

# Participatory Action Research With Older Adults: Key Principles in Practice

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**Purpose:** Although participatory action research (PAR) is increasingly viewed as an important complement to traditional investigator-driven research, relatively little PAR has taken place in which older adults have been prominent partners. This article provides a review of the literature on PAR in gerontology, highlighting key studies and their implications. **Design and Methods:** We searched PubMed, PsycINFO, and ERIC for relevant articles, supplementing our results through the bibliographies of articles identified and consultation with colleagues. This search yielded 75 articles of potential relevance, of which we selected 13 (covering 10 studies) that best adhered to the roles of PAR in gerontology. **Results:** PAR projects with older adults have utilized a variety of research methodologies in a broad range of social contexts. Each of the 10 studies examined illustrates several core principles of PAR. Furthermore, while suffering from some methodological limitations, each also highlights value added in terms of research quality, elders' skill building, and/or action outcomes. **Implications:** Involving older adults in PAR, while labor intensive and challenging, may offer promise as an underdeveloped resource for the field of social gerontology, as well as for elders themselves.

*Key Words:* Participatory action research, Elder researchers, Community-based participatory research, Qualitative methods, Health promotion, Survey research

Although gerontologists have increasingly incorporated in their practice participatory approaches that emphasize individual and community empowerment (Bernard, 2000; Levine & Greenlick, 1991; Ray, 2007; Ross et al., 2005), the involvement of older adults as partners in the research process itself is still relatively rare. A small but growing body of studies, however, suggests that participatory action research (PAR) with older adults may hold promise for helping to understand and address some of the complex health and social problems faced by elders while contributing to individual and community capacity building. Furthermore, with the growing emphasis on incorporating the preferences of elders in service delivery and public policy decision making, PAR offers an orientation to research with increasing relevance to gerontology.

Following a short introduction to PAR and its potential utility for work with elders, we describe the methods used to identify exemplars of PAR with older adults in domestic and international contexts. Using as a conceptual framework the principles of PAR described by Israel and colleagues (Israel, Schulz, Parker, & Becker, 1998; Israel et al., 2008), we then draw on 10 studies to illustrate each of 6 basic PAR principles in gerontological research and practice. Next, we discuss key themes and lessons learned, among them the need for greater attention to issues of research rigor and validity and to the training of older adults as researchers. The National Institutes of Health's (NIH) Resource Centers for Minority Aging Research (RCMAR) is identified as one of several foundation builders needed if PAR with older adults is to reach its full potential. We conclude that although PAR with elders is fraught with challenges, it offers an important complement to more traditional investigator-driven gerontology.

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## What is PAR?

PAR has been succinctly defined as “systematic inquiry, with the participation of those affected by the problem being studied, for the purposes of education and action or effecting social change” (Green et al., 1995, p. 2). In this approach, the individuals or communities to whom research applies maintain agency in key aspects of the research process: defining research questions; carrying out the research itself, building community capacity while gathering and interpreting data; disseminating research findings; and using such findings as the basis for social action.

As described by Israel and her colleagues (Israel et al., 1998, 2008), core tenets of PAR include that it is participatory and facilitates “collaborative, equitable partnership in all phases of research” (Israel et al., 2008, p. 50). Underlying PAR and related approaches is a power shift from academic institutions to communities, with participants becoming more than subjects of study and outside researchers embracing “the experience and partnership of those we normally are content simply to measure” (Schwab & Syme, 1997, p. 2050; see also Green & Mercer, 2001). PAR and related traditions often are seen as occurring along a continuum, at the “deep” end of which is community control over knowledge production, and ownership of its products (Bradbury & Reason, 2008). Although community partners may not wish to take part in all aspects of the research (e.g., in actual data gathering or analysis), “equitable partnership” indicates that processes undertaken should enable partners to participate as they wish to and are able.

PAR also is, by definition, an empowering process that strives to create the conditions in which participants can increase their sense of control, involvement in decision making, and critical awareness (Zimmerman, 2000). Such empowerment is reflected, in part, in a third principle, which emphasizes that PAR is a colearning process, in which community participants not only gain skills and competencies (e.g., in research and problem-solving methodology) but also contribute their lay knowledge and expertise bidirectionally. PAR thus contributes to capacity building and systems change, not only on the individual level but also, ideally, on organizational and community levels. This capacity building is enhanced by the fact that PAR balances research and action, rather than leaving others to engage in the translational

aspects of the work once the data gathering and analysis are complete (Minkler & Wallerstein, 2008). Finally, PAR entails commitment beyond the funding cycle-based relationships typical in social research to long-term collaboration for social and academic goals (Israel et al., 2008).

PAR is one of a number of approaches that tend to share the above tenets and values, and whose names, including “community-based participatory research” or CBPR, “action research,” “community-based research,” “participatory research,” and “feminist participatory research,” are sometimes used interchangeably. Although we use “PAR,” as it was the term favored by the majority of the works we cite, we employ this label broadly in reference to a host of related traditions sharing this participatory action-oriented research paradigm.

## Why PAR With Elders?

There is wide recognition that recruiting and retaining older research subjects can be difficult and that research with ethnic minority elders, in particular, faces major barriers to trust and participation (Carter, Elward, Malmgren, Martin, & Larson, 1991; Moreno-John et al., 2004; Norris et al., 2007).

