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## Community-Based Participatory Research with Families of Frail Elderly

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### Introduction

The increased percentages of the elderly and longer life expectancy are global issues. Japan has the fastest aging rate and the longest lifespan in the world. In Japan, the number of people over age 65 is expected to increase from 22% in 2007 to 40% in 2050 (Statistics Bureau, Japan, 2007). Also globally, families are changing in type, lifestyle patterns, and also support of the elderly is different from the past. As a result, two major needs families are the support of families of frail elderly and for frail elderly living alone. One recommended approach to assist these families is community-based participatory research (CBPR) (AHRQ, 2003). This paper discusses the purposes of CBPR; highlights the principles of CBPR, examines the CBPR process, highlights the major issues of families and frail elderly; and discusses how family nurses could use CBPR in nursing education, nursing practice, and

family nursing research, and health policy to support families of the frail elderly.

### The purposes of CBPR

CBPR is a research methodology that uses the processes of inquiry and problem solving (Israel, Eng, Shultz & Parker, 2005, AHRQ, 2003). Scholars from different disciplines use varied terms for this type of research (See Box 1).

The purposes of CBPR differ from traditional research where a primary focus is the researchers' goal to gather data for presentations, papers, and theses. In CBPR there is reciprocity and the participants are viewed as co-researchers. The key purposes of CBPR are to improve the capacity of stakeholders to take action; solve the issues; to increase knowledge and skill about a particular phenomenon; and to improve the quality of health and life of a group of people (Israel, Eng, Shultz & Parker, 2005). Another CBPR purpose is used to create culturally sensitive interventions, to make changes, and to inform policy (Israel et al, 2005). For more in-depth information on action research see the enclosed references and journals such as *Action Research Journal*.

#### Box 1. Selected names for participatory research

- 1) Action Research, action inquiry research (Lewin, 1947a, b; Reason, 1994; Stringer, 2007)
- 2) Participatory research (Takano & Nakamura, 2004)
- 3) Community-based participatory research & participatory action research (Israel et al 2005)
- 4) Critical action research (Kemmis & McTaggart, 2000)
- 5) Participatory feminist research (Reinharz, S. & Davidman, L., 1992)
- 6) Empowerment research (Perkins & Zimmerman, 1995)

## Is CBPR a new type of research?

CBPR is not a new type of research but rather a research philosophy that emerged from action research and views the study participants as equals conducting the study (Lewin, 1947). It is a type of collaborative action research with a specific focus to solve health and social issues that are not solved traditionally research processes. The difference is that researchers do not work independently, but instead facilitate community stakeholders to clearly define the research topic or the issue. The subjects are called participants or stakeholders. Culturally sensitivity is emphasized and participants equally take part in decision making at each phase of the project. Action research was started initially in public schools and later found useful for other settings (see Box 2 for other uses).

### Core essentials of CBPR

The core essentials of CBPR (principles, the process, and the stakeholders) were created by Kurt Lewin, (1947, a,b) an educator, and varied scholars and disciplines of the 21st century who built on Levin's work (Bargal, 2006). Descriptions of the history and processes of CBPR can be found on websites such as the Campus Community Partnerships for Health website (<http://www.ccp.h. info/>).

All participatory research should include the core essentials and follow the principles of CBPR. Box 3 lists key CBPR principles that are specific to health (Israel et al, 2005). Readers who want to know more about CBPR are encouraged to explore CBPR websites online, conferences, and formal courses.

#### Box 2. Uses for CBPR

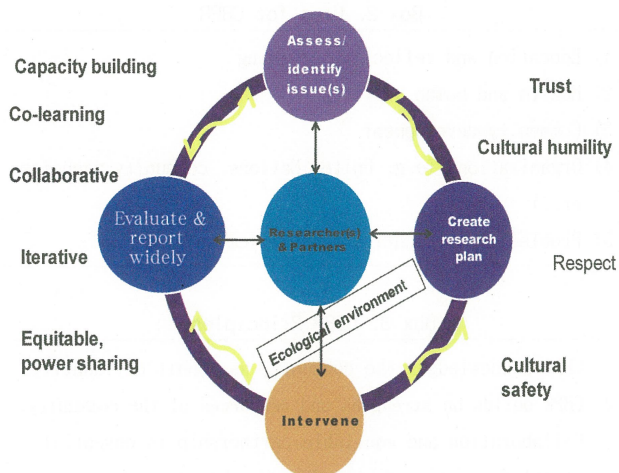
- 1) Education and reflective learning
- 2) Health and human services
- 3) Community development
- 4) Organizations (e.g. United Nations, community agencies, etc.)
- 5) Problem identification and problem solving

