# Community Engaged Research
# Literature and Methodology Review

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# 1. Executive Summary

This paper examines the use of Participatory Action Research (PAR) as a potential methodology for work with older women.  To set the context, we first identify and summarize issues effecting older women in BC.  PAR is an emergent and dynamic research approach conducted by, with, and for communities. PAR engages a range of people and perspectives, including community members and partners in pursuit of practical solutions to areas they identify as concerning.  PAR shows great promise as an appropriate methodology for work with diverse and marginalized populations. We conclude this paper with recommendations on how best to conduct research in a process of continual reflection and progressive problem-solving utilizing a participatory action research methodology.

# 2. Background

## (a) Introduction

When it comes to sociological research, there is a gap in knowledge to action.  This gap can be attributed to a number of causes, including the reality that research findings do not always make their way into practice in a timely fashion.  As well, when working with marginalized communities, a sensitivity is often required that can make traditional research methods inappropriate. There is increased interest in finding ways to minimize this knowledge to action gap.  With older women as a focus, we set out to do just this.

Preliminary research from the Older Women's Dialogue Project has identified some of the hallmarks of a methodological approach that is appropriate for research with older women.  Accommodating women from diverse backgrounds, cultures, and abilities is key.  The methodology must also be grounded in a human rights context and be advocacy-focused with an emphasis on an older woman's experience.

With this intent, we set out to conduct a literature review on potential methodologies to expand the Older Women's Dialogue Project.  Through this review, we establish the importance and necessity of performing research that is responsive to the needs of older women.  To help us reach this level of understanding, this paper first briefly describes the social determinants of health affecting older women in British Columbia.  A systematic literature review then provides the necessary background to evaluate PAR as an appropriate methodology for research with older women.

## (b) Issues Facing Older Women in BC

### (i) Demographics and Population Distribution

Any research, as it affects older women, must be based on a solid understanding of the issues facing older women, with particular attention to gender, age, and disability.  Older

women in BC are diverse in many respects and their experiences throughout the life course contribute to circumstances and identities.  Most women experience stereotyping, marginalization or discrimination throughout their lives and into old age.  We must address the circumstances of older women in the context of their accumulated life experiences.  This section first briefly describes the demographics of older women living in BC, followed by attention to health issues, socio-economic status, income security, housing, and poverty.

Population estimates from BC Statistics suggest that in 2012, approximately 15.85% of the population was over the age of 65.  This figure is expected to increase as the baby-boomer cohort ages.  Due to advances in medical care, improved public health, as well as higher educational attainment and per capita income, life expectancy after the age of 65 has been increasing (CIHI, 2011).  The majority of seniors are women and it is predicted that women will continue to outnumber men into the future (Turcotte & Schellenberg, 2007).  Metro Vancouver has a higher percentage of both immigrant and visible minority seniors in comparison to the rest of the province, with the majority self-identifying as Chinese, South Asian or Filipino (City of Vancouver, 2009).

While life expectancy is increasing at a population level for both men and women, relative disparities exist and distinct populations are not experiencing equal gains.  The BC seniors' population is made up of many different groups (e.g., First Nations, immigrants, employed), each with diverse needs, strengths, environments, and ambitions (Mental Health Commission of Canada, 2011).  Ageism is a key feature of discrimination and marginalization.  Distinct populations may be excluded from data collection and thus marginalized further on the basis of dimensions such as ethnicity and sexuality (Fenge, 2002).  For example, lesbian, gay, bisexual, and transgender (LGBT) seniors may experience barriers accessing mental health services because of their own encounters with discrimination or prejudice.  As a result, the incidence of mental illness among the LGBT community is likely underreported (Mental Health Commission of Canada, 2011).

It is important to keep the invisibility of traditionally marginalized groups in mind and interpret general indicators of health and well-being with caution.  Moreover, in part due to differential life expectancy, older women face unique challenges with respect to their aging-related experiences and health condition compared to their male counterparts.  The need for a gender-specific analysis is clear (Wanless et al., 2010).

The quality of senior women's health can be measured with the indicators of function status and multi-morbidity.  Functional capacity refers to one's ability to carry out everyday tasks, both activities of daily living:- walking, bathing, toileting, dressing and eating;- and instrumental activities of daily living:- shopping, food preparation and housekeeping.  A loss of functional capacity becomes more common and more severe with age (CIHI, 2011).  Practicing positive lifestyle behaviours can help stave off function declines in people with disabilities (Feinglass et al. 2005).

(ii) Health Indicators and Disability

Multi-morbidity is an indicator of quality of life that examines the presence of multiple chronic conditions[1]. The likelihood of having at least one chronic condition increases with age, then plateaus for those older than 84 (CIHI, 2011). Healthy seniors, however, need less health care. This suggests that the amount of health care services seniors need is not determined by their age *per se* but rather by the number of chronic conditions they have. It is important to note that apart from mood disorders, this measurement does not reflect the presence of mental illness.

Age-standardized prevalence rates for older women are highest for the conditions of hypertension (13.70%), asthma (11.48%), osteoporosis (8%), and osteoarthritis (6.63%) (Provincial Health Officer's Report, 2008). Older women are not only directly impacted by the effects of chronic illness, but they also frequently fill caregiver roles and may be responsible for caring for spouses of family members who are also facing chronic illness. For older men, hypertension (13.43%) is also the most prevalent condition, followed by asthma (10.18%), diabetes (5.88%), and COPD (5.75%). Hypertension is the most prevalent condition for both sexes, which is noteworthy because it is associated with high rates of co-morbidities including heart disease, kidney disease, and stroke (Pai-Feng et al., 2013).

The onset of impairment and retirement are important social markers of transition to old age. Gender norms often shape choices in occupation as well as vulnerabilities to certain health problems. Throughout the life course, women largely perform unpaid care-giving. As older adults, women are at higher risk for stress, emotional strain, and musculo-skeletal injuries (CIHI, 2009; Stacey, 2005).

