Published in final edited form as:

Patient. 2015 October ; 8(5): 455–467. doi:10.1007/s40271-014-0110-z.

Measuring the preferences of homeless women for cervical cancer screening interventions: development of a best-worst scaling survey

Eve Wittenberg¹, Monica Bharel², Adrianna Saada^{1,*}, Emely Santiago^{2,*}, John F. P. Bridges³, and Linda Weinreb⁴

¹Center for Health Decision Science, Harvard School of Public Health, Boston, MA

²The Boston Health Care for the Homeless Program, and Departments of Medicine, Massachusetts General Hospital and Boston Medical Center, Boston, MA

³Department of Health Policy and Management, Johns Hopkins Bloomberg School of Public Health, Baltimore, MD

⁴Department of Family Medicine and Community Health, University of Massachusetts Medical School, Worcester, MA

Abstract

Objective—Despite multiple risk factors, women experiencing homelessness are screened for cervical cancer at a lower rate than women in the general US population. We report on the design of a stated preference study to assess homeless women's preferences for cervical cancer screening interventions, to inform efforts to overcome this disparity.

Methods—We conducted focus groups with homeless women (n=8) on cervical cancer screening decisions, and analyzed data using thematic analysis. We applied inclusion criteria to select factors for a stated preference survey: importance to women, relevance to providers, feasibility, and consistency with clinical experience. We conducted pre-tests (n=35) to assess survey procedures (functionality, recruitment, administration) and content (understanding, comprehension, wording/language, length).

Results—We chose best-worst scaling (BWS, also known as object scaling) to identify decision-relevant screening intervention factors. We chose an experimental design with 11 “objects” (i.e., factors relevant to women's screening decision) presented in 11 subsets of 5 objects each. Of 25 objects initially identified, we selected 11 for the BWS instrument: provider-related factors: attitude, familiarity, and gender; setting-related: acceptance and cost; procedure-related:

Corresponding author: Eve Wittenberg, PhD, Center for Health Decision Science, Harvard School of Public Health, 718 Huntington Ave., 2nd floor, Boston, MA 02115, 617.432.6933 (p), 617.432.0190 (f), ewittenb@hsph.harvard.edu.

* at time research was conducted

Preliminary results were presented at the 35th Annual Meeting of the Society for Medical Decision Making, Baltimore, MD, October 2013.

All authors have no conflicts to declare.

EW and MB conceived of the study; LW provided guidance in implementation; AS and ES participated in data collection; EW and AS conducted data analysis; JFPB provided guidance in design; all authors participated in interpretation of results. EW wrote the manuscript; all authors reviewed and approved the final manuscript. EW serves as guarantor for the results.

explanation during visit and timing/convenience of visit; personal fears/barriers: concerns about hygiene, addiction, and delivery/fear of results; and a general factor of feeling overwhelmed.

Conclusions—Good practices for the development of stated preference surveys include considered assessment of the experimental design used and the preference factors included, and pretesting of presentation format. We demonstrate the development of a best-worst scaling study of homeless women's cervical cancer screening intervention preferences. Subsequent research will identify screening priorities to inform intervention design.

Keywords

stated preferences; best-worst scaling; homeless; cervical cancer; survey development

I. Introduction

Approximately 610,000 individuals experience homelessness on a given night in the US, of whom approximately 35% are women.[1] Drug overdoses, cancer, and heart disease lead all causes of death, and cancer kills the most women in the 45+ age bracket.[2] Women who experience homelessness are at particularly high risk of cervical cancer because of high rates of smoking, HIV infection, and multiple sexual partners, with their risk exceeding that of housed, low-income women.[3, 4]

Homeless women are screened for cervical cancer at lower rates than the general population: between 47-76% of homeless women have been screened within the past 12 months compared to 82% of the general population being up-to-date according to screening guidelines.[3-8] Over half of cervical cancer cases result from suboptimal screening, including 25-29% among women who had never been screened.[9, 10] Homeless women's screening disparity places them at higher risk of cancer incidence and the associated morbidity and mortality. Improved prevention and early detection are critical to ensure that recent decreases in cervical cancer disease burden are shared by women who are homeless. [10, 11]

The provision of cervical cancer screening among homeless women is complex, and optimal outcomes remain elusive.[3, 4, 12, 13] Barriers to homeless women's access to care include lack of knowledge of services, long waiting times, difficulty scheduling care, stigmatization, comorbid conditions, and poor health. [13, 14] The elimination of financial and other access barriers may not fully accomplish screening uptake.[12] Gaps in knowledge remain about screening decisions among this population.

Stated preference methods are a family of approaches that can be used to identify preferences and importantly, tradeoffs among priorities and decision components.[15] These methods have been applied in health contexts to identify the relative importance of preferences and to inform guidelines, practice, and policy. [16-18] While descriptive research on decisions (such as barriers and facilitators) identifies the landscape of preferences, it fails to elucidate the decision equations used to arrive at a choice. The goal of this research was to develop a method to measure homeless women's decision-relevant preferences with respect to cervical cancer screening interventions. We describe the process

of developing a stated preference methodology in a practice and policy relevant context, with an underserved and vulnerable population. Our results inform the application of stated preference methods, as well as guide the implementation of this method in the context of cancer screening for homeless women.

II. Methods

Our approach followed good practices for the design and implementation of stated preference methods described by Coast et al.[19] and Bridges et al.[20] We integrated qualitative data and clinical expertise to identify and select an experimental design and determine attributes¹ for inclusion in the preference instrument. Two investigators with clinical experience serving homeless women in dedicated health care for the homeless (MB) and primary care (LW) settings provided expertise to the process. Qualitative data were collected from focus groups and pre-tests to elicit the relevant preference attributes and to identify the optimal preference task and experimental design for the setting and population. [19] We describe our approach within the framework of the ISPOR checklist for good practices for conjoint analysis.[20]

