

From Rhetoric to Action: Establishing Community Participation in AIDS-Related Research

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Certains voient dans le syndrome d'immunodéficience acquise (sida) le plus redoutable défi médical de l'histoire moderne. Pour beaucoup de séropositifs et de malades du sida, l'accès à de bons services de relève et à des logements subventionnés constitue un besoin pressant. Pour répondre aux besoins des malades du sida en matière de logement, il est essentiel d'amener ce groupe à définir ses propres besoins. À cette fin, une enquête de type recherche participative (RP) a été réalisée auprès des malades du sida afin de s'assurer du bien-fondé et du caractère réalisable d'un foyer communautaire de type logement subventionné avec services de relève. La recherche participative est reconnue comme une méthode utile lorsqu'il faut s'assurer de l'à-propos d'une recherche et obtenir la participation de la communauté pour aboutir au changement. Même si on s'intéresse de plus en plus à la recherche participative dans le domaine des sciences infirmières, on y trouve peu d'exemples décrivant la réalisation d'une recherche participative. Cet article vise donc à décrire, à expliquer et à critiquer l'utilisation de cette méthode dans le cas d'un foyer de type logement subventionné avec services de relève. On y présente un cadre de recherche participative et on y décrit les étapes de la réalisation d'une telle recherche.

Acquired Immunodeficiency Syndrome (AIDS) has been described as the most challenging disease in modern history. For many people with HIV/AIDS (PWA), issues of appropriate respite care and supported housing are a pressing concern. To meet the housing requirements for PWAs, it is essential to engage this community in determining its own housing needs. To that end, a participatory action research (PAR) investigation was undertaken with the PWA community to ascertain the desirability and feasibility of a supported-living/respite-care community home. PAR has been heralded as an important research methodology in ensuring research relevance and community participation leading to effective change. Although nursing interest in PAR is increasing, there are few nursing examples that describe the process of undertaking PAR. The purpose of this article is to describe, explain, and critique the use of PAR in the case of a supported-living/respite-care home. A PAR framework is presented and the process of conducting PAR is outlined.

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Introduction

Acquired Immunodeficiency Syndrome (AIDS) has been described as the most challenging disease in modern history (Carr, 1996; Lenker, Lubeck, & Vosler, 1993). Fears of contagion, disability, and death are mixed with moral overtones concerning drug use, sexuality, sexual identity, and freedom. These responses to AIDS have profound consequences for individuals and communities touched by the disease. One issue of central importance is the type and location of care for persons with HIV/AIDS (PWA) who are unable to live independently (Beedham & Wilson-Barnett, 1995). Concerns about housing and access to appropriate health care often arise from rejection by family, partner, and/or roommate, fear of contagion (Curley, 1994; Haskell, Satten, Franks, & Parker-Martin, 1988; Schietinger, 1988), and the increasing strain and burden placed on caregivers of PWAs (Beedham & Wilson-Barnett; Brown, 1992; Cummings, 1993; Ravies & Siegel, 1990). As a consequence, PWAs lose support systems that allow for home care and are often placed in institutions even though this may not be the most appropriate or desirable alternative (Arno et al., 1996; Curley).

A response of the Victoria AIDS Respite Care Society (VARCS) to the problem of housing was to develop a supported-living/respite-care home for PWAs. In this context, supported living was defined as 24-hour care in an environment of physical and psychosocial support when home care is no longer an option and where traditional institutional care is either inappropriate or undesirable. Respite care was defined as temporary relief for the primary caregiver.

In order to determine the location and type of supported-living/respite-care home required by PWAs, it was critical that the community associated with and/or affected by HIV/AIDS be involved in addressing the question. Therefore, the community and researchers engaged in participatory action research (PAR) to address the question: What is the desirability and feasibility of a supported-living/respite-care home for PWAs in our community?

Although the nursing profession is increasing its interest in PAR (Campbell & Bunting, 1991; Henderson, 1995; Rasmussen, 1997; Stevens & Hall, 1992), it has provided few descriptions of the *process* of undertaking this form of research (Henderson). The purpose of this article is to describe, explain, and critique the use of PAR in the VARCS community initiative. Following an overview of PAR (including its historical development, theoretical influences, and methodological considerations), the importance of using PAR in community-based research will

be explored and the relational qualities inherent in PAR will be addressed. Using the supported-living/respite-care home research as an example, the process of engaging in PAR will be examined. Finally, some of the issues inherent in community involvement in PAR will be considered. A full report of this research has been submitted to an AIDS-related journal.