Although we do not focus exclusively on minority elders in this review, PAR may hold particular promise for research with minority elders and other marginalized groups. By incorporating community direction, PAR helps to dispel concerns that research is driven solely by academic priorities (Moreno-John et al., 2004; Norris et al., 2007). Researchers conducting PAR with elders in general, and with minority elders in particular, have reported improved recruitment and retention (Carrasquillo & Chadiha, 2007; Norris et al.). Furthermore, PAR helps insure that the topic under investigation matters locally; improves the relevance and cultural sensitivity of survey questions and other data collection tools; adds nuance to the interpretation of findings; and can help in the translation of findings into action to improve programs, practices, and policies (Minkler, 2005).

## Methods

For this literature review, we searched PubMed, PsycINFO, and ERIC with the terms “elders,” “elderly,” “seniors,” “aging,” and “older adults,” combined with the terms “action research,” “participatory action research,” “community-based

participatory action research,” and “CBPR.” No language filter was used. The original search was conducted in April 2008 and updated in July 2008. No specific age cutoff for older adults was employed in this search, in recognition of the fact that particularly in minority communities, functional aging and/or perceived seniority may occur well prior to such conventional benchmarks as ages 55 or 65.

Having begun our search with several necessarily ambiguous terms (such as seniors), we initially obtained more than 1,000 nonduplicated results. After reviewing all abstracts and removing those that did not involve older adults and/or PAR, we had a remaining pool of 48 peer-reviewed articles. These publications’ bibliographies revealed another 10 peer-reviewed articles for consideration. Finally, we consulted several colleagues for assistance in identifying any additional peer-reviewed studies that were “in press” or published in venues not likely to be identified through traditional search engines. These strategies together yielded a total of 75 published or in press articles. We selected 13 of these (covering 10 studies) whose adherence to core PAR principles was sufficient to merit their use as exemplars in this review (Table 1).

The studies we have not chosen to highlight generally did not incorporate older adults as coresearchers or analysts but rather as focus group participants or as the *subjects* of PAR conducted by *other* groups, such as nurses or younger members of ethnic minorities. Many of these studies are included in our background and discussion sections, despite the fact that only those that exemplify PAR with older adults, per se, make up the core of our analysis.

## Results

As noted earlier, core principles of PAR underscore its participatory, empowering, and colearning nature; its emphasis on capacity building and systems change; and its commitment to both balancing research and action and fostering sustainability through long-term collaboration (Israel et al., 1998, 2008). We now discuss each of the 10 studies examined as they illustrate these different, albeit often overlapping, principles.

### *PAR is Participatory and Facilitates “Collaborative, Equitable Partnership in All Phases of the Research”*

Although older community partners often are not interested in being involved in every aspect of

a PAR project (e.g., actual data collection or analysis), this first principle suggests that they should have the opportunity to engage as coresearchers in diverse aspects of the work. The dialogical processes central to PAR (Israel et al., 2008; Minkler, 2005), further, are critical to insuring that elders determine the extent of their own involvement in different phases of the research process.

With few exceptions (e.g., Glanz & Neikrug, 1997; Neikrug et al., 1995; Ostlund, 2008), the PAR studies examined here tended to begin with a topic identified by outside researchers, who then sought the involvement of older adults as members of a Community Advisory Board (CAB) or as coresearchers in various aspects of the study. The older adult participants tended to be substantially involved, however, in refining research instruments, helping to interpret findings, and/or using the findings to help effect change.

Although elders tended to be less involved in data collection or analysis, some good illustrations of such involvement also were uncovered. Gallagher and colleagues (Gallagher, Lindsey, & Scott, 2002; Gallagher & Scott, 1997), for example, describe a falls reduction initiative in which elders and people with disabilities (PWDs) were trained to staff a hotline for reporting falls in public places due to unsafe conditions. Elders and PWDs also served on the project steering committee for this study, helping to develop the project’s recruitment strategy and actively participating in the follow-up symposium to discuss findings and develop recommendations for subsequent research and action (Gallagher et al.). These methods proved successful: subsequent feedback from building owners and city engineers suggested that at least 30% of the reported hazards were repaired or marked as hazards (Gallagher & Scott). Although the study was initiated by professional researchers, the involvement of trained elder and disabled coresearchers in numerous aspects of the project helped give those most affected by unsafe conditions a role in remediating those conditions.

A study of elder abuse in Israel further illustrates the potential for elders trained as coresearchers to engage in successful data collection (Glanz & Neikrug, 1997; Neikrug & Ronen, 1993). In this study, eight older researchers, working with faculty members of Bar-Ilan University, surveyed Israeli adults to investigate perceptions of elder abuse. The study included a sample of 452 subjects differentiated along multiple demographic dimensions. Beyond the study’s findings on elder abuse itself, the

Table 1. Illustrative Participatory Action Research Studies With Older Adults

Sources	Key partners	Research aims	Methods	Nature of elder involvement	Sample	Key findings	Education and/or action outcomes
Neikrug et al. (1995) and Glanz and Neikrug (1997)	Older adult students; Social Gerontology Research Program at Bar-Ilan University	Understand vitality in active "old-old" people	Questionnaire administered to 43 subjects	Study design; instrument design; survey administration; analysis; coauthorship	43 Bar-Ilan University lifelong learning program students aged 80 years and older	Active subjects did not define themselves as "old people"	Elders trained in all aspects of gerontological research
Neikrug and Ronen (1993) and Glanz and Neikrug (1997)	Older adult students; Social Gerontology Research Program at Bar-Ilan University	Document perceptions of elder abuse in Israel	Questionnaire administered to 452 subjects	Study design; data collection	452 Israelis aged 17 years and older	Abuse rated more severely if physical or committed by nonfamily	Elders trained in study design and data collection for gerontological research
Jones et al. (2008)	Stroke patients; caregivers; professional care providers	Enhanced stroke services through user involvement	Interviews and focus groups, followed by formation of working groups	Consultation on interview findings; participation in working groups driving changes in policy and practice	33 stroke survivors; 2 caregivers	Lack of adequate information regarding prevention and diagnosis; instability in hospital discharge	"Information packs" for service users; socially integrated rehabilitation activities; enhanced caregiver involvement in discharge (planned)
Ostlund (2008)	39 older adults; faculty of Aging and Design Program at Lund University, Sweden	Explore feasibility of research circle method with older adults; facilitate participant-driven social change through research circles	Research circles (3); each focused on topics of elders' choice and change oriented	Participation in research circles; obtained funding to study feasibility of a potential local elder support service; planned launch of pilot social support service; produced community historical documentation for public use	39 older adults	Research circle method enabled successful projects in small group of highly motivated participants and contributed to capacity and social networking	Pilot social support program to enable elder independence; contribution to local historical society; networking among older adults at risk of isolation