1. Elicitation format

Stated preference elicitation formats (such as best-worst scaling, discrete choice experiments, and types therein) were assessed based on relevance to the research question and feasibility within the population and setting. We chose best-worst scaling as a format because our goal was to develop a method that assessed the relative prioritization of intervention preferences while maintaining administrative simplicity.[17, 21, 22] Best-worst scaling (BWS) prioritizes decision factors through a series of choice tasks; it provides a *scaling* of factors relative to one another.[23] Examples of its application in health contexts include colorectal cancer screening[24], dermatology services[25], and choice of cancer surgeon.[26] We considered two types of best worst scaling (BWS) designs, the “object case” and the “profile case.”[23] In the object case a set of preference attributes (i.e., objects) is presented to each respondent from which she indicates the “best” and “worst” on a specified criterion, such as importance, interest, desirability, etc. Objects are presented without a specified level (e.g., magnitude, duration, intensity), meaning that preferences are elicited for objects themselves and not levels within objects. The profile case incorporates levels for objects and the same selection procedure. We pre-tested a survey version using the profile case and found that women had difficulty comprehending the task, and specifically distinguishing among levels. We therefore chose the BWS object case because it provides maximal data on the research goal of the study within a set sample size and comprehension constraints. The absence of prior preference data in this specific health context makes preference data for objects alone highly informative regardless of level. Since our priority was to inform areas of focus for interventions, this format was suitable for our needs.

¹In this paper, we use “attribute” to refer to preference components used in any stated preference instrument. We use “object” to refer to an attribute specifically in the context of best-worst scaling. We use decision factor or component to refer to the elements that contribute to preferences in a general, non-experimental context.

2. Attribute identification

We conducted focus groups with homeless women to identify the range of preferences underlying cervical cancer screening choices. We developed a focus group guide to identify personal and contextual factors that could potentially influence the screening choice (Figure 1). The guide was open-ended to capture all decision-relevant factors, with prompts included on topics hypothesized to be relevant based on clinical experience and the literature (e.g., provider gender, sexual trauma history). The focus group sample was purposively selected to include women hypothesized to vary in screening preferences, including women of varying age, ethnicity, housing stability, and with different medical conditions (such as substance use and mental illness).[19]

- a. **Sample:** Women were recruited from five settings: a homeless medical respite center, an outpatient medical clinic, an emergency (i.e., overnight) shelter, a transitional housing program, and a residential substance use treatment program. Inclusion criteria included minimum age of 18 years, English or Spanish verbal proficiency, and sufficient coherence to participate in a group conversation (as assessed by the recruiter). Recruitment was conducted in areas where women congregate (in emergency shelter lobby, outpatient clinic waiting room, and transitional housing lobby), in patient rooms (in medical respite center), and by staff announcements prior to the groups (at substance use treatment program). One medical respite center group pre-screened female residents for Pap history and recruited only those without a documented Pap in last 3 years.
- b. **Procedure:** Groups were conducted in English or Spanish by trained moderators, audiotaped, and one investigator took written notes. Groups were conducted on-site at each location in a private room, refreshments were provided, and participants received a \$25 gift card as remuneration for participation. At one location on-site childcare was provided for participants' children.
- c. **Analysis:** Audiotapes were transcribed and translated, and read by two investigators (EW and AS) and a trained research assistant using thematic analysis. [27] Themes related to medical care seeking, uptake and access; and cervical cancer screening experiences, decisions and choice, were recorded in a Microsoft Excel spreadsheet. Themes that diverged from the research topic were excluded from the analytic data, such as personal stories on non-health topics and conversations among participants. Themes were then categorized into groups (e.g., test procedure included comments about instrumentation size, temperature, materials and draping) and transcripts re-reviewed to identify mentions of each category, and additional themes or sub-themes. Transcript review was conducted iteratively by three investigators and discrepancies resolved by consensus until a final thematic spreadsheet was produced.

3. Attribute selection

As described by Coast, attributes included in a preferences survey should be important to patients and policy makers, be plausible, and should be experimentally manipulable by an intervention. Moreover, they should characterize the “commodity”, not the person.[19]

Based on these principles, we reviewed focus group data in light of four criteria: (1) importance to women's screening choice (i.e., the influence in the screening decision that women ascribed to the attribute); (2) relevance to intervention design in this setting (i.e., service modifications that were under the control of homeless health care providers or organizations); (3) feasibility for providers (i.e., those that require fewer resources to implement were prioritized over those that require more); and (4) consistency with clinical experience. We considered both women's opinions and clinical expertise in identifying and selecting attributes, as is practice in stated preference methods.[19] We rated themes mentioned in the focus groups as high or low on these criteria: high "importance to women's screening choice" were attributes that women reported as critical to their decision to be screened. Frequency of mention across groups was indicative of the salience of an attribute to women's collective experience of being screened but not necessarily to individual women's screening choice (e.g., the test procedure itself was highly salient to women's experience but relatively unimportant in the choice to be screened). High "relevance to intervention design" was attributes that could be affected by an intervention based in a homeless health care provider setting (e.g., provider attitude); high "feasibility for providers" was attributes that required fewest resources to implement; and high "consistency with clinical experience" was those that were most commonly reported by clinicians anecdotally or in the medical literature. We considered combinations of themes if they overlapped in meaning.

4. Experimental design: tasks

We considered the setting, population and resource constraints in choosing the number of tasks we would present to each survey respondent, the construction of tasks, and the mode of administration. The settings in which homeless women are recruited are often chaotic with multiple demands on schedules and attention. We budgeted approximately 15 minutes per woman to complete the survey, and an approximate sample size of 150. Our design consisted of 11 objects (i.e., screening decision factors/themes) presented in 11 subsets of 5 objects each (representing a balanced incomplete block design[28]).

We developed a motivation and explanation for the task focusing on the goal of intervention design. We developed wording for each attribute that related to the context of intervention design, and that we judged to be understandable to the population. The attribute selection, motivation, scenario, and wording development process involved multiple rounds of prioritization and discussion among the clinical and methodological investigators (MB and LW, and EW and JB respectively), interspersed with pretesting among homeless women at two settings and feedback from field interviewers (AS and ES). Pretesting followed a protocol including queries of respondent understanding and comprehension and interviewer observations, and data were recorded on written forms. Iterative refinements of attributes, wording and implementation procedures continued until a final instrument was designed.

5. Instrument design

We planned for a computer-programmed survey administered on a tablet computer, self-completed or completed with interviewer assistance. We included respondent characteristics and other data for sample description and potential stratification during analysis (including

demographics, Pap screening history, health conditions). Pretesting of program functionality was conducted with non-homeless women (research staff).