Background

PAR is a social-action process that focuses on the empowerment of oppressed groups (Hall, 1992). One of its assumptions is that knowledge is related to power and power is related to change (Couto, 1987). Inherent in PAR is mobilization of people within the research process, leading to necessary and effective change. PAR has been defined as a way of creating knowledge that involves learning from investigations and applying what is learned to collective problem-solving through social action (Park, 1992). Thus the people affected by the problem are directly involved in the research process, from problem formulation, through the process of inquiry, through effecting necessary change.

The ideological and methodological debate about the differences between participatory research and action research (Yeich & Levine, 1992) appears to focus on the emphasis of the research — whether it is predominantly participatory or action-oriented. However, in contemporary dialogue these differences seem to be diminishing, and fundamental to both research paradigms are the underlying principles of community participation in research, leading to the generation of useful knowledge that results in effective change. Whyte (1991) coined the term Participatory Action Research to address these ideological and methodological similarities. Although the debate concerning the similarities, differences, advantages, and disadvantages of each of these methodologies is an ongoing one (Christholm & Elden, 1993; Yeich & Levine), the term PAR will be used in this paper to attend to the underlying principles of active community involvement in the research process in solving practical problems and promoting effective change.

In discussing PAR, confusion has also surrounded issues of epistemology, methodology, and method (Henderson, 1995). According to Harding (1987), epistemology addresses the theory of knowledge, or what can be considered legitimate knowledge in the research process. Epistemologies that are consistent with PAR, such as emancipatory, feminist, and critical theories, consider knowledge as consciousness-raising and liberatory (Henderson). Methodologies attend to “a theory and analysis of how research does or should proceed” (Harding, p. 22).

In this sense, the methodology of PAR refers to *how* the research should be carried out, or the attitude or approach to the research (Cornwall & Jewkes, 1995). Finally, method refers to the precise research method or technique used (Henderson). In PAR, the epistemology and methodology are of central concern in that the research must attend to issues of power, oppression, liberation, emancipation, and change, and must be conducted through inclusive, participatory, egalitarian, ethical, and moral means (Cornwall & Jewkes). The actual method may range among different forms of qualitative and quantitative research (Cornwall & Jewkes; Hall, 1992; Park, 1992). The important element in the research method is that it utilizes the epistemological and methodological principles of PAR.

The evolution of PAR began in the 1940s when Kurt Lewin used the term *action research* to describe a "spiral of steps each of which is composed of a circle of planning, action and fact-finding" (Lewin, 1946, p. 38). Throughout the years, this early definition has been expanded to emphasize community participation, research relevance, mutuality, negotiation, egalitarianism, collaboration, democracy, ethics, and issues of power.

PAR is also known as *collaborative research*, to highlight the egalitarian relationship between "researcher" and "client" and to break down the barrier between theory and practice (Nyden & Wiedel, 1992). In keeping with these principles, PAR is founded on the theoretical perspectives of social activism (Alinsky, 1946, 1969), critical social theory (Freire, 1990; Habermas 1987), and feminism (Campbell & Bunting, 1991; Hall, 1992; Henderson, 1995; Stevens, 1989; Stevens & Hall, 1992). Early in the social activism movement, Saul Alinsky commented that the work of "academics" was "irrelevant," a criticism related to academic researchers investigating problems of little social import. Critical social theory continued this response to the scientific community's insistence on accepting only empirical observations or logical deductions as legitimate knowledge (Campbell & Bunting, 1991). The central tenet of critical theory is the commitment to penetrating the world of objective appearances in order to expose the underlying social relationships. In keeping with PAR, the goal of critical social theory is to liberate or emancipate individuals from the constraints that, consciously or unconsciously, oppress them (Allen, 1990; Brent, 1993; Wilson-Thomas, 1995). Consistent with the principles, values, and goals of critical theory, feminism has contributed to the understanding and practice of PAR. Researchers have begun to describe negotiation, reciprocity, empowerment, and dialogue within the research process (Henderson). Both PAR

and feminist approaches are concerned with knowledge creation that empowers rather than oppresses and controls (Maguire, 1987). In addition, Maguire suggests that women have traditionally been excluded from scientific discourse and that gender, culture, race, and class should be of central concern. In this sense, PAR and feminist research enable marginalized groups to gain power and have a voice. Integral to critical theory, PAR, and feminist research are issues of research relevance, community involvement, democracy, negotiation, reciprocity, egalitarianism, ethics, morality, inclusion, power, voice, emancipation, and liberation.

