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Using community-based participatory research to address Chinese older women's health needs: Toward sustainability

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ABSTRACT

Although community-based participatory research (CBPR) has been recognized as a useful approach for eliminating health disparities, less attention is given to how CBPR projects may address gender inequalities in health for immigrant older women. The goal of this article is to share culturally sensitive strategies and lessons learned from the PINE study—a population-based study of U.S. Chinese older adults that was strictly guided by the CBPR approach. Working with Chinese older women requires trust, respect, and understanding of their unique historical, social, and cultural positions. We also discuss implications for developing impact-driven research partnerships that meet the needs of this vulnerable population.

KEYWORDS

Chinese community; community-based participatory research; older women

Introduction

The multifaceted nature of gender inequalities in public health is deeply rooted in a broad social, environmental, economic, and cultural fabric (Arber & Cooper, 1999; Dunlop, Manheim, Song, & Chang, 2002). While gender inequalities may cross all ethnic and class lines, there is a lack of culturally sensitive services and responses to address the needs of minority older adults. Therefore, the development of academic-community partnership for health promotion has become a popular strategy to help enhance health status of the disadvantaged populations, including women, older adults, or ethnic/racial minority groups (Israel et al., 2001). The collaborative ideal between university researchers and community groups is to maintain and sustain the partnership with a common goal (Williams, Labonte, Randall, & Muhajarine, 2005). The systematic collaboration, often coined as community-based participatory research (CBPR), is an innovative approach to engage a diverse range of partners representing various communities including academia, local community organizations, as well as the community members whose health is impacted (Wallerstein, 2006). With the emphasis on cocreating knowledge through a synergetic community-academic partnership, the strength of community-engaged research in increasing the relevance of epidemiology studies has been acknowledged as a paradigm shift in reducing gender disparities in health. In addition, community-engaged research has been institutionalized as a priority emphasis in translational research by the National Institutes of Health (Leung, Yen, & Minkler, 2004).

Whereas CBPR holds potential to bring rewarding outcomes in reducing gender inequalities in health, its practice can be challenging. Particularly, employing CBPR projects in minority aging populations may demand extra culturally sensitive measures tailored toward the local community's historical, cultural, and social contexts. A noticeable knowledge gap in the participatory research literature is the underreported exploration of addressing the health needs of older women from racial/ethnic minority groups, which often require additional culturally and linguistically sensitive measures.

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In order to fill in this critical void, the objectives of this study are to: (a) present the challenges faced in implementing a CBPR study approach to examine health inequalities facing Chinese older women in the greater Chicago area, and (b) detail lessons learned from addressing health inequalities facing Chinese older women.

Background

Health inequalities facing Chinese older women

Existing studies suggest that biological differences between older men and women could not fully account for the gender differences in health and well-being. Psychosocial factors may also play an important role by creating, maintaining, or reinforcing biological sex differences (Sánchez-López, Cuellar-Flores, & Dresch, 2012). Health studies of Chinese men and women have suggested differences in morbidity and mortality (E. Yu, 1982). Specifically, older women experience poorer physical, mental, and cognitive health; higher rates of elder mistreatment; lower rates of cancer screening; and higher rates of chronic disease and disability than men (Yi, Yuzhi, & George, 2003; Zhan & Montgomery, 2003). However, life expectancy of men is shorter than that of women (Zhan & Montgomery, 2003).

Similar to their counterparts in China, U.S. Chinese women have a longer life expectancy than men, with an average of 86.1 years (Centers for Disease Control and Prevention, 2013), but they do not necessarily live those extra years in good physical and mental health. Prior studies suggest that there are significant health disparities among older Chinese women, including lower preventive health service use, psychological distress, and social isolation (Dong et al., 2010; Kagawa-Singer et al., 2007). Cultural beliefs play a critical role in informing one's beliefs about health and illness; the stress of aging compounded with migration distress may make this group of immigrants even more vulnerable. With respect to preventive health, although evidence suggests that cancer screening is effective in detecting breast, cervical, and colorectal cancers, screening rates among Chinese older women have been lower than the general population (E. S. H. Yu, Kim, Chen, & Brintnall, 2001). Public health literature suggests that utilization of Eastern approaches to promote health and prevent illness may conflict with the Western health care concept (Tang, Solomon, & McCracken, 2000). For instance, Eastern approaches tend to include noninvasive remedies, whereas Western approaches implement chemically based therapies. Chinese older women who retain traditional beliefs may be less likely to seek cancer screening procedures.