Roe et al. (1995) Minkler et al. (1992)	Community members and CBO/Health Department reps in Oakland, CA; faculty and graduate students at UC-Berkeley and San Jose State University	Explore health and social status, needs and strengths of GRGs in crack epidemic; support related action on community-identified issues	Two in-depth interviews of each of 71 GRGs in crack involved households	CAB membership; interpretation of study findings; planning dissemination and use of findings and participation in action component of project (e.g., warmline; coalition; respite center)	71 African American GRGs involved households	Frequent, often downplayed health and social problems; strong coping; skills in advocacy and community building	Regional coalition to support grandparent caregivers; greatly expanded grandparent “warmline”; GRG respite care center; helped get supportive state legislation
Ross et al. (2005)	Consumer panel of 21 older adults; research team from King’s College London and other institutions; local care providers	Understand older adults’ views on fall risk and fall prevention to inform policy implementation	Interviews: individual and focus groups; questionnaire on involvement administered to consumer panel	Research design; analysis; data dissemination by consumer panel	Older adults; caregivers; health professionals	Consumer panel highly motivated to design and conduct research and disseminate findings	Networking with local policy initiatives and advocacy organization for older adults
Dickson (2000) and Dickson and Green (2001)	Older Aboriginal women in Saskatchewan, Canada; University of Saskatchewan faculty	Health assessment and promotion for older Aboriginal women	Individual and focus group interviews of 40 women; observation of group meetings	Research design; data analysis; editing final report; consultation with policy figures	40 Aboriginal women aged 40–70 years	Participants emphasized value of control of research with local government	Increased community networking; increased communication with local government
Baker and Wang (2006)	Chronic pain patients aged 50+; two academic facilitators	Determine usefulness of photovoice as mode of chronic pain analysis and communication	Modified photovoice method: self-directed, contemplative photography and reflection	Taking photos; writing narrative to explore themes related to chronic pain; reflecting on images and research process	7 clinic-based and 20 nonclinic-based chronic pain patients aged 50+; 13 completed study	Participants expressed feeling of helping themselves and others through expression of pain	Documentation of strengths and weaknesses of photovoice as a method for research on the experience of chronic pain
Gallagher and Scott (1997) and Gallagher et al. (2002)	Older adults; people with disabilities; health practitioners; academic researchers	Increase fall risk awareness; identify and eliminate fall risk hazards	Questionnaire-based telephone hotline survey	Staffing telephone for falls reporting hotline	791 self-selecting hotline callers, reporting falls in response to hotline advertisement	Even with a self-selecting sample, creating a hazard-reporting outlet enabled remediation of hazards	“At least 30%” of hazards reported addressed; networking between local officials, engineers, and citizens

Notes: CAB = Community Advisory Board; CBO = community based organization; GRGs = grandparents raising grandchildren; UC = University of California.

results illustrated the potential for elders, most of whom had no previous professional background in the social sciences, to participate as investigators in quantitatively sophisticated research.

Such participation can extend further to include professionals and other stakeholders. This possibility is discussed by Ross and colleagues (2005) within the context of a qualitative study of perceptions of fall risk among elders and health professionals in London. The study used community networks to attempt to recruit a large number of stakeholders, including elders, caregivers, and health and social service professionals, for participation in a consumer panel. The panel of 21 “consumers” was chaired by elders, who also helped broaden the study agenda; pilot the interviews; analyze data; and communicate directly with health and social services organizations, in order to develop recommendations and disseminate study findings. Here, the participatory aspect of PAR was expanded to include health professionals and caregivers, rather than stopping with elders themselves.

### *PAR is Empowering*

As suggested earlier, PAR is, by definition, an empowering process, enabling participants to gain an increased sense of mastery and address issues of importance to them. A second study at Bar-Ilan University (Glanz & Neikrug, 1997; Neikrug et al., 1995) is illustrative of the empowering dimension of PAR. The study was catalyzed by elder researchers’ concerns for their own futures as “old-old” people (defined here as 80+), which led them to formulate the research question: “what are the characteristics of active old-old people?” The elder researchers then interviewed 43 of the oldest participants in the University’s lifelong learning program; developed and administered a questionnaire, including some standardized survey questions; and compared their findings with those of other studies. The study concluded that although these very elderly subjects cannot be considered representative of their age group, neither should old-old people who are socially and physically marginalized be considered the norm—a finding the elder researchers deemed highly relevant to their own lives.

The empowering potential of PAR also is illustrated by a study that used the “photovoice” method with older adults experiencing chronic pain (Baker & Wang, 2006). Grounded in principles

of empowerment, feminist research, and documentary photography (Wang & Burris, 1997), photovoice provides participants with inexpensive cameras and teaches them how to take pictures capturing their realities. They then are engaged in critical dialogue about their photographs and select pictures and accompanying narratives for education or action to effect change (Wang & Burris). Photovoice thus adheres to the PAR tenets of subject control of data collection and analysis, as well as subject utilization of results to achieve social or political goals.