Women age 75 or older are more likely to be obese and physically inactive compared to men of the same age (Turcotte & Schellenberg, 2007). Physical inactivity not only increases an individual's likelihood of developing a number of chronic conditions, but also of mental health conditions. It can be difficult for seniors, their families, and health care workers to distinguish mental illness or substance abuse with problems related to growing older (Here to Help, 2009). The most prevalent mental illnesses among older people are, in descending order: mood and anxiety disorders, cognitive and mental disorders due to a medical condition, substance misuse, and psychotic disorders (Mental Health Commission of Canada, 2011). Although considered common in older adults, mental illness is not and should not be viewed as an inevitable consequence of aging.

As an illness, depression is the most common mental health disorder among older adults, affecting an estimated 15% of seniors in the community (CCSMH, 2006) and up to 44% of seniors in nursing homes (CIHI, 2010). Suicide is perhaps the most tragic consequence of mental illness affecting both men and women. Men over the age of 80 and older compose the largest cohort suicide rate in Canada (Mood Disorders Society of

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[1] Chronic conditions referred to are arthritis, asthma, cancer, chronic pain, depression, diabetes, emphysema or chronic obstructive pulmonary disease, heart disease, high blood pressure, a mood disorder other than depression and stroke.

Canada, 2009).  The National Advisory Council on Aging (2004) speaks well to the multifactorial lenses of developmental disability, mental health and illness:

> The notion and the reality of differences in capacity have often caused them to live parallel lives socially and economically.  This means that mainstream information on disease prevention may not be reaching them.  This is compounded by the rarity of experts of aging with developmental disabilities and the difficulties of communication- possible factors in preventable or undiagnosed conditions, and lack of access to proper care and other services in the areas of physical or mental health.  Social and financial supports are also critical to the continued well being of seniors with disabilities (p.6).

It is important to acknowledge the ways in which age and disability may intersect.  The incidence of certain types of impairments as well as activity limitations generally, though not inherently, increases with age.  Older women may not be affected with a disability *per se*, but may be discriminated against due to the perception that they will inevitably become disabled.  There are similarities in the ways in which older women and individuals with disabilities are situated in society, being associated with impaired bodies, incapacity, and a fear of becoming a burden.  Social distancing is furthered as both groups are largely excluded from the labour market, therefore experiencing structural dependency in combination with the experience of social segregation (Priestley, 2003).

### (iii) Social Indicators of Health

Housing also has a tremendous impact on quality of life.  Compared with those from poorer neighbourhoods, senior men living in Canada's wealthiest neighbourhoods had longer life expectancies.  Statistics Canada (2001) suggests that men age 65 and older in the highest neighbourhood income tercile could expect to live 1.1 years longer than senior men in the lowest tercile.  In contrast, senior women from the wealthiest neighbourhoods did not live longer than their counterparts in the poorest neighbourhoods, 0.2 years less on average.  Additionally, low-income seniors are more likely to live in neighbourhoods with fewer health-promoting features (McMunn et al., 2006) and are also more likely to engage in health-harming behaviours, such as smoking (Shanker et al., 2010).

Older women are more likely than men to live in poverty and have differential access to support systems, factors that may also shape health in later life (Pederson & Raphael, 2006).  Throughout the life course, women are more vulnerable to low-income status due to social and structural factors such as unpaid housework, care giving, low wages for so-called "women's work", lower pensions, and a lack of financial autonomy (PHSA, 2009).  Pathways to homelessness are also strongly gendered.  Low of income and violence against women are significant causes of homelessness (Chambers, 2013; Thurston et al., 2013).

Between 1998 and 2008 the average income for seniors living with family and unattached seniors has increased (National Advisory Council on Aging, 2006; Statistics Canada,

2009).  This is in combination with fewer seniors accessing public income-security programs such as Old Age Security (OAS) and the Guaranteed Income Supplement (GIS) (Milan & Vezina, 2011).  A senior woman who does not have a Canada Pension Plan or other source of income can receive an OAS of approximately $1,170 per month.  The same senior woman who has not lived in Canada for 40 years, but more than 10 years with residency prior to turning 65 is entitled to receive approximately $516 in OAS per month.  Individuals with an annual income below $15,672 may also qualify for a GIS maximum of $652 per month (City of Vancouver, 2010).

It is important to note the income gap between men and women.  The mean after-tax income from all sources for older women is 65% that of older men (Milan & Vezina, 2011).  This suggests that senior women are increasingly relying on retirement savings, other income sources, or simply doing without.  Aboriginal elders, recent immigrants, and unattached senior women are more likely than other seniors to be living in poverty (Preston et al., 2013; Statistics Canada, 2006).

Senior women continue to disproportionately be low-income, with significant barriers to employment, housing, and the attainment of the highest standard of health.  The combined effect of these barriers is, for many senior women, social and economic marginalization and the experience of sexism and ageism.  Despite these barriers there is remarkable resiliency among this population for overcoming challenges uniquely faced by senior women (Canadian Centre for Elder Law, 2013).

## 3. Participatory Action Research

Research needs to be adaptive to the diversity, strengths, and needs of senior women in BC. Older women may be discriminated against on the basis not only of age but also of other factors such as gender, ethnicity, class, disability, and sexuality.  Developing a research approach that is concerned with individual and community empowerment, issues of power and powerlessness, and honouring the experience of oppressed groups is paramount.

Participatory Action Research (PAR) is a method that has the potential to recognize and honour the capacity of older women to engage in research and bring about social change.  Following a brief background of PAR and its potential utility for work with senior women, this paper moves on to summarize the results of the literature review and concludes with a discussion of key themes.

### (a) Background

PAR and Community-Based Participatory Research (CBPR) are two examples of approaches that seek to bring together community and academic expertise to explore and create opportunities for social action and change.  There are many versions of these methodologies that are very broad in scope, with ancestral roots in action research (Whyte, 1991), participatory research (Cornwall, & Jewkes, 1995; Maguire, 1987;

Minker, & Wallerstein, 2010), and community development (Ife, 1995). Confusion exists within this field due to the multiple terms used to describe all or part of the process of moving from knowledge to action. In 2005, a literature review (Graham et al.) identified 29 terms used interchangeably either as nouns to describe the entire process or as verbs to represent specific actionable steps. More recently, Integrated Knowledge Translation (IKT) has gained popularity within health and social science research. IKT places great emphasis on partnered research.

