

## **Incontinence care needs in a U.S. rural border region: Perspectives of *promotoras***

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### **Abstract**

**Purpose:** The purpose of this study was to explore the incontinence care needs of rural, primarily Hispanic, community dwelling adults living along the U.S.-Mexico border of southern New Mexico from the perspective of the community health workers, or *promotoras*, who serve this community.

**Sample:** Community health workers (*promotoras*) attending a regional meeting were invited to participate in a focus group format to discuss their experiences with urinary incontinence; 25 *promotoras* provided verbal and/or written feedback.

**Method:** A participatory action framework guided this focus group session, which followed an outreach presentation on basic concepts of urinary incontinence. Participant feedback and discussion solicited following the presentation was used to assess perceived community needs for incontinence care and bladder health promotion. Participants' verbal feedback and written responses to open-ended questions were analyzed by methods of qualitative content analysis for themes depicting perceived needs of their community for bladder health education and behavioral strategies to alleviate incontinence.

**Findings:** The following themes were identified: predisposing conditions, treatments tried, home

remedies, psychosocial effects, and training requested. *Promotoras'* comments revealed the lack of information regarding the causes and associated factors of urinary incontinence, the lack of understanding of available behavioral treatment options and how to perform behavioral strategies to promote continence. *Promotoras* identified the negative effects of urinary incontinence on psychosocial health and asked for strategies to help rural adults cope with this condition.

**Conclusion:** Themes identified will guide the content development of future train-the-trainer sessions for community health workers or *promotoras* in urinary incontinence self-care strategies. Train-the-trainer sessions were identified through methods of participatory action to be the preferred strategy for bladder health promotion outreach to rural adults living in areas with limited access to medical services.

*Keywords:* incontinence, rural, promotoras, Hispanic, qualitative, needs assessment, participatory action, community health worker

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New Mexico is categorized as a rural state with 17.2 people per square mile and only four cities with a population of more than 50,000 people (New Mexico Department of Health, Office of Health Equity, 2018). The southwestern U.S.-Mexico border counties are comprised of approximately 65% Hispanic residents. Approximately 26% of families in these border counties are living below poverty level (New Mexico Department of Health, Office of Border Health, 2013). Over 40% of the residents in the Southwest Health Region of New Mexico who report an annual income of less than \$15,000 and approximately one-third of those with an annual income of \$15,000 – 25,000 describe their overall health as fair to poor (New Mexico Department of Health, Office of Health Equity, 2018). In addition, the New Mexico Department of Health, Office

of Health Equity (2018) reports that more than 40% of the State's population live in a Primary Care Health Professional Shortage Area. The New Mexico Department of Health, Office of Border Health (n.d.) has identified the lack of healthcare services and specialty services throughout the State as the impetus for development of rural community health centers and a state-wide certification program for community health workers and promotoras, with the goal of providing outreach health promotion services to these medically underserved communities.

### **Background and Significance**

Urinary incontinence (UI) is a prevalent condition for community-dwelling adults, with incidence rates of up to 66% of adult women and 41.5% of Hispanic women reporting any UI symptoms (Sampselle, Harlow, Skurnick, Brubaker, & Bondarenko, 2002). Approximately 16% of Hispanic women (Nygaard et al., 2008) and 17% of Mexican American women (Wu et al., 2014) report moderate to severe UI symptoms. Among urban community-dwelling Latino adults age 60 years and older who were participating in a behavioral intervention to increase physical activity, 29.5% of the women and 18.3% of the men reported living with UI (Smith et al., 2010).

