Western University Scholarship@Western

Occupational Therapy Publications

Occupational Therapy School

3-2019

Initiating Participatory Action Research with Older Adults: Lessons Learned through Reflexivity*

Colleen E. McGrath The University of Western Ontario, cmcgrat2@uwo.ca

Follow this and additional works at: https://ir.lib.uwo.ca/otpub

Part of the Occupational Therapy Commons

Citation of this paper:

McGrath, Colleen E., "Initiating Participatory Action Research with Older Adults: Lessons Learned through Reflexivity*" (2019). *Occupational Therapy Publications*. 48. https://ir.lib.uwo.ca/otpub/48

Research Note/Note de recherché

Initiating Participatory Action Research with Older Adults: Lessons Learned through Reflexivity*

Carri Hand,¹ Debbie Laliberte Rudman,¹ Colleen McGrath,¹ Catherine Donnelly,² and Michele Sands³

RÉSUMÉ

La recherche-action participative (RAP) apporte une perspective intéressante pour la recherche abordant l'exclusion et l'inclusion sociale des personnes âgées. Les exemples et réflexions sur la RAP impliquant des personnes âgées sont rares, en particulier à l'étape de l'initiation de la recherche, lorsque l'action participative cyclique est mise en place. Dans cet article, nous décrivons le démarrage d'un projet de recherche-action participative avec des personnes âgées et analysons la concordance entre ce processus et les principes clés de la participation, ainsi que son arrimage aux structures de recherche typiques. Les résultats soulignent les tensions entre le développement de relations de plus long terme et les demandes de financement préparées dans de courts délais. Cette étude montre comment les conceptions traditionnelles de la recherche peuvent influer sur la création de partenariats équitables et met en évidence la nécessité d'élaborer des lignes directrices en matière d'éthique et de publications qui traitent explicitement des approches participatives. Ces observations clés pourront être appliquées pour utiliser les potentialités de la recherche-action participative, qui consiste à aborder les enjeux importants à travers un travail collaboratif et une approche équitable intégrant les personnes les plus affectées.

ABSTRACT

Participatory action research (PAR) is well suited to research that aims to address social exclusion and inclusion in older age. Illustrations of and reflections on PAR with older adults are scarce, particularly the initiation stage, which sets the stage for the cyclical participatory action that follows. In this article, we describe the initiation of a PAR project with older adults and reflect on the alignment of this process with key participatory principles and fit within typical research structures. Findings point to the tensions between developing relationships over time and time-sensitive calls for funding, how traditional conceptions of research can influence creating equitable partnerships, and the need for development of ethical and publishing guidelines that address participatory approaches. These key insights can be applied to help achieve the potential of PAR: to address issues of concern by collaboratively and equitably working with the people most affected.

- ¹ School of Occupational Therapy and Graduate Program in Health and Rehabilitation Science, Western University, London, Ontario.
- ² School of Rehabilitation Therapy, Queen's University, Kingston, Ontario.
- ³ At the time of the study, Neighbourhood Watch London, London, Ontario.
- * There was a misspelling in the title of this research note in the original version published online. The error has been corrected and an erratum has been published.

Manuscript received: / manuscrit reçu : 20/06/18

Manuscript accepted: / manuscrit accepté : 23/12/18

Mots-clés : vieillissement, recherche participative, recherche collaborative, inclusion sociale

Keywords: aging, participatory research, collaborative research, social inclusion

La correspondance et les demandes de tirés-à-part doivent être adressées à : / Correspondence and requests for offprints should be sent to:

Carri Hand, Ph.D., B.Sc.O.T. School of Occupational Therapy Western University Elborn College 1201 Western Road London, ON N6G 1H1 (chand22@uwo.ca)

Canadian Journal on Aging / La Revue canadienne du vieillissement 38 (4) : 512–520 (2019) doi:10.1017/S0714980819000072