The study was approved by the Harvard School of Public Health Institutional Review Board. Informed consent was obtained from women prior to participation in the focus groups and pretests.

III. Results

1. Attribute identification

Eight focus groups were conducted between November 2012 and March 2013, including a total of 42 women (4-8 women/group) across 5 sites (2 groups were conducted at each of 3 sites and 1 at each of the other 2). Groups lasted 60-90 minutes and were conducted in English (n=6) and Spanish (n=2). Participants' mean age was 39 years (range 20-64); 45% were white, 29% were Hispanic/Latina, and 43% reported some college or more education. Nearly every woman in the sample reported at least one Pap smear in her lifetime (Table 1).

Women's reported factors that were important to their screening decision fell into six categories: the provider, the care setting, the test procedure, the test results, personal fears and barriers, and personal motivations. Each category contained multiple decision factors, which were mentioned with varying frequency across groups (Table 2). An overview of each theme is presented below with sample quotes from women in the groups, and additional quotes are presented in Table 3.

- a. **Provider:** The provider's gender was relevant for many women though one gender was not dominant in preferences. A small number of women said that they would refuse a Pap from a provider of the non-preferred gender, either male or female. For example: *"I prefer a man. ... I just have a thing about women touching me down there (participant M, respite center group 1)."* Familiarity with the provider was important for many women, and some women reported refusing a Pap from a provider they did not already know: *"When you've established a rapport with somebody it's, uh, a lot easier to have the process done (participant B, respite center group 2)."* Women were highly sensitive to feeling judged by providers, and perception of caring and respect was important for women to accept screening. For example, *"[I would refuse] Because they sure don't care for me, even as a human being (participant C, outpatient clinic group)."* Finally, a "doctor's" recommendation was sometimes reported as a motivator for screening.
- b. **Setting:** Women's comfort with the health care setting was important in their screening decision. Women reported being more likely to seek or accept screening in settings that they viewed as accepting of homeless individuals, in which drug use was not assumed or suspected: *"Now I know that there's a place like [local Health Care for the Homeless provider], I would keep my appointments up because I know that they are not going to judge me, you know what I'm saying? (participant L, substance use treatment program group 1)"* A few women mentioned temporary refuge from shelter life as a benefit of screening. Despite universal health insurance in Massachusetts, women reported cost as a barrier to screening. One participant

said: “*I don't really have health insurance right now, so it's like the last on my list to go worry about at the moment (participant D, emergency shelter group 2).*” And incentives such as gift cards or bags were acknowledged as motivators in this and other contexts.

- c. **Test procedure:** Timing and scheduling of the exam was important for many women who had to meet afternoon shelter intake timelines; tests needed to be done quickly without extended waiting periods and needed to be scheduled so as not to interfere with competing priorities. One woman said: “*There is always long waits at the clinic. Even if you have an appointment there, they usually don't see you for an hour after your appointment and you do have to make sure you're back by a certain time, for a [shelter] bed. You need to get back to the shelter at a certain time (participant E, outpatient clinic group).*” While women expressed strong preferences for the specific instruments used in a Pap (such as speculum size, material and temperature), most reported that these preferences could enhance the experience but not substantially affect their willingness to be tested. In other words, despite many women reporting discomfort with the procedure itself, very few said that the known discomfort influenced their decision to be screened. They did place importance, however, on explanations provided during the examination.
- d. **Test results:** Women expressed preferences for timely delivery of results, from someone in whom they had confidence, and accompanied by explanation and support. They also described anxiety and fear surrounding the receipt of results and a desire for support during that process (also described in Personal fears category). One woman explained: “*I wouldn't want a test, and deal with the results on my own, without a professional (participant C, emergency shelter group 2).*”
- e. **Personal fears/barriers:** Women expressed fear of the physical pain and discomfort of a Pap, as well as the invasiveness of the exam, though few said that they would avoid screening for these reasons. Many expressed fear of receiving abnormal results, and how they would cope with such news. As one woman described: “*Yeah, I get nervous [about what the test results could be] because I've had a lot of problems. ... I just think if it came back - like if I was diagnosed with cancer, I wouldn't want to be diagnosed with cancer because I wouldn't want to know. ... now I'm just afraid to find out (participant T, outpatient clinic).*” Some expressed embarrassment with the exam and their personal hygiene, especially those who were living in shelters. And many reported that addiction was an impediment to seeking care of any kind including screening, due to apathy and/or fear of discovery: “*I don't feel comfortable to go to the doctor if I don't shave myself, if I'm not clean, you know? And in my case, I used drugs in my past and I was not going to the doctor, the dentist ... I was not taking showers (participant V, substance use treatment program group 2).*” Some also reported fear of the exam due to prior sexual trauma.
- f. **Personal motivations:** Women's personal motivations to seek screening included valuing prevention to avoid future disease, and feelings of responsibility for their own ability to care and serve as role models for their dependents. For example, one

woman explained: *“It’s not really fun, but it could save your life (participant R, respite center group 2).”* Another said, *“This is part of being a woman, and one of the very, very many things we’re responsible for doing to take care of ourselves. For ourselves, for our families, and for our loved ones (participant L, respite center group 1).”* Many reported family histories of cancer that inspired screening. Some noted the support of friends and family as important in seeking care, as well as the structure and encouragement for self-care imposed by some housing and treatment programs (some of which integrated self-care, healthful behavior, and medical/social services into their treatment plans).

