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Negative experiences with public bathrooms and chronic illness-related shame

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Abstract

Introduction: The use of public bathrooms is a challenge for everyone, but especially for those who are affected by a bathroom-dependent condition. Being dependent on bathrooms is linked with different negative emotions. One of them is a clinically relevant emotion: shame associated with the chronic condition.

Materials and Methods: In a cross-sectional survey study ($n = 193$) of people who suffer a bathroom-dependent condition we asked about health conditions, well-being, and shame related to chronic condition outcomes.

Results: We show a link between negative public bathroom experiences, and diminished well-being and feelings of shame related to chronic illness. We found that this relationship between negative experiences with public bathrooms and shame is not specific to the different conditions.

Conclusion: We conclude that the negative experiences which people with different gastrointestinal illnesses face is an environmental stressor associated with more embarrassment as a result of the condition suffered.

KEYWORDS
chronic illness, environmental health, gastrointestinal disease, IBD psychology

1 | INTRODUCTION

1.1 | Public bathrooms and chronic diseases

People suffering from chronic gastrointestinal and urogenital diseases carry a silent burden, with the constant need to use—generally deficient—public bathrooms, which worsen their quality of life and well-being.[1–3] Public bathrooms are an environmental issue, especially for those who need them constantly due to a health condition. Those who cannot put off using public toilets or suffer pain and stress when delaying their use are referred to as people with a bathroom-dependent condition (BDC[4]). BDC is a term which covers a wide range of specific diseases like inflammatory bowel disease (2.4–294 cases per 100 000 prevalence[5]), irritable bowel disease (about 3800 per 100 000 by Rome IV criteria prevalence[6]), or urgency urinary incontinence (about 3000–17 000 per 100 000 prevalence[7]), and nonspecific conditions (such as those caused by cancer) related to (public) bathroom dependency. BDC is an umbrella term intended to cover any condition by its consequences (public bathroom dependence) rather than its cause. This dependence, together with the general inadequacy of public bathroom facilities, leads to the loss of personal autonomy, inappropriate behaviors, embarrassment, unpleasant situations, and shame.[2,8–11] These struggles with the urban environment impact patients' mental health significantly.[12,13]

1.2 | Shame and people with chronic diseases

One of the negative psychological consequences of suffering a chronic disease is the embarrassment derived from certain conditions resulting from the disease.[14] Shame, according to the communicative theory of emotions,[15] relates to the feeling of being incompetent and losing status. It is a reaction to the consequences of being limited and overwhelmed by circumstances while feeling inadequate. Consequences of shame include the avoidance of social relationships and contact with the environment interactions, which could actually alleviate the feelings that led to their disruption.[16] Feelings of shame have been consistently associated with lower self-esteem, higher hostility, and psychological distress.[17] Also, shame is a stressor which influences negative health outcomes[18] in that it negatively affects patients self-assessments of their health conditions, which are a protective factor in health-related well-being.[19]

The lack of personal autonomy and impediments of a life with a disease is a key driver of these experiences of shame, which lead to a diminished quality of life[20] and attempts to avoid any bodily sensation related to the source of anxiety, leading to maladaptive behavior (i.e., experiential avoidance).[8] The limiting nature of public bathrooms is a source of this lack of autonomy for people with inflammatory bowel disease[21] or gastrointestinal disease[3] (two of the main conditions leading to bathroom dependance). That is, public bathrooms as drivers of negative experiences are an environmental stressor which leads to worse well-being and increased shame in chronically ill individuals. Patients with inflammatory bowel disease have to cope with negative experiences when using public bathrooms which are often difficult to use and disgusting.[3] These difficulties significantly impact their life as they must cope with having to thoughtfully plan of their time outside the comfort of home, or avoid situations where adequate public bathrooms are not available.[2,8] These situations typically result in maladaptive coping behaviors and impair quality of life.[1] However, the impact of negative public bathroom experiences and their associated shame on the well-being of those with a BDC has not been sufficiently considered in the literature.