In addition, Chinese older women are disproportionally affected by psychological distress. Specifically, the suicide rate among U.S. Chinese older women is a higher leading cause of death compared with the general aging population (Centers for Disease Control and Prevention, 2010). A prior study noted a threefold higher suicide rate among U.S. Chinese women aged 65–74 years; sevenfold higher suicide rate among the U.S. Chinese women aged 75–84 years; and 10-fold higher suicide rate among the U.S. Chinese women aged 85 and over compared to White women of the same age groups (Liu & Yu, 1985). Furthermore, Chinese older women in the United States may be at high risk to be victimized by elder mistreatment, due to the historically unequal power relations between women and men. Gender norms established by the patriarchal system led to gender inequality, whereby men dominated and women were subordinated. Moreover, the male and female behaviors constructed by the gendered culture may have also led to violent relationships. The vulnerability of Chinese older women necessitates a better understanding of the issue of elder mistreatment in this population.

Moreover, regarding interventions for psychological distress, women tend to have a greater concern about interpersonal relationships compared to men. Studies suggest that the Chinese relational self contributes to traditional Chinese women's concern about others, especially their families. In the hierarchical family system, traditional Chinese women's positive emotions rely upon each family member's fulfillment of their obligations for the family's integrity. Therefore, women are

more prone to the stresses of deprivation of interpersonal ties and, as a result, to psychological distress (Horwitz, White, & Howell-White, 1996). Interventions such as psychotherapy emphasizing an individual's growth and autonomy may overlook the importance of maintaining interpersonal harmony for Chinese older women (Hsiao, Klimidis, Minas & Tan, 2006).

However, due to the lack of systematic data on the U.S. Chinese population, there exists rudimentary understanding of many critical psychological and social well-being issues facing Chinese older women, rendering public health and policy goals specific to the needs of this population underdeveloped.

Historical, social, and cultural contexts contributing to health inequalities

Traditionally, gender roles based on Confucian teachings prioritize women's roles as wives, mothers, and caretakers of the family. The domestic perception of Chinese women can be traced to long-standing cultural values rooted in Confucian and Mencian teaching, as well as the patriarchal family structure, which requires that a woman move to her husband's family home when she marries (M. Yu & Sarri, 1997). Chinese women are often expected to be subordinate to men and therefore of lower social status. Families may emphasize development in favor of sons at the expense of daughters. Therefore, gender inequality in Chinese culture has resulted in women's greater exposure to education and economic disadvantages.

In spite of the considerable increase of Chinese women's socioeconomic status since the 1950s, the process of female liberation in China has not been completed. Older women are more likely to have lower socioeconomic status compared to men. They are also much more likely to be financially dependent on others and in need of higher levels of social support (Zhan & Montgomery, 2003). This social-economic gender inequality in China can be observed in many aspects, including its impact on health. Studies suggest that women are disadvantaged in health for almost all of a woman's life cycle, ranging from infancy, girlhood, and the childbearing years to old age (Yu & Sarri, 1997).

In addition, Chinese culture also greatly emphasizes filial piety and provides guidelines regarding obligatory roles and responsibilities of each person in the family (Dong, Zhang, Zhang, & Simon, 2014; Kagawa-Singer et al., 2007). Despite the valued role of sons in the care of seniors, filial piety obligations traditionally dictate women, especially the son's wife (daughter-in-law) as key to the provision of assistance. The daughter-in-law is expected to assist with domestic responsibilities in caring for the son's parents. The cultural expectations for dealing with caregiving demands may further influence how women perceive the caregiver burden, which may render women more vulnerable to caregiver stress and burnout.