2. Attribute selection

Assessment of the identified decision factors on inclusion criteria is shown in Table 2. Selection was based primarily on the frequency of “high” ratings on the inclusion criteria, with occasional additional policy and clinical considerations; some factors were combined for clarity of presentation. All factors related to personal motivations were assessed as “low” on relevance to intervention design and feasibility for providers criteria, and were excluded. This blended approach to attribute selection is recommended by Coast et al.[19] The 11 factors included: provider gender, provider familiarity, and provider attitude, all rated as highly important to women, highly relevant to intervention design, and feasible for providers—except for gender which was included because it is commonly cited among providers as a screening factor; setting acceptance was high on all criteria; cost was included for policy relevance (and because its lack of importance in this sample was attributed to the unique financial access provided in Massachusetts); scheduling/convenience was high on all criteria; the part of the test procedure category that addressed explanation of the test and exam was included because it was highly relevant to women, for intervention design, and feasibility; test results delivery and fear of results categories were combined into an explanation of results factor, as they were together highly important to women, relevant to intervention design, and consistent with clinical experience; hygiene was included because of its feasibility for providers and frequency of mention in clinical experience; and substance use was important to women, relevant to intervention design and commonly noted in clinical experience. Finally, an additional factor was added that addressed the issue of being overwhelmed by homelessness, as an encapsulation of factors woven throughout women's comments and a hypothesized factor based on clinical experience.

3. Experimental design: task motivation and explanation

Based on our research question, the BWS task asked women to consider a new design for Pap smear testing and its influence on screening uptake (Figure 2). Decision factors were presented as a set of BWS objects describing this hypothetical situation, from which women were asked to choose which had the “biggest” and “smallest” influence on women's decisions to be tested. To assist in understanding, the task instructions included a clarification of “biggest” and “smallest” influence as the “most” and “least” important in encouraging women to be tested. Pretesting showed that these wordings were understood by women and guided respondents to distinguish between personal experience and their forecasts of future behavior.

4. Instrument design process: pre-testing

We conducted pretests with research staff (n=5) to assess program functionality, and with homeless women (two iterative rounds, total n=30) to assess comprehension and wording. Pre-tests began with a profile case version of BWS in which each attribute had two levels, described as high and low for that factor (e.g., for provider attitude, “provider is caring and respectful to you” versus “provider is indifferent toward you”). Women who completed profile case pretests exhibited difficulty assigning “least” important to the low levels of factors. We therefore changed our design to the object case to eliminate levels and focus on relative importance of attributes. Pretests also showed that some women interpreted the “most” and “least” important wording from a personal experience perspective as opposed to our intended forecast of population behavior, so we supplemented that wording with “biggest” and “smallest” influence on “women like you” to improve comprehension. Revision of objects was generally shortening the length of descriptors to decrease time for completion and repetition in the survey screens. Many women accepted the option of having the survey read aloud despite being presented on a touch screen, tablet computer, so minimizing repetition and length were important in maintaining attention during completion. The wording of each factor is presented in Table 4.

IV. Discussion

This paper illustrates the process of designing a stated preference study generally, and in the specific context of cancer screening among a vulnerable population. Homeless women suffer from a significant disparity in cervical cancer screening and the resultant burden of this disease. The development of critically needed, effective interventions to decrease homeless women's disparities will require experimental testing using randomized, controlled trials, which are costly and resource-intensive, and especially burdensome for low-resource clinical settings. Intervention design can benefit from knowledge of patient preferences prior to clinical testing to improve the efficiency of such research. Stated preference methods can provide intervention-relevant data to minimize resource expenditures and optimize experimental outcomes. This study reports on a rigorous development process for a best-worst scaling study to measure homeless women's preferences for cervical cancer screening, in order to guide the design of interventions. Our process informs the field of stated preference research by applying established practice to a unique population, providing a template for use in preference assessment for this and other vulnerable populations, and in other contexts.

Practicality and relevance were paramount in all aspects of the research. The best-worst scaling “object case” provides a prioritization of decision factors with relatively low respondent burden. Because this design assesses *relative* preferences among factors (meaning preferences across objects presented within a given set), it is important that the set of objects considered in the study is inclusive of all relevant to the research question. We derived our decision factors empirically from qualitative data, and incorporated clinical experience as a data source for purposes of selecting the factors included in the study. We also used purposive sampling to recruit our focus group participants, conducting groups in varied settings where we expected women to have different personal characteristics and

potentially preferences. Though this approach introduces some measure of subjectivity into the design process, it allowed us to maximize the research relevance of the final design and to ensure consistency with our research question. As noted by Coast and colleagues, multiple sources are commonly used in the identification and selection of decision attributes for stated preference research, and the inclusion of qualitative data from the relevant population enhances the final design.[19] We agree that careful collection of qualitative data is important to the design of preference assessment instruments, and such data drives but does not determine the final study design. This use of qualitative data to inform and guide stated preference designs distinguishes the approach from traditional qualitative research in both methods and application, and can improve the eventual outcome of stated preference research.

Our BWS object case approach also allowed us to prioritize preference information on the *attributes* of a specific choice, which was the focus of our research question, by presenting each attribute alone without distinguishing levels. In other words, within a given sample size in which each respondent considers a given number of sets of objects, there is a limited number of choices made that comprise the resultant preference data. Since each object was described at just one general level (e.g., “there is time for questions to be answered” as opposed to “the provider spends 10 [or 20, or 30] minutes answering your questions”; and “the provider is kind to all women” as opposed to “the provider is indifferent [or somewhat kind, or extremely kind] toward women”), we were able to collect more data on women's relative preference *across* attributes while we sacrificed some potential data on preferences *within* levels of attributes. We selected this method because it offered maximal information on the important elements for intervention design in a context in which little prior knowledge of preferences existed and the potential range was wide. The cost for this breadth of knowledge is the loss of discriminatory power within attributes. We believe the BWS object case was preferable in this context because the research goal was to provide initial preference data for screening choice; moreover, pretest data suggested improved comprehension compared to the profile case approach. In other contexts the trade-off might be different and another case or approach more suitable. Such considerations are important to weigh the trade-offs among data uses, study resources, and respondent capacity when arriving at a study design.

