Study Protocol

Urinary Incontinence: Lived Experience of Adult Women. A Phenomenological Study Protocol

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Abstract

Introduction. Urinary incontinence is a common yet underreported condition among women, affecting up to 69% but often hidden due to stigma. While various treatments exist, women's help-seeking and self-management are shaped by personal beliefs, emotions, and cultural context. In Italy, access to services, informal networks and the sensitivity of intimate health topics may influence how women perceive, talk about, and manage urinary incontinence.
Objective. Explore, within an Italian context, the lived experience of adult women with urinary incontinence, focusing on how they interpret and make meaning of their condition, their daily coping strategies, emotional responses, and the complex factors shaping their engagement with care.
Methods and Analysis. This qualitative phenomenological study will use Interpretative Phenomenological Analysis (IPA). Participants attending pelvic floor rehabilitation at an outpatient clinic in Northern Italy will be purposively sampled. Data will be collected through semi-structured interviews and socio-demographic questionnaires until interpretative sufficiency is reached. Audio recordings will be transcribed verbatim and analysed by the researchers, both manually and with NVivo. Reflexivity, double coding, triangulation, and an audit trail will be employed to ensure trustworthiness. Ethical approval has been obtained, and informed consent will be

secured from all participants.
Expected Results. The study will highlight psychosocial aspects often overlooked in care, informing person-centered, flexible interventions to improve patient engagement and adherence. It will support efforts to reduce stigma, promote timely help-seeking, and enhance healthcare professionals' empathy and communication skills. Limitations include exclusion of women not engaged in rehabilitation and the sensitive nature of the topic, which may affect participant openness.

Keyword: Coping Skills, Life Change Events, Qualitative Research, Urinary Incontinence, Women

Introduction

The International Continence Society defines urinary incontinence (UI) as "the complaint of any involuntary loss of urine" and classifies it as urge, stress, or mixed incontinence (Abrams et al., 2003). Unlike other chronic conditions such as type 2 diabetes or hypertension – which are widely acknowledged and openly discussed (Saklayen, 2018) – UI remains largely underestimated and underreported (Cardozo et al., 2023).

Although UI can also affect men, epidemiological evidence consistently shows a higher prevalence in women, with rates ranging from 25% to 45% and peaking at 69% (Cardozo et al., 2023). In addition, female UI, mediated by biological and life-course events such as pregnancy, vaginal childbirth, menopause, and gynecological surgeries including hysterectomy, contributes significantly to the construction and lived experience of female identity. Many perceive it as a threat to bodily integrity and femininity, with implications for self-image, self-esteem and sexual wellbeing (Yilmaz & Erkal Aksoy, 2023). The intimate nature of UI generates stigma and embarrassment, which in turn contributes to its invisibility (Elenskaia et al., 2011). In fact, many women avoid disclosing symptoms or seeking help, often perceiving UI as an inevitable and irreversible aspect of ageing (Dugan et al., 2001).

Although various management options are available — from physical and behavioural interventions to pharmacological or surgical treatments — women's motivation to adhere to such treatments is often influenced by their beliefs, emotions, and cultural background (Wójtowicz et al., 2014).

Women may adopt self-management strategies such as using sanitary pads, reducing fluid intake, or avoiding physical and social activities, which in some cases lead to social withdrawal (Delarmelindo R De et al., 2013; Park et al., 2017). While the literature demonstrates the negative impact of UI on women's physical, psychological, and social well-being (Pizzol et al., 2021), few studies have explored how women make sense of their emotional experiences and cultural perceptions when living with UI, and how these meanings shape their daily self-management and interactions with treatment pathways (Yilmaz & Erkal Aksoy, 2023).

International studies are increasingly addressing these aspects, but there is still a lack of research conducted in the Italian context, where cultural norms and local healthcare structures may play a key role in shaping women's experiences. In Italy, traditional gender roles and family-centred cultural norms may shape how women perceive their bodies and communicate about intimate or reproductive health concerns (Pandolfi, 1990). Topics related to female sexual wellbeing or intimate health are often considered sensitive, which may limit open discussion and awareness (WHO, 2015).

Family and informal networks continue to play a crucial role in providing emotional sustenance and active coping assistance (Thoits, 2011); however, they may also exert social control and reinforce traditional norms, which can discourage individuals from seeking formal sources of help (Pescosolido, 1992). At the same time, middle-aged women who already experience urinary symptoms during menopause are nonetheless expected to remain socially and professionally active, while balancing work, family responsibilities, and their own wellbeing

(Lai et al., 2025). Nevertheless, UI often disrupts everyday rhythms and embodied routines which can be especially challenging in sociocultural contexts that valorize women's uninterrupted productivity, multitasking, and caregiving roles (Mendes et al., 2017).