Moderate to severe UI increases the risk of skin maceration, breakdown, and infection (Benbow, 2012). Medical treatment for UI in the U.S., including pharmacologic treatment, physical therapy, and surgical treatment, is estimated at \$12.4 billion annually (Wilson, Brown, Shin, Luc, & Subak, 2001). Depending on frequency, severity, and type of UI, the individual woman's mean annual expenditures for managing capture and clean-up of urinary leaking range from \$550 to \$993 (Subak et al., 2006). These costs are generally not covered by medical insurance and so represent an out of pocket expense for the rural poor, who also may have limited access to incontinence supplies. Chronic UI is associated with depression (Dugan et al., 2000). Other significant psychosocial sequelae of UI include loss of mobility, impaired social function,

and risk of social isolation (Jamison, Weidner, Romero, & Amundsen, 2007). These findings were supported by theme analysis from focus groups comprised of low-income Hispanic women (Longworth, Davila, & Sampsel, 2003). Indirect costs of managing UI symptoms are difficult to estimate and may include lost productivity in the workforce (Sung & Hampton, 2009).

Although there are significant physical, economic, and psychosocial costs to living with UI, people who have mild to moderate UI symptoms respond well to behavioral interventions that may be taught and performed at home. For example, up to 80% of participants experience complete or significant reduction of symptoms following pelvic floor muscle therapy (PFMT) training (Burgio et al., 1998). Bladder training and a bladder-friendly diet are also effective interventions that may be performed at home (Sampsel, 2000). Community-dwelling women demonstrate low knowledge regarding UI causes and treatment options, with Hispanic women being reportedly less informed than other U.S. women (Mandimika et al., 2014). Only four of 31 low-income Hispanic women participating in focus groups reported performing recommended PFMT (Longworth et al., 2003). Development of a community-based, culturally appropriate bladder health promotion educational intervention that may be sustained through nurse partnership with promotoras is needed in southern New Mexico.

Further complicating treatment of UI is the documented phenomenon of non-disclosure of this condition and the effect of symptom management on quality of life. People living with UI tend not to report symptoms to physicians, with Hispanic people in particular preferring not to disclose symptoms for fear of being stigmatized (Elstad, Taubenberger, Botelho, & Tennstedt, 2010). People live with UI for an average of seven years before reporting symptoms to a health care provider (Beji, Yalcin, Erkan, & Kayir, 2005; Berglund, Eisemann, Lalos, & Lalos, 1996), waiting until the effect of symptom management on their quality of life becomes more severe

(Melville, Newton, Fan, & Katon, 2006). By the time people with UI are in distress and seek care, the symptoms may be too severe to respond to behavioral intervention. A community-based strategy to improve screening, identification, assessment, and early intervention for UI would be key to improving outcomes for rural Hispanic adults living in the U.S.-Mexico border region, for whom access to health care providers is limited.

### **Participatory Action Guiding Framework**

This study was guided by Persily and Hildebrandt's Theory of Community Empowerment (2008) and follows the Community Involvement in Health (CIH) 8-step program development model (Hildebrandt, 1994). The Theory of Community Empowerment proposes to improve the health of individuals in the community through involvement of lay community health workers in the reciprocal health processes of teaching community members proactive health promotion behaviors (Persily & Hildebrandt, 2008). Community-based lay health workers such as promotoras are members of the communities they serve. Community health workers empower communities through sharing health promotion knowledge in a culturally relevant context (Persily & Hildebrandt, 2008).

In the CIH participatory partnership model, a necessary step prior to developing the nurse-led educational intervention is to identify the community assets in terms of practices, strategies, strengths, and resources and then identify the community barriers to implementing the health promotion program (Hildebrandt, 1994). This study followed Hildebrandt's (1994) Step 1: Seek information and assess the community needs in bladder health promotion and continence care, from the perspective of southern New Mexico promotoras. Through implementing this first step, critical information was obtained to assess community health worker knowledge base and concerns. This was a necessary first step in beginning the process of developing trust between the

nurse researcher and the lay community health workers. Open dialogue and trust are essential components of community empowerment. The overall goals of this study were to lay the groundwork for a trusting relationship between the nurse researcher and promotoras and to obtain information useful in guiding development of a nurse-led bladder health/incontinence care educational intervention. The purpose of this research was to perform a continence care needs assessment from the perspective of the promotoras who work in the community along the U.S.-Mexico border in southern New Mexico, as Phase 1 of an ongoing outreach program for community health workers to educate and support rural, primarily Hispanic, adults living with urinary incontinence.