#### Box 3. CBPR Principles

- 1) CBPR acknowledges the community as a unit of identity
- 2) CBPR builds on strengths and resources of the community.
- 3) Collaboration and equitable partnership is essential (includes empowerment and power-sharing).
- 4) CBPR fosters co-learning and capacity building among all partners.
- 5) Balance between knowledge desired and community needs.
- 6) The issue should be relevant to the community & researcher.
- 7) It provides a system that is iterative and cyclical and values competencies of partners.
- 8) Partners and researcher determine the plan and approach to disseminate results.
- 9) CBPR is a long-term process that requires flexibility and commitment to sustainability (Israel et al, 2005).

### The CBPR process

Figure 1 depicts the cyclical and reflective nature of the CBPR process. The traditional steps of the research process are used. However, at each stage, it is critical for researchers to reflect and analyze the process (Dick, 1998). CBPR principles must be evaluated while giving continual attention to co-learning, collaboration, iterative, equitable roles in each step of the process. Other CBPR concepts include mutual trust, cultural humility, respect, and cultural safety. Two crucial culturally sensitive CBPR processes are cultural humility and cultural safety. *Cultural humility* occurs when the researcher is willing to learn from participants and trusts their wisdom. *Cultural safety* occurs when researchers protect the culture's privacy of information as well as their confidential data. Similarly participants ensure the researchers safety in



the community.

The researcher must assure that the appropriate community partners are co-researchers. For example, to resolve issues of 21st century frail elderly, community partners, family members and if feasible the elderly must be include as co-researchers.

The CBPR process is cyclical, democratic, and researchers always return to the previous stage for reflection, clarification or revision (Israel, et al, 2005). Through the process of reflection, researchers will know if a change is needed. Both qualitative and quantitative research methods maybe useful. The design can be descriptive, experimental or intervention research. For example, qualitative analysis could be used to study the lived experiences of frail elderly, the lived experiences of daughter-in-laws caring for frail elderly; quality of life, stress, disease of caregivers; or quality of life of frail elderly, etc. Quantitative analysis is vital for evaluating the effects of interventions.

The issues are identified by the community and clarified by researcher. Together, they create a research plan of action, analyze data, interpret the findings, and disseminate finds widely. The process is applicable to nursing in Japan (Ashara, 2006).

### Why CBPR with families of the frail elderly?

The issues of families of the frail elderly are dynamic and complex. Families often provide the care and/or support for the frail elderly in the adult child's home, or "aging in place" (the senior's own homes or condos) or in senior care facilities. The rapid social changes in Japanese families such as smaller family sizes and fewer multiple generational families' households increases the strain on community, fiscal, social, and family resources (Health & Welfare Bureau for the Elderly, 2002).

Stressors of frail elderly and caregivers are extensive due to inadequate societal resources. Similar to Western countries, the Japanese societal support systems such as long term care, skilled care, nursing homes, and in-home care are not adequate to meet the needs of increasing numbers of frail elderly and caregiving families. Family nurses are encouraged to examine CPBR to as an approach to design culturally sensitive, group specific, meaningful interventions for families of the frail elderly.

### The types of frail elderly in Japan are:

- 1) **Lives independently** indoors but requires assistance to go out. Spends most of day out of bed.
- 2) **Nearly bedridden** Requires some assistance living indoors and spends most of the day in bed but keep sitting up.
- 3) **Completely Bedridden**. Spends all day in bed and requires assistance for toileting. (Health and Welfare Bureau for the Elderly, 2002).

Women (wives and daughters) are often the caregivers globally. One Japanese cultural practice is that a wife is expected to care for

her husband's parents even if there are living capable siblings. Support for caregivers could be significant cultural intervention. While living in Japan, I with a lady whose mother-in-law was being admitted to the hospital. While the mother-in-law was being transported by ambulance, her daughter who visits once a year called the sister-in-law and asked "What have you done to my mother". This is one example of caregiver stress and suggests a need for caregiver support. It would be useful to use CBBR to assess the issues and to design interventions for daughter-in-law caregivers as well as for all types of caregivers.

