

*Article*

**Using PAR or Abusing Its Good Name?  
The Challenges and Surprises of Photovoice and Film  
in a Study of Chronic Illness**

Dawn Allen, PhD  
Postdoctoral Fellow  
Programs in Whole Person Care  
McGill University  
Montreal, Quebec

Thomas Hutchinson, MB  
Director of Programs in Whole Person Care  
McGill University, Montreal, Quebec

© Allen. This is an Open Access article distributed under the terms of the Creative Commons Attribution License (<http://creativecommons.org/licenses/by/2.0>), which permits unrestricted use, distribution, and reproduction in any medium, provided the original work is properly cited.

---

**Abstract**

Without dispute, kidney dialysis treatment has been successful in saving lives. As a result of this intervention, increasing numbers of people are now facing the many physical, social, and emotional challenges of living with ESRD (end stage renal disease). Compromised vision, mobility, dexterity, and overall health have presented important methodological challenges to the authors' participatory action research (PAR) study of ESRD patients' quality of life. This article proceeds broadly in three steps: (a) an explanation of the authors' interest in PAR and the challenges that ESRD poses for PAR, (b) a description of how they adapted two visual techniques (photovoice and documentary film making) to address those challenges, and (c) a discussion of how they have and have not overcome the challenges of working with PAR.

**Keywords:** end-stage renal disease, quality of life, photovoice, documentary film-making

**Authors' note:** We thank the Kidney Foundation of Canada for its generous support of this project and the patients and health care professionals who have so openly and generously shared their experiences and insights. We also thank Mary Ellen Macdonald, Franco Carnevale, and the McGill Qualitative Health Research Group, who provide ongoing support with their always valuable and sometimes challenging feedback.

---

## **Introduction**

Participatory action research (PAR) developed in the last half of the 20th century partly in response to what Hagey (1997) referred to as “hit and run” research, where the first priority of the researcher was to the researcher community rather than the community being studied. In contrast, PAR is a research orientation that prioritizes empowering participants toward owning the research and improving the quality of their lives (Hagey, 1997; McTaggart, 1991).<sup>1</sup> Broadly, PAR can be understood to be guided by several key principles: (a) democratic participation of the study’s consumers or users in all aspects of the research, (b) equal power and equal respect for the knowledge domains of all participants, (c) bidirectional education between the researchers and participant-collaborators, (d) particular attention to the needs of those who are marginalized, and (e) a general goal of social action for a better quality of life for the study’s principal consumers (e.g., G. White, Suchowierska, & Campbell, 2004; Stringer, 1996; Hall, 1981).

Notwithstanding, McTaggart (1991) has argued that “despite some considerable emergent agreement about what participatory action research is, any literature search using the descriptors ‘participatory research,’ ‘action research,’ or ‘participatory action research’ will still identify a confusing and meaningless diversity of approaches to research.” (p. 169). Both McTaggart and Hagey (1997) believe this confusion arises from the misuse of the term PAR in an attempt to “represent research deliberately as inspired by communitarian values when it is not” (p. 170). Hagey has stated,

The most common abuse of PAR is using its good reputation, gained from its ethical relations and practices, while conducting research within the conventional sets of relations. The obvious motivation is to retain control of research and to be accountable to one’s bureaucracy, which calls for efficiency in research. (para. 11)

As university-based researchers we are both constrained by the university research culture (as regards, for example, authorship and publication) and accountable to this study’s funding source. We are also committed to a PAR approach for studying the quality of life for people living with end-stage renal disease (ESRD), also known as chronic kidney failure. Drawing on our combined expertise in kidney disease and qualitative inquiry, we approached this study believing that patients’ perspectives on suffering and healing with ESRD are better indices of quality of life than are medical assessments of disease state. We wanted patients’ voices and experiences to be at the center of our study. Furthermore, because we wanted our study to both express patients’ interpretations of their quality of life and to actively engage in improving it, we felt PAR was the most appropriate orientation for our study’s goals.

We have found it difficult to meet all of the PAR criteria in the context of this chronic illness, which compromises the mobility and health of the people who live with it. For example, according to the principle of participant inclusion in all phases of the research, PAR studies should arise from the community they are intended to serve/target. However, in the context of chronic illness, a sense of “community” may be absent, and the challenges of the illnesses themselves might make it difficult for those who are most in need of social action to organize and initiate it. In this article we explore the nature of those challenges and how we have chosen to respond to them using photovoice (Wang, 1999) and film. Despite the success of these methods for the purposes of our study, we remain unsure as to whether we are really using PAR or, as Hagey (1997) has cautioned, merely “using its good reputation” (parag.11). We discuss this concern in our conclusion.