In the PAR study investigating the desirability and feasibility of a supported-living/respite-care home for PWAs, the basic tenets of critical social theory, PAR, and feminist research were the guiding principles. Epistemologically, knowledge was generated through a process of consciousness-raising and liberation. It was created as shared meanings of experiences and perceptions evolved through dialogue among the participants. Methodologically, the process of PAR depended on community participation and involvement throughout the research process. The method used was qualitative and inductive. This research provides a case study of the processes of actualizing PAR, to produce relevant, meaningful results leading to effective change.

First, the case study will be presented and the research methods described. Then the process of conducting this study will be explained. Finally, some of the issues inherent in using PAR will be considered.

A Case Study

This research came about as a result of an expressed need by the HIV/AIDS community to consider a supported-living/respite-care home for PWAs. VARCS, a community organization devoted to providing respite care for PWAs and their primary caregivers, was founded by several gay men in response to burnout in those caring for loved ones with HIV/AIDS at a time when the only option for respite care was hospital admission. The men created a volunteer organization that provided respite care by either going to the PWA's home or bringing the PWA to a volunteer's home. VARCS was very successful in providing volunteer respite care, but the need for a community supported-living/respite-care home for PWAs was evident. To this end, VARCS invited an academic researcher and a community volunteer (both nurses) to conduct a study of the desirability and feasibility of a community-based home for PWAs.

There were two important reasons for using PAR methodology in this research. First, the PWA community was disillusioned and angered by experiences of having research “done to them” with little obvious relevance or advantage for the AIDS community. Thus the community insisted on participating in the research and being actively engaged in the resulting initiative. Second, the two nurse researchers involved in the project came from a philosophical orientation of community inclusion and participation. They had experience in community development and PAR. Information about the research population and methods of data collection and analysis will be provided for this case. A broader discussion about how PAR was actualized with the community will follow.

Population

Purposive sampling (Morse, 1991) was used to guide the selection of participants and respondents. *Research participants* refers to the community members and researchers who became the team. *Research respondents* refers to the broader population who provided data and validated the results.

First, a comprehensive analysis of the relevant population within the community was undertaken, ensuring that people associated with AIDS care and housing issues, and other stakeholders, were identified so that they could be informed of the research process and invited to participate. PWAs, their primary caregivers, health and social service professionals and non-professionals, and AIDS service organizations (ASOs) were the major stakeholders in the supported-living/respite-care home initiative. In order to ensure the inclusion of less obvious choices as well, the different stakeholders were asked to identify community groups that might be asked to participate. They suggested municipal and cooperative housing representatives, street-associated people and their workers, drug and alcohol workers, police officers, city engineers and architects, representatives of municipal and provincial health and finance agencies, and an accountant and lawyer from a community group. Representatives from each of these groups were invited to participate.

The next step was deciding who would be the *research participants* and who would be the *research respondents*. The selection was made in two ways. First, the researchers, together with the Executive Director of VARCS, invited key stakeholders to become *research participants* — that is, to join the research team. Second, an invitation to join the team was

extended to those in the pool of potential respondents; some members of the stakeholder group also agreed to join the research team. Other identified members of the population agreed to become *research respondents*. In this way, the two researchers, the Executive Director of VARCS, two street workers, two PWAs, and two VARCS staff members became the research team, while a total of 78 people became *research respondents*.

Data Collection

Based on the primary question guiding this research — What is the desirability and feasibility of a supported-living/respite-care home for PWAs in the Capital Regional District? — the research team developed the following interview questions:

- What is your opinion about the initiation of a supported-living/respite-care home for persons living with HIV/AIDS in our community?
- What would this home look like?
- What issues would have to be addressed when considering the development of this home?
- What would get in the way of the success of this project?
- How could we best facilitate the development of a supported-living/respite-care home for persons living with HIV/AIDS in our community?
- What advice do you have to help this project along?
- Do you have anything else you would like to add?