**Who should partner on the issues for the frail elderly?**

In the past and currently often disciplines tend to work alone and families were not co-researchers. The solutions are multidimensional and require collaboration to implement change and action for the elderly and their families.

CBPR requires a bottom-up approach with input from the all stakeholders (Hutchinson, 2008; World Assembly on Aging, 2007).

The partners for taking action to improve the quality of life for families and the frail elderly include families, multiple health, social, and policy agencies (see Figure 2).

Box 4 provides share a case story of a frail elderly lady from the U.S. who has excellent

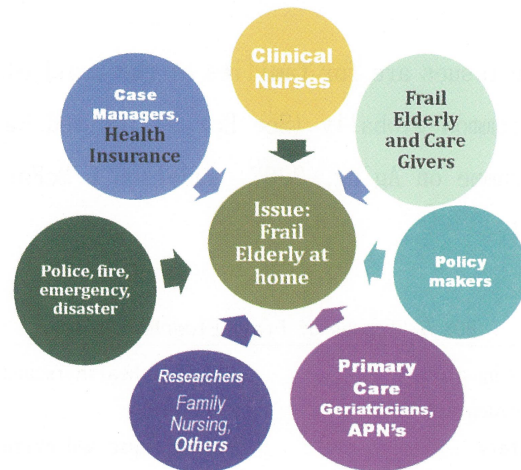


Fig 2. Partners on issues of the frail elderly

**BOX 4. Sample case study**

Mrs. Jane Doe is an 85 years old African-American women living alone in Northern USA. She has Parkinson's disease and high blood pressure. She is often dizzy, sometimes falls, and sometimes forgets to turn off the stove when cooking. She has no children. Her only sister is 74 years old and lives 800 miles away. Finances include social security and a modest pension. Her two story home is paid for. On the second floor are the only bathroom and her bedroom.

She is an excellent example of "aging in place" by choice. The closest family members are two nieces one lives 8 miles away and the other (care manager and power of attorney) lives 80 miles away. A neighbor man calls or stops by nearly every day and often shops for her.

Instrumental support provided by Medicare is a case manager, a health aid, and standard medical care. The health aid comes five days for 5 hours to bathe her, clean house, open mail, and run errands. Lunch and dinner are delivered. She talks by phone every day to a younger sister. She refuses invitations to go and live with her sister or niece. The mother of a child she previously baby brings him to visit often. Emergency and phone numbers are posted near the phone. She wears an emergency alert necklace.

Her nieces call often and accompany her to doctor's visits. She seldom leaves her home anymore and refuses invitations on holidays. Social services offered to build a bathroom on the first floor and to convert one room on the first floor to a bedroom. Ms. Doe refused because says the climbing the stairs are her daily exercise and no one will take it away from her. She insists on staying in her home as long as she can walk the stairs every day.

The doctors and social worker recommend that Mrs. Doe be moved assisted living because she falls occasionally, is unsteady on her feet, is weak, and cannot go outside the home even with assistance. Currently, she avoids talking about the issue with her family and care-manager because she wants to remain independent. According to the categories of the frail elderly, she is level 2.

**Safety issues** are: at risk for falling due to fragility and use of stairs for the rest room and sleeping, at risk for fires from cooking, vulnerable to crime, and poor nutrition. She is alone most of the time.

**Solution:** There needs plan for of total care for her current limited mobility and safety. Also a plan is needed for when she is completely bedridden and at end of life. The interventions should be based on evidence-based practice guidelines and planned while she is cognitively competent.

support for “aging in place” (remaining in her own home).

This case study is an example of the issues of frail elderly in the 21<sup>st</sup> century and “aging in place”. It also is an example of when the family nurse could use evidence-based practice guidelines for safety and other aspects of aging in place.

### Frail Elderly Challenges, Risks & Concerns

The issues are for families of the frail elderly are common globally (See Box 5) (United Nations Programme on Aging, 2007; Anderson & McFarlane, 2008).

