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Using Concept Mapping to Explore Barriers and Facilitators to Breast Cancer Screening in Formerly Homeless Women with Serious Mental Illness

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Abstract: Women with serious mental illness (SMI) have disproportionately worse breast cancer profiles than those of other women. The purpose of this project was to examine barriers to and facilitators of breast cancer screening, specifically in formerly homeless women with SMI using the participatory methodology of concept mapping. A series of three concept mapping focus groups were held with 27 women over the age of 40 with a diagnosis of a SMI who live in supportive housing programs, and with 16 housing program staff. Data from the focus groups were combined through multidimensional scaling to create a visual cluster map. Barriers and facilitators to mammography screening generated by the participants clustered into eight categories. Participants rated addressing educational issues as most important and feasible. Interventions designed to improve mammogram screening in this population should address patients’ perception of personal risk and should target education and support systems as modifiable factors.

Key words: Breast neoplasms, mental disorders, homeless persons, concept mapping, screening, preventive health model.

Significant health disparities separate people with serious mental illness (SMI) from the general population, mostly due to treatable and preventable physical illness.1

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Some estimates show that in the United States people with SMI die 25 years earlier than the general population.\textsuperscript{2} Increased prevalence of morbidity and mortality in people with serious mental illness stems from multiple interacting factors, including genetic, environmental, psychiatric, social, pharmaceutical, and economic factors. Although there were conflicting findings among early studies, cancer is now recognized as a significant contributor to excess morbidity and mortality in this population.\textsuperscript{3–7} A recent large prospective study of patients with schizophrenia revealed an all-cause death rate nearly four times higher than the rate of the general population, with cancer as the second most common cause of death after suicide (and before cardiovascular disease). Among women in this population, the risk of death from breast cancer was significantly higher than in the general population, with a standardized mortality ratio of 2.8.\textsuperscript{3}

A constellation of breast cancer risk factors has recently been described in women with schizophrenia;\textsuperscript{8} these include: obesity, elevated prolactin levels, high prevalence of diabetes, low parity, low incidence of breastfeeding, high levels of smoking and alcohol consumption, and low activity levels.\textsuperscript{8} Despite these elevated risks, rates of mammography screening are low. Aggarwal recently performed a systematic literature review, which included 19 studies on breast and cervical cancer screening in women with mental illness, and confirmed significant disparities when comparing these women with the general population.\textsuperscript{9} This finding is supported by an earlier study of over 1,400 women with schizophrenia in Canada, which found a 20% lower rate of breast cancer screening in this population than in non-mentally ill women.\textsuperscript{10} In terms of the effect of SMI on breast cancer screening, Carney, and Werneke, have reported that severity of mental illness negatively affected screening rates.\textsuperscript{11,12} Chochinov, also found that low income and lack of continuity of care were found to significantly negatively influence screening in women with schizophrenia.\textsuperscript{10}

Similarly, several studies among women with SMI found an association between low socioeconomic status and low screening rates.\textsuperscript{9} Other reported barriers include transportation difficulties, embarrassment, adverse experiences, high depressive burden, and fear of pain or discomfort caused by the machine used for mammography.\textsuperscript{9} Facilitators of screening include connections to primary care, primary care recommendation, and positive family history.\textsuperscript{9}

The rate of homelessness among those with serious mental illness is estimated to be as high as 24%, even in an enhanced community-based mental health system.\textsuperscript{13} The literature regarding breast cancer screening in homeless women is limited. However, a recent study of a general population of homeless women in the New York shelter system found that 59% of women had a mammogram in the past two years.\textsuperscript{14} An earlier study of homeless women in Los Angeles County found only 32% of women reported having a mammogram in the past year.\textsuperscript{15}

Two recent reviews have outlined client-directed interventions to increase community access\textsuperscript{16} and community demand\textsuperscript{17} for breast cancer screening in the general population. Recommendations to increase community access include reducing structural barriers and reducing out-of-pocket client costs.\textsuperscript{16} Recommendations to increase community demand include client reminders, small media, and one-on-one education.\textsuperscript{17} However, it is unclear if these interventions are applicable to women with SMI or
who are homeless. A recent Cochrane Review reported that there are no high-quality randomized controlled trials of interventions to encourage cancer screening in people with SMI, suggesting that knowledge gained in prior studies has not been translated into evidence-based interventions to improve screening.