Understanding female UI experiences is therefore both a clinical and social priority, as it calls for an integrated and phenomenological perspective that illuminates how women live through and make sense of this condition, linking its bodily and physiological determinants with the gendered meanings, identity processes, and everyday practices through which they negotiate control, vulnerability, and belonging in their lifeworld.

Although the Italian healthcare system is universalistic, the organisation and accessibility of specialised services for women's health can vary significantly both across and within regions (Cicchetti & Gasbarrini, 2016). These cultural and systemic factors highlight the need for context-specific research to better understand women's experiences of UI within the Italian setting. Without understanding how adult women interpret and live UI – how they make sense of symptoms, negotiate care pathways and enact self-management in light of their cultural context – healthcare services may fail to offer interventions that are meaningful, acceptable and effective (Mendes et al., 2017).

Therefore, this study aims to explore, within a Northern Italian context, how adult women experience and make sense of living with UI. In particular, it seeks to gain an in-depth understanding of how they perceive and navigate this condition in their everyday lives, the emotional and behavioural responses they develop, and how these experiences shape their attitudes towards seeking care and engaging with available treatment options, especially conservative approaches such as pelvic floor rehabilitation.

Methods and Analysis

Qualitative Approach and Research Paradigm

This study will be conducted using a qualitative phenomenological approach, adopting the Interpretative Phenomenological Analysis (IPA) methodology (Smith et al., 2022). Grounded in phenomenology, hermeneutics, and idiography, IPA aims to explore in depth how individuals make sense of their major life experiences, focusing on the lived experience and the meanings attributed within personal and social contexts. IPA involves a double hermeneutic, whereby participants make sense of their experiences while researchers interpret that sense-making.

This process requires deep engagement with the data and reflexive awareness of the researcher's preconceptions, which are critically examined rather than bracketed. The study adopts an interpretative–constructivist epistemological stance, recognizing that knowledge is co-constructed between researcher and participant. The analysis privileges participants' subjective accounts and seeks to illuminate their meanings and interpretations, rather than pursuing objective generalizations (Kacprzak, 2017).

All methodological choices, including data collection, sampling, and analysis, will be explicitly documented to enhance transparency. Quality standards for qualitative research (Tong et al., 2007) and Standards for Reporting Qualitative Research (SRQR) guidelines (Obrien et al., 2014) will be strictly followed to ensure rigor.

Researcher characteristics, reflexivity and trustworthiness

The research team will comprise female nurses and midwives with clinical expertise in pelvic floor rehabilitation and formal training in qualitative research methods. Researchers' clinical background, assumptions, beliefs and prior experiences regarding UI will be explicitly acknowledged and continuously reflected upon throughout the research process. No prior personal relationship with participants is foreseen, although professional proximity may influence interaction.

Reflexivity will be maintained through reflective diaries, peer discussions, and team debriefings; these strategies will help identify and minimise potential bias. The credibility of the findings will be further enhanced through triangulation, which will involve the use of multiple data collection methods (interviews, field notes, and questionnaires) and the participation of several researchers in the analytic process, thereby minimizing the risk of subjective interpretation.

However, qualitative research acknowledges that researchers cannot completely separate their own experiences and biases from the research process (Johnson-Bailey & Ray, 2008), as knowledge is inherently subjective and co-constructed (Love et al., 2020).

To strengthen the analytical rigor, two researchers will independently analyze the data before engaging in a critical comparison of their interpretations, allowing for the identification of convergences and discrepancies. The emerging themes will then be compared with existing literature to assess their relevance and consistency with current evidence and theoretical frameworks.

An audit trail will be carefully maintained throughout the study, providing detailed documentation of each stage of the analytical process to ensure transparency, traceability, and methodological integrity (Finlay, 2002; Smith et al., 2022).

Context

The study will be conducted in an outpatient pelvic floor rehabilitation clinic within a Northern Italian hospital. This specialised setting provides multidisciplinary care to women with pelvic floor dysfunctions. The context is chosen to ensure participants have direct experience of both the suffering associated with the phenomenon under investigation and the rehabilitative process, ensuring the collection of rich, meaningful and relevant data.

The clinic operates with a multidisciplinary team including uro-gynecologists, nurses, and midwives, providing integrated care tailored to each patient's needs. Generally, the rehabilitation cycle involves 8 to 10 sessions, each lasting approximately 45 minutes, held on a weekly basis. The services offered include counselling and pelvic floor rehabilitation through pelvic-perineal kinesitherapy, biofeedback, functional electrical stimulation, posterior tibial nerve neuromodulation, and electromagnetic wave therapy.