#### BOX 5. Issues of Frail Elderly Globally

- |                                  |   |
|----------------------------------|---|
| · Living alone                   | · Chronic health issues                     |
| · Accidents & Falls              | · Arthritis                                 |
| · Safety                         | · Elder abuse and crime victim              |
| · Poor Nutrition                 | · Elder Transportation                      |
| · Hygiene                        | · Access to geriatric health care providers |
| · Medications                    | · Vulnerable in disasters                   |
| · Finances & Long term care cost | · Long term care shortage of facilities.    |
| · Medication errors              |   |
| · Mental health                  |   |

#### BOX 6. Interventions for Families of Frail Elderly

- Primary care by physicians that understand the special needs of the elderly.
- Support for family caregivers and family care manager
- Case Management that is sensitive to the family psycho-socio-cultural-spiritual issues.
- Providing for home safety and home maintenance
- Healthy nutrition provided in the home
- Accessible, affordable and appropriate, Transportation to health care and other crucial places shopping, paying bills etc.
- Social support for frail elderly living alone (instrumental and informational, and emotional and spiritual).
- Age and condition specific health promotion.
- Strength and balance training site article. As well as able to turn self and to do personal care.

### Common interventions needed

According to Hutchinson (2008), interventions are complex for community dwelling frail elders and their families (See Box 6).

Health promotion and disease prevention specifically to meet the mental, physical and social issues of the frail elderly are needed to extend the period of independence, enhance the quality of life for elders and also to provide improved and high levels of functioning for the frail elderly.

### Solutions to Solving the Issues of the Frail Elderly are Multidimensional

As shown in Figure 2 the solutions to the health issues of families are multidimensional. First, the lived experiences of families, providers, and agencies must be obtained. Secondly, funding is needed to complete large scale descriptive and intervention studies. Lastly, clinicians can use published evidence-based care guidelines to intervene for the frail elderly and their families. Networking with national and international colleagues assists the family nurse to examine evidenced-based approaches and research reports. Thirdly, keeping abreast of the emerging trends in the care of the frail elderly is essential. Also networking with local interdisciplinary colleagues and families, attending conferences, knowing helpful websites and journals are useful.

For example, I have used the CBPR process to collaborate with 6 rural communities in the USA to identify health issues, design culturally sensitive interventions, and to build two rural health centers in their region. The project provided data on the health disparities and

demographics to legislators. The CBPR project resulted in grants over six million dollars to construct the primary care centers and provided interdisciplinary staffing. The centers were staffed by a family nurse practitioner. This CBPR project is an example of "strength in numbers (university, nursing, social work and community) advocacy and diversity" and co-learning.

### Implications for family nursing education

It is crucial for faculty to provide learning experiences with elder care in basic nursing education (see Box 7) and use CBPR (Examining Community-Institutional Partnerships, 2006). Early experiences with frail elderly and their families is an excellent strategy to sensitive students to the needs of the frail elderly and to design, to recruit, educate and train nurses for the future practice in gerontologic nursing.

### Implication for CBPR in family nursing

Family nurses in clinical practice should design CBPR and evidence-based interventions to promote family and elder resilience. Examples of programs needed are:

- 1) Caregiving training
- 2) Caregivers respite
- 3) Enhancing bodymindspirit nursing care
- 4) Health promotion for elders & caregivers

CBPR culturally sensitive evidence-based programs are needed to prevent elder falls (Thomas, et al, 2002), depression, elder abuse prevention, medication safety, etc. Also needed are mental health and spiritual health promotion programs. For examples of evidence-based guidelines for the elderly see [http://www.nursing.uiowa.edu/products\\_services/evidence\\_based.htm](http://www.nursing.uiowa.edu/products_services/evidence_based.htm).

[edu/products\\_services/evidence\\_based.htm](http://www.nursing.uiowa.edu/products_services/evidence_based.htm).

### Implications for Family Nursing Research

In nursing globally, many descriptive studies and intervention studies with a small sample size have been completed to describe the issues of Japanese caregivers and the frail elderly.