For Baker and Wang (2006), the decision to use photovoice was grounded in concerns that although there are validated quantitative tools for evaluating pain, opportunities for those living with chronic pain to communicate *outside* the boundaries of depersonalized pain scale instruments are largely absent from professional literature. Photovoice helps to fill this gap by offering an opportunity for health service providers and policymakers to witness older people’s own representations of their chronic pain. The project’s 13 participants produced pictures rich in symbolism, including a rose with thorns and a knife on a table. In the accompanying narrative, the participant who photographed the knife explained, “Sometimes my pain is so bad that I feel like taking that sharp knife and chopping both hands off ... and what is so disappointing is that there is not one pill I have taken that has helped” (Baker & Wang, p. 1409). Despite participants’ inability, due to their chronic pain, to complete all aspects of traditional photovoice methodology, the study demonstrated the value of even a modified photovoice approach in providing a means of self-expression for isolated, disempowered elders.

### *PAR is a Colearning Process*

The colearning aspect of PAR is well illustrated in two articles on a health promotion program for and by aboriginal “grandmothers” in Saskatchewan, Canada (Dickson, 2000; Dickson & Green, 2001). Although the external researcher conducted the interviews and focus groups with approximately 40 grandmothers and undertook initial data analysis, the grandmother “coresearchers” (two of whom were hired and trained as research associates) worked with her to design the interview guides and consent forms and provided interpretations of study findings through such means as secondary analysis of preliminary written reports

(Dickson & Green). The authors' reflections on the process of this program indicate that just as the grandmothers were trained in data analysis, the academic partners learned about community traditions, and how to build the relationships necessary to navigate the deep history of mistrust of research in the grandmothers' communities.

### *PAR Contributes to Capacity Building and Systems Change*

Beyond incorporating traditional subjects as empowered proactive stakeholders, PAR builds such participants' capacity to conduct further research, ideally also contributing to their communities' ability to effect desired changes in programs or policies. In a study of stroke-related health and social services in the United Kingdom, Jones, Auton, Burton, and Watkins (2008) formed four working groups, totaling 63 participants, to turn interview and focus group findings among stroke survivors, caregivers, and health professionals into tangible outcomes. These working groups helped create "information packs" for navigating stroke care, as well as a new rehabilitation program that deliberately incorporated social contact, in response to widespread complaints of social isolation. Individual-level capacity building (e.g., increased analytic and problem-solving skills), community capacity (e.g., enhanced user-provider networks), and concrete systems change thus resulted from this work.

Capacity building also was of central concern to the Grandparent Caregiver Study by Roe, Minkler, and Saunders (1995), conducted in Oakland, CA, during the crack-cocaine epidemic in the early 1990s (Minkler, Roe, & Price, 1992). Although the topic was initially identified by academic researchers, they partnered with a grassroots senior organization and a local health center, which, in turn, helped form a CAB comprised of mostly older African American women. CAB members not only made substantial contributions to the study (e.g., expanding sampling criteria, helping refine interview questions to make them more culturally sensitive, and helping interpret the findings) but also gained valuable new skills themselves in areas such as survey research design, fundraising, and media advocacy. On a broader scale, as noted below, the many action outcomes of this project also improved community capacity for addressing the needs of grandparent caregivers and their families.

### *PAR Balances Research and Action*

As suggested above, PAR typically pursues two goals: performance of the research itself and application of research findings to effect change. In the Grandparent Caregiver Study just discussed, outside researchers, CAB members, and interested study participants themselves helped plan and conduct the action component of the project, which included creation of a regional coalition on grandparent caregiving; expansion of a CAB member-initiated grandparent caregiver "warmline"; a church-based respite center for grandparent caregivers; and a newsletter for and by grandparent caregivers, edited by a study participant (Roe et al., 1995).

The balancing of research and action also was illustrated by Reed, Pearson, Douglas, Swinburne, and Wilding (2002) in their "appreciative inquiry" (AI) study of hospital discharge in the United Kingdom. "AI" is an approach in which "the research is directed towards appreciating what it is about the social world that is positive and exploring this" (Reed et al., p. 38). In their AI evaluation of hospital discharge practices, Reed and colleagues involved people from both the institutions and the community in a series of workshops, in which they assessed current strengths of discharge practices, envisioned better outcomes, and strategized to make those outcomes a reality. Elders' roles included analyzing data from previous workshops and collaborating to turn such recommendations into an "action plan" of tangible results, including an information packet on hospital discharge and augmented staff training in hospital discharge.

The integration of research and action also is illustrated in the article by Ostlund (2008) describing three "research circles," in which elders in Sweden collaborated to discuss areas of shared interest and to translate their discussions into social change. Two of three research circles chose to direct their discussions toward community and social change. The study's elder housing-themed research circle received government funding for a needs assessment and feasibility study, emphasizing support with instrumental activities of daily living. That group has since begun piloting its own support program. The "aging in place"-themed circle also produced tangible results, collaborating with its local historical society to develop public historical knowledge of participants' own neighborhoods.

## *PAR Involves a Long-Term Process and a Commitment to Sustainability*

As is clear from several of the above studies, PAR entails a commitment beyond the timescale dictated by funding cycles or paper submission deadlines. The work by Dickson and Green (2001), for instance, lasted well beyond the research itself, and the action phase of the Grandparent Caregiver Study continued for 6 years beyond the originally funded research period. The latter project also included subsequent fundraising to support several elder-driven interventions (e.g., a respite center, newsletter, and resource center), which grew out of the initial research (Roe et al., 1995).