Breast cancer screening recommendations in the U.S. vary. All groups agree that mammography is the best test to screen for breast cancer in average-risk women. The American Cancer Society (ACS) recommends that asymptomatic women age 40 and older should have a mammogram every year and should continue to do so for as long as they are in good health. The United States Preventive Services Task Force (USPSTF) recommendations were changed in 2009 and are in the process of being further revised. The USPSTF recommends screening mammography every two years for women ages 50 to 74 years. Prior to 2009, the USPSTF recommended screening mammography every one to two years for all women 40 years and older. Currently, the USPSTF states that the decision to start regular, biennial screening mammography before the age of 50 years should be an individual one and take patient context into account, including the patient’s values regarding specific benefits and harms.

The purpose of this study was to examine barriers to and facilitators of breast cancer screening specifically in formerly homeless women with SMI using the participatory methodology of concept mapping (CM). We hypothesized that women with histories of both mental illness and homelessness may experience barriers to and facilitators of mammography screening different from those reported in the literature for women with SMI, but with no history of homelessness, based on potential differences in health care-seeking behavior. For women with experiences of both homelessness and mental illness, healthcare seeking behavior could be influenced by the double stigma towards homelessness and mental illness they may encounter in the health care system as well as the reordering of priorities that occurs during homelessness. We chose the concept mapping methodology specifically as one that is fully participatory and well suited to working with this population. This methodology also allowed us to illustrate any potential mismatch between our population and the staff members in the supportive housing setting.

A secondary aim of this study is to discern if elements of the Preventive Health Model (PHM) map onto the views of study participants. The PHM forms the theoretical basis for the project. The PHM considers what is called the self-system as critical in explaining the use of preventive health modalities (such as screening) that are intended to diagnose, risk-stratify, and/or prevent chronic disease. According to the model, the self-system includes both socio-cultural-health background and cognitive, affective, and social representations about disease, risk, and available preventive health behavior alternatives. This PHM hypothesizes that the likelihood that an individual will engage in a recommended behavior is influenced by the presentation of information and the preference clarification process. Furthermore, the PHM posits that the likelihood of action plan implementation is increased when assistance is given to help individuals address cognitive, affective, and social obstacles to behavior. However, the relevance of the PHM for populations with experiences of homelessness and SMI is unknown.
Methods

This project is part of a needs assessment and program planning initiative to develop
an intervention to improve mammogram screening rates in formerly homeless women
with SMI, which can be delivered through supportive housing programs. The implement-
ation framework for the entire project is shown in Figure 1 to provide context
for the overall process, with phase 2 representing this project.

Study setting. This project was carried out in partnership with Project HOME and
Pathways to Housing Pennsylvania (PA), two nationally recognized homeless services
agencies working to end homelessness for people with serious mental illness in the
city of Philadelphia.

Project HOME. Project HOME currently has 365 units of supportive housing for
people with serious mental illness in seven locations throughout Philadelphia. Project
HOME’s supportive services include mental health services, recovery services, educa-
tion, and employment.

Pathways to Housing PA. Pathways to Housing PA uses a housing first model and
offers immediate access to permanent supportive scattered-site housing for people with
experiences of chronic homelessness and serious mental illness. Pathways to Housing
PA currently houses 300 people in individual one-bedroom apartments throughout
the city. Pathways to Housing PA delivers their supportive services in five multidis-
ciplinary teams configured as modified assertive community treatment (ACT) teams.
Each team is composed of social workers, a registered nurse, a part-time psychiatrist,
a peer counselor, and a community integration specialist.

Participants. Participants in this project were 27 women over the age of 40 with a
diagnosis of a SMI who were part of the Project HOME or Pathways to Housing PA
supportive housing programs. Also participating in this study were 16 staff members
at the sites.