### **Background on end-stage renal disease**

With the availability of chronic dialysis treatment and kidney transplantation since the 1950s and 1960s, the prevalence of ESRD has risen steadily in developed countries. People who would otherwise have died now survive with treatment. This success has brought with it the difficulties of living with ESRD (Hutchinson, 1999). Research in the area of health-related quality of life has identified a multitude of challenges that ESRD patients face, including unemployment; limited physical mobility, sleep disturbance, depression, and anxiety (Hagren, Pettersen, Severinsson, Lutzen, & Clyne, 2001; Janssen van Doorn, Heylen, Mets, & Verbeelen, 2004; Kouidi, 2004). A small number of qualitative studies and narratives of ESRD patients' experiences describe several identity-altering phenomena, including loss of freedom; increased dependence on caregivers; disrupted marital, family and social life; and low sense of self worth (Gregory, Way, Hutchinson, Barret, & Parfrey, 1998; Polaschek, 2003a; Sollod, 2002). Other studies identify several challenges related to the dialysis services, including the unpleasant physical environment of dialysis units, inadequate social and financial support services, the length of time required to receive a kidney transplant, and difficult interactions between health professionals and ESRD patients (Noble, 2000; Polaschek, 2003b; Rundle, Keegan, & McGee, 2004). Preliminary analysis of our own data from two dialysis units suggests many of these challenges are present for our patient-collaborators and the health care professionals who provide their care.

### **Using PAR with and for people living with chronic illness**

To date, there is relatively little published literature on PAR in the context of chronic illness. In our review of the literature (Ovid, MedLine, PsychInfo), 13 of the 16 publications found were based on empirical studies in which chronically ill people were key collaborators. If we understand McTaggart's (1991) previously mentioned reference to communitarian values to mean attention to "the common good within particular communities" (Pryor, 2005, p. 1543), then all but one of the 13 studies (Baker & Wang, 2006) meet this PAR criteria as they focus on improving the lives of their participants through both individual transformation and improvements to the participants' community-based health services. However, all of the 13 studies emphasize individual transformation as the starting place for community action, thus giving credence to McTaggart's concern that community transformation receives too little attention in many PAR studies.

The work of Koch and Kralik (e.g. Koch & Kralik, 2001; Koch, Mann, Kralik, & van Loon, 2005), who have conducted PAR through a community nursing service in southern Australia, is a case in point as the authors emphasized individual transformation as something of a prerequisite for making changes to the community. Of the 13 publications we reviewed, the large majority (10) included authorship by either or both Koch and Kralik. In their work with people living with multiple sclerosis, diabetes, HIV, and asthma (e.g., Jenkin, Koch, & Kralik, 2005; Koch, Jenkin, & Kralik, 2004; Koch & Kralik, 2001; Koch, Mann, Kralik, & van Loon, 2005), the authors have often drawn on Stringer's (1996) cyclical "look, think, act" model to structure the information gathering (look), data analysis (think), and subsequent action of their chronically ill collaborators (act). For Koch and Kralik, moving on, or transitioning from a life that is interrupted by illness to a life that includes illness, is a central goal for their PAR collaborators. To this end, empowerment and action for the chronically ill collaborators occurs through self-reflection and narrative identity reconstruction in discussion groups facilitated by the authors (Kralik, Koch, & Eastwood, 2002). The authors view this therapeutic research (Jenkin et al., 2005) as promoting individual change that can then lead to social action (Koch, Jenkin, et al., 2004).

Two of the remaining three empirical PAR studies, also conducted in collaboration with community-based health services, point to another concern in the potential to misrepresent PAR principles when they hint at the asymmetries inherent in working with the chronically ill. In one study (Balcazar et al., 2004), the researchers worked with a center for independent living to promote self-advocacy and empowerment in people living with chronic fatigue syndrome (CFS). Initially the people with CFS acted as consultants, giving the researchers feedback on the needs of CFS participants in terms of research design, pace, location, and transportation. More high-functioning individuals with CFS were then identified and trained as peer counselors. Participants, working with these peer counselors, chose key problem areas (from a list generated in a previous study of CFS) and became investigators and peer educators as well as self-advocates. In biweekly meetings with their group and peer counselor, individuals with CFS gave educational presentations and discussed their progress on specific personal goals they hoped to achieve as a result of their participation in the project. The researchers found that by the end of the 14-week project, participants were able to be active participants in all phases of the study, increase control over their own health and raise awareness and presence of the CFS community, educate themselves and each other about the services available to people living with CFS, build on their own strengths and resources to accomplish their goals, and see new possible activist roles for themselves in their families and communities. In this study, education of self and others is the focal point for empowering the participants to have more control over their health. Central to this educational process, it seems, was the presence of high-functioning CFS participants who acted as peer counselors. The study thus depended in some ways on asymmetrical relations (high-functioning participants serve as educators and counselors to lower functioning participants) for its structure and to achieve its goals.