## **Discussion**

### *PAR With Older Adults: New Developments and Paths Forward*

Although much work remains to be done, the foundations of PAR have been strengthened substantially in recent years, both methodologically and with regard to funding and other forms of institutional support (Cargo & Mercer, 2008; Minkler & Wallerstein, 2008). Recent developments in the United States, the United Kingdom, and elsewhere are helping further to catalyze such research. Key among these developments in the United States is an NIH-funded network of six RCMAR's which promotes research on minority elder populations by investigators who identify racially and ethnically as members of the populations they are researching (Moreno-John et al., 2007; Norris et al., 2007). CBPR has been designated as a major strategy for the work at each center. To date, most sites have incorporated this approach by establishing and working closely with CABs comprising local leaders and service providers, yet have not deliberately included minority elders themselves as part of the research effort.

Movement toward such inclusion is taking place, however. The Wayne State/University of Michigan's Healthier Black Elders Center, for example, involves 10 senior aides from each of Detroit's 10 districts in actively advising CAB members regarding their communities' perceived health needs and methods for improving recruitment strategies (Moreno-John et al., 2007). As the RCMAR sites further develop their bidirectional learning strategies, involving minority older adults and their caregivers as CAB members and in other community partner capacities, they may provide an important avenue for progress.

In the United Kingdom, the Joseph Rowntree Foundation has produced reports offering guidelines for elders engaging in research and self-advocacy (Clough, Green, Hawkes, Raymond, & Bright, 2006; Older People's Steering Group, 2004). Their ample references to specific programs reflect the growing knowledge base regarding elders in research.

The potential utility of PAR with elders also has been underscored by research emphasizing elders' roles as health care consumers, controlling delivery of services. In the United Kingdom and Australia, in particular, a robust literature has developed under the banner of action research, with an emphasis on "user involvement" for elders directing medical care, in both institutional and community settings. Authors in this arena have elucidated the complexities of service users' control (Chenoweth & Kilstoff, 2002; Clare & Cox, 2003), nurse-patient interactions (Hancock, Chenoweth, & Chang, 2003; Lindeman et al., 2003; Reed, 2005), and community relationships with health care accessibility (Cawston, Mercer, & Barbour, 2007; Hildebrandt, 1994). Other notable studies have developed networks that incorporated elders' input in enriching community-based mental health care (Lindamer et al., 2008; Schensul et al., 2006).

All these efforts have helped to lay the groundwork for more robust PAR in social gerontology, building elders' engagement in social processes while coming to useful conclusions about the same elders' needs and strengths. As gerontology increasingly looks to home- and community-based care as alternatives to institutionalization, to user-driven appraisal of quality of care, and to the potential for community partnerships to improve delivery of care, these traditions of user involvement provide an important base for PAR's continued development and utilization in the field.

However, as Ray (2007) has pointed out in her critical account of the participation of older people in research, even with these promising developments, many dilemmas remain, particularly with regard to "power imbalances and interpersonal dynamics between the 'researcher' and the 'researched'" (p. 80). Learning from the experiences of others and carefully evaluating the state of the art of elders' participation in research, she argues, are essential if we are to promote genuine and high-level involvement of older adults that respects their needs and concerns; honors and builds on their strengths; and, in the process, helps address power imbalances.



Despite important recent developments, PAR with older adults is a surprisingly underdeveloped field. Although many factors may contribute to this underdevelopment, key among them may be questions about whether elders, in particular, may be up to the task. In the latter regard, Ray (2007) has suggested that “... many older people have been effectively prevented from participating in research ... because of assumptions about the ability of older people to ‘meaningfully’ engage in participation” (p. 79).

The 10 studies examined above may help address this concern by illustrating the many ways in which authentic engagement of elders can enhance research processes and outcomes while also assisting in the translation of research findings into action. At the same time, several core themes and lessons emerged from these studies that need to be further addressed if PAR with older adults is to reach its full potential.

### *Honoring the Life Experience of Elders*

A cardinal lesson from the studies reviewed involves the importance of genuinely valuing the life experience of elders. Several authors (Dickson & Green, 2001; Glanz & Neikrug, 1997) suggested that for elder researchers to achieve full participation, the knowledge they bring to the table must be valued and reinforced. Roe and colleagues (1995) further noted that appreciation of participants’ lived experience is also a political strategy, in which individual stories can powerfully complement quantitative data. Although such leveraging of personal stories applies to any demographic, the life experience of elders may make this tool especially powerful in policy-oriented gerontology (Curry, Shield, & Wetle, 2006).

### *Building Bidirectional Trust*

A second theme, congruent with the literature on PAR and community-based research more generally (Cargo & Mercer, 2008; Minkler & Wallerstein, 2008), involves both the need to gain the community’s trust and the difficulty of doing so, particularly in socially marginalized populations. Taking seriously the tenets of authentic community participation in research and committing to the action phase of the research were important means by which trust was enhanced. For Dickson and Green (2001), working among First Nations elders in Canada, initial

lack of trust was seen to reflect not just the elders’ skepticism of academic research but also their objections to being framed as a needy or troubled community. Elders’ ownership of the project was crucial, with collaboration requiring more trust from academic researchers than is typically accorded research subjects (Dickson & Green). Enhancing trust, in short, must be seen as a fully bilateral goal in PAR. As Averill (2005) has pointed out, to achieve this goal, the academically trained researcher does not simply represent her or his own agenda but “becomes the facilitator and the linker of dialogue among the groups of interest, aiming eventually for a collective identification, description, and analysis of specific problems, priorities, strengths and assets, and needs” (p. 16).