Figure 1. Implementation framework for breast cancer screening project.
Participant demographic characteristics. Of the 27 client participants 20 (74%) identified as African American and seven (26%) identified as White. All client participants were female. Of the 16 staff participants, four (25%) identified as African American and 12 identified as White (75%). Twelve staff participants (75%) were female and four (25%) were male. The breakdown of staff position was as follows: Case Manager (4), Program Manager (2), Assistant Team Leader (1), Case Aide (1), Community Coordinator (1), Master of Social Work Intern/Case Manager (1), Peer Case Specialist (1), Program Assistant (1), Psychiatrist (1), Residential Case Manager (1), Student Intern (1), and Team Nurse (1).

The project was approved by the Thomas Jefferson University Institutional Review Board (IRB), the City of Philadelphia IRB, and by Project HOME and Pathways to Housing PA administration. All client and staff participants completed an informed consent, and each client participant was given $20 and two transportation tokens (if traveling some distance from their residence) for each meeting they attended.

Concept mapping. Concept mapping is a group participatory process in which many ideas generated by a group through a brainstorming exercise are represented simultaneously. It therefore lends itself well to group processes where many different ideas must be concurrently considered and integrated. The content of the resulting concept map is entirely determined by the group: the group brainstorms the ideas about which concepts belong, provides all the information about how these concepts are interrelated, interprets the results of the analyses, and decides how the maps should be used.24 Concept mapping was chosen because it is a participatory methodology that has been well described in needs assessments, evaluations, and program planning involving individuals with SMI.25-28 Concept mapping is gaining attention as a potentially powerful participatory research methodology,29,30 and has been used in explorations of shared decision-making in cancer screening,31 perceptions of cancer risk,32 and barriers to breast cancer screening.33 Concept mapping is particularly appealing in program planning as it is efficient (three meetings) and produces results in a relatively short time that can be easily interpreted, communicated, and acted on by the community (as compared with, for example, focus groups, which require in-depth qualitative analyses by trained researchers).34

Data collection and analysis. Following the concept mapping methodology of Kane and Trochim, we structured the project into three activities: brainstorming, sorting and rating, and analysis and interpretation of the concept maps,24 displayed in Figure 2. Concept Systems Core software (V4.0) was used for data tracking and analysis.

Brainstorming. For the brainstorming activity, participants generated ideas in response to the following focus prompt: “A health care provider recommends that you get a mammogram to screen for breast cancer. What kinds of things affect whether or not you actually get the mammogram?” Responses were recorded on a flip chart during each session. At the conclusion of all brainstorming sessions, authors LW and KH refined the list of statements, eliminating duplicates, and produced a final list of 111 unique statements. Each brainstorming session lasted approximately 60 minutes.

Sorting and rating. For the sorting activity, participants were given sort cards, each printed with one statement from the 111 final statements produced during brainstorming. The participants were instructed to group the cards into categories that made sense
to them and to label the categories. As suggested by the Concept Systems instructions manual, participants were also asked not to sort the statements in terms of importance, not have a “miscellaneous” pile, and to sort into more than two piles. Following the sorting, the participants were given two separate paper surveys, which asked them to rate each idea (statement) in terms of importance, and again in terms of feasibility based on a 5-point Likert scale ranging from 1 ‘Not Very Important/Easy to change’ to 5 ‘Extremely Important/ Easy to Change.’ All participants in the brainstorming activity were invited to return for the sorting and rating activity. Notably, when the sorting data were examined, it was found that sorting data from 11 women were unusable because participants did not follow instructions despite reminders and prompting (e.g. sorted statements based on importance, sorted statements into a “miscellaneous” pile, sorted statements into just two piles). These data were excluded from analysis, however having sort data excluded did not prevent participants from completing other steps in the concept mapping process. All participants were able to complete the rating activity.