Methods

Population and settings

The PINE study

The **P**opulation Study of Ch**IN**ese **E**lderly in Chicago (松年研究), or PINE, is a community-engaged, population-based epidemiological study of U.S. Chinese older adults aged 60 and over in the greater Chicago area. To our knowledge, the PINE study presents the largest epidemiological study of Chinese older adults in the Western hemisphere, and the word *pine* in Chinese symbolizes longevity, wisdom, resilience, successful aging, and inner strength. Briefly, the purpose of the PINE study is to collect community-level data of U.S. Chinese older adults to examine the key cultural determinants of health and well-being. The project was initiated by a synergistic community-academic collaboration among the Rush Institute for Healthy Aging, Northwestern University, and over 20 community-based social services agencies and organizations throughout the greater Chicago area (Dong, Wong, & Simon, 2014).

Based on the available census data drawn from the U.S. Census of 2010 and a random block census project conducted in the Chinese community in Chicago, the PINE study is representative of the Chinese aging population in the greater Chicago area with respect to key demographic attributes including age, sex, income, education, number of children, and country of origin (Simon, Chang, Rajan, Welch, & Dong, 2014). The study was approved by the institutional review boards of the Rush University Medical Center.

Strictly guided by the CBPR approach, the PINE study implemented extensive culturally and linguistically appropriate community recruitment strategies. With over 20 social services agencies, community centers, health advocacy agencies, faith-based organizations, senior apartments, and social clubs serving as the basis of study recruitment sites, eligible participants were approached through routine social services and outreach efforts serving Chinese Americans families in the Chicago city and suburban areas. Older adults who agreed to participate in the PINE study were then scheduled for a face-to-face in-home interview. We surveyed participants in their preferred language and dialects, including Mandarin, Cantonese, Toishanese, Teochew dialect, or English. Out of 3,542 eligible participants who were approached, 3,159 agreed to participate in the study, yielding a response rate of 91.9%.

Research outcome

Based on our findings, U.S. Chinese older women are vulnerable to psychological and social distress. The PINE study consisted of 1,833 older women and 1,326 older men. Depressive symptoms were more prevalent in U.S. Chinese older women than in older men; more than half of the older women (58.9%) reported having depressive symptoms, as compared to 48.1% of the older men (Dong, Chen, Li, & Simon, 2014). Older women were more likely to present somatic depressive symptoms and to develop moderate to severe depressive symptoms. Older age ($r = .09$, $p < .001$), lower income ($r = .07$, $p < .01$), poorer health status ($r = .34$, $p < .001$), inferior quality of life ($r = .17$, $p < .001$), and worsening health changes over the past year ($r = .23$, $p < .001$) were positively correlated with any depressive symptom in older women.

In addition, Chinese older women were more likely to report suicidal ideation than older men. Our findings show that the prevalence of lifetime suicidal ideation in older women was twice as high as that in older men (12.7% vs. 5.0%, $p < .001$). Our data further suggest that elder mistreatment is common among Chinese older women; a total of 15.8% of women participants reported being victimized by elder mistreatment since they turned 60 years old (Dong, Chen, Fulmer, & Simon, 2014). The prevalence of elder mistreatment was higher among women who had higher levels of education, higher levels of income, lived with two to three persons, were separated or divorced, spoke English or Mandarin, had only one child or had one to two grandchildren. In addition, our previous qualitative work further suggests that older women may identify psychological distress differently from men (Chang et al., 2012; Dong, Chang, Wong, & Simon, 2012). Older men were more likely to associate social conflicts as contributing factors to depression, whereas women were likely to report family conflicts. In addition, men often associated worsening of health outcomes with the impact of depression, whereas women perceived worsening social isolation in association with depression.