In the second study, Giachello and colleagues (2003) conducted a large coalition-based (multiple community services organizations) study for people living with or at risk of getting diabetes. Broad goals included engaging all of the stakeholders in community capacity-building activities (e.g., training, research methods, project planning) and in understanding the social causes of health disparities related to diabetes. The coalition collected epidemiological data as well as focus group data from health professionals and other ill and non-ill members of the community. The authors indicate no difficulties in maintaining their commitment to the three PAR characteristics they identify as key: (a) all participants work on a level playing field, (b) all levels of project governance must be participatory, and (c) a key goal for the project is to build community capacity. However, the authors point out in their discussion of “level playing field” that

the inherent inequality between academic researchers, health care providers, and community organizations has to be recognized, and action must be taken to ensure that *to the extent possible* these structural inequalities are remedied in the context of the partnership and the work at hand” (p. 312; emphasis in original).

Furthermore, although the study included ill people as participants from the community organizations, the extent to which that chronic illness inhibited the participation of people with the disease is not addressed.

Finally, Baker and Wang (2006) conducted a pilot PAR study using photovoice (a data gathering method using photos taken by participants) with a group of older adults living with chronic pain. The purpose of the study was to see how well photovoice worked as a method of understanding and communicating pain. The authors encountered several problems with the study. First, they found clinically ill patients to be much more difficult to recruit into and maintain in the study because of problems with disability and transportation. These health and travel constraints meant that these participants never met as a group and, therefore, engaged in the project independent of

the other participants, taking photos, writing a narrative of how the photo speaks of their chronic pain, and sending the package into the researchers. It seems from the authors' description that the clinically ill participants were not really involved in a PAR study. Rather, they were providing data about chronic pain (and the effectiveness of a particular data gathering method) to the researchers who conducted the analysis. The authors' discussion of their problems with this particular method is particularly pertinent for our exploration of PAR in the context of ESRD. We, too, are working with people who are struggling with their chronic illness much of the time and who, for reasons similar to those given by Baker and Wang, find it difficult to meet on a regular basis.

Although our work with those who live with ESRD does not take the therapeutic approach so central to the work of Koch, Kralik and their colleagues (as described earlier), like many PAR researchers we understand individual self-reflection to be integral to social action in the larger community. Furthermore, drawing on the work of M. White (1990), we understand narrative and "re-storying" to be potentially transformative for the chronically ill people with whom we work. However, we do not understand our PAR study to be focused solely or even primarily on transitions occurring within the individual participants. Rather, we understand our study's ultimate goal to be the translation of research results into new policies, programs, or social initiatives (G. White et al., 2004) that improve the quality of life and treatment for people living with ESRD. Like McTaggart (1991), we believe that "participatory action research is concerned simultaneously with changing both individuals and the culture of the groups, institutions, and societies to which they belong" (p. 172). Toward that general PAR goal, we have tried to accommodate the various constraints in the lives of all of our participants (patients, health care professional collaborators, and family/friends of patients). However, we have paid particular attention to the needs of a core group of participants who have agreed to be patient-collaborators, and we continue to seek their advice and approval in determining the design and direction of the study. Because we chose to prioritize patient perspectives in this study, finding ways around the constraints in our patient-collaborators' lives has determined how we gather data (look), analyze that data (think), and work with the data to make positive changes in the lives of people living with ESRD (act).

### **The challenges of designing PAR in the context of ESRD**

We began our study<sup>2</sup> with the intention of recruiting approximately 10 patient-collaborators, whom we hoped would meet with us on a monthly basis to collaborate in as many aspects of the study as possible (e.g., identification of key issues for patients, study design, data collection and analysis, translation of study results into new policies and/or programs). Because the hemodialysis population of the two hospitals in which we are conducting the study exceeds 300 patients and because informational flyers are generally viewed as an ineffective means of patient recruitment, we solicited the help of physicians, nurses, and volunteer coordinators in both sites to identify patients who they felt would have the energy (an inherent limitation to PAR and status leveling) and interest necessary to participate in regular collaborative meetings dealing with quality-of-life issues. Drawing on the second author's 24 years' experience as a nephrologist, we initially felt these two selection criteria were compatible. However, as more than 20 names came forward from the health care professionals, it became clear that we might have to choose between our two selection criteria because patients who both had energy and interest in the study tended to be the youngest and healthiest. To avoid having a skewed perspective on the quality-of-life issues for the dialysis population, we decided to accept patients based first on their interest and only second on their physical energy. Over the course of several months, 11 patients agreed to work with us as patient-collaborators. This was on the condition that the bulk of our work together occur during their dialysis treatments.