### *Training Older Adults for Their Roles in PAR*

Most studies reviewed involved some training of elders for their roles in the PAR projects described. Such preparation ranged from focused task-oriented training (e.g., for conducting interviews) to the development of a multifaceted program training elders as gerontologists (Glanz & Neikrug, 1997). In the latter regard, two of the studies reviewed (Glanz & Neikrug; Neikrug & Ronen, 1993; Neikrug et al., 1995) had in common their association with the Brookdale Program of Applied Gerontology, created in 1990, to train elders as gerontologists at Bar-Ilan University in Israel (Glanz & Neikrug). The program reports having trained 16,500 older learners since its inception in 1990 (Bar-Ilan Brookdale Program, 2008) using, in part, experiential sessions that provide training in study design, data collection and analysis, and other topics, as exemplified by the studies discussed previously.

Although the training component of the studies examined in this paper was seldom described in detail, its value frequently was highlighted, in terms of both improving data collection and contributing to older participants’ skills and self-esteem. In addition to the Brookdale Program, several systematic efforts to train elders in gerontology have been developed, including programs at the University of Massachusetts–Boston (Bass & Caro, 1995); Simon Fraser University in British Columbia (Cusack, 1995); and L’Institut Universitaire du Troisième Âge de Montréal (Lemieux, 1995). As Ray (2007) cautions, however, merely providing training may

not address power imbalances if those most likely to avail themselves of such training are already more privileged in terms of resources, health status, and lack of burdensome competing responsibilities.

### *Concerns About Research Rigor and the Need for "Broadening the Bandwidth of Validity"*

Most of the studies included in this review involved qualitative research, in which traditional means of insuring validity have often proven inadequate. In all the studies we reviewed, the small numbers of participants, and/or the use of purposive or other nonrandom samples, rendered impossible the collection of generalizable data. As Jones and colleagues (2008) noted with respect to their PAR study with stroke patients, however, the purpose of such research is typically "to provide exemplary rather than generalisable information" and as such, study designs, methods, and sample sizes tend to differ from those of more traditional investigator-driven quantitative studies (p. 1278). Indeed, many of the studies reviewed appeared to illustrate the concern of Reason and Bradbury (2008) with "broadening the bandwidth of validity" in PAR, such that attention is devoted to such issues as whether the research *question* is valid, in the sense of coming from, or being important to, the often marginalized communities involved.

Although this concern is an important one in PAR, however, the need for increased attention to issues of both internal and external validity in PAR has been widely discussed (cf. Bradbury & Reason, 2008; Buchanan, Miller, & Wallerstein, 2007) and is particularly germane in the field of gerontology, where the use of PAR remains in its infancy.

As Green and Glasgow (2006) note, participatory research improves one facet of external validity, its relevance to end users of findings, but the more we make a study locally relevant, the more we make it potentially ungeneralizable beyond that setting and population. As Green and Glasgow further argue, however, such research remains relevant to others insofar as it reflects actual circumstances, rather than settings that are artificially constructed and controlled for academic purposes. This point is consistent with qualitative researchers' frequent use of the replication logic known as "transferability," which is enhanced through thorough description of both the research context and the assumptions implicit in its conduct.

Issues of internal validity have been less explicitly addressed in PAR, although, once again, concepts from qualitative research—for example, credibility, or "truth value," and confirmability, or being able to show that participants' perspectives and lived experience are accurately reflected in the data—may usefully inform this process. Maintaining a record for tracking the process leading to study conclusions, and including, for example, raw transcripts and instrument development information (Ulin, Robinson, & Trolley, 2005), may enhance confirmability in PAR projects that utilize qualitative research methods.

### *Personal Investment and Delayed Outcomes*

A fifth theme in the studies reviewed here arose from the tension between the personal motivation and the delayed time frame within which desired project outcomes could be achieved. Ostlund (2008) and Reed and colleagues (2002) thus recognized the role of personal motivation in engaging elders in gerontology but also acknowledged that participants may become discouraged if they believe that they will not live to see the results for which they have been working. This theme also was articulated by Dickson (2000), who noted that "considering their age and the pace of change, any sociopolitical effects from [the grandmothers'] activity would likely benefit the grandmothers less than it would the upcoming generations" (p. 211). As Dickson and Green (2001) concluded, however: "each PAR initiative needs to be viewed not in terms of whether it creates the revolution ... but whether it contributes to individuals' well-being and thus to a better society" (pp. 481–482). Each of the studies considered here appeared to demonstrate such a contribution, however incremental.

### **Concluding Note**

In their commentary for *The Gerontologist* over a decade ago, Glanz and Neikrug (1997) cited the critique of Marshall and Tindale (1978) of much gerontology as constituting a "tinkering trade" that primarily was engaged in repair work (p. 826). Glanz and Neikrug went on to suggest that:

when seniors themselves begin to "tinker" with social gerontology's theories and ideas as a result of conducting their own research, we may discover that 'the graying of social gerontology' is just what we need to help find new paradigms for understanding aging in the twenty-first century (p. 826).

Echoing and extending this theme, Estes, Phillipson, and Biggs (2006) more recently have argued that for this new century, “the key issue will be studying ageing as a global phenomenon *while at the same time incorporating older people as participants into the processes of research and theorizing*” (p. 154, emphasis added).

This article has attempted to review the literature on the involvement of older adults in PAR as one means of moving us toward this end. As we enter the second decade of the 21st century, the time appears ripe for heeding the call of Glanz and Neikrug, and that of Estes and her colleagues, and expanding social and critical gerontology’s scope to include research *with*, rather than solely *on*, older adults and their caregivers. In so doing, we may expand, as well, the relevance of our field for studying and addressing not only the complex health and social problems faced by elders but also these individuals’ unique strengths and the invaluable knowledge they can offer as coresearchers.