There are limitations to our design process that affect our results and conclusions. First, our eligibility criteria excluded women with severe mental illness and/or current intoxication; such women are challenging to include in research. We included a substance use treatment program where we found women willing to speak about their experiences during episodes of addiction, and we also found that women in other settings were willing to speak openly about prior addictive behavior. These reports added perspectives from women with addiction despite sample selectivity. Second, the use of focus groups to collect qualitative data required consent to participate in a 90 minute, scheduled activity, which might have been cumbersome for some women in these settings. We found a higher reported level of education and Pap screening rate among our sample compared to the general population of women experiencing homelessness, possibly suggesting selection and reporting bias.[4, 29] Third, the use of focus groups to elicit decision factors may have resulted in social

desirability bias in factors mentioned. We collected screening history and demographic data confidentially (on written forms) to overcome potential reporting bias for some data, and encouraged full participation in the groups via active moderating. Nevertheless, focus groups are by their nature group interactions and provide both benefits and limitations therein. Individual interviews with women are an alternate approach to elicit qualitative preference information though are more resource intensive. Finally, our qualitative data are self-reported, and may contain further desirability bias though this is difficult to overcome. The high Pap rate reported by our sample may be due to such reporting bias. The women in our one group pre-screened for no medical record documentation of prior Pap smears (n=4) reported receiving testing at other locations, suggesting potential inaccuracy in medical records or misreporting by women (e.g., misunderstanding difference between pelvic examination and Pap smear). Selection into screening and into this type of study may also be correlated, resulting in our omission of the views of women who are not screened. It is likely that preferences of women who have not been screened differ from those who have, though we tried to elicit alternative views from women by querying times in the past that they declined screening or views of other women whom they knew. Nevertheless, it is possible that our results contain bias and future research should explore differences in preference between women who are and are not screened.

In consideration of these potential biases we scrutinized data that were inconsistent with clinical experience and the literature and integrated expert opinion into our design. While expert opinion can also introduce bias by way of anecdote, we protected against this somewhat by our clinical experts representing multiple perspectives: that of a Medical Director of a Health Care for the Homeless program and that of an established homeless researcher and primary care provider. We also opted for an experimental design that allowed us to maximize the number of factors in our study and protect against exclusion of relevant factors. In sum, consideration of potential bias in the study design process is important to minimize effects that can be carried forward into preference data when the study is implemented, and sources of bias in design should be considered in the interpretation of study findings.

V. Conclusion

Rigorous preference data are useful for understanding and improving services and hence outcomes. This paper describes a design process to develop a stated preference instrument to understand homeless women's priorities for cervical cancer screening interventions. Our methods inform other stated preference research in general and specifically with vulnerable populations. Our future reports will present the results of the implementation of our best-worst scaling study in this population.

Acknowledgments

The authors gratefully acknowledge the assistance of Erika Alvarez and Inez Adams, PhD, in conducting the focus groups; Zachary Ward, MPH, in survey formatting and programming; and Danielle Hollenbeck-Pringle, MPH, in data analysis and manuscript preparation. We also thank the organizations who generously allowed us to collect data from their guests and clients: the Boston Health Care for the Homeless Program, Pine Street Inn, Casa Esperanza, and Crittenton Women's Union. Finally, we are most appreciative of the women who shared their views and experiences in our focus groups, without whom this research would have been impossible.

Funding source: Research reported in this publication was supported by the National Cancer Institute of the National Institutes of Health under Award Number R21CA164712. The content is solely the responsibility of the authors and does not necessarily represent the official views of the National Institutes of Health. The funding agreement guaranteed the authors' independence in the research.

References

1. National Alliance to End Homelessness. The State of Homelessness in America 2013. Washington, DC: 2013.
2. Baggett TP, et al. Mortality among homeless adults in Boston: shifts in causes of death over a 15-year period. *JAMA Intern Med.* 2013; 173(3):189–95. [PubMed: 23318302]
3. Chau S, et al. Cancer risk behaviors and screening rates among homeless adults in Los Angeles County. *Cancer Epidemiol Biomarkers Prev.* 2002; 11(5):431–8. [PubMed: 12010856]
4. Weinreb L, Goldberg R, Lessard D. Pap smear testing among homeless and very low-income housed mothers. *J Health Care Poor Underserved.* 2002; 13(2):141–50. [PubMed: 12017905]
5. Centers for Disease Control and Prevention (CDC). Cancer screening—United States, 2010. *MMWR Recomm Rep.* 2012; 61:41–5.
6. Diamant AL, et al. Use of preventive services in a population of very low-income women. *J Health Care Poor Underserved.* 2002; 13(2):151–63. [PubMed: 12017906]
7. Long HL, et al. Cancer screening in homeless women: attitudes and behaviors. *J Health Care Poor Underserved.* 1998; 9(3):276–92. [PubMed: 10073209]
8. Teruya C, et al. Health and health care disparities among homeless women. *Women Health.* 2010; 50(8):719–36. [PubMed: 21170815]
9. Janerich DT, et al. The screening histories of women with invasive cervical cancer, Connecticut. *Am J Public Health.* 1995; 85(6):791–4. [PubMed: 7762711]
10. Watson M, et al. Burden of cervical cancer in the United States, 1998–2003. *Cancer.* 2008; 113(10 Suppl):2855–64. [PubMed: 18980204]
11. Downs LS, et al. The disparity of cervical cancer in diverse populations. *Gynecol Oncol.* 2008; 109(2 Suppl):S22–30. [PubMed: 18482555]
12. Bharel M, Casey C, Wittenberg E. Disparities in cancer screening: acceptance of Pap smears among homeless women. *J Womens Health (Larchmt).* 2009; 18(12):2011–6. [PubMed: 20044864]
13. Gelberg L, et al. Access to women's health care: a qualitative study of barriers perceived by homeless women. *Women Health.* 2004; 40(2):87–100. [PubMed: 15778140]
14. Hwang SW, et al. Universal health insurance and health care access for homeless persons. *Am J Public Health.* 2010; 100(8):1454–61. [PubMed: 20558789]
15. Bridges JF. Stated preference methods in health care evaluation: an emerging methodological paradigm in health economics. *Appl Health Econ Health Policy.* 2003; 2(4):213–24. [PubMed: 15119540]
16. de Bekker-Grob EW, Ryan M, Gerard K. Discrete choice experiments in health economics: a review of the literature. *Health Econ.* 2012; 21(2):145–72. [PubMed: 22223558]
17. Louviere JJ, Lancsar E. Choice experiments in health: the good, the bad, the ugly and toward a brighter future. *Health Econ Policy Law.* 2009; 4(Pt 4):527–46. [PubMed: 19715635]
18. Marshall D, et al. Conjoint analysis applications in health - how are studies being designed and reported?: An update on current practice in the published literature between 2005 and 2008. *Patient.* 2010; 3(4):249–56. [PubMed: 22273432]
19. Coast J, et al. Using qualitative methods for attribute development for discrete choice experiments: issues and recommendations. *Health Econ.* 2012; 21(6):730–41. [PubMed: 21557381]
20. Bridges JF, et al. Conjoint analysis applications in health—a checklist: a report of the ISPOR Good Research Practices for Conjoint Analysis Task Force. *Value Health.* 2011; 14(4):403–13. [PubMed: 21669364]
21. Flynn TN, et al. Best–worst scaling: What it can do for health care research and how to do it. *J Health Econ.* 2007; 26(1):171–89. [PubMed: 16707175]