Action research is a particular approach to systematic inquiry, as opposed to a research methodology as such. It differs from conventional quantitative and qualitative research paradigms in three ways: "in its understanding and use of knowledge; its relationship with research participants; and the introduction of change into the research process" (Hockley & Froggatt, 2006). The key principles guiding structured and rigorous CBPR are described well by Isreal (1998) (see Table 1, Appendix A). Action research is:

> a participatory, democratic process concerned with developing practical knowing in pursuit of worthwhile human purposes, grounded in a participatory worldview which we believe is emerging at this historical moment. It seeks to bring together action and reflection, theory and practice, in participation with others, in the pursuit of practical solutions to issues of pressing concern to people. (Reason & Bradbury, 2001, p.1)

For the purpose of this paper PAR will be used broadly as a term to encompass the above-noted dimensions. The roots of PAR recognize the importance of community members, especially racial and ethnic minorities, including groups who have historically or currently experience social, economic and/or political marginalization. Guiding principles of PAR are collaboration, mutually respectful relationships, shared responsibilities and an emphasis on local capacity building.

With all of the above approaches to action research there is a clear emphasis on community[2]. This is contrary to community-placed research, located in but not significantly involving the community (Horowitz et al. 2009). The term 'community participation' may elicit different perceptions of what level or process of community engagement qualifies participation. It is reasonable to question what is meant by community participation. Engagement with community members is "a process whereby community members take part in the identification of their needs, setting priorities, identifying and obtaining means to meet those priorities, including the development, implementation, and evaluation of those means in terms of their outcomes" (Koelen & Van der Ban, 2004, p.138). Although definable in theory, it can be difficult to interpret the notion of community engagement when there is inconsistency in describing the research process. The use of general terms such as participation, engagement, or involvement when there is no reference to what these terms actually encompass or how they will occur may lead to differential interpretation. Pretty (1995) has developed an

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[2] Community should be interpreted abstractly as all who will be affected by the research.

instrument to distinguish different levels of community participation, which can help to screen projects on their participatory characteristics (see Appendix B).

The operating principles that guide PAR are conceptually well-grounded. However, in practice they remain broad in scope and are seldom mapped out in explicit terms. As PAR gains currency as a research strategy of choice for the community sector we believe there is a need to revisit what have become the conventions of PAR and consider how these are enacted in practice. We seek to address the conceptual and operational practices of conducting PAR day-to-day. Various epistemological, methodological, and practical challenges confront PAR. With this in mind, we move on to explore the conventions of PAR and examine how these are enacted in practice.

## (b) Literature Review Methodology

For this literature review, we searched PubMed, Medline, ERIC, Web of Science and EBSCOhost with the search terms: community based participatory research, participatory action research, action research methodology, community research, participatory research, and peer research. The review was conducted between July -August 2013. The initial search produced over 3,000 non-duplicated results. Our next step was to combine the search results with the key words: seniors, older people, older women, elders, and geriatrics. Only journal articles written in English were included.

The results of this process yielded 261 articles. After reviewing all abstracts and removing those that did not involve older adults and PAR, there was a remaining pool of 136 articles. Because of the limited research exclusively on older women, articles that involved older women and men were also included. A full list of references for the sources included in our review can be found in Appendix C.

We divided the articles into two categories: first, PAR research methods and, second, PAR case studies. The first pool of articles (n=49) contains discussion articles that informed the background section of this paper. The second pool (n=87) contains research articles involving seniors with PAR. This is where we chose to focus our analysis. We reviewed all 87 articles and selected 32 of these whose adherence to PAR principles was sufficient to merit their use as exemplars in this review. Following the lead of other successful literature reviews under this topic area (Blair & Minkler, 2009), articles that referred to PAR but did not emphasize the methodology were excluded from further analysis.

## (c) Summary of Review

The literature review identified a variety of PAR approaches within a broad range of social contexts. The results of the analysis can be seen in Appendix D. Results of research are dichotomous and focus on either the exploratory or action stages of PAR.

## (i) Exploratory Process

The aim of the exploratory phase is to generate knowledge to better inform health and social research. It includes making sense of phenomena. Of the 32 articles reviewed, 9 focused on knowledge creation. This approach was used with populations with whom there was limited previous research in order to examine perceptions and help-seeking behaviours and to capture the experiences of a population.

Methodology included questionnaires, surveys, observation, focus groups, sharing circles, and phone interviews. Older adult involvement in the research varied. Consulting the Ladder of Pretty (see Table 2, Appendix B), the highest form of engagement within this vein of PAR literature was Functional Participation.

## (ii) Action Process

The action component of PAR represents the implementation or application of knowledge. Central to this stage is identifying an issue that requires attention and researching solutions or creating a tool to address the problem. The "doing" of research in this stage is broad in scope, including: adapting knowledge to a local context, tailoring interventions, monitoring use, and evaluating outcomes. Of the 32 articles reviewed, 23 addressed the action stage of research.

Approaches to this stage include model or program evaluations, focus groups, theater performances, stakeholder meetings, photovoice, and sharing circles. Key concepts in this vein are tailoring research questions to address the problems identified by stakeholders and tailoring dissemination strategies to better reach the intended users.

## (iii) Conceptual Frameworks

A number of conceptual frameworks have been identified in this review. The interrelated stages of PAR are depicted well by Everingham et al. (2009) (see Appendix D). This approach is common in PAR. In this approach, potential gatekeepers are identified and asked to participate in the research process. Participants then identify areas of concern and agree on priorities. In a linear fashion, participants brainstorm solutions and actionable steps followed by a reflection process. Alternatively, this process may also be viewed as a cycle of planning, observing, and acting, outlined well by Riel (2007) (see Figure 2, Appendix E).