1.3 | Overview and research questions (RQ)

Our objective is to explore the role of that negative experiences with public bathrooms have on the shame experienced by those with chronic diseases which cause the need for the frequent use of public bathrooms (people with a BDC). To evaluate our statistical models, we consider it relevant to control for the following relevant variables: gender, age, disease or condition, and public bathroom use frequency. We aim to answer three RQ:

RQ1: To evaluate the association between negative experiences in public bathrooms and the shame associated with chronic diseases.
RQ2: To evaluate the effect of specific diseases which lead to the frequent use of toilets on shame associated with those chronic diseases.
RQ3: To evaluate the impact of negative experiences with public bathrooms on well-being understood according to positive affect and negative affect scores.

2 | METHOD

2.1 | Participants and procedure

This was an observational cross-sectional study. Our study includes 193 complete responses (26% men, $M_{age} = 39$ years, $SD_{age} = 10.3$) which reported to have a BDC.

Participants who gave their consent answered a web-based survey. The link to the survey was circulated on social media by nonmedical related profiles and via the email lists of patient associations. We did not specifically select BDC participants. We presented the study to potential participants as a study of the general population about quality of life and environment. The study was conducted in accordance with the Declaration of Helsinki and national regulations and was approved by the [ANONYMIZED] Institutional Ethics Committee. The Data was collected in accordance with Organic Law 3/2018 of December 6 on the protection of personal data and guarantee of digital rights, which guarantees the total confidentiality of the information provided and its non-use for purposes unrelated to the scientific project. The survey took about 15 min to complete. The collected data is part of a project with different aims and hypotheses, and the data set is available on the online repository with all the measures taken (https://osf.io/dzpwx/). We confirm to report all measures, conditions, data exclusions, and how we determined the sample sizes.

2.2 | Measures

The participants provided information on gender ("*male*," "*female*," "*other*," and "*I prefer not to answer*"), as well as whether their gender is different to that assigned at birth.

As in previous studies, participants stated whether they suffer or have ever suffered from any disease or condition that leads to the frequent use of bathrooms with yes/no as the response options and a text box in which to state the disease. Then, we coded the open responses based on medical criteria, with clinical advice (inflammatory bowel disease, irritable bowel disease, urogenital disease, incontinence, and menstruation disorders).

Also, participants answered a question about the frequency of the symptoms suffered ("Every day," "Almost every day," "1 or 2 days each week," "1 or 2 days each month," "Few symptoms in the last 6 months," and "I have been well in the last 6 months, in remission, or without symptoms"). We coded this variable numerically, assigning higher values to higher frequencies of disease symptoms.

Participants were asked about how often they use public bathrooms to urinate and/or defecate. Response options were "At least once a day," "More than once a week," "At least once a week," "At least once a month," "At least once every 6 months," "At least once a year," and "Never." The frequency was coded as the higher the score, the more frequent use of bathrooms.

To assess the extent to which the participants suffered negative experiences with public bathrooms we developed a questionnaire: the negative experiences with public bathrooms questionnaire (NEPB). The development of this tool was made by means of focus groups made up of inflammatory bowel disease patients. The resulting questionnaire assesses the frequency of eight different negative situations with public bathrooms (including "Being unable to find an open unoccupied public toilet," "Using a public toilet that does not meet appropriate privacy standards i.e., no lock on the door, the door opening from the outside and so forth," "Using a dirty, stained, flooded, or bad-smelling public toilet," "Using an ill-equipped public toilet i.e., without toilet paper, without a coat hanger and so forth," "Difficult access to a public toilet on a particular premises because of certain requirements for public use," "Feeling the need to hurry the time while using the public toilet because of long queues or requests to hurry up from those in the queue," "Feeling unsafe or exposed in a public toilet," and "Rejecting an activity for fear that the toilets on the premises are inadequate for your needs"). The psychometric properties of test scores in the present sample are satisfactory (mean interitem correlation is high (0.57), the minimum item-rest correlation is 0.67, the maximum 0.87, and Cronbach's Alpha ($\alpha = 0.90$) is above the acceptable threshold of 0.80). Response options were: "One or more times in a day," "More than once a week," "About once a week," "About once a month," "About once every 3 months," "About once every 6 months," and "Never happened to me." We calculated the mean of the numerically coded responses, with higher numbers representing higher frequencies. Higher scores represent more negative situations faced when using public bathrooms.

