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Disease stigma and intentions to seek care for stress urinary incontinence among community-dwelling women

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ABSTRACT

Objectives: Urinary incontinence (UI) threatens women's physical and mental health, but few women seek healthcare for their incontinence. Evidence is substantial that stigma may be associated with health service utilization for such diseases as mental illness, but sparse for UI. We examine the relationship between disease stigma and intentions to seek care for UI.
Design and setting: A cross-sectional community-based study was used. A purposive sample of 305 women aged 40–65 years in a Chinese city who had stress urinary incontinence (SUI) was enrolled from May to October in 2011.
Measurements: Data were collected on socio-demographic characteristics, UI symptoms, disease stigma and intentions to seek care.
Results: Social rejection was positively linearly related to intentions to seek care for UI ($\beta = 0.207$; 95% CI = 0.152, 0.784), indicating that more social rejection predicted stronger intentions to seek care. Significant curvilinear association between internalized shame and intentions to seek care was observed ($\beta = -0.169$; 95% CI = −0.433, −0.047). Compared to women with the low and high levels of internalized shame, those with the moderate level of internalized shame reported stronger intentions to seek care.
Conclusion: The impact of stigma on intentions to seek care varies by aspects and levels of stigma. Social rejection enhances intentions to seek care while internalized shame influences intentions to seek care in a quadratic way. The crucial step of targeted interventions will be to disentangle subgroups of SUI women with different aspects and levels of stigma.

1. Introduction

Urinary incontinence (UI) is one of the five leading chronic conditions that threaten women's physical and mental health [1], with prevalence ranging from 25% to 45% [2]. Stress urinary incontinence (SUI) is the most prevalent subtype, reported by half the UI women [3]. Although effective treatment measures had been developed [4,5], the majority of the affected women managed their UI themselves silently rather than seeking professional help [6,7].

Several studies indicate stigma is the main reason for not seeking treatment among UI women [8,9]. Stigma is defined as an attribute discrediting an individual, reducing him or her "from a whole and usual person to a tainted, discounted one" [10], and it is typically a social process of rejection, blame, or devaluation [11]. The stigmatization of physical or mental diseases involves not only the public stereotyping (i.e. social rejection, exclusion, or discrimination) of these patients but also the internalization (i.e. shame, humiliation, or embarrassment) of these stereotypes by the patients [12]. UI is a stigmatized attribute, and the level of shame and embarrassment for UI is higher than that for depression and cancer [13]. UI has frequently been linked with incompetence because control and self restraint is important to notions of adulthood in Western society [14]. Many feel humiliated with their condition and uncomfortable discussing UI with healthcare providers [15]. A Chinese study also found that many patients considered UI as shame and their own fault, and were unwilling to talk about incontinence with their families, friends or doctors [16]. However, the previous research on stigma and care-seeking behaviors for UI falls short in the measurement of stigma. Self-reported single-term shyness or embarrassment was often used instead of a valid conceptualized instrument, which may obscure the association of stigma with care-seeking behaviors.

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Despite limited understanding for UI, there has been substantial research that systematically examined the stigma and its relationship with care-seeking behaviors for other diseases, such as mental illnesses [17] and dementia [18]. These studies found the mixed results but generally negative effect [17,18]. A literature review on psychiatric disorders concluded that perceived rejection or discrimination is associated with a reduced readiness to seek professional help. A similar trend was observed in a study among dementia populations that stigmatizing attitudes toward dementia are a hindrance to early help-seeking [18]. However, stigma did not seem to be substantial barriers to initiate care-seeking behaviors for posttraumatic stress disorders (PTSD), and greater levels of stigma is related to more psychotherapy visits and counseling [19]. Additionally, a differential impact of public stigma and internalized stigma has been observed. A study among U.S. veterans with PTSD indicated that a significant association with reduced care-seeking intentions was observed for internalized stigma but not for public stigma [20]. Therefore, we conjecture that the relationship between stigma and care-seeking behaviors for UI may be likewise complex, possibly non-linear (quadratic curvilinear), and vary by aspects of stigma. To the best of our knowledge, no study has explored the non-linear relationship between stigma and care-seeking behaviors. The aim of the present study is to assess the stigma using a conceptualized instrument and examine its relationship with intentions to seek care among community-dwelling women with SUI, both in a linear and curvilinear way.

