversity of the national population, which operates under varying regional healthcare systems. Additionally, data collection relied on self-reported responses, and using an online platform may have excluded specific demographics, such as older adults or those less adept at using digital tools. Finally, the study's cross-sectional nature prevents the establishment of causality. While associations between factors and shame were identified, it cannot be determined whether these factors directly cause feelings of shame.

Conclusion

The findings of this study emphasize the importance of adopting a sensitive approach to incontinence that addresses not only its physical aspects but also its emotional and psychological dimensions. Promoting educational initiatives for both healthcare professionals and individuals with incontinence enhances awareness and provides accurate, reliable information to patients and caregivers. Implementing structured training programs for healthcare professionals can improve their ability to recognize and address the emotional burden of incontinence with empathy and sensitivity. Additionally, integrating incontinence education into routine medical consultations may help normalize discussions, ensuring that patients receive accurate and evidence-based information. Creating an environment of openness and trust is crucial to helping individuals with incontinence feel comfortable initiating honest discussions without fear and receiving support and guidance from competent professionals. Associations dedicated to incontinence are pivotal in fostering welcoming, empathetic, and nonjudgmental environments. These spaces allow individuals to share their struggles with others experiencing similar challenges, reducing feelings of shame and improving access to care.

By addressing these emotional and psychological barriers, this study contributes to advancing the overall care and quality of life for individuals living with incontinence.

Statement on informed consent and use of artificial intelligence

Informed consent was obtained from all subjects involved in the study. AI or AI-assisted tools were not used in drafting any aspect of this manuscript.

Ethical aspects and conflict of interest

The authors have no conflict of interest to declare.

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