The shame experienced was assessed via the chronic illness related shame scale (CISS) developed by Trindade et al.[14] This seven-item scale measures shame associated with chronic illness and symptomatology. Examples of items are "I feel that my illness is embarrassing" or "I feel inadequate because of my illness and symptoms." The response options range from 0 ("Never true") to 5 ("Always true"). The scale is coded as higher values indicating more shame. Psychometric properties of test scores in this sample are satisfactory (mean interitem correlation is high (0.56); the minimum item-rest correlation is 0.54 and the maximum 0.83; and Cronbach's α reliability was 0.90, which is above the acceptable threshold of 0.80). We translated and back translated the items to Spanish from Portuguese.

Two affective state dimensions (positive affect and negative affect) are measured with the PANAS scale.[22,23] Positive affect reflects the extent to which a person feels enthusiastic, active, and pleasurable engagement. On the other hand, negative affect is a dimension of unpleasant engagement with guilt, fear, and other aversive mood states. Together, they assess affective components of subjective well-being. Participants were asked to what degree they felt a list of positive and negative affect labels in the last month. Response options were "At all," "A little," "Moderately," "Quite," and "A lot." We calculated the means for positive affect (10 items) and negative affect (9 items), with higher values reflecting a higher score on each scale. Psychometric indices of test scores in this sample are satisfactory for both dimensions (mean interitem correlations are high [positive = 0.59, negative = 0.49]; the minimum item-rest correlation is 0.65 for positive dimension, 0.52 for negative dimension, the maximum is 0.86 for positive and 0.73 for negative; Cronbach's α reliability was 0.94 for positive and 0.90 for negative dimension, above the acceptable threshold of 0.80)

2.3 | Analysis

We provide descriptive statistics for the variables of interest and different disease groups (see Supporting Information: Material 1). We tested different hierarchical regression models for each outcome (CISS score, PANAS positive affect, PANAS negative affect) and compared each step. We performed an initial model that had the following variables: disease group, the disease symptoms

frequency, age, frequency of public bathroom use to urinate and/or defecate, and gender. Our second model included the NEPB score as predictor. The third model included the interaction between disease and NEPB score. We selected our model based on the *F* value of the nested models. We report fit indices for each model. Continuous variables were mean-centered before the inferential analysis. Full models are presented in Supporting Information material (see Supporting Information: Material 2). Multiple regression model assumptions were checked by visual inspection. All analyses were performed with the R Statistical Software and the *easystats* package. Graphical displays were made with the *ggplot2* and *tidyverse* packages.

With respect to power analysis, we did not predetermine the required sample size a priori. However, we studied the minimum detectable effect size given the selected model parameters (number of predictors and study's sample size) which led to a 0.80 power to detect small effect sizes (according to Cohen criterions we can detect small effect sizes f^2 value of 0.04 equivalent to a R^2 of 0.04). As our study can detect small effect sizes, we consider it appropriate.

3 | RESULTS

3.1 | Descriptive results and correlations

The conditions reported by the participants were inflammatory bowel disease (44%), irritable bowel syndrome (25%), urogenital disease (15%), incontinence (4%), and menstruation disorders (3%) means of variables of interest are reported by condition in Supporting Information material. All variables means were about the middle point of the scales range (see Figure 1 for visual depiction). CISS scores were positively correlated with disease symptoms frequency ($r = 0.42$, $p < 0.001$; see the Supporting Information material for a visual representation), NEPB mean scores ($r = 0.42$, $p < 0.001$), and negative affect ($r = 0.48$, $p < 0.001$) while negatively correlated to positive affect ($r = -0.40$, $p < 0.001$), and frequency of use of public bathrooms to defecate ($r = -0.19$, $p < 0.001$). The correlation between our predictors is moderate to high. The NEPB score correlated positively to negative affect ($r = 0.30$, $p < 0.001$) and negatively to positive affect ($r = -0.26$, $p < 0.001$). Negative affect and positive affect mean scores are negatively correlated ($r = -0.42$, $p < 0.001$). Also, disease correlated to negative affect ($r = 0.23$, $p < 0.001$). We dichotomized gender labels to perform the correlation analysis which did not yield any statistically significant correlation.

3.2 | Regression analyses

Across all the dependent variables, the selected model is M2. This model includes NEPB scores and disease labels, as well as control variables as predictors (see Table 1). When we added the interaction between disease labels and NEPB score, we did not find any significant improvement. The complete list of coefficients is available in the online Supporting Information material.