22. Potoglou D, et al. Best-worst scaling vs. discrete choice experiments: an empirical comparison using social care data. *Soc Sci Med.* 2011; 72(10):1717–27. [PubMed: 21530040]
23. Flynn TN. Valuing citizen and patient preferences in health: recent developments in three types of best-worst scaling. *Expert Rev Pharmacoecon Outcomes Res.* 2010; 10(3):259–67. [PubMed: 20545591]
24. Imaeda A, Bender D, Fraenkel L. What is most important to patients when deciding about colorectal screening? *J Gen Intern Med.* 2010; 25(7):688–93. [PubMed: 20309740]
25. Coast J, et al. Preferences for aspects of a dermatology consultation. *Br J Dermatol.* 2006; 155(2): 387–92. [PubMed: 16882179]
26. Ejaz A, et al. Choosing a cancer surgeon: analyzing factors in patient decision making using a best-worst scaling methodology. *Ann Surg Oncol.* 2014
27. Guest, G.; MacQueen, K.; Namey, E. *Applied Thematic Analysis.* Thousand Oaks, CA: Sage Publications, Inc; 2012.
28. Louviere JJ, Flynn TN. Using best-worst scaling choice experiments to measure public perceptions and preferences for healthcare reform in Australia. *Patient.* 2010; 3(4):275–83. [PubMed: 22273434]
29. Burt, M., et al. *Homelessness: programs and the people they serve.* Washington, D.C.: Interagency Council on Homelessness; 1999. Washington, D.C

Key points for decision makers

- There is a disparity in cervical cancer screening for women experiencing homelessness relative to the general population.
- Effective interventions to eliminate disparities depend on knowledge of screening preferences, which can be identified with stated preference methods.
- Systematic development of stated preference approaches, including identification of preference factors, construction of tasks, and choice of experimental design, are critical to provide valid preference data from these methods.

1. **Have you ever had a Pap test? It is also sometimes called a Pap smear.**
 - In your own words, how would you describe what it's like to have a Pap test?
 - How would you describe the experience to a friend?
 - How did you feel about having one?
 - Is there anything that could have been done to make you feel more comfortable?
 - Where did you have your last one done?
 - Why did you agree to have one done that day?
 - What did you like about that experience?
2. **Has anyone not had a Pap test in the last year?**
 - Have you been asked to have one?
 - What made you decide to say "no" that time?
 - What would have made you say "yes"?
3. **Have you ever had an experience that made you uncomfortable about having a Pap?**
4. **Is there anything about being homeless that makes it especially hard or easy to get a Pap test?**
5. **If we could make the Pap test better, how would you imagine it would be?**
 - Where would it be done?
 - Who would do it?
 - How would it feel?
 - How would you find out the results?
6. **In the last year, was there a time when you didn't feel well, but decided not to see a doctor?**
 - What did you do instead?
 - Why didn't you try to get care?
7. **When was the last time that you went to a doctor or a clinic for a check-up, in other words, when you felt fine?**
 - Why did you go?
8. **When your housing is not stable your health might not be your top priority. In these times, what are some reasons why you might seek medical care?**
 - Where do you go for care?
 - What are some barriers to seeking care?
 - What are some ways to overcome them?

Fig 1. Focus Group Moderator Guide: abbreviated list of questions posed to groups, and prompts used to encourage discussion if necessary (following bullets)

“A Pap smear is the standard test done to detect cervical cancer. We are designing a new way of providing Pap tests for women like you. We know which parts of testing are important to some women and we want your opinion as well.

“We will show you some descriptions of how Pap testing could be offered to women. Each description will include five different parts. For each description, tell us which part would have the BIGGEST influence on women’s decisions to get tested and which would have the SMALLEST influence.

“The BIGGEST influence means the things that will really encourage women to get Pap smears. The SMALLEST influence means the things that will have little or no impact on whether women get Pap smears.

“Another way to think about this is how we can encourage women to get tested, and which part of each description would be MOST IMPORTANT in encouraging women and which would be LEAST IMPORTANT.”

Fig 2. Best-worst scaling task motivation and explanation

Table 1
Focus group sample characteristics (n=42)

Characteristic	Category	No. (% [*])
Age (mean, range; years)		39.4 (20-64)
Race	White	19 (45.2)
	Black or African American	12 (28.6)
	More than one race	3 (7.1)
	Other	7 (16.7)
	Unreported	1 (2.4)
Ethnicity	Non-Hispanic/Non-Latina	27 (64.3)
	Hispanic/Latina	12 (28.6)
	Unreported	3 (7.1)
Education	<12 years	13 (31.0)
	High school diploma or GED	9 (21.4)
	Some college or college diploma	18 (42.9)
	Unreported	2 (4.8)
Lifetime Pap smear status	Ever	41 (97.6)
	Never	0
	"I don't know"	1 (2.4)
Recruitment Site	Medical respite center; 2 groups	8 (19.0)
	Outpatient medical clinic; 1 group	6 (14.3)
	Emergency shelter; 2 groups	12 (28.6)
	Residential substance use treatment program; 2 groups	10 (23.8)
	Transitional housing program; 1 group	6 (14.3)

No. = number; GED= General Educational Development test

* Percentages may not sum to 100 due to rounding.