**Development of concept maps.** Results of the sorting and rating exercises were entered into the Concept Systems Core software (V4.0). The software first creates a similarity matrix from the sort data, which shows the number of participants who sorted each pair of statements together during the sorting process. The software then uses multidimensional scaling, which locates each statement as a separate point on a two-dimensional map. In this map, points located more proximal to each other reflect statements that were more frequently grouped together by the study participants and points more distal to each other were grouped together less frequently. The stress
value for our data set was 0.297, below the acceptable upper limit threshold of 0.390, indicating that the map represents a good fit to the grouping data.\textsuperscript{30} (Average stress values for concept mapping projects generally range from 0.205–0.365.)\textsuperscript{24} Next, the software uses hierarchical cluster analysis of the multidimensional scaling to partition the points on the map into clusters, which generates more general conceptual groupings of the original set of statements. This produces the concept map. Multiple cluster maps (cluster solutions) are possible using this technique, so the research team met to review the various cluster solutions to determine the number of clusters that best reflected the ideas of the group, following guidelines from Kane.\textsuperscript{24} The research team worked backwards from 16 clusters and combined like concepts until we found the cluster level that retained the most useful level of detail among the clusters, while merging those clusters that conceptually belonged together. While the software generates labels for each cluster, the research team worked together with the participants during the final meeting to determine the accuracy of the labels, and start the process of re-labeling the clusters as necessary. After the production of the concept maps we conducted four final interpretation meetings at each study location consisting of a mix of staff and clients with a total of 22 client participants and one staff participant.

Following the development of the concept map, bivariate analysis was used to compare mean cluster-level importance and feasibility between women and staff. Mean importance and feasibility are generated from the responses on the Likert scale. This analysis creates what is known as a pattern match graph. Bivariate analysis was also used to plot all statements in terms of mean importance versus mean feasibility. This graph, known as a Go-Zone, illustrates strategies deemed both most important and most feasible plotted in the upper right hand quadrant of the graph.

Results

Cluster map. Authors LW and KH, working with the all the participants determined that an eight-cluster solution provided the best fit with the data. Additionally, a cluster boundary was redrawn for one statement because it was felt by the team to produce a better fit in a different cluster. The final cluster map is shown in Figure 3. Location and proximity in space represent relationships among clusters, with more centrally located clusters being perceived by the participants to be more strongly related to other clusters. Similarly, the size of the clusters indicates how closely focused the statements in the cluster are to each other. The eight clusters, with sample statements from each cluster, are shown in Box 1.

Analysis of clusters. Beliefs regarding preventive care/lack of knowledge. This cluster included statements that reflected an orientation away from conventional preventive care, such as use of home remedies/alternative medicines or not thinking you need a mammogram if you feel healthy. This cluster also encompassed statements that reflected lack of knowledge such as having unanswered questions about the procedure, or not knowing what breast cancer is. This cluster included several unmodifiable factors that could impact beliefs in the importance of a mammogram, such as age and health status.

Fears and concerns. This cluster had the largest number of statements (23) and was relatively dense, indicating a strong conceptual cluster. Statements in this cluster grouped
around three central themes: fears and concerns about the procedure, fears and concerns relating to outcomes, and personal fears and concerns. Fears and concerns about the procedure included statements such as being afraid it would hurt, not knowing what was going to happen, concerns about privacy, and concerns that the technician would be a man. Fears and concerns relating to outcomes included statements such as fear of losing a breast and fear of surgery. Personal fears and concerns included concerns about personal hygiene when homeless, fear of public transportation, and claustrophobia.

**Mental health.** This relatively small cluster included statements specific to a population with experiences of SMI, such as: not taking psychiatric medications, feeling depressed, feeling paranoid, and having trouble thinking. This cluster also included experiences of trauma such as being in an abusive relationship or having a history of sexual abuse.

**Logistics of procedure.** This cluster contained a large number of statements around the logistics of getting a mammogram such as getting a referral, having transportation, and having to give a co-pay. This cluster also included issues of prioritization such as being homeless, or being overwhelmed by the number of doctors’ appointments.

**Perception of personal risk.** This cluster dealt with personal or family issues with breast cancer, such as feeling a lump or having a family history. Interestingly, this cluster also included the statement: “if your mental health/substance abuse is stable/under control.” This statement did not occur anywhere near the mental health cluster so it was retained in cluster 5 even though it seems to be an outlier. We can only speculate why this statement was grouped in the cluster, however it may be attributable to the fact that all women share a history of mental health and substance abuse issues. This cluster received the highest importance rating of 3.68.

Figure 3. Cluster map.
Box 1.

Clusters with Sample Statements

Focus Prompt: “A healthcare provider recommends that you get a mammogram to screen for breast cancer. What kinds of things affect whether or not you actually get the mammogram?”