When we predicted CISS scores, the model explained 33% of variance with the inclusion of NEPB explaining 8% of it. Our results suggest a relationship between NEPB scores and CISS scores ($b_{NEPB} = 0.38$, 95% CI: [0.24–0.52], $t(181) = 5.31$, $p < 0.001$; see Figure 2 for a visual depiction and comparison with other coefficients). When we predicted positive affect, our significant model explained 8% of total variance with 4% increment associated to NEPB scores. Our results suggest negative experiences with public bathrooms are negatively associated with positive affect scores ($b_{NEPB} = -0.31$, 95% CI: [−0.47 to −0.14], $t(181) = -3.58$, $p < 0.001$). Finally, the model predicting negative affect explains 15% of total variance with a 6% increment associated to NEPB scores. Coefficients show a positive significant relationship between NEPB scores and negative affect ($b_{NEPB} = 0.30$, 95% CI: [0.14–0.46], $t(181) = 3.74$, $p < 0.001$).

4 | DISCUSSION

In our study we found that negative experiences with public bathrooms had by people with BDC are associated with more chronic disease shame. Also, these negative experiences in bathrooms are associated with well-being variables: positive affect and negative affect. The association is present even after adjusting for relevant variables like gender, age, disease symptoms frequency, and public bathroom use frequency.

Regarding RQ1, we found the expected association between negative public bathroom experiences and shame. However, we did not find that including the interaction between specific disease groups (e.g., inflammatory bowel disease or urogenital disease) explains a significant different variance when predicting the outcome (RQ2). We interpret in these findings that BDC is a useful term to denominate a group of people who suffer common circumstances related to specific outcomes. That is, although the causes of frequent use of and dependance on bathrooms can be very varied, the lived

