Homelessness, Mental Illness and Citizenship: Intervention Research and Outcome Measure Development

Rowe M, Clayton, A, O’Connell, MJ
Yale Program for Recovery and Community Health

*Work on this presentation was funded by NIMH grant R21 #MH08776201
“Social Inclusion and Mental Illness: Outcome Measure Development

LA SANTE MENTALE DES PERSONNES
SANS LOGEMENT PERSONNEL

COLLOQUE INTERNATIONAL
PARIS, 26 ET 27 OCTOBRE 2011
Background – I

- Citizenship for persons with psychiatric disabilities involves the view that community residence and comprehensive mental health treatment and psychiatric rehabilitation, supports do not, by themselves, assure access to a full life in the community.

- People need to have a sense of belonging and of contribution to community life that is objectively matched by their acceptance and valued status as community members (Rowe et al., 2009).
• Many persons with psychiatric disorders, due to their reliance on mental health & social service staff, experience an extremely limited form of community membership called “program citizenship” (Rowe 1999)

• Based on previous experience working with persons who are homeless, we developed a conceptual model of democratic citizenship as a strong connection to the 5 Rs – Rights, Responsibilities, Roles, Resources, & Relationships – that society offers its members through public & social institutions and associational life in their communities (Rowe, 1999; Rowe et al, 2001, 2007, 2009, 2011)
114 persons with serious mental illness and criminal justice histories were randomly assigned to usual services (control) or usual services plus a 4-month citizenship intervention involving nontraditional classes, valued role projects, and wraparound peer mentor supports, with research interviews at baseline, 6 and 12 months.
Methods

• Baseline differences were assessed using Analysis of Variance (ANOVAs)

• Linear Mixed Model analyses were run to assess differences between groups over time, holding significant baseline differences, as well as the dependent variable, as covariates
Results

- Citizenship intervention participants reported significantly lower drug use at 6 months and significantly lower drug and alcohol use at 12 month follow-up.

- Those who received the citizenship intervention had significantly higher quality of life overall at 12 month follow-up than those who received treatment as usual.

- Of those who were working part- or full-time within the 6-months previous to the baseline interview (n=42), persons who participated in the citizenship intervention had significantly higher satisfaction with work at both 6 and 12 month follow-up and higher levels of satisfaction with their finances at 6 months.
Results Cont.

- Citizenship intervention participants, however, reported having significantly higher levels of anxiety/depression, as well as higher levels of activity (agitation, tension, etc.) on the BPRS at 6 months. No difference between groups was found at 12 month follow-up.

- At 12 month follow-up, intervention participants also reported having significantly higher levels of negative symptoms (disorientation, emotional withdrawal, etc.) than those who did not receive the intervention.
Discussion

- A significant increase in quality of life for those who received the citizenship intervention suggests that the intervention facilitated, to some degree, participants’ efforts to build a life in the community.

- The citizenship intervention appears to be effective in increasing both the amount of and satisfaction with participants’ activity levels.

- The citizenship intervention also appears to be effective in reducing alcohol and drug use among persons with severe mental illness and criminal histories.
Discussion cont.

- It is possible that a significant increase in negative psychiatric symptoms at the 12-month follow-up could be a response to termination of the intervention for participants after 4 months, perhaps leading a letdown or “what’s next?” sense of loss.

- The intervention group had significantly higher levels of anxiety/depression as well as activity (tension, excitement, distractibility, etc.) measured by the BPRS at the 6-month assessment. This finding is not surprising given that drug use decreased and participants were more involved in the community, both of which can lead to increased symptoms.
Outcome Measure Development

- This study uses participatory methods and concept mapping techniques to develop: a) a greater understanding of the multifaceted construct of citizenship and b) an instrument to measure individual status in regard to domains of citizenship.

- We found that citizenship is a multi-dimensional construct. Individuals with different life experiences perceive varying degrees of inclusion or involvement in relation to a number of associated activities, social constructs, and values. A 45-item instrument of citizenship was developed.
Measure Development

• Full citizenship requires not only that people have access to participation in society but that they perceive others as welcoming, valuing, and protecting their participation.

• A key question is: What are the elements that constitute and make possible a full life in the community?
Method

• Using community-based participatory action (Wallerstein & Duran, 2006) and concept mapping methodologies (Trochim & Kane, 2005), we are exploring the perspectives and processes involved in claiming or reclaiming one’s citizenship for persons whose life trajectories have been disrupted by a serious mental illness and/or other life disruptions (previous incarcerations and serious medical illness).