Another approach is to involve stakeholders and end-service users in the project through the formation of working groups. In this process, stakeholders participate in brainstorming sessions to share ideas, stories, and ideals. A timeframe and initial focal point is determined. Co-researchers then record group interactions and the path that leads to the topic under discussion. Participants' views are rooted in their lived experience and researchers analyze themes from different working groups. The final stage is to reflect on observations and engage participants in reflecting on their experience. Triangulation is often used to validate research findings. An example of this approach is described well in Ottmann et al. (2011) (see Appendix D).

Ethnography and critical social theory is another approach present in the PAR field. A framework for this approach is described well by Averill (2005). The guiding principles of this approach are to evoke the perspectives of the community through ethnography and to conduct ethnography from a critical perspective. This means integrating relevant sociopolitical contexts such as culture, aging, and gender throughout and within the analysis. In many ways this approach is a critique of ideology and power in combination with the tenants of PAR. The stages of this process may be adapted depending on the context of research. It is important to note that ethnography and critical social theory are deep areas of study that are outside the scope of this review.

## (d) Discussion

In this section, we seek to confront the nuanced understandings of PAR principles and concepts as identified in the literature review. PAR is underscored by a shared set of core principles and values including a focus on empowerment, capacity building, and system change as well as intent to balance research and action (Isreal et al, 2008). Given the pragmatic position of PAR, it is possible to analyze the quality of research by its ability to meet these requirements. For conceptual purposes, we linearly describe six themes generated from the literature review, although it is important to note that the themes are often interconnected:

> (i) Participation, Democracy, and Emancipatory Agenda
> (ii) Developing Relationships
> (iii) Forming Community Partnerships
> (iv) Concerns about Research Rigour
> (v) Implications of Researching Vulnerable Populations and Sensitive Issues
> (vi) Democratic Nature and Types of Knowing

We pay particular attention to the issues of community engagement, partnerships, empowerment, and working with diverse and potentially marginalized older women.

## (i) Participation, Democracy, and Emancipatory Agenda

Many researchers addressed the issue of participation, which distinguishes work in the PAR field. Implicit in this is a recognition of power relations that many constrain involvement. This has been identified as a challenge for researchers who are typically accustomed to making decisions. Understanding the context of inequality and power, and therefore facilitating individuals to voice their own ideas and beliefs, contributes to an alternate system of knowledge production by older people themselves.

Unpacking the who, what, and how of PAR means thinking about what would make sense for a particular population. Optimal participation will depend on the purpose and context of the PAR project. Adaptivity is key. PAR has the potential to contribute to capacity building and systems change at the individual, organizational, and community level.

When working with minority and marginalized senior women the process of incorporating them in the research direction has been met with success (Fenge et al., 2009; Ottmann et al., 2011). This is despite a well-established perception that recruiting and retaining older adults in research can be difficult (Norris, 2007). Incorporating senior women in the development of knowledge translation tools has many benefits including: increased efficacy, improved relevance and cultural sensitivity of data collection tools, greater nuance in the interpretation of findings, and also helping in the translation of findings into action to improve programs, practices, and policies (Blair, 2009). Participants in the research process have reported the following benefits: development of new skills and knowledge, personal development, support and friendship, enjoyment, and satisfaction. Alternatively, negative impacts can include: feeling emotionally burdened, overloaded with work, and frustrated with the limitations of involvement. From a pragmatic perspective, participation is an instrument for improving the quality of the research.

## (ii) Developing Relationships

From the outset of a project, the division of labour, responsibilities, expectations, and remuneration should be made transparent. Developing bidirectional trust is essential. This can be challenging when not all PAR participants or stakeholders will participate equally in the project. Addressing equity in PAR is fundamental. One promising approach is to develop project expectations collaboratively with all partners and compose a memorandum or letter of understanding (Love, 2011). Forming relationships with community members takes time best invested at the outset of a PAR project.

Time constraints, funding deadlines, and quality of data collection can be significant challenges for participatory research. Even the perception of time constraints can act as a threat, impacting interpersonal dynamics of a project. This may project defensiveness to a community as tasks are split and aspects of the research are neglected. Such behaviours have the potential to undermine integrity. It is important to consider how PAR can facilitate community control and involvement within time constraints.

Communication skills that foster reciprocal relationships and dialogue are essential. Kur, DePorres, and Westrup (2008) refer to a threefold process: dialogue with self, with peers, and with supervisors or coaches. In PAR there is an opportunity to incorporate all three processes within a learning situation. The reflection that follows this process can facilitate researchers to reflect on interpretations, hidden assumptions, and bias.

The hallmark of a genuine PAR process is adaption as both participants and researchers come to understand what is happening and what is important to them. A major benefit reported from PAR for researchers is the challenge of their beliefs and attitudes as well as a better knowledge and understanding of the community. This is in tension with a loss of power over the research process, higher demands on resources, and a slower pace of research compared to non-PAR projects.

Inherent in this dialogue is an acknowledgment of power and powerlessness. Critical reflexivity addresses the position of the researcher at all stages of the research process itself. Analyzing the PAR process includes questioning underlying assumptions and addressing the power differential inherent in the relationship with the community and stakeholders. Critical reflexivity can be a valuable tool to assist in the continual questioning of assumptions and thus of the knowledge creation process. Researchers agree that incorporating a critical reflexivity process with an explicit values base can increase the quality of PAR in terms of rigor, authenticity, transparency, and transferability (Springette, Wright, & Roche, 2011).

### (iii) Forming Community Partnerships

Partnership formation is the cornerstone of successful PAR. Given the importance of forming collaborative partnerships between community members and researchers much attention has been given to the daunting nature of this task. Notably, Braithwaite et al. (1989) suggest an approach that may be helpful in guiding researchers through the community partnership process (see Table 3, Appendix F).

The process of coming to know a community is an art as much as a science. Good partnerships originate from the development of positive, beneficial relationships that are mutually supportive between local leaders, funders, and participants. Quality PAR identifies community strengths and assets, not solely an itemization of problems. A major strength reported by many studies was the formation of a community advisory group that was valuable in verifying cultural appropriateness.