There is a need for culturally sensitive, cost savings large scale clinical trials, larger sample sizes, evidence-based studies and using

#### BOX 7. Family Nursing Education

- Provide experiences with elder care in all basic nursing curriculum.
- Design strategies to recruit, educate and retain nurses for gerontology.
- Provide experience for all students to interact with teach and care for diverse families [seniors, caregivers, and the frail elderly] (Bomar, 2004).
- Teach evidence-based practice to improve the quality of care and reflective practice so students can understand their feelings.
- Teach moral and humanistic caring and nursing as a caring science (Watson, 2008).

#### BOX 8. CBP Sample research topics about families and the frail elderly

- Culturally specific CBPR strategies for care-giving training. Are the training programs for caregivers meeting needs?
- Caregiver interventions and health promotion and respite.
- Support programs for working caregivers.
- EBPR that informs policy.
- CBPR designed health promotion and disease prevention programs for elderly (physical activity, strengthening, balance, etc.
- Study techniques for independent living.
  - Use technology for self-care and for caregivers.
- Assist families to plan for frailty and end of life.
- Provide autonomy in day-to-day life.
- Include teaching valuing CBPR to researchers and families.
- Teach families that their "voices" and opinions are valued.
- Encourage families to plan for frailty and end of life.
- Finally, always include disseminate the findings to professional and to ordinary people and to policy makers. Use lay language for ordinary people and legislators.

traditional research and CBPR. Box 8 gives examples of research topics.

Sometimes, nurses from the same culture do not acknowledge the culture of their region in planning care. For example, it could be that the perception of attitude toward aging has cultural differences. According to Asai sensee, researcher Tokyo Metropolitan Institute of Gerontology and Kameoka sensee at University of Hawaii a major barrier for Japanese families to seeking in home care and accepting assistance for elder care is the concept of *sekentei*. *Sekentei* is a Japanese practice of not asking for external help to portray that one is strong and need to not accept in home assistance because people will judge them negatively. *Sekentei* means social appearance, reputation, or dignity in the public or community (Asai & Kameoka, 2003). Collaborating with Japanese families to acknowledge cultural beliefs, while at the same time designing interventions with them to reduce family stress is crucial. Also, the implementations are more likely to be sustained if the "affected community" takes part in each step of the research process.

It is important to note that CBPR does not end with the implementation of the study and the formal report. The community and researchers lead by researchers must present the qualitative (the lived experiences of the participants and statistical data to policy) makers to inform policy. The process begins with the issue identified by the community and ends with resources and funds for problem solving.

### Health Policy to Support Families of the Frail Elderly

The most effective strategies to obtain fiscal

and informational support for families of the frail elderly is to obtain legislative and social support. Family nurses should advocate for health policy reform for families of the frail elderly. Advocacy begins with information provided to the policy makers and social agencies by researchers who used CBPR. For example nurses, social services, case managers, police, fire and emergency response personnel, families and the affected must inform policy makers and law makers of the unmet needs.

For example, safety is an issue for "aging in place" frail elderly who live alone. Culturally specific evidence-based community-based participatory strategies are needed to inform police, fire and emergency responders about the needs of seniors and families. Family nurses can partner with other health professionals, agencies, and affected individuals or at risk individuals and to share the story of the need for support of the frail elderly to policy makers.

An easy activity for family nurses is to request a meeting with the policy maker or law maker. The primary task is to gaining access to policy makers and to provide succinct and concrete data about frail elderly and their families. The following are examples of information that can be provided.

- 1) Share stories of the families with frail elderly
- 2) Provide statistics of the cost of inadequate care and health promotion to reduce family burdens
- 3) Provide statistics on the number of people affected
- 4) Ask policy makers' assistance to make appropriate changes.

According to Florence Nightingale (2001), each nurse can be a solitary dissenter for health

care reform. Positive dissent by a single dissenter can lead to great reform. Family nurses in collaboration with families, and community partners must be dissenters who do not accept the current stressful conditions of families with frail elderly members. Nurses must serve as advocates for families in social, health and fiscal policymaking. Guidelines for health policy advocacy can be found with the Japanese Nurses Association.

With the rapid changes in health care and the population, twenty first century family nursing family nurses has the unique and compelling opportunity to create innovative, culturally sensitive and family research interventions that will increase the capacity of families to care for frail elderly family members (Bomar, 2004). Also, there is a vital need to collaborate with families and interdisciplinary colleague to advocate to policy makers; and to use CBPR to increase the capacity of families and improve the health of frail elderly and their families.

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