### **Method**

This study used processes of participatory action and an exploratory, descriptive, qualitative design to contribute information regarding a rural community needs assessment on bladder health and incontinence care from the perspective of community health workers, or promotoras. A one-hour focus group was conducted with an opportunity to provide both verbal and written responses to the following questions:

What are some examples of people who have asked you about incontinence? What are their concerns? What questions do they ask?

What symptoms do they have with leaking urine? When do they leak?

What management strategies have they tried?

What information about incontinence would you like to have in order to provide care for people with incontinence?

What other issues or concerns do you have about incontinence?

### **Sample and Setting**

Following University Institutional Review Board approval (Study #14862), methods of purposive convenience and snowball sampling were used to enroll community health workers from rural areas of southern New Mexico. Inclusion criteria were as follows: self-identified community health worker, promotora, or lay health resource person. Exclusion criteria were as follows: unable to speak or write in Spanish or English. The target audience was the promotoras attending a regularly scheduled area meeting of the Southern New Mexico Promotora Committee, which serves the three southernmost counties of New Mexico (Luna, Dona Ana, and Otero counties). Target sample size was 30 participants, representing community promotoras who work in rural communities along the U.S.-Mexico border.

### **Data Collection**

The nurse researchers attended a scheduled meeting of the Southern New Mexico Promotora Committee, along with a representative from the New Mexico Department of Health Office of Community Health Workers as a trusted liaison. A translator was present for simultaneous translation during the meeting and the focus group. All written materials were presented in both English and Spanish. A description of the study and purpose of the needs assessment was presented. Prior to collecting promotora perspectives, the nurse researcher established a timeline of future communication and workshops, and provided nurse researcher contact information. A brief oral presentation was used to open discussion, along with informational handout with introductory information on the three common types of incontinence (stress, urgency, and functional) found among community-dwelling adults in the rural setting. An outline of possible causes and strategies to lessen symptom impact was provided for the community health workers to take home as a resource. After this information was provided, the promotoras completed written informed consent and were then offered the opportunity to voluntarily share, in focus group format,

their perceptions and concerns about the people they work with who come to them with concerns about UI. Promotoras were offered the opportunity to ask questions and provide feedback and examples of experiences with incontinence. Those who did not wish to share in the discussion were offered the opportunity to write their feedback on an anonymous feedback form with the same open ended-questions that were used to guide the focus group discussion.

Promotoras in attendance chose either to participate or not to participate, without consequence and without affecting their membership. No individual participant identifiers were collected. Notes were taken on audience comments. A written feedback form was provided during the meeting for those promotoras who did not wish to verbalize their thoughts on this potentially sensitive topic at a general meeting, or for those who wanted to provide more extensive feedback. Stamped return envelopes were provided for those who might take the feedback forms and mail them at a later time, or to increase the feeling of anonymity in response. No participant identifiers were noted on the written feedback forms.

### **Data Analysis**

Participants' responses noted during the meeting were combined with written responses from the open-ended feedback form. Responses in Spanish were translated into English. Participant responses were de-identified, edited for spelling, and formatted. Participant responses were analyzed for themes by methods of content analysis. Researchers performed an independent analysis of the transcripts for themes and then conferred together to reach consensus.

### **Results**

Following invitation by the Office of Border Health liaisons, the topic of urinary incontinence was presented during the lunch hour of a regional meeting of the Southern New Mexico Promotora Committee in December of 2017. This venue allowed the nurse researchers to

establish community connections with promotoras and run a focus group session for the needs assessment phase of this participatory action research. This outreach opportunity for the promotoras was advertised through the Office of Border Health, and numerous calls of interest were received prior to the meeting. The topic of urinary incontinence was of interest to the promotoras, several of whom mentioned their attendance was motivated by their interest in learning more about incontinence prevention.