In large part due to the inherently social and collaborative nature of PAR, it is inevitable that a PAR project will have both foreseen and unforeseen challenges. While this report points to common pitfalls, it is essential that challenges be transparently addressed as they arise. In an ideal situation all barriers encountered would be discussed with partners and jointly addressed through a problem-based approach. Some barriers that may arise, as identified in the literature, are summarized in Table 4, Appendix G.

### (iv) Concerns about Research Rigour

Another issue identified in the literature is the concern that PAR is not a robust research methodology. PAR faces many of the same criticisms as other qualitative research methodologies. The smallest sample size in the literature review was 7. Almost all samples were nonrandom, rendering the generalization of data impossible. It is reasonable to question when a researcher would know they are conducting "good" PAR.

Although this concern is important, PAR seeks to provide exemplary rather than generalizable data. PAR study designs tend to have more flexibility than traditional investigation-driven quantitative research. Reason and Bradbury (2008) speak well to the issue of rigour in PAR, noting that the researcher's attention is devoted to questioning if the research question is valid, in the sense of coming from, or being important to the

community. The tension here is between research conducted in artificial settings where bias can be controlled as opposed to research undertaken within a community where bias may only be minimized.

## (v) Implications of Researching Vulnerable Populations and Sensitive Issues

One of the major benefits of PAR projects is in honouring the knowledge and experience of oppressed groups. Literature has identified the "invisibility" of older lesbian woman, both within and outside research (Averett, Yoon, & Jenkins, 2013). "Triple discrimination" has been termed to describe the experience of both ethnic and gay older woman (Harper & Schneider, 2003). This is particularly important to research involving older lesbian women who have lived and grown old in a society with changing views towards homosexuality. Awareness of power and control when working with traditionally marginalized and or discriminated populations is essential. PAR promotes an alternate system of knowledge based on people's role in setting the agenda, heavily weighted on an egalitarian stance.

It is important to keep in mind the paradox of PAR. Minority populations are frequently only made "visible" after researchers have identified them. PAR is a useful tool for allowing vulnerable populations to have a voice in defining their lives and research needs but only to the degree that they are identified by researchers. Self-representation and the identities of minority groups are socially constructed phenomena. The way we interpret gender, class, race, culture, and ethnicity is as important as ever.

Recognizing and providing the space for diversity in PAR is essential. Diversity should be seen as a key theme. The experiences of older women from ethnic backgrounds are vast. It would be both impossible and inappropriate to try to cast a wide description of the population. Older women may be hesitant to participate in research for fear of identifying with a particular group, facing shame, discrimination, reliving a painful experience, or a perception of danger. For these reasons sampling and recruitment of vulnerable populations about sensitive or personal issues may be difficult. Research using snowball sampling has been met with success to overcome this challenge.

First Nations communities have much strength, including interconnectedness to family and a pervasive spirituality. Dominant methodology in work with First Nations emphasizes the role of family, spirituality, and traditional ways of knowing. As with any research with First Nations communities, due attention is required to ensure cultural sensitivity. The OCAP principles of ownership, control, access and possession of research are particularly salient.

## (vi) Democratic Nature and Types of Knowing

A large focus of the research in this field incorporates a worldview within which all forms of knowledge that come to the table are valued. This is in line with the concept of an experiential expert. A number of studies, while conceptually well-grounded in PAR principles, have questioned the tension between community lay perspectives and the

pursuit of scientific rigour. It is important to recognize differences not only between participants and researchers, but also between participants themselves may move the research in unexpected directions. Again, we note the co-creative nature of PAR requires facilitation so that trust can be built and maintained based on the values of dignity, mutuality, and reciprocity (Springett, Wright, & Roche, 2011).

Central to literature in this field is the impact of PAR beyond the production of academic knowledge. In 9 studies a tool, often referred to as an outcome of knowledge translation, was produced. Quantifying the outcomes of this process can be difficult. A tool may be developed for practical use or, more abstractly, an emancipatory outcome may be changing the way people think or act in their community (Johansson & Lindhult, 2008).

Evaluating project outcomes and communicating results to funders may need to be adaptive to abstract perceptions of community change. Primacy of the local context cannot be overstated. The strength of PAR is the development of local theory. However, this can also be problematic if stakeholders and funders are accustomed to standardized interventions. In this regard, PAR researchers are often in a difficult position when competing for funding. Narrative accounts of the local situation, especially for marginalized communities, can be an effective starting point to ground knowledge production in lived realities.

Caution is needed when scaling up PAR initiatives. The results of this analysis can by no means replace the important process of coming to know a community. The transfer of methodology from one community to the next is largely viewed as inappropriate. Respecting the primacy of the local context is about understanding the contextual conditions of a community and how they differ from the setting in which the knowledge was produced and reflecting on the consequences of this difference.

## 4. Concluding Remarks

Our analysis has revealed large variability in the qualitative methodology of PAR. Common approaches included focus groups, semi-structured interviews, and working action groups. It is likely that the most appropriate method will depend on the context, needs, and desires of the community. Flexibility is key. Rigid assumptions about senior women requiring a particular methodology (e.g. focus groups or semi-structured interviews) may be a significant constraint on the research.

A successful PAR project will require reflexivity and a willingness to critically appraise personal and contextual biases. This includes dedicating serious time to engaging stakeholders and identifying potential stumbling blocks at the onset of a project. Dialogue about roles, responsibilities, and outcomes with the understanding that PAR is a dynamic process is essential.

The democratization of knowledge – viewing the participant as an expert with important information to share – has the potential to lead to healthier communities, not only

because of the results of a research project, but also through the process of conducting research itself.  In an ideal situation, long-lasting relationships with community members will emerge from the project.  Community activism may further flow from a project by putting the research results into the hands of concerned, engaged, and empowered women.

Given the emancipatory and empowering nature of PAR, we believe it is an appropriate approach to research with older woman.  We are excited at the potential for charting new directions and to continually question how we may better integrate community perspectives.  By putting the voice of older woman firmly on the agenda we hope to gain valuable insights into their lived experiences and produce quality research that is accountable to the community that it serves.