Sampling strategy

Participants will be selected through purposive sampling (Smith et al., 2022), with the aim of selecting information-rich cases relevant to the research question. Eligible participants will include women aged 18 years or older with a clinical diagnosis of UI, who have attended at least two rehabilitation sessions. Participants must have sufficient understanding of the Italian language to provide informed consent and participate in interviews.

Exclusion criteria will include: male individuals, women under the age of 18, those currently pregnant, women in the puerperium period (defined as the first 40 days following childbirth), individuals with cognitive impairments or neurological conditions that may compromise the ability to provide reliable narratives, and those who do not provide informed consent.

Recruitment will take place through the researchers' professional networks. Potential participants will first be invited to an informal conversation to establish trust and clarify the purpose of the study. They will then receive study information and consent forms via email and will provide verbal consent at the beginning of each interview, after being reminded of their right to withdraw from the study at any time.

Sampling will continue until conceptual depth, information power, and theoretical sufficiency are achieved, defined respectively as the richness of data, the quality and relevance of data, and the robustness of support for the study's claims (Sims & Cilliers, 2025). This strategy aims to capture a wide range of perspectives relevant to the study objectives.

Ethical considerations

Ethical approval was obtained from the Territorial Ethics Committee Lombardia 1 (Approval Number: CET 207-2024). Written informed consent will be collected from all participants prior to data collection. It will be explained that participation in the study is voluntary, and the benefits, data confidentiality management, and the right to withdraw from the study at any time will also be clarified. The autonomy of participants will be respected by providing information that ensures a free and informed choice (National Health and Medical Research Council, 2007).

Participants will be guaranteed that all personal data will be securely stored and treated confidentially. During transcription, any potentially identifying information will be removed and pseudonyms will be used

instead of real names, in compliance with EU Regulation 2016/679 (GDPR). In the verification and publication phases, data and citations from interviews will be reported only in anonymized form, ensuring that individual participants cannot be identified (Holloway & Wheeler, 2013). The study complies with the Declaration of Helsinki and applicable national guidelines.

Data collection methods

Data will be collected through semi-structured individual interviews and socio-demographic questionnaires. The setting will ensure privacy, comfort, and an atmosphere conducive to open sharing. Interviews will be audio- and video-recorded with participants' consent through Microsoft Teams, selected for its secure professional infrastructure that ensures data confidentiality and institutional ownership of all recordings.

Given that UI may deeply affect women's sense of identity, body image, and emotional well-being, the research team recognizes the sensitive nature of the topic and the potential psychological discomfort associated with the interviews and their video-recording. To mitigate this, interviews will be conducted by trained female researchers in an empathetic and respectful manner, consistent with phenomenological interviewing principles, to foster openness and trust between researcher and participant. Participants will be explicitly informed that they may disable the camera, opt for audio-only recording, pause, skip any question, or interrupt the interview at any time should they feel uncomfortable, without any consequence. Additionally, participants will be assured that they can request the review or deletion of any part of the recording, ensuring full control over their participation. If emotional distress arises, participants will be offered the opportunity to discuss it with a qualified healthcare professional within the clinical unit.

Data collection and data analysis will proceed concurrently to support iterative refinement of questions and emerging interpretations, consistent with the interpretative phenomenological approach. Triangulation of sources and field notes will be employed to strengthen the credibility of the findings.

Data collection instruments

The main data collection tool will be a semi-structured interview guide exploring experiences of UI ("lived experience"), its impact on daily life, and perceptions of rehabilitation. In this type of interview, the content of the questions is not rigidly pre-established; rather, the structure is flexible and can be adapted to each participant's narrative flow and emotional state. The interview will be guided by a schedule of "screwdriver questions" – open-ended prompts that introduce the topic of UI while allowing participants to respond in a way that is personally meaningful and contextually grounded (Riessman, 1993).

The interview schedule was developed following a "funneling technique", which progresses from broad, open topics to increasingly specific themes (Smith et al., 2022). This approach ensures a coherent structure across interviews while allowing flexibility for participants to express their experiences freely and for rich, nuanced data to emerge. In line with the hermeneutic and idiographic orientation of IPA, "hermeneutic sensitivity" and researcher discretion will be exercised in deciding whether and how to introduce additional questions ("probes") not contemplated in the preliminary phase of the research, in order to deepen the exploration of emerging meanings (Rubin & Rubin, 2000).