It should be noted that these questions were used as a guide to data collection; they were adapted to address the specific experiences, perceptions, and opinions of the different stakeholder groups.

The next task for the research team was to consider how best to collect the data. It was decided that focus-group meetings (Kreuger, 1993; McDaniel & Bach, 1994) and open-ended individual interviews (Patton, 1987) would be the most appropriate methods. Focus-group interviews were used to facilitate open discussion, and a total of 60 people participated in 7 focus-group interviews, each lasting approximately 1.5 hours. With the consent of each participant, all interviews were audiotaped and transcribed. As well, field notes were recorded on flip charts to ensure accuracy of researcher understanding and to validate each participant's responses.

Individual interviews were conducted with 18 respondents who were uncomfortable participating in focus groups. After informed con-

sent had been secured, some of these interviews were audiotaped and transcribed. Street workers conducted interviews with street-associated people, hand-writing the responses. It should be noted that the research team carefully considered who should conduct the focus-group and individual interviews, acknowledging that the different needs and comfort levels of the various populations required sensitivity. For example, the nurse researchers (together with a PWA) conducted the focus-group meeting with physicians and specialists in infectious-disease control, whereas the street workers conducted focus-group and individual interviews with the street-associated people. In this way, many combinations of the research team were formulated, respecting the needs and comfort levels of the various respondents.

Data Analysis

The transcribed and hand-written data from the focus-group and individual interviews were analyzed following Patton's (1987) and Hycner's (1985) guidelines for qualitative data analysis. Patton and Hycner suggest that, in order to get a sense of the data as a whole, in the initial stages of data analysis the researcher should listen to the audiotapes several times as well as play them over the transcriptions and field notes. Hycner reminds us that this process provides the context for the emergence of themes later in the analysis. This process was used to break the data into segments and code the data into themes. Subsequently, patterns and meta-themes addressing the research question were identified. Issues of validity and reliability will be addressed in the section that describes the PAR process.

The Research Process

An overview of the philosophical and methodological considerations of PAR, and an outline of a case study using PAR as the research methodology, are presented above. The *process* of undertaking research following the methodological guidelines and philosophical considerations of PAR will now be presented.

Bailey (1992) provides the following organizing framework for conducting PAR: (a) entry into the community and development of a collaborative relationship so that the community's issues can be explored, (b) collaborative data collection whereby researchers and community members act as a team, (c) data analysis and feedback to ensure a collective understanding of the data and the issues, (d) action

planning and implementation of initiatives to resolve these issues, and (e) evaluation of the results of the action and commencement of the iterative process. This framework was used to actualize the process of PAR in the study investigating the desirability and feasibility of a supported-living/respite-care home for PWAs. Bailey's organizing framework will now be used to describe this PAR process.

- (a) Gaining entry into the community and developing a collaborative relationship. It should be noted that the community approached the researchers to request that the possibility of initiating a community home for PWAs be investigated. The two researchers were known to the community for different reasons. The academic nurse researcher had been involved in PAR and community-development initiatives with people living with chronic illnesses and was respected for her egalitarian relationships in the community. The nurse volunteer was a Clinical Nurse Specialist in palliative care and had done a considerable amount of volunteer work with the HIV/AIDS community, undertaking educational initiatives and providing personal care to PWAs. Thus both researchers had developed credibility in the PWA community.
- (b) Establishing collaborative methods of data collection whereby community members and the researchers act as a team. Members of the VARCS community were the primary source in identifying the research population and sample. They had first-hand knowledge of the stakeholders who might be invited to participate in the research. In addition, research relevance is a central issue in PAR, and these community members could explain the relevance of this research to the various communities. Ensuring community participation in the data-collection processes was an exciting and complex undertaking. In keeping with the principles of PAR, the researchers first asked VARCS community members to identify those people who should be *research participants* and those who should be *research respondents*. The HIV/AIDS community decided that VARCS members (the Executive Director, street workers, PWAs, and VARCS staff members) should be *research participants*, and that other major stakeholders should be invited to participate as *research respondents*. The important element here is that it was the *community* that identified the team members and the community respondents and it was the *community* that extended the invitation for them to participate.

Members with expertise in conducting research interviews held training sessions for other members of the team, who then joined the researchers in conducting the interviews. In this way, the researchers and community members created a partnership to ensure extensive community participation in the project.

