Community-based system dynamics modeling of sensitive public health issues: Maximizing diverse representation of individuals with personal experiences for model development

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Community-based system dynamics (CBSD) is an increasingly popular method within public and community health research that accounts for complexity and provides translatable findings that can inform and implement change. CSBD can holistically account for health disparities and inequity, which is essential when modeling sensitive public health issues that are disproportionately experienced by marginalized and vulnerable populations (e.g., substance misuse, community and family violence, mental health). Including participants with personal experience (PEP) in model building activities such as group based modeling is necessary for model accuracy. However, the extent of PEP inclusion varies between studies; participants who are from marginalized backgrounds (e.g., racial, sexual, socioeconomic) are often difficult to recruit for a variety of reasons, including distrust of researchers/research and the relatively high time commitment burden placed on group model participants. A common approach is to have a small number of PEP act as representatives for all PEP / marginalized populations, in proportion to representatives from other system areas. However, the wide variety of PEP experiences may not be fully represented with a small group of individuals, and this underrepresentation may bias model development.

The purpose of this study was to explore a method to increase representation for marginalized and vulnerable PEP of sensitive issues in model development, and to highlight the diversity of models that can be developed with PEP who have a range of experiences related to this issue. We use a case study from a CBSD project on the association between alcohol misuse (AM) and intimate partner violence (IPV), and how this cycle disproportionately impacts Northern Plains Indigenous women. The community was a small metro area within the Northern Plains with a strong Indigenous population. 1½ hour group model building sessions, facilitated by the project PI and her staff, were held at three community organizations (a faith-based re-entry facility for women, a substance use rehabilitation center for pregnant women and mothers, and a domestic violence shelter for women) who are community partners with the researchers, and who are part of the project community advisory board. Participants were clients from each facility, and participation was open to all clients who were able to attend the session. Recruitment was conducted by sharing a meal with clients, talking about the project, answering questions, and facilitator disclosure of the personal motivations and reasons for their own interest in the topic. There was one modeling session held within each organization. Group 1 consisted of 5 women, Group 2 consisted of 20 women, and Group 3 consisted of 4 women. No identifying information was collected to increase annonyminity. We learned during the sessions that the majority of participants in each group self-identified as Indigenous (although this was never asked explicitly). Facilitation guides were tailored to accommodate a 1 ½ hour timeframe, while providing 1) sufficient time to develop a causal loop diagram model while accommodating busy schedules and external demands of participants, and 2) accounted for potential emotional or psychological distress elicited when discussing highly personal issues. Activities included variable elicitation and causal loop diagraming. For the latter, we opted for an informal "talking circle" style structure by prompting discussion with a question or variable, which allowed for conversation to progress naturally and respectfully, and encourage new insights, ideas, and themes to progress naturally, with a facilitator serving as the model illustrator.

In total, there were 35 variables generated from the three groups. Out of the 35 variables, 23 variables were mentioned in only one of the three groups. Figure 1, referred to as our "conceptual" model provides the main thematic constructs present in a model combining all 3 individual models. Colors for the model indicate the individual contributions of Group 1 (the faith-based re-entry facility; blue), Group 2 (the substance use rehabilitation for pregnant women or mothers; red) and Group 3 (the domestic violence shelter; green), and the consensus contributions (black). As seen in Figure 1, there was little overlap in what was discussed between all three groups. All three groups discussed the bidirectional reinforcing loops between heightened rates of AM and IPV, as well as heightened rates of AM and decreased rates of mental health. Critical subthemes, such as the mental health process, engagement in child welfare and justice institutions, community norms, and the importance of AIAN culture and identity to childhood family wellbeing, were unique contributions from individual groups. We present the individual organization models (Supplemental Figures 1-3) and our full consolidated model (Supplemental Figure 4).

The current study demonstrates that it is feasible to build comprehensive models with a variety of participants who are difficult to recruit to model building groups through the partnership with collaborative organizations. In addition, differences between group models demonstrate the need for (and strength of) diversity in regards to the ways that modeling issues of interest are experienced by individuals.This method illuminated the diversity of ways in which individuals with personal experience can perceive AM-IPV systems. Similar model building strategies can complement existing efforts to build representative models for stigmatized public health within communities.

Figure 1: Conceptual thematic causal loop diagram model representing the consolidation of all 3 individual organization group model