**Table 1. Characteristics of CBPR**
1. Recognizes community as a unit of identity;
2. Begins with and builds on strengths and resources within the community;
3. Facilitates collaborative, equitable partnership in all phases of the research, involving an empowering power sharing process;
4. Promotes co-learning and capacity building among all partners involved;
5. Integrates and creates a balance between knowledge generation and action for mutual benefit of all partners;
6. Emphasis on local relevance of public health and social problems and ecological approaches that address the multiple determinants of disease and well-being;
7. Disseminates findings to all partners and involves all partners in the dissemination process;
8. Involves a long-term process and commitment (Isreal et al., 1998).

**Table 2. The Ladder of Pretty (1995)**

| | |
|---|---|
| 7. Self Mobilization | Community members set their own agenda and organize for action. Professionals have a role in the background, are facilitative and supportive but only if asked. |
| 6. Interactive Participation | Professionals and community members work as equal partners in defining the problems or needs and the strategies for change. There is a sharing of knowledge and valuing of 'local' or lay knowledge. Professionals facilitate and support the process. |
| 5. Functional Participation | Community members are involved in decision-making and the development and execution of programs or activities. Professionals are in control and take responsibility for the process. |
| 4. Participation by Consultation | Community members are asked to give their opinions on the program plans. The professionals decide what to do. |
| 3. Participation by Information | Community members are informed in an early stage about the program plans and are given the opportunity to ask questions. |
| 2. Passive Participation | Professionals are in control of the program; community members are informed about the program. |
| 1. No Participation | Community members are not informed about the program, only about the activities for which they have been recruited. |

Table 2: Adapted from Pretty et al. 1995

*Appendix C - Literature Review Sources*

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## Appendix D - Analysis of Literature

| Authors | Key Partners | Sample | Research Aims | Nature of Older Adult Involvement | Methods | Key Findings | Action Outcomes |
|---|---|---|---|---|---|---|---|
| Baur, V., & Abma, T. (2012) | Older adults in Dutch care home; researchers | 7 | Explore relational empowerment though resident participation | Advocated for policy change, set agenda | Weekly meetings with participatory approaches to democracy | Building interpersonal trust, social identity and joint purpose facilities empowerment | Group empowerment and meal improvement |
| Brown et al. (2011) | Nursing staff | 48 | Identify and change barriers to pain-management | Participated in a facilitated critical reflections | Emancipatory action research approach | Psychological safety, leadership and oppression influences effective nursing practices | "Psychologically safe spaces" to develop effective person-centered care |
| Chadiha et al. (2011) | Researchers; older urban African Americans; Healthier Black Elders Center | 541 | Explore volunteer recruitment methods | Data collection; recruited volunteers | Logic model program evaluation | Over 7 years enrolees in a research volunteer registry increased from 102 to 1273 enrolees. | Targeted outreach to underrepresented groups to build a registry of volunteers for health research promising strategy |
| Dennis, B., & Neese, J. (2000) | Researchers; Neighbourhood Outreach Program | 153 | Recruitment and retention of African Americans into research studies | Interviewed | Spheres of justice; interactional model; multisystem approach | Successfully engaged diverse populations by: historical cognizance, sanctioning, trust-building, mutuality, | Recommendations for community engagement |

| | | | | | | recognition of heterogeneity and researcher self-reflection and introspection | |
|---|---|---|---|---|---|---|---|
| Dong et al. (2012) | Chinese American Service League; Researchers at Rush University Medical Center | 78 | Examine the perceptions, social determinants of depressive symptoms of a Chinese aging population in Chicago | Participated in interviews and focus groups | Questionnaires and semi-structured focus group interviews | Depressive symptoms common among older adults in study population | Identified health concern |
| Dong et al. (2011) | Researchers; Chicago community centre | 39 | Examine perception, knowledge and help-seeking tendency toward elder mistreatment among Chinese older adults | Participated in focus groups | Focus group interviews | Chinese older adults have limited knowledge of help-seeking resources other than local community centers | Need to highlight the pervasive public health problem of elder mistreatment |
| Doyle et al. (2010) | Researchers; informal group of service providers; older adults | 205 | Older people's use and perceptions of community services. | Consultation on questionnaire design and administration; delivery of surveys; report | Administration of a questionnaire to 205 older adults and 7 focus groups with service providers, | Perceptions and uses of community services | Elders trained in research methods; knowledge sharing |

| | | | | | | | |
|---|---|---|---|---|---|---|---|
| | | | | approval; implementation | caregivers and support workers | | |
| Everingham et al. (2009) | Researchers; stakeholders; service providers; Australian seniors | 37 | Understand issues impacting on older people's capacity to access relevant information | Composed working action group, participated in group meetings. Advised interpretation of results | Working action groups to explore criteria for improved systems of information dissemination. Formation of a working action group for advisory purposes | Relevance and accessibility are barriers to relevant information at the local level | Developed framework for the participants to implement development plans. Empowerment of working action group |
| Feldman et al. (2011) | Researchers | 250 attended performance; 29completed survey | Investigated using theater performance as an engagement tool for key life events | Watched play and conducted semi-structured qualitative surveys | Likert scale survey; qualitative 'general comment' feedback | Theater performance useful is a useful learning tool for working with older adults | Further investigation of theater performance as BCPR method |
| Fenge et al. (2009) | Older lesbian women and gay men; Help and Care voluntary agency; Bournemouth | NA | Reflective study on the needs, experiences and aspirations of older lesbian women and gay men | As volunteers designed questionnaires; undertook qualitative interviews; analyzed data | Volunteer conducted narrative interviews | Volunteers from marginalized communities can undertake research projects with appropriate support | Narratives of PAR process |