- (c) Analyzed data were provided to community participants and feedback was sought to ensure collective understanding of the data and the results. It is generally agreed that considerable knowledge is required to conduct qualitative data analysis. For this reason, the researchers took a leadership role in analyzing the focus-group and individual interviews. However, in keeping with PAR, the analyzed data were returned to all research participants to ensure validation of the analysis; they were asked to consider whether the analysis fully represented their experiences, perceptions, and opinions and were invited to make further comments. Reliability was ensured by each researcher undertaking preliminary data analysis independent of the other. The VARCS Executive Director then joined the researchers in checking consistency of the independent analyses; all three agreed there was consistency between the independent analysis of each researcher. The final meta-analysis was undertaken by the two researchers in partnership.

The following six themes emerged from the study: (i) closer to home, (ii) flexibility of options, (iii) ambience, (iv) consistency of care, (v) partnerships, and (vi) barriers. A full description of these results has been submitted to an AIDS-related journal. Overall, the results indicate that the research respondents supported the idea of a home that was cost-effective, provided options for PWAs, and featured a home-like environment that shared a "closer to home" philosophy. They expressed a need for consistency of AIDS care at each level of the disease trajectory and for building effective and supportive partnerships with the community associated with AIDS care. The barriers they envisioned to realizing a community home for PWAs were AIDS stigma, costs, "turf wars," "red tape," and "not in my backyard" attitudes.

- (d) Planning action and implementing initiatives to address the research findings is the next step in Bailey's (1992) PAR framework. The researchers have moved into a peripheral role at this stage in the PAR process. The VARCS Executive Director and Board of Directors are at the initial steps in writing proposals to government agencies, mobilizing resources, and engaging the community in

various forms of action. The province of British Columbia has recently undergone a restructuring of its health-care system, and various important stakeholders who participated in the research are no longer involved at the government or community level. This restructuring highlights the need to continually develop partnerships and create opportunities for community involvement. Throughout the project, it has been critical that the community remain educated and engaged. Because of the disruption to the health-care system, planning and initiating various actions has been stalled. However, some actions are underway. The street-associated community has recently been provided with a motel to help house the homeless, particularly those with HIV/AIDS. Housing cooperatives are being approached to see if the supported-living/respite-care home might be located in one of their communities. The researchers have been reviewing the literature on initiatives for seniors' housing, cooperative housing, housing for street-associated people, and so on. In addition, proposals are being prepared for presentation to various levels of government.

- (e) The final element in Bailey's (1992) framework is evaluation of the actions taken and commencement of the iterative process. This community project is still in the early stages of action, so the evaluative, iterative process is just commencing. However, each action undertaken is discussed by the VARCS Board of Directors and rated for its efficacy. As a result, initiatives are planned and undertaken by various members of the community. This process is iterative and cyclical; as action plans are evaluated, new initiatives are considered and the process of community participation and action recommences. An example of this iterative, cyclical process was the initiative to consider locating the home in a housing cooperative. As community members approached various housing cooperatives, they realized they needed information about similar initiatives. They conducted a literature review of housing for different population groups in order to present this information to the cooperatives. The key element here is that each action is judged for its efficacy and new or additional strategies are considered.

Relevant Challenges in PAR

As a result of this experience of engaging in PAR, several important issues emerged. First, it was critical to ensure that all important community stakeholders had an opportunity to participate in the research.

Such full community engagement poses considerable challenges. The significant community must be identified, and it must be determined who will be invited to join the team as *research participants* and who will be *research respondents*. The important stakeholders must be persuaded of the importance of the research and the need for their involvement. In addition, strategies must be developed to ensure their continued involvement in the research and their subsequent involvement in the resulting action. The three ASOs in the area often worked in isolation from one another. Ensuring collaborative partnerships among stakeholders from the three posed a challenge. However, the overall aim of the study was the unifying factor.

An important element of PAR is that diversity must be valued. Again, actualizing this philosophy posed considerable challenges. Some members of the health and social-service agencies questioned the ability of the AIDS community to carry out data collection. In addition, a decision was made to have homogeneous focus groups (i.e., groups of health-care professionals, groups of street-associated people, etc.). It was determined that more discussion and elaboration within the interviews would be forthcoming with homogeneous group mixing. So, although diversity was valued at a philosophical level, on a practical level the researchers found valuing of diverse opinions and abilities among community members to be more problematic.