This particular monthly meeting of the Southern New Mexico Promotora Committee was a 4-hour workshop to promote certification of community health workers, cover State guidelines for certification, and provide information on opportunities available through the New Mexico Department of Health. State, regional, and local leaders were present. More than 50 participants filled the round tables in the conference room and were served lunch during the focus group session, which lasted for one hour. Most of the participants were women, and most spoke primarily or exclusively in Spanish. Simultaneous English-Spanish translation through headsets with microphones by an experienced, bilingual interpreter, provided for a lively real-time exchange of ideas and concerns, regardless of spoken language of choice.

Thirty-four promotoras signed informed consent to participate in the focus group on perceived needs of the promotoras' community members in the area of urinary incontinence. A total of 25 promotoras provided oral and/or written comments. Notes were taken on the verbal feedback provided during the focus group, and translated from Spanish to English as needed. Discussion was lively. Following the focus group session, time was provided to complete the written feedback forms if the participant had more information to share. Twelve of the 17 written responses were translated from Spanish into English.

Promotora’s shared observations and concerns about working with adults in their communities who experience urinary incontinence clustered into the following themes: predisposing conditions, treatments tried, home remedies, psychosocial effects, and training requested (Table 1). Themes identified in the promotoras’ comments revealed the lack of information regarding the causes and associated factors of urinary incontinence, the lack of understanding of available behavioral treatment options and how to perform behavioral strategies to promote continence, and the negative effects of urinary incontinence on psychosocial health.

Table 1

*Themes and Subthemes Found in Promotoras’ Comments*

<b>Themes</b>	<b>Subthemes</b>	<b>Quotes</b>
Predisposing Conditions	Pregnancy Hysterectomy Age	“With time have problems holding their urine.” “Nervous bladder.”
Treatments Tried	Surgery Medication Kegel exercises	“Didn’t work.” “Nothing worked.”
Home Remedies	Sanitary pads Diapers Tight stockings Restrict water intake	“Where can I access treatment other than going to the doctor?” “Some women do nothing!”
Psychosocial Effects	Embarrassing Feel humiliated Annoying Bad odor Stay home	“Nobody wants to talk about it!” “I don’t want to get older and then smell bad.”
Training Requested	Affects sexual activity Need information Need to train <i>promotoras</i> to provide educational outreach	“Why does it happen?” “How to keep it from getting worse?”

**Predisposing Conditions**

The promotoras consistently associated development of urinary incontinence with pregnancy and delivery – particularly multiple pregnancies. One noted a common shared experience of

women she worked with who delivered their babies vaginally during the 1970's and received episiotomies having ongoing issues with urinary incontinence unresponsive to surgical treatment. Promotoras spoke of women who experienced incontinence following a hysterectomy. Several asked if urinary incontinence was a normal consequence of aging. One added: "What about men? They have the same problem!" Aging was considered a process that worsened or brought on UI, as manifested in the statement, "My concern is the progression of the situation."

### **Treatments Tried**

The promotoras expressed frustration with the lack of teaching and treatment options. Several commented that medications, surgery, and Kegel exercises were not consistently helping the adults in their rural communities. The promotoras reported not understanding pelvic floor muscle therapy, or Kegel exercises, in terms of how they worked and how to perform the exercises. One recounted a personal experience with a rural patient traveling to California for a surgical procedure following unsuccessful treatment in her own community. The promotoras discussed their experiences with reports of doctors who were not responsive to patient concerns about urinary incontinence, or from women who were too embarrassed to talk about UI symptoms with a male physician.

### **Home Remedies**

Promotoras wrote about the strategies that people used in the rural settings to try to control or hide their UI. Often large sanitary menstrual pads were used rather than the more expensive (and more embarrassing) "diapers" to capture urinary leakage. Other remedies tried were to restrict fluid intake and to isolate themselves due to fear of the odor of urine being noticed by others in public. The desire to manage symptoms at home without having to resort to medication or surgery was expressed by many of the participants.