Time and energy were the primary concerns for those patients who agreed to collaborate. Most dialysis patients receive 4-hour treatments in the hospital at least three times per week. The treatment is both physically draining and time consuming, especially for those patients who rely on public transportation to get to and from the hospital. Furthermore, dialysis patients spend additional time visiting various specialists for the treatment of illnesses and symptoms related to or commonly associated with ESRD. For example, two patient-collaborators make frequent visits to the ophthalmology unit for help with failing vision associated with diabetes; another patient-collaborator has poor dexterity due to vascular problems associated with years of hemodialysis. All but two of the patient-collaborators used canes or wheelchairs. For most, visits to the vascular and or orthopedic clinics were common for treatment of circulation-related wounds or broken bones made brittle by certain medications. Thus, our original idea that patient-collaborators be willing to meet even once monthly represented too much of a challenge for even the keenest patient-collaborators. During recruitment, therefore, we began reshaping our study to meet the needs of our future collaborators.

### **Responding to the challenges of PAR through photovoice and film**

As we recruited, we adjusted our study design by eliminating the monthly meetings and agreeing to have as much participation as possible occur during each participant's dialysis treatments. This accommodation, however, challenged our plan to engage our patient-collaborators in team and consensus building. Because at least half of the patient-collaborators did not have Internet access, creating blogs or chat rooms was not a viable alternative to regular meetings. Furthermore, the compromised vision and dexterity of several patients as well as the limited arm movement during treatment (two needles connect one forearm to the dialysis machine) meant that written communication among the patient-collaborators for purposes of consensus building, data collection, and idea sharing were virtually impossible. As a result, we spent much of the first several months of the study chatting informally with the patient-collaborators during their dialysis treatments about their illness experiences, their quality of life since diagnosis with ESRD, and the study's goals and design. As an alternative to team meetings, we sought the patient-collaborators' feedback on the study design and focus by sharing the suggestions and concerns of each of the collaborators with the others during these informal chats. This one-to-one consensus building remained, however, a poor replacement for the kind of collaborative team communication so central to PAR principles and practices encountered in our review of the literature (Balcazar et al., 2004; Kralik et al., 2002; Marinowitz, 2003; McTaggart, 1991; G. White et al., 2004).

After several months, each of the patient-collaborators had given individual feedback on the study focus and design, and had shared some of their experiences of living with ESRD. At this point, we felt that a team meeting was essential to foreground the patient-collaborators' voices and priorities in keeping with a PAR orientation. The patient-collaborators were open to the idea, especially with the provision of an ESRD diet-sensitive lunch as well as transportation as limited mobility and restricted diets make social engagements more challenging. We agreed to meet on a Sunday (the only nondialysis day for everyone) for a 3-hour discussion of their experiences and the study's focus and design. To give structure to our meeting without dictating its agenda and without relying on written texts (difficult for some patient-collaborators to see), we proposed the use of photovoice, "a participatory action research method in which individuals photograph their everyday health and work realities" (Baker & Wang, 2006, p. 1405).

### **Photovoice: Its uses and unanticipated benefits**

Developed by Wang and Burris (1994), photovoice is a fairly simple technique that involves participants in taking photos of objects and people that represent particular elements of their everyday life. Generally, participants are asked to take photographs that respond to a particular question, statement, or theme. The photos are then developed and given back to the participants for a wide range of uses, including reflection in journals and in individual interviews (Douglas, 1998), consciousness raising in publicly-displayed photo posters (Mitchell, DeLange, Moletsane, Stuart, & Buthelezi, 2005), and semiformal presentations to policymakers or community leaders (Wang, 1999). For the immediate concerns of our study, we found photovoice appealing for several reasons: (a) the photos could be a good icebreaker for our first meeting, (b) the same image can evoke different meanings for different people and thus serve as a rich source for discussion, and (c) the use of the patient-collaborators' photos could help ensure participant-driven focus in our discussion.

When we introduced this research and reflection method, the patient-collaborators were generally quite open to it. One, who said he was "perfectly capable of using [his] words," chose not to participate in the activity. We experienced a bit more resistance from the nursing staff, who expressed concern about the patient-collaborators' use of cameras to take photos of patients without consent and the potential for Internet display of images not meant for public use. The assurance of our rules about consent and our control over the use of images seemed to quell the staff's discomfort.