PAR stresses the importance of developing egalitarian relationships throughout the research process. In this study, egalitarian relationships evolved through each person valuing another's expertise at different stages of the research. The community identified the research question, engaged in data collection, and began to take action. It was determined that for the most part the community members of the team had the greatest expertise at these stages in the research process. In contrast, the researchers took a leadership role in data analysis; however, the community was involved in reliability and validity checks. Issues of power imbalance were initially raised by members of the research team. For instance, the researchers were mindful of their power in facilitating the project, and members such as health-care providers were perceived to have more power than PWAs. These perceived power imbalances were discussed as part of the research process; continued sensitivity to this issue was critical to the project's success.

Issues of leadership posed another challenge. At times it was essential for the VARCS community members to take a leadership role on the team, while at other times the researchers had to assume that role. The

challenge was to determine when a change of leadership was necessary, and under what conditions. For example, VARCS members promoted the project in the community. However, the researchers took a leadership role in persuading various funding agencies that the quality of the research was sound. In addition, throughout the research process leadership was a matter of facilitation rather than direction, although there were times when direction was required. The important element here is that all members of the research team must be sensitive and responsive to the need for different forms of leadership at different stages of the project.

Finally, PAR is time-consuming. A substantial amount of time was devoted to identifying the communities that would be invited to participate in the project. Time had to be allotted to training the team members in data-collection methods. It also took considerable time to check validity and reliability of the analysis and results. Finally, mobilizing the community for action is a time-consuming endeavour. With the change of the Ministry of Health mandate, this movement to action has been further impeded, resulting in more time lost in initiating the supported-living/respite-care home. Sufficient time must be allowed to ensure full community participation in the research process and to activate the cyclical process of implementing and evaluating effective change.

Conclusion

Interest in PAR by nursing and related health and social-science disciplines is increasing (Bailey, 1992; Campbell & Bunting, 1991; Hall, 1992; Henderson, 1995; Rasmussen, 1997; Stevens & Hall, 1992). However, few examples describe the process of engaging in PAR leading to effective change (Henderson). The purpose of this article was to describe and explain the process of engaging in PAR by presenting a research project investigating the desirability and feasibility of a supported-living/respite-care home for PWAs. PAR's historical development, theoretical influences, and methodological considerations have been described. The importance of using PAR in community-based research has been explored. Finally, some of the issues inherent in community involvement in PAR have been presented. This article has provided a summary of one PAR experience. This example might encourage other nurse researchers to consider PAR when addressing research relevance in nursing.

References

- Alinsky, S. (1946, 1969). *Reveille for radicals*. New York: Vintage Press.
- Allen, D. (1990). Critical social theory and nursing education. In N. Greenleaf (Ed.), *Curriculum revolution: Redefining the student-teacher relationship* (pp. 67-86). New York: National League for Nursing.
- Arno, P.S., Bonuck, K.A., Green, J., Fleishman, J., Bennet, C.L., Fahs, M.C., Maffeo, C., & Ducker, E. (1996). The impact of housing status on health care utilization among persons with HIV disease. *Journal of Health Care for the Poor and Underserved*, 7(1), 36-49.
- Bailey, D. (1992). Using participatory research in community consortia development and evaluation: Lessons from the beginning of the story. *American Sociologist*, 23(4), 71-82.
- Beedham, H., & Wilson-Barret, J. (1995). HIV and AIDS care: Consumers' view on needs and services. *Journal of Advanced Nursing*, 22(4), 677-686.
- Brent, K. (1993). Perspectives on critical and feminist theory in developing nursing praxis. *Journal of Professional Nursing*, 9(5), 296-303.
- Brown, M.A. (1992). Caregiver stress in families of persons with HIV / AIDS. In S.L. Feetham, S.B. Meister, J.M. Bell, & C.L. Gillis (Eds.), *The nursing of families* (pp. 211-223). Newbury Park, CA: Sage.
- Campbell, J., & Bunting, S. (1991). Voices and paradigms: Perspectives on critical and feminist theory in nursing. *Advances of Nursing Science*, 13(3), 1-15.
- Carr, G. (1996). Ethnography of an HIV hotel. *Journal of the Association of Nurses and AIDS Care*, 7(2), 35-42.
- Christholm, R.F., & Elden, M. (1993). Features of emerging action research. *Human Relations*, 46(2), 275-298.
- Cornwall, A., & Jewkes, R. (1995). What is participatory research? *Social Science and Medicine*, 41(12), 1667-1676.
- Couto, R.A. (1987). Participatory research: Methodology and critique. *Clinical Sociology Review*, 4, 83-92.
- Cummings, M. (1993). Difficulties in developing a respite care program. *Journal of Palliative Care*, 9(3), 18-22.
- Curley, D.J. (1994). An approach to supported housing for people with mental illness and HIV disease. *Psychosocial Rehabilitation Journal*, 17(4), 160-168.
- Freire, P. (1990). *Education for critical consciousness* (M. Ramos, Trans.). New York: Continuum.
- Habermas, J. (1987). The theory of communicative action. Vol. 2: *Lifeworld and system: A critique of functionalist reason*. Boston: Beacon Press.
- Hall, B.L. (1992). From margins to center? The development and purpose of participatory research. *American Sociologist*, 23(4), 15-28.
- Harding, S. (1987). *Feminism and methodology*. Bloomington: Indiana University Press.