The "screwdriver" questions (reported in a hypothetical interview scheme in Supplementary File 1) were formulated starting from scientific literature (Hägglund & Ahlström, 2007; Million et al., 2021; Peroni et al., 2022) and subsequently discussed in a focus group composed of a uro-gynecologist, two midwives, a nurse, and an expert in qualitative methodology. The final screwdriver questions resulting from the focus group were tested on a small group of women. Feedback from this pilot phase was used to make minor linguistic and conceptual adjustments, leading to the final version of the interview guide that will be used in the study.

Participants will also complete a socio-demographic and clinical questionnaire, developed based on scientific literature (Park et al., 2017; Yilmaz & Erkal Aksoy, 2023), to provide a descriptive overview of the study sample (Supplementary File 2). The questionnaire will collect information such as age, parity, time since delivery, type and duration of UI, treatment

history, and relevant comorbidities. In addition, it will include the ICIQ-UI SF (International Consultation on Incontinence Questionnaire – Urinary Incontinence Short Form) to assess the severity of urinary symptoms (Tubaro et al., 2006). Although the study adopts a qualitative design, the inclusion of this standardized measure will allow for a contextual characterization of participants' experiences and facilitate a more nuanced interpretation of narratives in relation to the clinical profile of each woman.

Units of study

Approximately 20 women experiencing UI will be included in the study. The number of participants is not predetermined a priori but guided by the principles of conceptual depth, information power, and theoretical sufficiency, which will be continuously evaluated during the iterative process of data collection and analysis, as it is only at this stage that a researcher can determine whether the sampling, data collection, and analysis are sufficient (Sims & Cilliers, 2025).

Beyond thematic redundancy, the narrative depth and emotional resonance of the accounts will be used as additional indicators of data adequacy, ensuring that the dataset provides a comprehensive understanding of the lived experience under study.

The number and relevant characteristics of participants, as well as the communication openness and engagement observed during interviews, will be reported in the Results section. These elements will help to contextualize the interpretative process and provide transparency regarding the sample composition and the quality of participants' contributions.

Data processing

Audio recordings will be transcribed verbatim and anonymized to ensure participant confidentiality. The accuracy and completeness of the transcripts will be verified by comparing it with the original audio file.

An initial manual coding will be conducted in Microsoft Word to allow close familiarization with the data and to begin identifying preliminary meaning units. The coded material will then be imported into NVivo for further organization, refinements of codes and development of emerging themes through iterative comparison and clustering. Socio-demographic information will be managed using Microsoft Excel and linked to qualitative data for contextual interpretation.

Data security will be ensured through encrypted storage and restricted access to the research team only. An audit trail will be maintained throughout the study to document analytic decisions, coding iterations, and interpretative steps, ensuring transparency and dependability of the analytical process.

Data analysis

Data will be analysed using Interpretative Phenomenological Analysis (IPA), following the multi-step process described by Smith et al. (2022), as illustrated in Figure 1. This approach supports an in-depth exploration of how

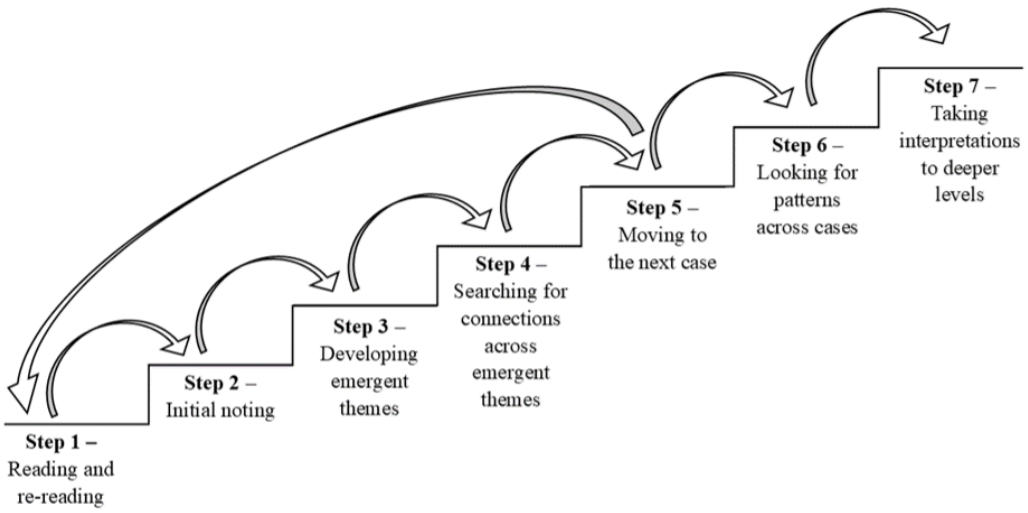

Figure 1. Steps of the Interpretative Phenomenological Analysis.

participants make sense of their experiences and meanings.