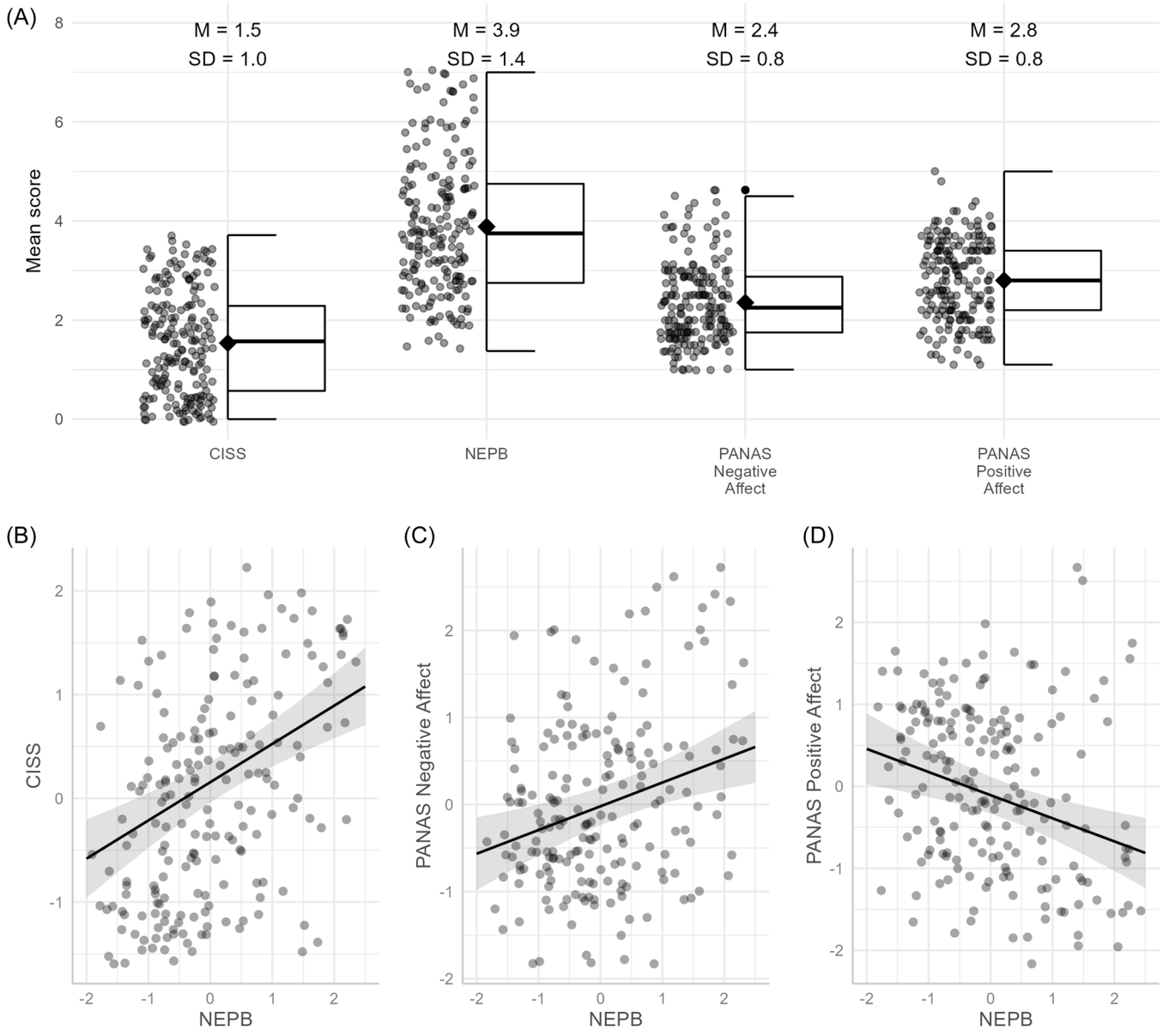

FIGURE 1 Description of variables of interest and regression lines. Panel (A) shows descriptive statistics of variables of interest showing boxplot, raw data, and mean (black diamond). Panel (B–D) show the adjusted prediction line for regressions and standardized data.

TABLE 1 Adjustment indices for each step of the hierarchical regressions and coefficients

	CISS	PANAS positive affect	PANAS negative affect
	R^2 (Δ R^2), F, p	R^2 (Δ R^2), F, p	R^2 (Δ R^2), F, p
M1	**0.26**	**0.04**	**0.09**
M2	**0.33 (0.08), 28.35, $p < 0.001$**	**0.10 (0.06), 13.88, $p < 0.001$**	**0.15 (0.06), 13.46, $p < 0.001$**
M3	0.33 (0.00), 1.22, $p = 0.301$	0.10 (0.00), 0.80, $p = 0.554$	0.15 (0.00), 0.79, $p = 0.552$

Note: Statistically significant results ($p < 0.05$) are shown in bold. R2 refers to the adjusted fit index.

Abbreviations: CISS, chronic illness related shame scale; M1, only controls model; M2, previous variables plus NEPB score as predictor; M3, previous variables plus interaction between disease and NEPB score; NEPB, negative experiences with public bathrooms questionnaire.

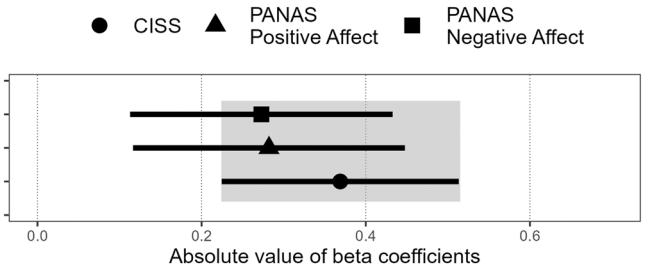

FIGURE 2 Visual depiction of the beta coefficients of NEPB scores predicting each outcome. Horizontal lines represent the 95% confidence interval (CI). PANAS positive affect is shown in absolute value to make the values comparable. The shaded area represents the 95% CI of the CISS model. CISS, chronic illness related shame scale; NEPB, negative experiences with public bathrooms questionnaire.

experience of that dependance in terms of shame and poor well-being seems homogeneous.

When we compare the association between NEPB and CISS scores and the association between NEPB and positive and negative affect we found that the NEPB-CISS association is higher than the others and the explained variance is also higher for the NEPB-CISS association. We interpret in this finding that while struggles with public bathrooms are associated with a loss in general well-being (less positive affect, more negative affect), the impact is greater with the shame associated to chronic disease. That is, constantly struggling with public bathrooms may become difficult to handle especially due to the taboo and self-stigma associated with public bathroom use on chronic patients.[11] However, the overlapping in the confidence interval makes it hard to interpret if the associations are truly different between them.