| | University | | | | | | |
|---|---|---|---|---|---|---|---|
| Fragnar, L., & Depczynski, J. (2011) | Older nurses and allied health workers; researchers | 80 | Identify aspects of work that have become more difficult for rural health workers as they age | Attended workshops and focus groups | Focus group; thematic content analysis | Identified tasks and aspects of work that have become more difficult for older health workers | Report of older health workers difficulties at work |
| Goins et al. (2011) | Researchers; tribal authorities | 28 | Develop a tribal participatory research conceptual model | Trained in research methods; input in study design | Focus groups | Recommends incorporating dissemination as a central tribal participatory research method | Identified tribal participatory research model |
| Gong et al. (2009) | Service Employees International Union United Long-Term Care Workers Union; Public Authority; University of California; National Institute for Occupational Safety and Health | 46 | Describe case study to illustrate how alliances among various community partners could be united to formulate policy directions | Some seniors on project team; conducted | Focus groups; key informant interviews; stakeholder meetings | Strong community partnership, participation, and shared values contributed to successful formulation of policy initiatives | Formative evaluation of partnership team capacity |
| Green et al. (2012) | Older people; researchers | 43 | Provide commentary by older people on | Study design; fieldwork; report writing | Focus groups | Identified concerns of hospital visitation | Recommendations for practice that could improve |

| | | | | their experiences as visitors to hospital or as patients receiving visitors | | | | hospital visiting |
|---|---|---|---|---|---|---|---|---|
| Gum et al. (2012) | Researchers; four African American churches | 60 | Solicit input to address older adults mental health needs | Participated in focus groups; Older church leaders acted as facilitators | Focus groups; survey | Participants viewed mental health holistically; identified strengths and resources in church's; open to collaboration | Wellness program developed |
| Harrison, A, & Brandling, J. (2009) | Researchers; clinical staff in hospital; patients; care givers | NA | Explore concepts of action research within senior mental healthcare | Participated in focus groups, interviews, and collaborative reflection sessions | Observational; focus groups; interviews; collaborative reflection sessions | Identified potential solutions to address caring for older people with mental health needs | Highlights complex nature of action research |
| Holkup et al. (2007) | Researchers; community facilitators; Native American families | 10 families | Piloted and implemented a elder mistreatment program in a northwestern Native American community | Participated in family meetings | Family meetings with information sharing and plan development | Families accepted and appreciated family care conference intervention | Culturally anchored and individualized means of identifying Native American elder's needs |
| Hulko et al, (2010) | Health authority; Elders from 3 | 21 | Explore the views of First Nations Elders on | Advisory board members; | Sharing circles; interviews | Memory loss and memory care in First Nations | Means to protect and revive traditional |

| | | | | | | | |
|---|---|---|---|---|---|---|---|
| | First nations communities; researchers | | memory loss and memory care in later life | participated in sharing circles and interviews | | communities has changed over the past century, including attributes that cause memory loss and community response | knowledge and ways of life in order to prevent dementia |
| Hutnik et al, (2012) | Researchers | 16 | Describe socio-economic stories of Centenarians | Interviewed | Interviews | Identified common experiences and themes | Narratives of 16 Centenarians |
| Lichtenberg, (2011) | Researchers; Older adults; Community Centre | 723 | Examine strategies to recruit minority elders into health research | Interviewed; Advisory board members | Telephone surveys | Older women had higher participatory rate and reported less disability compared with men | Telephone recruitment may be used effectively |
| Liu, et al. (2006) | Researchers; Elders; Government officers; village leaders | 25 | Determine health promotion issues concerning disadvantaged elders health in a rural Chinese village | Participated in focus groups; advisory group | Focus groups | Partnerships are challenging and time consuming yet necessary | Identified barriers and solutions to academic-public partnerships |
| Nomura et al. (2009) | Researchers; older people with dementia; caregivers | 37 | Describe the implementation and process evaluation of a program evaluation based on cognitive rehabilitation | Focus group interview used for assessment | Observational; written comments from caregivers; phone interviews | Cognitive rehabilitation theory was useful to restore lost procedural skills | Illustrated importance of interventions for both community dwelling elderly with early dementia and their family caregivers |
| Ottmann et | Researchers; | 8 | Reports on the | Focus | Focus groups | Outlines key | Development of |

| | | | | | | | |
|---|---|---|---|---|---|---|---|
| al. (2011) | older people; service providers; government representatives | | implementation of a multi-stakeholder coproduction approach to the development of a consumer directed care model | groups; deliberation sessions | | considerations regarding engagement methods including the involvement of older people with complex needs | coproduction methodology |
| Perry et al. (2011) | Researchers | 30 | Examined a framework on promoting action on research implementation in health services | Older adults among those interviewed but no explicit inclusion | Qualitative interviews | Matched factors described by staff as important with a previously identified framework model. | Knowledge translation of staff recommendations |
| Phillps et al. (2011). | Researchers | 405 | Investigated the psychometric properties of an instrument designed to assess clinician confidence during end of life care | Older adults among those interviewed but no explicit inclusion | Instrument was administered | Instrument identified as useful in assessing and monitoring clinicians perceived capacity to provide a palliative approach | Enhancement of clinicians' self-efficacy because of t increased opportunities to acquire and apply palliative care competencies |
| Ling et al. (2010). | Hospital staff; Researchers | 9 | Action research project designed to improve the care of older people at risk of delirium | Older adults among those interviewed but no explicit inclusion | Sharing stories and experiences caring for people with delirium in group | Development and implementation of a Delirium Alert Protocol | Staff learned about PAR process and empowered on how they can change practice |

| | | | | | meetings | | |
|---|---|---|---|---|---|---|---|
| Jini et al. (2009). | Community partner; two graduate students; research faculty; external funder | NA | Documents a community-based participatory evaluation research project | Participated in interviews and focus groups | Observation; interviews; two matched comparison focus groups | Participatory evaluation model is an effective means to know if program services are effective | Identification of promising aspects and shortcomings, contributing to the methodological understandings of CBR |
| Radda & Jean. (2011). | Community research group; multiple community organizations; older people | NA | Describes the process of creating and maintaining alliances to address the health of older adults | Participation varied from one case to the next | Descriptive analysis of alliance building processes | Provides examples of the alliance building process, challenges faced and lessons learned | Termed 'living alliances', contributing to the field of CBPR methodology |
| Radebaugh et al. (2011). | Researchers; health professionals; rehabilitation centre | 16 participants of interview; 11 of focus group | Describes the process of creating a fall prevention toolkit | Participated in interviews and focus groups | Key informant interviews; focus groups | Determined criteria to develop education and awareness criteria for fall prevention among older adults | Developed a fall prevention toolkit |
| Roberto et al. (2013). | Researchers; community advisory group representing victims | 72 in focus groups; 10 individual interviews | Identify opportunities and challenges in promoting community support for older women experiencing | Participated in interviews; comprised part of advisory committee | Focus group interviews with service providers; individual interviews with survivors of domestic | Insights generated during this project produced a framework to address intimate partner violence among older women in rural communities | Development of framework |