## References

Averill, J. B. (2005). Studies of rural elderly individuals: Merging critical ethnography with community-based action research. *Journal of Gerontological Nursing*, 31(12), 11–18.

Baker, T. A., & Wang, C. C. (2006). Photovoice: Use of a participatory action research method to explore the chronic pain experience in older adults. *Qualitative Health Research*, 16, 1405–1413.

Bar-Ilan Brookdale Program. (2008). *About us*. Retrieved August 1, 2008, from [http://www.biu.ac.il/Community/brookdale/about\\_brookdale\\_en.html](http://www.biu.ac.il/Community/brookdale/about_brookdale_en.html)

Bass, S. A., & Caro, F. G. (1995). Older people as researchers: Benefits to research and the community. *Educational Gerontology*, 21, 467–478.

Bernard, M. (2000). *Promoting health in old age*. Buckingham, UK: Open University Press.

Bradbury, H., & Reason, P. (2008). Issues and choice points for improving the quality of action research. In M. Minkler, & N. Wallerstein (Eds.), *Community-based participatory research for health* (2nd ed., pp. 225–239). San Francisco: Jossey-Bass.

Buchanan, D., Miller, F. G., & Wallerstein, N. (2007). Ethical issues in community based participatory research: Balancing rigorous research with community participation. *Progress in Community Health Partnerships*, 1, 153–160.

Cargo, M., & Mercer, S. L. (2008). The value and challenges of participatory research: Strengthening its practice. *Annual Review of Public Health*, 29, 325–350, Full version published online, April 2008.

Carrasquillo, O., & Chadiha, L. (2007). Development of community-based partnerships in minority aging research. *Ethnicity & Disease*, 17, S3–S5.

Carter, W., Elward, K., Malmgren, J., Martin, M. L., & Larson, E. (1991). Participation of older adults in health programs and research: A critical review of the literature. *The Gerontologist*, 31, 584–592.

Cawston, P. G., Mercer, S. W., & Barbour, R. S. (2007). Involving deprived communities in improving the quality of primary care services: Does participatory action research work?. *BMC Health Services Research*, 7, 88–97.

Chenoweth, L., & Kilstoff, K. (2002). Organizational and structural reform in aged care organizations: Empowerment towards a change process. *Journal of Nursing Management*, 10, 235–244.

Clare, L., & Cox, S. (2003). Improving service approaches and outcomes for people with complex needs through consultation and involvement. *Disability & Society*, 18, 935–953.

Clough, R., Green, B., Hawkes, B., Raymond, G., & Bright, L. (2006). *Older people as researchers: Evaluating a participative project*. York, UK: Joseph Rowntree Foundation.

Curry, L., Shield, R., & Wetle, T. (2006). *Improving aging and public health research: Qualitative and mixed methods*. Washington, DC: American Public Health Association and Gerontological Society of America.

Cusack, S. A. (1995). Developing a lifelong learning program: Empowering seniors as leaders in lifelong learning. *Educational Gerontology*, 21, 305–320.

Dickson, G. (2000). Aboriginal grandmothers’ experience with health promotion and participatory action research. *Qualitative Health Research*, 10, 188–213.

Dickson, G., & Green, K. L. (2001). Participatory action research: Lessons learned with Aboriginal grandmothers. *Health Care for Women International*, 22, 471–482.

Estes C., Biggs S., & Phillipson C. (2003). *Social theory, social policy and ageing: A critical introduction*. London: Open University Press.

Gallagher, E. M., Lindsey, E., & Scott, V. J. (2002). Promoting health through participatory action research: Lessons learned from “STEPS” (Study of Environments that Promote Safety). In L. E. Young, & V. E. Hayes (Eds.), *Transforming health promotion practice: Concepts, issues, and applications* (pp. 284–296). Philadelphia: F.A. Davis.

Gallagher, E. M., & Scott, V. J. (1997). The STEPS Project: Participatory action research to reduce falls in public places among seniors and persons with disabilities. *Canadian Journal of Public Health*, 88, 129–133.

Glanz, D., & Neikrug, S. (1997). Seniors as researchers in the study of aging: Learning and doing. *The Gerontologist*, 37, 823–826.

Green, L. W., George, M. A., Daniel, M., Frankish, C. J., Herbert, C. P., Bowie, W. R., et al. (1995). *Study of participatory research in health promotion: Review and recommendations for the development of participatory research in health promotion in Canada*. Vancouver, BC: Royal Society of Canada.

Green, L. W., & Glasgow, R. (2006). Evaluating the relevance, generalization, and applicability of research: Issues in external validation and translation methodology. *Evaluation & The Health Professions*, 29, 126–153.

Green, L. W., & Mercer, S. L. (2001). Can public health researchers and agencies reconcile the push from funding bodies and the pull from communities? *American Journal of Public Health*, 91, 1926–1929.

Hancock, K., Chenoweth, L., & Chang, E. (2003). Challenges in conducting research with acutely ill hospitalized older patients. *Nursing and Health Sciences*, 5, 253–259.

Hildebrandt, E. (1994). A model for community involvement in health (CIH) program development. *Social Science & Medicine*, 39, 247–254.

Israel, B. A., Schulz, A. J., Parker, E. A., & Becker, A. B. (1998). Review of community-based research: Assessing partnership approaches to improve public health. *Annual Review of Public Health*, 19, 173–202.