Table 2
Respite Ctr.2 and evaluated by inclusion criteria for BWS instrument

Group(s) in which factor mentioned							Factor inclusion criteria for instrument ^f				Selected for inclusion
Respite Ctr.2	Outpt. Clinic ^b	Emerg. Shelter ^c 1	Emerg. Shelter 2	Sub. Use Trmt. ^d 1	Sub. Use Trmt. 2	Trans. housing prog. ^e	Importance to women's choice	Relevance To intervention design	Feasibility for providers	Clinical experience	
X	X <i>Patient.</i>	X	X	X	X	X	High	High	Low	High	
X			X	X	X		High	High	High	Low	
X	X	X	X	X	X	X	High	High	High	High	
	X			X		X	Low	High	High	Low	
	X	X		X	X		High	High	High	High	
	X		X		X		Low	Low	Low	Low	
			X		X		Low	Low	Low	Low	
	X				X		Low	High	Low	Low	

Category	Decision factors and description	Group(s) in which factor mentioned								Fac	
		Respite Ctr. ^a 1	Respite Ctr.2	Outpt. Clinic ^b	Emerg. Shelter ^c 1	Emerg. Shelter 2	Sub. Use Trtmt. ^d 1	Sub. Use Trtmt. 2	Trans. housing prog. ^e	Importance to women's choice	Relevance To intervention design
Test procedure	Timing: wait time for appointment; duration of procedure	X		X	X					Low	High
	Scheduling: ease of scheduling/ convenience; competing priorities	X		X	X	X				High	High
	Test procedure: speculum size, type, temperature; draping; explanation of test	X	X	X	X	X	X	X	X	High	High
Test results	Timing: results shared in timely manner	X		X			X	X	X	High	Low
	Confidence: suspicion of inaccuracy; understanding of results				X	X				Low	Low
	Delivery method: who delivers results; explanation of results	X		X	X	X	X	X	X	High	High
Personal fears and barriers	Fear of procedure: delay screening to avoid pain and discomfort		X	X	X	X	X		X	Low	Low
	Fear of results: delay screening to avoid abnormal results; denial, unable to cope		X	X	X	X	X	X	X	High	Low
	Hygiene/ Embarrassment: shame from poor hygiene;		X	X	X		X	X		Low	Low

		Group(s) in which factor mentioned								Fac	
Category	Decision factors and description	Respite Ctr. ^a 1	Respite Ctr.2	Outpt. Clinic ^b	Emerg. Shelter ^c 1	Emerg. Shelter 2	Sub. Use Trtmt. ^d 1	Sub. Use Trtmt. 2	Trans. housing prog. ^e	Importance to women's choice	Relevance To intervention design
	<i>embarrassed by intimacy of test</i>									W. Berg et al.	
	Sexual trauma: screening provokes anxiety and fear due to history of sexual trauma					X	X			High	Low
	Substance use: drug/alcohol use impedes care seeking	X		X			X	X		High	High
	Prevention: catch diseases early to prevent bad outcome	X	X			X	X	X	X	High	Low
Personal motivations	Responsibility: take care of oneself and stay healthy as woman/mother	X				X			X	High	Low
	Family history: perceived high risk of cancer due to family history		X		X	X	X		X	High	Low
	Role model: importance of the need to model good behavior for children	X								High	Low
	Support: family/friend encourages care seeking and/or accompanies to visit	X			X	X	X			High	Low
	Substance use treatment: admittances treatment center motivates care seeking							X			High

^aRespite Ctr., Medical respite center, 1 = focus group 1 and 2 = focus group 2

Author Manuscript

Author Manuscript

Author Manuscript

Author Manuscript

b Outpt. Clinic, Outpatient clinic
c Emerg. Shelter, Emergency shelter, 1 = focus group 1 and 2 = focus group 2
d Sub. Use Trmt., Substance use treatment program
e Trans. housing prog., Transitional housing program
f Factors assessed as high or low on each criterion by investigators; bold/italics indicates factor included in final BWS instrument.
* = factors combined

Additional samples of statements by focus group participants (n=42), by category and decision factors