Cluster 1: Beliefs regarding preventive care/Lack of knowledge
- If you do not know what breast cancer is
- If you had unanswered questions about mammograms
- Your health status
- If you think you don’t need one because you are healthy/feeling good
- Your age
- If you do not believe in Western medicine

Cluster 2: Fears and Concerns
- If you are scared of having surgery
- Fear of losing a breast
- If you are afraid it would hurt
- If you are concerned about your privacy
- If you do not trust doctors and hospitals
- If you had fears of public transportation or going outside

Cluster 3: Mental Health
- If you were not taking your psychiatric medication
- If you were depressed
- If your physical health is not a priority because you have mental illness
- If you were having trouble thinking
- If you felt paranoid

Cluster 4: Logistics of Procedure
- If you do not have insurance
- If you didn’t know how to get there
- If you forgot the referral
- If it is hard to access the mammogram place from where you live
- If you are homeless
- Transportation costs

Cluster 5: Personal Risk
- If you felt a lump or had pain
- If you have a family history
- If your mental health/substance abuse is stable or under control
- If you had a mammogram in the past
- If you don’t feel anything with a self-exam
- If other tests you have taken have been normal
- If you had biopsies before and they were negative

Cluster 6: Support Systems
- If you have positive encouragement from doctors, family, and friends
- If you have a good healthcare professional that recommends it
- If you have a good connection with family

(Continued on p. 917)
Support systems. This cluster contained items having to do with general support, such as having a good connection with family, or receiving positive encouragement from doctors, family and friends. It also included ideas regarding specific support for the process, such as having someone to go with or being able to go with a group.

Access to services. This cluster included items that make it more convenient to access mammogram services, such as being able to walk right in, having childcare, and combining the mammogram with another appointment.

Desire for information and comfort. This relatively large cluster encompassed statements expressing a desire for more information, such as, “if the doctor told you what to expect.” Other statements reflected a desire for friendly and comfortable service, such as “if you had access to a peer specialist/counselor in the waiting room.”

Cluster ratings and pattern match. Across the eight clusters, the mean scores for importance ranged from 3.16 to 3.68, between ‘moderately important’ and ‘very important.’ The clusters perception of personal risk and support systems were rated first and second in order of importance. The mean scores for feasibility ranged from 2.19 to 3.21 between ‘somewhat easy to change’ and ‘very easy to change.’ The clusters desire for more information and comfort and support systems were rated first and second in order of feasibility.

Importance ratings were compared for the group of client participants versus the staff participants, results of this pattern match are shown in Figure 4. The correlation coefficient for this comparison was r=.17. Women participants rated perception of personal risk and use of support systems as the most important factors in obtaining a mammogram and beliefs regarding preventive care/lack of knowledge as the least important to address. Staff participants rated mental health and support systems as most important issue to address and desire for more information and comfort as the least important issue to address. Feasibility ratings were compared for the group of client participants
versus staff participants, results of this pattern match are shown in Figure 5. There was much stronger relationship in this pattern match with a correlation coefficient of $r=.92$. All participants rated desire for information and comfort as the most feasible factor to address. A go-zone map was created and is shown is Figure 6. Statements that were rated both as highly important and feasible to address are clustered in the right upper quadrant and are listed in Box 2. All participants rated educational issues as important and feasible to address.

**Discussion**

The purpose of this study was to utilize a participatory methodology to obtain ecologically valid information to use in planning a mammography intervention for formerly homeless women with SMI. We sought to use a methodology which fosters empowerment and gives voice to these historically marginalized women who have increased risk factors for breast cancer, yet lower than optimal screening rates.
Figure 5. Pattern match feasibility.

Figure 6. Go zone.
The focus question for this concept mapping project was designed to elicit multi-level and contextual factors that may affect the ability of a woman with experiences of homelessness and serious mental illness to get a mammogram. The concept mapping brainstorming and sorting processes resulted in a concept map clustered in eight areas: beliefs regarding preventive care/lack of knowledge; fears and concerns; mental health; logistics of procedure; perception of personal risk; support systems; access to services; and desire for information and comfort. The clusters perception of personal risk and support systems were rated first and second in order of importance. The clusters desire for information and comfort and support systems were rated first and second in order of feasibility. Client versus staff ratings of the importance of mental health issues were completely divergent, with clients rating mental health issues as the least important factor and staff the most important factor. We can only speculate about the meaning of this finding, although it provides further evidence for the importance of including the perceptions and opinions of clients/consumers in mental health service planning. Client and staff ratings of feasibility were highly correlated and all participants rated educational issues as important and feasible to address.