Drawing on the practical suggestions of Wang (1999), Douglas (1998), and Mitchell and colleagues (2005), we distributed disposable cameras and instructions to each of the patient-collaborators asking them to (a) reflect on the challenges and solutions to living well with ESRD and (b) take approximately 12 pictures of people, places, or objects that represent challenges and approximately 12 pictures that represent solutions. The week before our meeting, we collected the cameras, developed the photos, and set them aside for the meeting. To enable patient-collaborators' spontaneous selection of photos for discussion throughout the meeting, we used a document camera to enlarge and project the printed photos onto a screen for shared viewing. The use of the document camera also allowed us to incorporate into our discussion photos from the patient-collaborators' personal collection that were not taken with our project in mind. This was especially important for the one patient-collaborator who was a professional photographer. Furthermore, because the flash feature on the disposable cameras was not automatic and instructions for its use were too small for some to read, images in the underexposed photos were somewhat clearer with the use of the document camera.

Over the course of the 3-hour meeting, the patient-collaborators spoke to three different sets of photos, with each set having a focus on which we had previously all agreed. The focus of each of these three different sets of photos and their corresponding explanations were as follows: (a) solutions for living well with ESRD, (b) realities of living with ESRD, and (c) two photos most reflective of the patient-collaborator. We started the meeting by inviting the patient-collaborators to introduce themselves to each other. Although some of the patients knew each other from overlapping dialysis sessions or occasional patient meetings, most did not know each other well or at all. Despite the general lack of intimacy, most of the patient-collaborators spoke openly and abundantly about their experiences with chronic illness. Prior to beginning the photovoice activity, we all agreed to the following turn-taking rules: Each person would speak to the photo of his or her choice for as long as he or she wished without interruption but with a sensitivity to the time constraints of our meeting.

Photovoice proved to be a more powerful PAR tool than we had anticipated. Not only did the images facilitate turn taking and equality of voice, but they allowed for the exposition and exploration of a much wider variety of topics than we would have likely covered in a more traditionally conversational style of exchange. Because photos rather than conversational coherence dictated the topics to be discussed, a sudden change of topic or perspective was not only acceptable but welcomed. Differences of opinion were expressed indirectly and without confrontation through what we have come to think of as the patient-collaborators' photo-focused I-messages (personal-experience-based messages). Shared opinions and experiences were also touched on as the turn taker referred to the photos and comments of others. Perhaps the most surprising benefit of the use of this research method was the powerful response the images evoked in the patient-collaborators, most especially for the image-presenters themselves. With the permission of two patient-collaborators (and the subject of one photo), two of what we found to be the most compelling examples of the patient-collaborators' emotional engagement in this process follow.

### Jay's Son

Jay (a pseudonym) is a White man in his early 60s who has been living on various forms of dialysis for 33 years. A former photographer for a local newspaper, he is now unemployed and depends on disability checks for his income. In his many years of dialysis, Jay has undergone a multitude of medical interventions, including 16 surgeries. He is currently in hospital with health complications. His son, Steve, is the featured subject of this photo and has given full permission for its use along with his father's comments.

When I took ill I lived in Barbados. I went to the hospital there and they told me I had two or three days to live so I had to leave Barbados right away. Flew to Toronto and went on dialysis. (*pause 2 seconds*). And that's my son. . . . My son lives in Barbados now . . . . He's now an executive chef for a very large company in Barbados. And that is what I live (*sudden, surprising tears, 30 seconds*) . . . (Voice thin and strained) That's what I live for. (*Clears throat*). That's what I live for. I externalize my thoughts (*gesturing toward projected picture, tears, 3 seconds*). That's it. (February 11 workshop transcript – Jay)



Figure 1. Jay's son

## Sarah's Corner

Sarah is a White, 49-year-old single mother of a 19-year-old son. She was diagnosed with diabetes at age 17 and lived virtually symptom free for almost 20 years. She has been living on dialysis for 11 years. She is a former model and clothing clerk who is currently unemployed because of the demands of her illness. Because of the vascular problems commonly associated with diabetes, Sarah has struggled with loss of vision and poor circulation in her feet, which has led to the partial amputation of one foot and ongoing need for wound treatment of the other. Both health complications mean that Sarah spends a lot of time at the hospital in addition to the hours she spends receiving dialysis.



Figure 2. Sarah's photo

That's me on the wall, and it helps me remember (*tears 4 seconds, bows head, wipes tears, and whispers to self "I didn't think this would happen"*) who I am. Because you do lose sight of it sometimes. (*tears continue*) . . . This just represents something that I can recognize of myself (*pause, tears 3 seconds*) and be totally away from the medical situation that I'm in. And it brings joy to have a little spot that focuses a little bit on who I am (*wiping tears, 2 seconds*) Sorry. (February 11 workshop—Sarah)

These two photographs highlight an important finding in our study so far: The patient-collaborators identify relationships of various sorts (with children, spouses, other family, pets, and themselves) as central to what helps them live well with ESRD. Another key finding is that the patient-collaborators want to be heard, and this has directed our recent decision to use film as a primary data-gathering tool.