- Haskell, G.W., Satten, N.F., Franks, P., & Parker-Martin, P. (1988). *Developing AIDS residential settings*. San Francisco: Visiting Nurses and Hospice of San Francisco.
- Henderson, D.J. (1995). Conscious raising in participatory research: Method and methodology for emancipatory nursing inquiry. *Advances in Nursing Science*, 17(3), 58-69.
- Hycner, R.H. (1985). Some guidelines for the phenomenological analysis of interview data. *Human Studies*, 8(3), 279-303.
- Kreuger, R.A. (1993). *Focus groups: A practical guide for applied research*. Newbury Park, CA: Sage.
- Lenker, S., Lubeck, D.P., & Vosler, A. (1993). Planning community-wide services for persons with HIV infection in an area of moderate incidence. *Public Health Reports*, 108(3), 285-293.
- Lewin, K. (1946). Action research and minority problems. *Journal of Social Issues*, 2, 34-46.
- Maguire, P. (1987). *Doing participatory research: A feminist approach*. Amherst: Center for International Education, University of Massachusetts.
- McDaniel, R.W., & Bach, C.A. (1994). Focus groups: A data gathering strategy for nursing research. *Nursing Science Quarterly*, 7(1), 4-5.
- Morse, J.M. (1991). Strategies for sampling. In J.M. Morse (Ed.), *Qualitative nursing research: A contemporary dialogue* (pp. 127-145). Newbury Park, CA: Sage.
- Nyden, P., & Wiedel, W. (1992). Collaborative research: Harnessing the tensions between researcher and practitioner. *American Sociologist*, 23(4), 43-55.
- Park, P. (1992). The discovery of participatory research as a new scientific paradigm: Personal and intellectual accounts. *American Sociologist*, 23(4), 29-42.
- Patton, M.Q. (1987). *How to use qualitative methods*. Newbury Park, CA: Sage.
- Rasmussen, S. (1997). Action research as authentic methodology for the study of nursing. In S. Thorne & V.E. Hayes (Eds.), *Nursing praxis* (pp. 254-266). Newbury Park, CA: Sage.
- Ravies, V., & Siegel, K. (1990). Impact of caregiving on informal or formal caregivers. In *Community-based care of persons with AIDS: Developing a research agenda* (pp. 17-28). (DHHS Publication Number [PHS] 90-3456.) Washington: US Government Printing Office.
- Schietinger, H. (1988). Housing for people with AIDS. *Death Studies*, 12(4), 481-499.
- Stevens, P.A. (1989). A critical social reconceptualization of environment in nursing: Implications for methodology. *Advances in Nursing Science*, 10(4), 56-68.
- Stevens, P.A., & Hall, J. (1992). Applying critical theories to nursing in communities. *Public Health Nursing*, 9(1), 2-9.
- Yeich, S., & Levine, R. (1992). Participatory research's contribution to a conceptualization of empowerment. *Journal of Applied Sociology*, 24, 1894-1908.
- Whyte, W.F. (1991). *Participatory action research*. Newbury Park, CA: Sage.

Wilson-Thomas, L. (1995). Applying critical social theory in nursing education to bridge the gap between theory, research and practice. *Journal of Advanced Nursing*, 21(3), 568-575.

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