2. Materials and methods

2.1. Study design, setting and participants

This cross-sectional study was carried out from May to October in 2011 in three randomly selected community settings in Jinan, the capital city of Shandong Province in Eastern China. A purposive sample was recruited using the following eligibility criteria. Inclusion criteria: (i) aged 40–65 years; (ii) being incontinent at least once a month for a period of at least three months; (iii) capable of understanding study procedures and research questions. Exclusion criteria: (i) terminal illness/hospice care; (ii) current urinary tract infection; (iii) currently pregnant or gave birth within the past three months.

Data were collected by trained postgraduates using a standardized protocol after nurses' home visiting. A woman was invited to participate in our study if she responded "yes" to the following question: "have you experienced any urine leakage upon coughing or sneezing in the past four weeks?" Women who were eligible and consented to participate in our study were asked to complete a paper–pencil questionnaire. Personal help was also conducted for those who had either visual or writing difficulties.

2.2. Ethical approval

The study was approved by the Institutional Review Board of Shandong University. Written consent was obtained from all participants. All information was kept confidential and secure at all times, ensuring confidentiality for the participants. The study was carried out in accordance with the principles of the Declaration of Helsinki.

2.3. Sample size calculation

The sample size was determined with the prior knowledge that the prevalence of seeking care for UI is 25% in a Chinese representative sample [21], similar to that in western countries [22]. A minimal sample of 288 women was calculated assuming that at least 25% of surveyed women would seek care for UI with a 5% desired precision and a 95% confidence ($1-\alpha$).

2.4. Measurements

2.4.1. Socio-demographic and clinical characteristics

Socio-demographic characteristics included age, marital status, educational level, and income. Clinical characteristics included menses status, parity, the presence of chronic conditions (including diabetes mellitus, hypertension, cardiac disease, cancer, and gynecological disease), severity and duration of SUI symptoms. Severity of SUI symptoms was assessed using the International Consultation on Incontinence Questionnaire-Urinary Incontinence Short Form (ICIQ-UI SF). The Cronbach's alpha coefficient of this questionnaire ranged from 0.71 to 0.96 [23]. The sum of the first three items (representing frequency of leakage, amount of leakage, and impact on QOL, respectively) identifies the impact of UI in a range from 0 to 21 [24]. A higher score indicated the more severe symptom of SUI.

2.4.2. Disease stigma

Disease stigma was measured using an 18-term Social Impact Scale (SIS) with three domains: social isolation, social rejection and internalized shame [25]. Social isolation indicates a feeling of loneliness, inequality with others and useless; social rejection means the individuals feeling discriminated against in society; internalized shame is an outcome of experiencing isolation and rejection, incorporating feelings of being set apart from others who are well, blaming oneself for the illness and a need to maintain secrecy [26]. SIS was tested in a sample of 506 Chinese women with UI, with the composite reliabilities of the domains being 0.78, 0.81 and 0.87 respectively [25]. Response categories were 4-point Likert-type scale with 1 representing 'strongly disagree' and 4 representing 'strongly agree'. A higher score demonstrated higher level of disease stigma individuals perceived.

2.4.3. Intentions to seek care for SUI

One item evaluated respondents' intentions to seek care for SUI. Respondents indicated on a 5-point Likert-type scale (strongly disagree to strongly agree) the likelihood of their engaging in this behavior (During the next month, I intend to consult with a health professional to treat my symptoms of SUI). A higher score represented higher intentions to seek medical care for SUI.

2.5. Statistical analysis

All statistical analyses were implemented using SPSS 16.0 (Statistical Package for Social Sciences, Inc., Chicago, IL, USA). Descriptive statistics were used to summarize the socio-demographic, clinical characteristics, the level of stigma and intentions to seek care of the participants. Hierarchical regression models were fitted for care-seeking intentions to examine its association with stigma. The scores for three dimensions of stigma were first mean-centered and then squared to create the quadratic terms. Linear and quadratic components of the relationship between stigma and intentions to seek care were examined. The linear terms and quadratic terms of three domains of stigma were sequentially entered into the regression models after adjusting for socio-demographic and clinical characteristics. The level $P<0.05$ was considered as the cutoff value for significance. All regression analyses were assessed for multicollinearity by calculating tolerance and variance inflation factors (VIFs). No multicollinearity emerged in the light of the criteria with tolerance more than 0.2 and VIFs less than 5 [27].