Israel, B. A., Schulz, A. J., Parker, E. A., Becker, A. B., Allen, A. J., III, & Guzman, J. R. (2008). Critical issues in developing and following community based participatory research principles. In M. Minkler, & N. Wallerstein (Eds.), *Community-based participatory research for health* (pp. 46–66). San Francisco: Jossey-Bass.

Jones, S. P., Auton, M. F., Burton, C. R., & Watkins, C. L. (2008). Engaging service users in the development of stroke services: An action research study. *Journal of Clinical Nursing*, 17, 1270–1279.

Lemieux, A. (1995). The university of the third age: Role of senior citizens. *Educational Gerontology*, 21, 337–344.

Levine, S., & Greenlick, M. (1991). Removing barriers to the empowerment of the elderly in health programs. *The Gerontologist*, 31, 581–582.

Lindamer, L., Lebowitz, B. D., Hough, R. L., Garcia, P., Aquirre, A., Halpain, M. C., et al. (2008). Improving care for older persons with schizophrenia through an academic-community partnership. *Psychiatric Services*, 59, 236–239.

Lindeman, M. A., Black, K., Smith, R., Gough, J., Bryce, A., Gilson, B., et al. (2003). Changing practice in residential aged care using participatory methods. *Education for Health*, 16, 22–31.

Marshall, V. M., & Tindale, J. (1978). Notes for a radical gerontology. *International Journal of Aging and Human Development*, 9, 163–175.

Minkler, M. (2005). Community-based research partnerships: Challenges and opportunities. *Journal of Urban Health*, 82 (2 Suppl. 2) 3–12.

- Minkler, M., Roe, K. M., & Price, M. (1992). Physical and emotional health status of grandmothers raising children in the crack cocaine epidemic. *The Gerontologist*, *32*, 752–761.
- Minkler, M., & Wallerstein, N. (2008). Introduction to community-based participatory research: New issues and emphases. In M. Minkler, & N. Wallerstein (Eds.), *Community-based participatory research for health: From process to outcomes* (2nd ed., pp. 5–23). San Francisco: Jossey-Bass.
- Moreno-John, G., Fleming, C., Ford, M. E., Lichtenberg, P., Mangione, C. M., Perez-Stable, E. J., et al. (2007). Mentoring in community-based participatory research: The RCMAR experience. *Ethnicity & Disease*, *17*, S33–S43.
- Moreno-John, G., Gachie, A., Fleming, C. M., Napoles-Springer, A., Mutran, E., Manson, S. M., et al. (2004). Ethnic minority older adults participating in clinical research: Developing trust. *Journal of Aging and Health*, *16*, 93S–123S.
- Neikrug, S. M., & Ronen, M. (1993). Elder abuse in Israel. *Journal of Elder Abuse and Neglect*, *5*(3), 1–19.
- Neikrug, S. M., Ronen, M., Glanz, D., Alon, T., Kanner, S., Kaplan, A., et al. (1995). A special case of the very old: Lifelong learners. *Educational Gerontology*, *21*, 345–355.
- Norris, K. C., Brusuelas, R., Jones, L., Miranda, J., Duru, O. K., & Mangione, C. M. (2007). Partnering with community-based organizations: An academic institution's evolving perspective. *Ethnicity & Disease*, *17*, S27–S32.
- Older People's Steering Group. (2004). *Older people shaping policy and practice*. York, UK: Joseph Rowntree Foundation.
- Ostlund, B. (2008). The revival of research circles: Meeting the needs of modern aging and the third age. *Educational Gerontology*, *34*, 255–266.
- Ray, M. (2007). "Redressing the Balance? The Participation of Older People in Research." In M. Bernard & T. Scharf (Eds.), *Critical perspectives on aging societies* (pp. 73–88). Bristol, UK: The Polity Press.
- Reason, P., & Bradbury, H. (2008). *Handbook of action research* (2nd ed.). London: Sage.
- Reed, J. (2005). Using action research in nursing practice with older people: Democratizing knowledge. *Journal of Clinical Nursing*, *14*, 594–600.
- Reed, J., Pearson, P., Douglas, B., Swinburne, S., & Wilding, H. (2002). Going home from hospital—An appreciative inquiry study. *Health and Social Care in the Community*, *10*, 36–45.
- Roe, K., Minkler, M., & Saunders, F. F. (1995). Combining research, advocacy, and education: The methods of the grandparent caregiver study. *Health Education Quarterly*, *22*, 458–475.
- Ross, F., Donovan, S., Brearley, S., Victor, C., Cottee, M., Crowther, P., et al. (2005). Involving older people in research: Methodological issues. *Health and Social Care in the Community*, *13*, 268–275.
- Schensul, J. J., Robison, J., Reyes, C., Radda, K., Gaztambide, S., & Disch, W. (2006). Building interdisciplinary/inter-sectoral research partnerships for community-based mental health research with older minority adults. *American Journal of Community Psychology*, *38*, 79–93.
- Schwab, M., & Syme, S. L. (1997). On paradigms, community participation, and the future of public health. *American Journal of Public Health*, *87*, 2049–2052.
- Ulin, P. R., Robinson, E. T., & Trolley, E. E. (2005). *Qualitative methods in public health*. San Francisco: Jossey Bass.
- Wang, C. C., & Burris, M. (1997). Photovoice: Concept, methodology, and use for participatory needs assessment. *Health Education and Behavior*, *24*, 369–387.
- Zimmerman, M. A. (2000). Empowerment theory: psychological, organizational and community levels of analysis. In J. Rappaport & E. Seidman (Eds.), *Handbook of community psychology* (pp. 43–63). New York: Academic/Plenum.

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