## Film: Serendipity and surprises

Our interest in using film as a principal means of data-collection arose quite serendipitously out of this first meeting with the patient-collaborators. Our original research design included the making of a documentary film of the patients' engagement in this project, anticipating that engagement as a potentially transformative experience. The film was intended to document the process of conducting the study, not serve as part of the study itself. Further, it was contingent on

our finding the necessary supplemental funding. When, after a few months of the project, we were unable to secure the extra funding, this documentary project was relegated to the back burner.

When the patient-collaborators agreed to our Sunday meeting, we invited local filmmakers to witness the importance and complexity of quality-of-life issues for people living with ESRD. With the patient-collaborators' permission, three filmmakers were invited. One was unable to make it and requested that we film the meeting so that she might see it; further, this might provide material to work with to secure funding for our full-length documentary. Again, with the patient-collaborators' permission, we invited a professional cameraman and soundman to film the meeting. To our surprise, the patient-collaborators' responses were overwhelmingly positive. Not only were they fairly comfortable with the large camera and microphone whirling around the room throughout the meeting, but when the meeting was over, several patient-collaborators said that the filming made them feel that what they had to say mattered and that someone was really listening.

The participants' sense of empowerment by the film process fit nicely with what several had said in the meeting, that kidney disease needs a public awareness campaign similar to those so effectively conducted for AIDS, heart failure, and breast cancer. When we proposed that film be used as both empowering and as a possible tool for action, they agreed that we should try to find a way to use film as both the primary data-gathering tool for the project and the mechanism for social action (consciousness raising) in the larger community. Rather than looking for a filmmaker to make a film about the project, we decided to collaborate with a filmmaker to help us use film as the central form of communication and action in our project.

We have discovered in this process several potential benefits to using film as a means of data collection. For example, members of different stakeholder groups who cannot easily meet at the same time because of very conflicting schedules (e.g., health professionals and dialysis patients) can use film as a means of communication. Raw footage of group discussions can be edited to speak concisely and efficiently of specific issues. It can then be burned onto DVDs and member-checked either in the hospital on a laptop computer or at the participants' convenience in their own home. Prior to use of the DVD in cross-group communication, it can be re-edited according to the collaborators' preferences (e.g., to foreground issues that were not included or to delete undesirable selections). Furthermore, if high-quality filming is conducted throughout the project, the footage may eventually be edited into a documentary film for use in a larger public awareness campaign or for various other more specific audiences, such as medical and nursing students or hospital administration.

We have begun such a process in our study. All of the patient-collaborators were given a copy of a 16-minute video of our meeting and agreed to have it shown as a starting place for discussion with dialysis physicians and nurses. Most recently we showed that video to six physicians and nurses who have also agreed to be collaborators in our study. These new collaborators also agreed to have their responses to the video filmed. In this way we hope to proceed in a film-based conversation including other patients, health care workers, and friends or family members who provide support to people living with ESRD.

Although there are certain advantages to using film, as just outlined, there are also some important drawbacks. Doing good research is not the same as making a good film. A good film might result from the use of high-quality materials and skilled filmmakers, but focusing on the production of a high-quality film can insidiously replace in-depth understanding and careful analysis as the study's goal. This is perhaps particularly the case in a PAR study such as ours, in

which making a film became the social action we thought most appropriate to pursue in light of our patient-collaborators' interest in raising public awareness about their illness. Largely for this reason, we chose to invest a large portion of our grant budget into gathering and editing high-quality footage on the lives of people living or working in the context of ESRD. As a result, our study has not remained as methodologically flexible as is perhaps ideal. Furthermore, relying on professional filmmakers (and their equipment) for most data gathering means that the researchers are somewhat limited in their access to their data, which can be viewed and manipulated only on specialized equipment that is cost prohibitive. Amateur filmmaking software such as iMovie would substantially reduce these costs and would bring the researchers into relatively easy contact with their data; but this alternative represents an important learning curve and eliminates the possibility of producing a high-end film for the wider public. In either case, an even greater concern is that participants are almost totally excluded from the analysis process because the editing equipment is not mobile. We are engaging the participants in a kind of editing-by-proxy when we ask them to give us feedback on the draft versions of the short films we make. However, this should not be confused with the careful analysis, selection, and interpretation that occur as part of the initial editing process.