With respect to preventive care services, Chinese older women in the greater Chicago area reported a lower rate of cancer screening than the general population, including breast cancer, cervical cancer, and colorectal cancer. Of the 1,833 community-dwelling Chinese older women in the PINE study, 59.7% of the participants reported ever having mammograms in the past, 46.8% ever having clinical breast exams, 40.8% ever having pap tests, 24.4% ever having blood stool tests, and 28.5% ever having colonoscopies. These findings further underscore the urgent need to advance research and educational initiatives with culturally and linguistically appropriate measures.

Results: Challenges faced and lessons learned

Building on community strengths to address older women's health needs

Due to anti-Chinese sentiment and harsh racial discrimination in the past, the Chinese community has mistrusted government- and federally sponsored activities (Lee, 1992). Therefore, from the inception of this academic-community collaboration, our priority was to build trust with the community. Establishing a sustainable community-academic partnership allows us to develop appropriate research methodology closely knitted to the Chinese cultural context, in which a community advisory board (CAB) played a critical role in providing useful perspectives and strategies for conducting public health research in gender inequalities.

Board members were community stakeholders and residents enlisted through over 20 civic, health, social, and advocacy groups, community centers, and clinics in the greater Chicago area. Over half of the board members were women. The board is deeply involved in guiding a series of ongoing community health outreach initiatives on women and health issues. It was through the CAB meetings that the investigative team identified several pressing health needs facing older women, including depression, suicide, elder mistreatment, social support, breast cancer awareness, and preventive care issues. The board members worked alongside the investigative team in integrating these topics into community health outreach forums. Overall, the health workshops significantly improved older women's understanding of important health topics, particularly the topic of the risk factors and consequences of breast cancer (Dong, Li, Chen, Chang, & Simon, 2013). In addition, our CBPR approach added rigor to the PINE study methodology. With full community engagement and interviews conducted in the participants' preferred dialects, participants may have been more comfortable, more trusting of research assistants, and more willing to express emotions and to acknowledge their feelings.

Empowering Chinese older women through prevention and intervention initiatives

There is a great knowledge gap in our understanding of evidence-based prevention and intervention strategies regarding ways to improve the use of cancer screenings among U.S. Chinese older women. Knowing the risk factors and consequences of breast cancer may give Chinese older adults the impetus to utilize cancer screening. Chinese American women have a low level of cancer screening tests because of acculturation and modesty (E. S. H. Yu et al., 2001). In addition, Chinese older adults prefer to use Chinese medicine and delay Western therapies so as to preserve modesty, money, and time (Facione, Giancarlo, & Chan, 2000). Delay in the screening and treatment of breast cancer may decrease a woman's chance of survival. In order to overcome the barriers and challenges facing Chinese older adults, it is crucial to design, evaluate, and promote health education programs that are culturally relevant. Given the complexity of health determinants and disparities experienced by marginalized groups, such as older adults and ethnic minorities whose health behaviors are strongly intertwined with cultural beliefs, intervention must be developed from the knowledge of and respect for the community's cultural values (Minkler, 2005).

In addition, the rapid population growth of U.S. Chinese older adults demands a better understanding of their health indicators and inequalities (Lee-Lin et al., 2013; Taylor et al., 2002). A recent review suggests that there exists little evidence on effective strategies to disseminate and implement evidence-based cancer control interventions (Rabin, Glasgow, Kerner, Klump, & Brownson, 2010). Furthermore, few cancer control studies have focused on the dissemination and implementation of cancer control interventions among immigrant populations. As a result, not only are Chinese American women subject to unique language and cultural barriers, furthermore, their belief in Eastern approaches to medicine, avoidance of thinking about cancer, excessive embarrassment in discussing reproductive system-related topics, and using medical services only upon noticing symptoms may also delay their use of preventive health services.

Through conducting the PINE study, the research team has learned the critical importance of disease prevention and early intervention specifically tailored toward older women. Not only is the promotion of successful and healthy aging especially critical, we also need more targeted efforts in identifying at-risk older women. The research team is currently piloting a patient navigator program with the goal of improving breast and cervical screening rates among Chinese women and increasing the timeliness of diagnostic resolution of an abnormal breast or cervical screening. This comprehensive, community intervention developed between established community organizations and providers has proved to be effective for other racial/ethnic groups (Nguyen et al., 2006).