Provider	Setting	Test Procedure	Test Results	Personal Fears and Barriers	Personal Motivations
<p>Gender: preference for provider conducting the screening</p> <p><i>I had a male GYN before, and it was very uncomfortable. I felt he was uncomfortable as well. - Partic. a B, Respite Ctr. b 2</i></p> <p><i>No, absolutely not, it's gotta be a female. - Partic. K, Respite Ctr. 1</i></p> <p><i>If it's a woman she knows what it feels and she is very gentle. - Partic. L, Sub. Use Trmt. c 1</i></p> <p>Familiarity: woman knows and has seen provider prior to time of screening</p> <p><i>I refused when I didn't particularly have a relationship with the doctor, like I didn't feel comfortable with the doctor. - Partic. C, Emerg. Shelter^{d 2}</i></p> <p>Attitude: provider perceived as caring, respectful, trustworthy, attentive, non-judgmental</p> <p><i>I'd say it has to be someone delicate who treats you with respect and at the same time with delicacy because some people are rude. - Partic. M, Sub. Use Trmt. 2</i></p> <p>Recommendation: provider recommends screening</p> <p><i>I didn't get it for a few years and then I got it when Dr. [name] who works here. She told me, "You need to get a Pap smear". And that's when they discovered it [cancer]. - Partic. K, Trans. housing prog^f</i></p> <p><i>For me, it was kind of a barrier because you don't have a regular doctor saying, "It's time for your Pap smear, time for this test, time for that test." I found out during that time, I had missed a mammogram. I had missed a Pap test. - Partic. C, Outpt. Clinic</i></p>	<p>Acceptance: accepts homeless individuals; no suspicion of drug use</p> <p><i>If you walk in there, as soon as they hear you're there from [Emergency shelter] they automatically think you're there for drugs or something. - Partic. S, Emerg. Shelter 1</i></p> <p>Refuge: screening setting provides temporary relief from homelessness</p> <p><i>For some people, it could be a way for them to have some place to go and sit down and rest, while they wait for their appointment. Some place warm to go, and stuff like that. - Partic. A, Outpt. Clinic</i></p> <p><i>I think that if you want, they should ask you, ...if you want it immediately or overnight. You can go, stay, sleep and in the morning you can have the exam done. ... It should be an option if you want, because you don't have a house and that night beforehand you can prepare well. A good bath, you can change clothes. - Partic. M, Sub. Use Trmt. 2</i></p> <p>Cost: fee associated with screening</p> <p><i>There are people who still don't have insurance, who don't have money. - Partic. M, Sub. Use Trmt. 2</i></p> <p>Incentives: gift card or bag offered in return for screening</p>	<p>Timing: wait time for appointment; duration of procedure</p> <p><i>[She would say no to a Pap even if they are already at a clinic] because they want to rush home to the shelter ... make sure they have a bed for the night. - Partic. S, Outpt. Clinic</i></p> <p>Scheduling: ease of scheduling/convenience; accommodation of competing priorities</p> <p><i>I'm in a shelter now and I get more Pap smears than I did when I wasn't because the clinic's right there ... it's easy to get to. - Partic. A, Outpt. Clinic</i></p> <p><i>When you're homeless the last thing you think about is a Pap smear. You know what I mean? ... You're thinking about getting a bed for the night, getting food, finding somewhere warm to spend the day. - Partic. E, Outpt. Clinic</i></p> <p>Test procedure: speculum size, type, temperature; draping; explanation of test</p> <p><i>I prefer plastic, disposable. I know they sterilize them [metal] but they've been in someone else's vagina. - Partic. U, Respite Ctr. 2</i></p>	<p>Timing: results shared in timely manner</p> <p><i>I want to know the next day. In case there is something that's going on. - Partic. C, Respite Ctr. 1</i></p> <p><i>They sent it [the results] by mail. ... That was too long. It was like two weeks. - Partic. E, Sub. Use Trmt. 2</i></p> <p>Confidence: suspicion of inaccuracy; understanding of results</p> <p><i>[I refused a test because] they wouldn't explain or talk to me about why they wanted me to come back or anything. - Partic. M, Emerg. Shelter 1</i></p> <p>Delivery method: who delivers results; explanation of results</p> <p><i>She only said I had abnormal cells and that I could get cancer. ... She didn't explain anything and only caused me fear. I didn't go get checked for many years. - Partic. L, Sub. Use Trmt. 2</i></p>	<p>Fear of procedure: delay screening to avoid pain and discomfort</p> <p><i>It's definitely horrible. ... It's the worst thing in the world. - Partic. N, Respite Ctr. 2</i></p> <p><i>I don't like anybody looking at me down there. I cry every time I go to the doctor. It's just uncomfortable to me. ... physically uncomfortable. - Partic. B, Trans. housing prog.</i></p> <p>Fear of results: delay screening to avoid abnormal results; denial, unable to cope</p> <p><i>They ... wanted to question a hysterectomy and I got scared. If it came back abnormal, I probably couldn't handle it. - Partic. T, Outpt. Clinic</i></p> <p>Hygiene/Embarrassment: shame from poor hygiene; embarrassed by intimacy of test</p> <p><i>I think that being homeless it's more difficult for hygiene and all of that, one doesn't feel comfortable. You won't go to a hospital. - Partic. L, Sub. Use Trmt. 2</i></p> <p>Sexual Trauma: screening provokes anxiety and fear due to history of sexual trauma</p> <p><i>If you have suffered from a rape or an attack you know, sexually just opening your legs just to anybody is a very, you know ... if you have trauma or if you have issues of that kind, you know, it can be a little traumatizing. - Partic. J, Sub. Use Trmt. 1</i></p> <p>Substance use: drug/alcohol use impedes care seeking</p> <p><i>I was caught up in drugs so ... drug use was more important. - Partic. A, Outpt. Clinic</i></p>	<p>Prevention: catch diseases early to prevent bad outcome</p> <p><i>It's a necessity today in women to make sure that there is nothing and to not risk one's life. Because if you don't find out with time, you can die. - Partic. M, Sub. Use Trmt. 2</i></p> <p>Responsibility: take care of oneself and stay healthy as woman/mother</p> <p><i>Now I have my son and I want to say healthy for him and I just want to make sure that I'm okay so that I can take care of my son. - Partic. K, Trans. housing prog.</i></p> <p>Family history: perceived high risk of cancer due to family history</p> <p><i>Since my mother has been going through this [cancer] for three years I want to make sure I'm alright. - Partic. L, Sub. Use Trmt. 1</i></p> <p>Role model: importance of the need to model good behavior for children</p> <p><i>If you neglect yourself you can't be of any good to anyone else. You can't set an example. Setting an example, that's really important. I can tell my daughter all day long how important it is to do these things, but if "why isn't mum doing it" - it's just not setting an example. - Partic. L, Respite Ctr. 1</i></p> <p>Support: family/friend encourages care seeking and/or accompanies to visit</p> <p><i>Like, I wanted a friend of mine to just come with me for support. I'm not afraid. It's just like, I'm more apt to go if like for lack of a better term, she's like dragging me. ... it's just nice not being alone. - Partic. K, Respite Ctr. 1</i></p> <p>Substance use treatment: admittance to treatment center motivates care seeking</p> <p><i>When there's a place like that help us all that, health issues ... we gotta take advantage. I came here and I'm a mess. ... [now] I'm up to date with my</i></p>

^aPartic., Participant; initial indicates individual respondent within group;
^bRespite Ctr., Medical Respite Center, 1 = focus group 1 and 2 = focus group 2;
^cSub. Use Trtmt., Substance Use Treatment Program focus group;
^dEmerg. Shelter, Emergency Shelter, 1 = focus group 1 and 2 = focus group 2;
^eOutpt. Clinic, Outpatient Clinic focus group
^fTrans. Housing prog., Transitional Housing program focus group

Table 4
Decision factors and wording of objects included in best-worst scaling instrument

Category	Factor	Wording of object
Provider	Gender	"Women have a choice of male or female provider"
	Familiarity	"The woman knows the provider"
	Attitude	"The provider is kind to all women"
Setting	Acceptance	"Testing is done in a homeless health care clinic"
	Cost	"Testing is done at no cost to the woman"
Test procedure	Timing/convenience of visit	"Testing is done at a convenient time for the woman"
	Explanation during visit	"There is time for questions to be answered"
Personal fears/barriers	Hygiene	"There is a place to wash up before the test"
	Substance use	"Testing is done regardless of whether women are clean/sober"
	Delivery of results/fear of results	"Counseling is available to discuss results"
Cross-domain	Feeling of overwhelm	"Support is available for all issues the woman is facing"