### **Overcoming the challenges: Using or abusing PAR?**

We are enthusiastic about our decision to take a film-based approach to this study and about the potential film holds for effecting change in and for the kidney dialysis community. However, we remain concerned that we have not been or will not be able to sustain our commitment to certain basic PAR principles. For example, although our study focus and design were adjusted according to the suggestions of our patient-collaborators, we, rather than our patient-collaborators, continue to be in primary control of the decisions affecting our study's evolving focus, design, and data-gathering methods. Based on the interest of some of the patient-collaborators, we took the decision to use film as our primary data gathering tool, believing it would be the most powerful means of increasing communication within the dialysis units as well as raising social consciousness of ESRD. However, because of the technology, limited physical space, and time demands, we cannot include patient-collaborators in the editing (analysis) of the film data. Rather, we have had to content ourselves with the member-checking technique described earlier. Because of constraints on our resources, we have been unable to respond to all of the recommendations of various stakeholders in terms of both research design and social action initiatives (e.g., expanding the study to include people on home dialysis treatments and people who have received successful transplants, promote changes to the patient transportation system). Rather, we have had to be selective about where and how we invest our resources so that the project will meet our primary goal of translating our research results into consciousness-raising communication toward the development of new policies, programs, or social initiatives that improve the quality of life for people living with ESRD. Although we have checked almost all of our decisions with our patient-collaborators, we have not achieved consensus throughout. Perhaps most important, our patient-collaborators have not been interested or able to meet as a group on a regular basis to work collectively toward a commonly agreed on goal. As a result, our decisions could be interpreted by some as impositions promoting our agenda rather than those of the patient-collaborators.

However, if we view PAR as an orientation that exists on a continuum, then our study qualifies as one that Campbell and colleagues (2002, cited in G. White et al., 2004) referred to as user sensitive. Balcazar and colleagues (2004) also referred to "low-level PAR," whereby participants act more as advisers or consultants than as principal decision makers and analysts for the study. Is it enough that we listen to the patients' concerns and motivations and then represent those

concerns in a way that we feel reflects their priorities and that falls within the possible for our budget and research mandate? Is it enough that we are slowly including representatives from almost all of the stakeholders in our advisory team? Campbell and colleagues and G. White and colleagues explained that PAR participant roles have to be practical for all parties involved, but it is undeniable that in this context, where patient-collaborators have neither the time, nor the energy (nor the inclination?) to participate closely in all phases of the research, it is up to the researchers to resist the temptation to use the study and its findings for primarily academic ends rather than community and/or social action. In the context of increasing demand for decreasing research funds, academics conducting PAR studies can find themselves awkwardly situated between meeting the demands of the institution to publish or perish, and fulfilling the promise of social action for the community and/or users with whom they have worked.

### Notes

1. Although we subscribe to the term *PAR*, there are many others that share virtually the same methodological and philosophical orientations, such as community-based participatory research (CBPR), action research, or collaborative action research (Minkler & Wallerstein, 2003). Debate about which term best encapsulates the principles we have outlined is ongoing. Rather than reflecting significant differences in approach to research, the various names for PAR-type research reflect their disciplinary research histories and trends (Minkler & Duran 2003; Israel, Eng, Schulz, & Parker, 2005).
2. Permission to conduct this study was granted by the ethical review board of McGill University.

### References

- 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(10), 1405–1413.
- Balcazar, F., Taylor, R., Kielhofner, Tamley, K., Benziger, T., Carlin, N., et al. (2004). Participatory action research: General principles and a study with a chronic health condition. In L. Jason, C. Keys, Suarez-Balcazar, Y., Taylor, R., Davis, M., Durlak, J., et al. (Eds.), *Participatory community research: Theories and methods in action* (pp. 17–36). Washington, DC: American Psychological Association.
- Douglas, K. (1998). Impressions: African American first-year students' perceptions of a predominantly White university. *Journal of Negro Education*, 67(4), 416–431.
- Giachello, A. L., Arrom, J. O., Davis, M., Sayadb, J. V., Ramirez, D., Nandie, C., et al. (2003). Reducing diabetes health disparities through community-based participatory action research: The Chicago Southeast Diabetes Community Action Coalition. *Public Health Reports*, 18, 309–323.
- Gregory, D. M., Way, C. Y., Hutchinson, T. A., Barret, B. J., & Parfrey, P. S. (1998). Patients' perception of their experience with ESRD and hemodialysis treatment. *Qualitative Health Research*, 8, 764–783.
- Hagey, R.S. (1997). The use and abuse of participatory action research. *Chronic Diseases in Canada*, 18(1), 1–4.