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|---|---|---|---|---|---|---|---|
| | | | intimate partner violence | | violence | | |
| Sabir et al. (2006). | Researchers; practitioners | 18 practitioners; 7 researchers | Seek to develop a process to bridge the gap between aging-related research and practice | Participated in workshop | Consensus model workshops | Demonstrated the value of close interaction between the ageing-related research and practice communities | Recommendation of consensus-conference model as bridge between research and practice |
| Saltus, & Folkes, (2013). | Researchers | 21 | Report on a qualitative exploratory study conducted to explore what dignity and care mean from the perspectives of older Black Welsh individuals | Participated in interviews | Semi-structured interviews | Notion of care is understood as 'caring about' and is seen to be a key indicator of dignity | Reveals the intersections of care and minority ethnicity |

Come together → Identify common concerns and agree on priorities → Explore and analyse → Plan → Act → Review → Modify Plans → Revise Action → Evaluate

Figure 2: Cycle of Problem Solving with Action Research. Adapted from Riel (2007).

| Table 3: Effective Community-Academic Partnerships |
| --- |
| 1.) Learn the 'community ecology' before entering the community |
| 2.) Establish relationships with community gatekeepers |
| 3.) Build credibility before proceeding |
| 4.) Develop a community coalition board, otherwise referred to as an advisory committee |
| 5.) Work with board to conduct a needs assessment |
| 6.) Collaborate with the board to develop and implement one or more projects |

Adapted from: Braithwaite, R. L., Murphy, F., Lythcott, N., & Blumenthal, D. S. (1989).

Table 4: Summary of Common Barriers and Potential Solutions in PAR

|  | Barrier | Potential Solutions |
|---|---|---|
| Power Imbalance | Power differentials in the project between participants and researchers may intimidate participants from full participation. It is important to remember no group is homogenous and there will also be power differentials within the group. Between stakeholders or board committee members an imagined hierarchy between disciplines can also lead to feelings of unease. | Recognizing power differentials is essential. While it may not be feasible to make long-entrenched power imbalances disappear over the course of a project, it is important to take steps to minimize their impact. This can be in part achieved through effective facilitation and the development of a respectful environment where people can participate without fear of being cut off by someone in a position of higher power. Equally important is recognition that not all participants have equal access to privilege, equal speaking space and feel equally valued in the research process; use different methods such as small group work, breakout sessions, individual writing time and so on, to engage all participants rather than just the most outspoken. |
| Time Constraints | Every PAR project reported difficulties organizing and finding the time to complete work. This is especially true for work with community partners, who may not be able to spend valuable human resources to assist the research project. In this case, partners may be frustrated at the lack of control they have in the research process due to the limited hours they can dedicate to the project. Academic or professional partners may also face time constraints and limitations due to organizational mandates and funding cycles. | Scheduling around the needs of community partners is essential. This includes taking advantage of less formal opportunities such as lunch meetings to help all partners become actively engaged in the project. Another helpful approach could be to create a timeline with community partners with key milestones so that everyone is aware of the schedule, ideally at the grant application stage. Co-writing grant applications with a community partner may also provide the opportunity for a more thorough bidirectional understanding of time constraints from the outset of a project. |
| Compensation | Community members and | Ideally, grants will permit |

| | research participants may be financially, intellectually, and physically challenged by the commitments of PAR projects, e.g. evening and weekend work. | budgeting for salary release time for partners. A community may co-write a grant proposal or provide letters of reference. Compensation should be provided for partners and participants who volunteer their time. Be mindful of the cost for the participant to make it to the meeting, which may include subsidizing a bus passes and providing food. |
|---|---|---|
| Ethnocultural diversity | A homogenous methodology for engaging participants of diverse language groups, cultural backgrounds and disability groups will not work and at its core, is in contradiction to PAR principles. Some participants may be unintentionally excluded from the project if they have difficulty reading, speaking or writing a different language than the researchers. Both situations result in a participant not fully expressing him or herself. | The onus is on the researchers to ask themselves what they are doing to engage traditionally excluded and marginalized communities. Forming a community advisory committee can help identify gaps in researching participants and help design a more inclusive methodology. Every effort should be made to provide translations or interpreters for participants. |
| Coming to know the community | It may be difficult for researchers to spend the required amount of time in a community. Face-to-face contact is essential in developing trust and collaborative relationships, yet travel times may be long or freeing time away from the office may be difficult. | Particularly given the geographic scope of BC, if possible, travel costs should be built into grant submissions. Skype, FaceTime, and other information technology resources should also be exploited with the caution that they cannot replace face-to-face contact. Various platforms also exist for joint editing of word documents. The onus here falls largely on the researcher to make every effort to participate in and become part of the community. Another strategy could be to hire project staff and facilitators who are well known and respected in the community to lead group work. |

| Conflicts with mandates and unfamiliarity with research processes | Non-profit and community organizations may be less prepared to engage in PAR than an academic institution. Organizational hurdles and unfamiliar ethics approvals may limit a partner's involvement. | Offers to work with partners to overcome organizational hurdles should be made. Communication here is key, and partners should not have to overcome barriers in isolation. Advocating by providing letters of support outlining the importance of a partner's role in the research process may be convincing to senior management. Simple things like invoicing for work on the project may be an unfamiliar process, especially when working with an academic institution that has multistep processes. Researchers can support this process by explaining the process and providing templates. If a partner is included in the research ethics application, they will be required to complete an online ethics tutorial. Efforts should be made to ensure the partner has access to a computer and is comfortable with undertaking the tutorial. |
|---|---|---|

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