• Our research team includes persons who identify as having a mental illness, as well as other life interruptions.
Research Design

Phase 1.2: Conducting Focus Groups
- Mental Illness: N=14
- Physical Illness: N=6
- On probation or parole: N=4
- Combo of above (24) or returning war veterans (3): N=27
- Non-interrupted population: N=24

Phase 1.4: Focus Group Analyses
- Mental Illness: N=35
- Physical Illness: N=18
- Recently incarcerated: N=19

Phase 1.5: Concept Mapping Sessions
- Mental Illness: N=18
- Physical Illness: N=18

Phase 2: Measurement Development
- Non-interrupted population: N=18

Groups:
- A, B, C
- D, E, F
- G, H, I
- J, K, L
- M, N, O
- P, Q, R
- S, T, U
- V, W, X

Additional notes:
- On probation or parole: N=4
- Non-interrupted population: N=24

Diagram details:
- Connections between groups indicate relationships and data flow.
Focus Groups

- A total of seven focus groups were conducted with people who: (1) have a mental illness and receive care in a public mental health facility, (2) have a medical illness that interferes with their daily life, (3) are on probation or parole, (4) have one or more of the above, or (5) do not have any of the above.

- Focus group participants generated statements about citizenship by answering the prompt: “To me being a citizen means…”

- The research team analyzed and reduced c. 700 statement to 100 citizenship items.
Sample Focus Group Statements

• “Raise our kids to be better than us for the next generation”
• “Right to refuse medical treatment”
• “Supposed to have laws that protect you”
• “Freedom of speech...when you're in a shelter, being able to speak your mind without everyone turning on you”
• “Being treated equal... When someone gets killed in our community...a white person, they have rallies, they have it on every channel but when it happens in our community it’s just another black man dead”
Concept Mapping Sessions

- Participants (n=66) were asked to sort the 100 items that were generated from the focus groups into piles/categories based on similarity.

- They also ranked each item on 2 dimensions (importance and possibility for self).

- Concept mapping software was used to analyze the individually-sorted categories. A seven cluster solution was revealed.
Based on the focus groups, research team meetings with persons in recovery, and concept mapping analyses, we have refined our conceptual framework of citizenship to include 7 domains:

- Personal Responsibilities
- Government & Infrastructure
- Caring for Others in Community
- Civil Rights
- Legal Rights
- Choices
- Stewardship
Citizenship Measure

• Our 45-item measure includes items from each of the 7 domains. Items were chosen based on the concept mapping analysis and research team meetings.

• Our purpose in developing this instrument was to help persons with mental illness, peer staff, mental health professionals, program planners and researchers enhance the citizenship of persons with mental illness through measurement of their “citizenship status” and through developing more targeted, precise, and effective citizenship interventions and supports.

• Note, however, that measure is one of citizenship generally, not solely for persons with mental illnesses.
Measure Validation

• The measure was administered to 110 individuals receiving services at a local community mental health center

• Convergent and discriminant validity was assessed through concurrent administration of the Quality of Life Interview (Lehman), Social Capital (World Bank), Sense of Community (Chavis and McMillan), Recovery Markers Scale (Ridgway)

• Citizenship subscale scores were computed based on average scores across items associated with each of the original 7 clusters
Demographic Characteristics

- 42% female, 55% African-American, 33% Caucasian, 19% Hispanic/Latino
- 65% single, 53% attended spiritual groups, 28% attended clubs/meeting
- 47% of the sample had a history of involvement with criminal justice, 54% had been homeless within their lifetime, 55% had a history of substance and/or alcohol abuse
Analyses

- Descriptive statistics on demographic characteristics
- Correlations between composite scores on all measures
- One-way ANOVAs was used to examine scores on Citizenship measure as a function of demographic characteristics
- Stepwise Linear Regression was used to examine demographic, sense of community, and social capital predictors of scores on citizenship, individual recovery, and overall well-being
Main Findings

• On average, respondents had lowest scores on Government and Infrastructure and highest scores on Choices

• Individuals with a history of involvement with the criminal justice system had significantly lower scores on 6 of the 7 subscales than individuals without criminal justice history. (Caring for Self/Others was not significantly different for this group)

• There were no other demographic characteristics that differentiated scores on the measure
Correlations

- Higher levels of citizenship is related to higher levels of:
  - Satisfaction with: living situation, activity, family relationships & social relationships, finances, safety, and health
  - Overall Quality of Life
  - Greater sense of wellbeing
  - Individual levels of Recovery
  - Sense of community (all domains)
  - Social capital -- trust: (in the government)
Citizenship scores were related to the satisfaction with activity level and relationships but NOT the amount of activity or contact.
Predictors of Citizenship

- Predictors of higher scores on Citizenship:
  - No Criminal history
  - Higher Sense of Community Emotional Connectedness
  - Higher Quality of Life: Satisfaction with Social Relationships
  - Higher Quality of Life: Satisfaction with Health
Summing Up

• Through this process, we believe we have gained a more nuanced understanding of citizenship. We hope to link measure development to future efforts to enhance citizenship and social inclusion for persons with mental illnesses.
Next Steps

In future research we will determine further convergent and discriminant validity of our instrument compared with related constructs. Additional psychometric properties to be evaluated include principal components factor analysis on responses to citizenship items. We also hope to test the impact of an enhanced citizenship intervention on community and clinical outcomes for persons with serious mental illness and criminal justice charges, a high percentage of whom will be currently or previously homeless or at current risk of homelessness.
References

- Rowe M. *Crossing the border: Encounters between homeless people and outreach workers*. Berkeley: University of California Press, 1999