- Hagren, B., Pettersen, I. M., Severinsson, E., Lutzen, K., & Clyne, N. (2001). The haemodialysis machine as a lifeline: Experiences of suffering from end-stage renal disease. *Journal of Advanced Nursing*, 34(2), 196–202.
- Hall, B. L. (1981). Participatory research, popular knowledge and power: A personal reflection. *Convergence: An International Journal of Adult Education*, 14(3), 6–19.
- Hutchinson, T. (1999). The price and challenges of extraordinary success: Treating end-stage renal failure in the next millennium. *Canadian Medical Association*, 160(11), 1589–1590.
- Israel, B. A., Eng, E., Schulz, A. J. & Parker, E. A. (2005). Introduction to methods in community-based participatory research for health. In B. A. Israel, E. Eng, A. J. Schulz & E. A. Parker (Eds.), *Methods in community-based participatory research for health* (pp. 3–26). San Francisco: Jossey-Bass.
- Janssen van Doorn, K., Heylen, M., Mets, T., & Verbeelen, D. (2004). Evaluation of functional and mental state and quality of life in chronic haemodialysis patients. *International Urology and Nephrology*, 36(2), 263–267.
- Jenkin, P., Koch, T., & Kralik, D. (2005). The experience of fatigue for adults living with HIV. *Journal of Clinical Nursing*, 15, 1123–1131.
- Koch, T., Jenkin, P., & Kralik, D. (2004). Chronic illness self-management: Locating the “self.” *Journal of Advanced Nursing*, 48(5), 484–492.
- Koch, T., & Kralik, D. (2001). Chronic illness: Reflections on a community-based action research. *Journal of Advanced Nursing*, 36(1), 23–31.
- Koch, T., Mann, S., Kralik, D., & van Loon A. M. (2005). Reflection: Look, think and act cycles in participatory action research. *Journal of Research in Nursing*, 10(3), 261–278.
- Kouidi, E. (2004). Health-related quality of life in end-stage renal disease patients: the effects of renal rehabilitation. *Clinical Nephrology*, 61(S1), S60–S71.
- Kralik, D., Koch, T., & Eastwood, S. (2002). The salience of the body: transition in sexual self-identity for women living with multiple sclerosis. *Journal of Advanced Nursing*, 42(1), 11–20.
- Marincowitz, G. (2003). How to use participatory action research in primary care. *Family Practice*, 20(5), 595–600.
- McTaggart, R. (1991). Principles for participatory action research. *Adult Education Quarterly*, 41(3), 168–187.
- Minkler, M., & Duran, B. (2003). The conceptual, historical, and practice roots of community based participatory research and related participatory traditions. In M. Minkler & N. Wallerstein (Eds.), *Community-based participatory research for health* (pp. 27–52). San Francisco: Jossey-Bass.
- Minkler, M., & Wallerstein, N. (2003). Introduction to community based participatory research. In M. Minkler & N. Wallerstein (Eds.), *Community-based participatory research for health* (pp. 3–26). San Francisco: Jossey-Bass.

- Mitchell, C., DeLange, N., Moletsane, R., Stuart, J., & Buthelezi, T. (2005). Giving a face to HIV and AIDS: On the uses of photo-voice by teachers and community health care workers working with youth in rural South Africa. *Qualitative Research in Psychology*, 2, 1–14.
- Noble, H. R. (2000). Experiences of patients called to hospital for a renal transplant. *EDTNA ERCA J*, 26(1), 22–25.
- Polaschek, N. (2003a). Living on dialysis: concerns of clients in a renal setting. *Journal of Advanced Nursing*, 41(1), 44–52.
- Polaschek, N. (2003b). Negotiated care: A model for nursing work in the renal setting. *Journal of Advanced Nursing*, 42(4), 355–363.
- Pryor, E. (2005). Introduction. *American Behavioral Scientist*, 48(12), 1543–1544.
- Rundle, K., Keegan, O., & McGee, H. M. (2004). Patients' experiences of dialysis services: Are national health strategy targets being met? *Irish Journal of Medical Science*, 173(2), 78–81.
- Sollod, R. N. (2002). Beyond a sense of safety: A psychologist's tale of serious chronic illness. *Psychotherapy in Practice*, 59, 1397–1409.
- Stringer, E. (1996). *Action research: A handbook for practitioners*. Thousand Oaks, CA: Sage.
- Wang, C., & Burris, M. (1994). Empowerment through photo novella: Portraits of participation. *Health Education Quarterly*, 24, 171.
- Wang, C., (1999). PhotoVoice: A participatory action research strategy applied to women's health. *Journal of Women's Health*, 8(2), 185–192.
- White, G. W., Suchowierska, M. A., & Campbell, M. (2004). Developing and systematically implementing participatory action research. *Archives of Physical Medicine Rehabilitation*, 85(Suppl. 2), S3–S12.
- White, M. (1990). *Narrative means to therapeutic ends*. New York: Norton.