Each transcript will be read multiple times with care, and the corresponding audio recordings will be listened to in full to allow the researchers to become deeply familiar with the data and to capture all nuances in the participants' accounts.

Transcripts will be then annotated focusing on different layers of meaning: particular attention will be paid to the linguistic aspects to understand how language will be used to convey experience, to the descriptive content to identify what will be described, and to the conceptual dimension to explore underlying meanings (Treweek et al., 2019).

Based on these initial notes and selected the quotations – brief narrative excerpts that capture participants' own words (Eldh et al., 2020) – similar concepts will be grouped under codes or labels, and connections and recurring ideas will facilitate the gradual abstraction of these labels into broader categories, which will be then organised into overarching themes with semantic coherence.

Emergent themes will be examined in relation to one another to identify patterns, relationships and clusters, forming thematic code groups; this iterative and recursive process will help identify themes grounded in the lived experiences of participants. Each subsequent case will be analysed idiographically, applying the same depth of engagement and openness, to respect the uniqueness of each participant's narrative.

Cross-case analysis will be then conducted to identify shared patterns and meanings across all interviews while recognising individual variability and nuance. In the final phase, interpretations will be critically examined and refined through team discussions to reach deeper, more nuanced understandings of the themes and to consider the broader implications of the findings.

Two researchers independently will code the transcripts and compare their interpretations; differences will be discussed within the research team and resolved by consensus. To facilitate interpretative depth, memos will be used throughout the coding process to document analytic reflections, conceptual links, and evolving interpretations.

Discussion

This study will offer an in-depth exploration of the lived experience of adult women with UI, with a particular focus on the emotional, social, and practical implications of managing the condition. By giving voice to patients' experiences, the research will contribute to a deeper understanding of how UI affects various dimensions of everyday life—beyond its clinical manifestations. The narratives collected will help to trace how cultural expectations, personal beliefs, and emotional burdens intersect with the practical challenges of managing involuntary urination (Panesar et al., 2025).

The findings may help to highlight gaps in current pathways of care that often overlook the psychosocial dimensions of the condition. In the context of Northern Italy, gaining insight into how women interpret and navigate UI is essential to designing interventions that truly reflect their everyday realities. By revealing how feelings of stigma, embarrassment, and the quiet struggle to maintain bodily control influence decisions about seeking help and continuing treatment, this study may offer useful directions for rethinking current care services (Lamerton et al., 2010). Making support interventions more responsive could also mean exploring more discreet and flexible ways for women to access support, helping to reduce barriers and encourage engagement (Åström et al., 2021; Wessels et al., 2021).

The emphasis on person-centred care is especially relevant in this context (Freeman, 2007): incorporating the psychosocial dimensions of illness into treatment planning may foster greater patient active involvement, improve therapeutic adherence, and ultimately enhance rehabilitation outcomes.

Beyond individual care, the study holds broader implications for public health. Making women's experiences visible may act as a catalyst for educational campaigns that challenge misconceptions and normalise open discussion of UI (Franzén et al., 200). This visibility could encourage earlier disclosure and timely access to treatment, counteracting the tendency to accept UI as an inevitable part of ageing (Baum et al., 1991).

The women's narratives may also prove valuable for training healthcare professionals. By highlighting how knowledge, attitudes,

beliefs and practices shape the management of UI, these accounts can help deepen practitioners' understanding of the emotional and cultural dimensions that influence care (van Vuuren et al., 2021). In turn, this awareness may strengthen communication skills and empathy — qualities essential for supporting women living with a condition often burdened by stigma and silence.

However, certain limitations must be acknowledged. The qualitative, phenomenological design does not allow for statistical generalisation. Focusing on women who have already undertaken pelvic floor rehabilitation means the voices of those who remain outside formal care — or who have discontinued it — may be underrepresented. Moreover, despite efforts to build trust, the sensitive nature of the topic might limit how openly some participants share their experiences. Finally, the reliance on interpretative sufficiency, while methodologically appropriate for qualitative inquiry, could mean that less common yet meaningful perspectives remain unheard.

Despite these boundaries, this study seeks to bring women's realities with UI into clearer view — within families, communities, and healthcare settings. In doing so, it contributes to a cultural shift: from silence and resignation towards awareness and more responsive forms of care.

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