Our study shows how the environmental burden of bad experiences with public bathrooms is relevant and attributable to different outcomes, especially experienced shame. Shame is a clinically relevant outcome as it is related to the worst clinical outcomes[24] as well as the worst psychological adjustment.[14,25] This shame could be a consequence of those with a BDC handling situations in which both their personal autonomy is diminished and they are struggling with a cultural sensitive issue, as public bathrooms experiences are seen as a very intimate topic.[26] Altogether the environmental burden may contribute specifically to the emergence of shame. On the other hand, positive and negative affect is also associated with health outcomes. Kushlev et al.,[27] found that positive affect is positively correlated with better health outcomes. In this way, the improvement of public bathrooms could be seen not only as a source of general well-being and relief for people with a BDC, but a means for improvement in their health.

The strengths of the study include the novelty of relating a specific understudied environmental burden to psychological outcomes in multiple urogenital and bowel disease patients. This association is relevant for a wide range of people who suffer conditions related to increased public bathroom use. More than 70% women will experience some degree of urinary tract symptoms[28] in their life. On the other hand, the prevalence of inflammatory bowel disease as well as other bowel-related conditions that are difficult to diagnose, is increasing.[29] We show how the BDC label is useful for understanding the negative consequences of bad experiences with public bathrooms beyond the condition patients suffer as we consider the consequences of BDCs. Nevertheless, it is an understudied topic with further research needed.

The practical consequences of this study are focused mainly on practitioners and urban planners. Practitioners working with BDC sufferers may focus on how the environment could increase the shame related to the chronic illness. Shame, as with other negative emotions,[30] is known to impact health, psychological well-being, and the course of illness. Particularly with regard to inflammatory bowel disease patients, Trindade et al.[8] found a moderate relationship between shame and the loss of psychological health. Practitioners who work with BDC sufferers could design interventions focused on helping patients manage this environmental disadvantage and handle its consequences. On the other hand, urban planners and health authorities may consider the impoverishment of well-being from bad experiences with public bathrooms when designing the urban environment and health-related facilities.

This study has limitations. Because of its cross-sectional study design, causal relationship could not be established. Moreover, the recruited sample is not randomly selected, so it could be that those who struggle more with chronic illness may be more prone to complete the survey. Also, online recruitment could favor younger participants and participants with fewer physical difficulties. Probably, as it is a sample collected in a single country, it reflects a cultural condition associated with health education and the design of environments. Finally, the study did not cover aspects of trans and gender non-conforming people who face added inclusion challenges, and are also more prone to suffer from problems resulting from a BDC due to social vulnerability.[31,32] Further studies in different countries are required to see if the results are either consistent or environmentally dependent. Also, the inclusion of other variables would show which strengths and risk factors may play a role on the relationship between negative experiences and psychological outcomes.

5 | CONCLUSION

We identified struggles with public bathrooms as a potential source of shame resulting from chronic illness and diminished well-being for people whose illness means they cannot postpone using public toilets, or suffer pain and/or stress when delaying their use. Also, we found a useful label (BDC) to identify people with varied conditions who suffer these things similarly. Our results highlight the relevance of the environmental burden on health psychology outcomes.

AUTHOR CONTRIBUTIONS

Guido Corradi: conceptualization, methodology, formal analysis, writing – original draft, funding acquisition. **Leticia Leon**: writing – review & editing. **Cecilia Theirs**: conceptualization. **Eduardo García-Garzón**: formal analysis. **Daniel Clemente**: supervision. **Juan Ramon Barrada**: formal analysis, writing – review & editing. All authors approved the final version of the article.

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CONFLICT OF INTEREST

The authors declare no conflict of interest.

DATA AVAILABILITY STATEMENT

Data and scripts are available in https://osf.io/dzpwx/?view_only=54920a85ace2401895d13e89ddd47fb8.

ETHICS STATEMENT

The current study was approved by the Ethics Committee of Universidad Camilo José Cela (CEI-UCJC)

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SUPPORTING INFORMATION

Additional supporting information can be found online in the Supporting Information section at the end of this article.

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