## **Psychosocial Effects**

The stigma and embarrassment felt by rural adults living with UI was noted by many of the promotoras. The negative effect of UI on self-identity was evident in the following comment: “They ask - do they need to wear diapers already?” Promotoras participating in this study reported that their patients were avoiding social settings and intimacy with partners. There was a palpable worry about how bad things could get with UI in terms of symptom progression and a feeling of powerlessness to make things better.

## **Training Requested**

The consistent message of the participants in this study was the overwhelming need for information and the desire to help people in their community alleviate or lessen their UI symptoms and effect on quality of life: “Take their info into rural areas to help young and over 60.” One expressed concern about the lack of prenatal care affecting the ability to teach women how to do Kegel exercises in time to prevent urinary incontinence. One experienced promotora, near the end of the focus group session, emphatically declared: “I see young women here not talking; just laughing! Ask questions; need knowledge!” She went on to request help in learning prevention strategies and with strategies to raise awareness of the issues with urinary incontinence. Information was requested to help male residents of rural communities who experience UI, as well. As one participant noted, education was requested for “Everything possible, and not just for women but for men as well.” The promotoras in this study overwhelmingly voiced a desire for a program of “train-the-trainer” style educational modules to both empower them as a community health resource in evidence-based UI self-care strategies for rural residents and in order to have a more effective outreach to the rural communities they serve than could be achieved through

occasional offerings of nurse-led UI education programs in traditional community settings, such as a health clinic.

### **Discussion**

The community health workers participating in this study demonstrated a lack of knowledge regarding evidence-based behavioral interventions (e.g., pelvic floor muscle training exercises, bladder calming strategies, and bladder retraining programs) that could resolve or lessen UI symptom impact. The participants did not know what interventions were available other than Kegel exercises, how the behavioral interventions worked and how to perform the interventions, including how to perform Kegel exercises. More importantly, although the promotoras expressed a lack of faith in the effectiveness of behavioral interventions, they were very receptive to learning about UI self-care management strategies. Because rural residents are reluctant to seek medical care for UI and health care services are difficult to access in rural settings, the promotoras were eager to be trained to provide that outreach bladder health promotion education themselves rather than rely on outsider services, such as nurse-led community seminars or clinic office visits, that may not reach rural residents. Promotoras are in a unique position to offer the ongoing support that has been demonstrated to increase the effectiveness of behavioral interventions. The request by the participants in this study for “train-the-trainer” educational modules needs to be addressed in order to provide rural residents living with UI much needed educational support to manage UI at home and to improve quality of life.

### **Limitations**

This study was limited by the sensitive nature of the topic and by the large group setting in which the focus group took place. Another limitation included the concern expressed by one promotora that the nurse researcher did not take information from the focus group without a plan

for future outreach education and a follow-up to share findings with the participants. A plan for providing educational programming was agreed to prior to the promotoras feeling comfortable sharing their perceptions and concerns. Trust between academic researchers and community health workers must be nurtured and consistently maintained through communication and action.

### **Conclusion**

*Promotoras* participating in the focus group expressed an urgent need for comprehensive nurse-led training in behavioral interventions to support the primarily Spanish-speaking women who are living in rural settings, do not have ready access to healthcare services, and who are too embarrassed to bring up the topic of UI to their male physicians. Both urinary incontinence symptom severity and the effect of symptoms on quality of life may be improved through nurse-led “train-the-trainer” programs to allow for evidence-based and *promotora*-provided education in UI self-care management strategies. The eventual goal of this research is to develop, through a participatory action framework, a community-based support system to keep rural adults who live with urinary incontinence as active and independent as possible, mitigating through education any negative effect of incontinent episodes on lifestyle or overall quality of life. The information from this community needs assessment regarding the incontinence care needs of adults living along the U.S.-Mexico border, evaluated from the shared perspectives of the community health workers who live in the rural communities, will be used to guide development of future nurse-led community-based continence care educational modules targeted to support the *promotoras* in outreach services to rural residents. Future research includes evaluating outcomes of the educational modules in terms of reducing knowledge deficits of *promotoras* regarding health promotion strategies for urinary incontinence and in improving quality of life concerns of the rural residents they serve.

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