While many of the results of this project reinforce those from previous studies suggesting important roles for previously identified barriers, there were several new findings. Support systems, which ranked highly in both importance and feasibility, were not mentioned in previous studies, except with reference to the support of a primary care physician. Support systems may figure more prominently in the lives of formerly homeless women living in supportive housing settings. Additionally, desire for friendly service and comfort factors received little mention in previous studies. In our study these included ideas such as having access to a peer counselor, receiving a gift, or combing the mammogram with another activity. These ideas again, may reflect the

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**BOX 2.**

SELECTED STATEMENTS IN UPPER RIGHT HAND QUADRANT (THE “GO ZONE”)

Focus Prompt: “A healthcare provider recommends that you get a mammogram to screen for breast cancer. What kinds of things affect whether or not you actually get the mammogram?”

#1 If you had unanswered questions about it
#7 You don’t know where to go to get a mammogram
#11 If you got a reminder
#34 If you learned more about what the test is
#35 If the mammogram was at no cost
#42 If you don’t know what breast cancer is
#76 If the doctor told you what to expect
#79 If you have positive encouragement from doctors, family, and friends
#102 If you have a good healthcare professional that recommends it
#103 If you had the mammogram done by someone you trust
#111 If your mental health/substance abuse is stable or under control
experience of living in supportive housing settings. Lack of knowledge and educational issues figured prominently in our project as they did in the study by Kahn.35 This finding has led us to develop a tailored educational module for use in our intervention to improve screening. Finally, our group identified belief regarding preventive care as a possible barrier, which has not emerged in previous studies. Beliefs regarding preventive care are also being addressed in the development of our educational module. These findings support the important differences between these women and other women with serious mental illness, and as shown above, have provided important direction for the development of our intervention. Of particular note, we were impressed with the empowering effect this project had on the client participants. All women stayed engaged in the project and a subset helped to develop the educational module that will later be incorporated into a mammography screening intervention. Some women later shared with us that they had completed a mammogram for the first time after participating in this research project.

The results of the concept mapping process correlate well with features of the PHM. For example the clusters beliefs regarding preventive care/lack of knowledge, fears and concerns, mental health, and perception of personal risk can all be considered elements of the Intrapersonal Self System. The cluster support systems exactly correlates with the concept of the Interpersonal Decision Making Support System. Logistics of the procedure describes part of the Macro System. Education and decision support form the core elements of the intervention in our theoretical model. Importantly the ideas found in the clusters of beliefs regarding preventive care/lack of knowledge and desire for information and comfort are directly addressed in the intervention.

Limitations. The results of this project are specific to our study population and may not be generalizable to other populations of women with experiences of homelessness and serious mental illness, although we believe these findings would transfer well into other supportive housing settings. Small sample size is also a limitation. We were unable to use sorting data from a subgroup of participants who were unable to follow the sorting directions even with support and prompts. Similar issues with sorting have been reported in other studies using concept mapping methods in populations with psychiatric disabilities.28,37 As a result, the final clusters may not accurately reflect views of all participants, however this is part of the nature of participatory methodology and we feel that all views were fairly represented in discussions during our final meetings.

Conclusions. In summary, through this concept mapping study we have furthered our understanding of barriers to and facilitators of mammography in a population of formerly homeless women with serious mental illness. In particular we have gained an appreciation for the importance of support systems in planning for a mammogram and the feasibility and applicability of addressing educational issues when designing an intervention. Additionally, this study provides further evidence for the usefulness of participatory concept mapping projects in eliciting the individual views of people with psychiatric disability and providing a rapid and easily understood group interpretation of the issue at hand. The feedback from this study and an earlier photovoice study38 highlights the need for an effective intervention strategy to provide women with education and support in the process of considering mammography screening. As a result of these insights, we have designed a novel education, decision support and
navigation intervention to assist formerly homeless women with serious mental illness obtain a mammogram. Preliminary testing of this intervention is currently in progress.

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