Leverage research for advocacy and public policy changes

Our study findings suggest that gender inequalities in public health issues, including elder mistreatment, depression, suicide, and social isolation, requires comprehensive advocacy and policy efforts in legislation at the local community, city, state, and federal levels (Dong, 2012). A major gap in the field of gender inequalities identified through our CBPR research projects is in the realm of public policy. Currently, two relevant legislations may have significant impact on addressing gender disparities in older populations: the Violence Against Women Act and the Elder Justice Act. The Violence Against Women Act is one of the most pertinent programs for the well-being of victimized women. The Act authorizes the attorney general to formulate grants for enhancing training and services and to end violence against women. This program is intended to assist law enforcement, prosecutors, and local courts on the issues of elder mistreatment. Furthermore, it allows social services organizations to conduct cross-training and to create as well as support multidisciplinary collaborative community responses to persons experiencing elder mistreatment. Despite interest in the prevention and treatment of violence against older women, it constitutes a very small fraction of the legislation (Dong & Simon, 2011).

On the other hand, the Elder Justice Act may be a potential opportunity to address gender inequalities in health and aging, as it is responsible for sponsoring and supporting training, services, reporting, and the evaluation of elder justice programs in community and long-term care settings. The full appropriation of the Elder Justice Act is critically needed, due to major gaps in funding, policy, research, education, and training in dealing with gender inequalities.

In addition, disparities in cancer, including incidence and mortality, facing Chinese older women warrant further attention. Economic barriers, such as socioeconomic and insurance status, can be lessened through general education about funding sources, free or sliding-scale clinics, and information related to state programs available to Chinese older women. Barriers can further be alleviated through education and broad policy changes. More research is needed to focus on current and anticipated developments in policy and legislation, treatment and technology, as well as environmental health issues.

Sustain academic–community partnerships with a humble approach

With the acknowledgment of the inherent power imbalance between researchers and disadvantaged older women, we have learned that a humble approach toward academic-community partnership in examining culturally and socially sensitive issues is of particular significance. Cultural humility is an ongoing process that requires researchers to enter into engaging conversations with older adults, communities, and colleagues (Tervalon & Murray-Garcia, 1998). Cultural humility and respect for the local community are critical for lowering sociocultural barriers facing Chinese older women. The starting point of the cultural humility approach is to fully engage in self-critique and self-evaluation with the goal of recognizing the inherent power imbalance between researchers and the local community at large (Cooper-Patrick, Gallo, & Gonzales, 1999). It is crucial for health care professionals to first acknowledge the assumptions and beliefs that are embedded in their own understanding before delving into the community's belief system (Hunt, 2005).

During our training for research staff, culturally and socially sensitive issues of elder mistreatment, psychological distress, and suicidal thoughts as such were given particular emphasis: for instance, how to encourage Chinese older women to speak up without being authoritative or making them feel a sense of losing face. The humble exchange of knowledge and experiences deepened trust among the community partners, researchers, and study participants from the outset.

In addition, much literature has been published on the strong structural challenges facing sustainability in community-academic partnerships. When combining two different systems, each presents its own goals, values, and limitations; this inevitably results in a series of debates and compromises in order to achieve a valued goal (Williams et al., 2005). The voluntary basis of collaboration further calls for a process-orientated, consent-based leadership with a humble approach in order to achieve this goal.

Conclusions

Despite a growing demand in CBPR studies, there exists limited empirical work on how to conduct community-based, action-oriented research with Chinese older women in the United States. We have learned that building on community strengths to address older women's health needs, empowering Chinese older women through prevention and intervention initiatives, leveraging research for public policy changes, and sustaining academic-community partnerships with a humble approach are important considerations in this collaboration. We believe our lessons shed light on the emerging CBPR literature in eliminating gender inequalities in this vulnerable population.

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