Participatory action research (PAR), with its focus on exploring and addressing issues of shared concern collaboratively with the individuals and groups most affected (Israel et al., 2008), holds promise for enhancing the lives of older adults (Blair & Minkler, 2009). Key aspects of PAR include a focus on meaningful collaboration and power sharing among all parties, and balancing research with action (Kidd & Kral, 2005). Many terms are used for approaches that share similar values, such as "action research" or "community-based participatory research," and following Blair and Minkler (2009) we use PAR to refer broadly to such approaches. Despite its potential, PAR with older adults is an underdeveloped area, with few examples reported in the literature. At the same time, exemplar PAR projects implemented with older adults support the relevance and potential impacts of this methodology. Examples include a project in which older adults in a Dutch residential home collaborated with researchers and residential home staff to make meals more appetizing and improve their quality of life (Baur & Abma, 2012), and a project in which Canadian older adults created advocacy materials, built skills, and advocated to local government regarding services for seniors (Trentham & Neysmith, 2018).

PAR is well suited to projects that aim to address social exclusion and inclusion in older age, given that many aspects of context are implicated in these experiences, and approaches to transforming contextual features require knowledge of the lived experiences of individuals and collectives. Enhancing social inclusion often requires collaboration among multiple stakeholders, strategies that are grounded in the daily lives of older adults, and promoting long-term sustainability practices that are key within PAR. For example, Fenge (2010) used PAR to explore older lesbians' and gay men's experiences of social exclusion and implement strategies to promote greater social inclusion. The approach enabled diverse perspectives to emerge, and resulted in raising awareness of issues of aging and sexuality among local and national stakeholders. Further, a review of general PAR literature has identified a number of benefits of PAR to communities, including increased capacity and competence of stakeholders, sustained outcomes, and the creation of new and unanticipated projects beyond immediate project goals (Jagosh et al., 2015).

PAR is based on respect for the people engaging in the process, and values their expertise and lived knowledge of the conditions shaping their lives. Ideally, participants are engaged in the research process from the beginning, when research questions are developed. PAR projects, however, are carried out along a continuum of engagement, from projects that are initiated by an outside researcher and subsequently embraced by the community to projects that are fully user led (Minkler & Wallerstein, 2008). Israel et al. (2008) described key principles that PAR should embody, including:

- 1. Collaborative, equitable partnership in all phases of the research project
- 2. An empowering process
- 3. Co-learning among all partners
- 4. Capacity building and systems change
- 5. A balance of research and action
- 6. Long-term involvement with a commitment to sustainability.

Despite the utility of PAR, more attention to issues of reflexivity, positionality, and power relations is needed within participatory research (Sultana, 2007), particularly related to projects involving older adults. Illustrations of and reflections on PAR with older adults are scarce, particularly at the initiation stage, which is a crucial yet challenging stage that underpins the cyclical participatory action that follows. The pervasive ageist attitudes and practices within Western societies, amongst researchers and older adults themselves, may work against achieving participation within PAR (Trentham & Neysmith, 2018). Within published PAR projects purportedly incorporating older adults as co-researchers, older adults typically do not have any influence on the research questions asked nor do they engage substantially in data collection or analysis (Blair & Minkler, 2009). Also, within the broader literature addressing PAR processes, it has been noted that typical institutional structures based in nonparticipatory forms of research may present challenges to carrying out PAR in ways commensurate with key underlying principles (Khanlou & Peter, 2005). Reflexively examining PAR processes and describing effectiveness of different strategies can contribute to researchers using PAR with older adults more often, and more successfully. Therefore, the objective of this article is to describe the initiation of a PAR project with older adults and to reflect on the process, including alignment with key PAR principles and fit within typical research structures, in order to contribute to efforts to optimize participatory action research processes with older adults.

Methods

Within PAR, the initiation phase can be considered as encompassing the development of a partnership, the identification of a shared concern, and an intention to work collaboratively to address it. This article describes the development of an ongoing project aimed at promoting social connectedness and inclusion within a seniors' apartment building, and includes reflections on this process, from project conception to the first few meetings with the community of co-researchers. Given our focus on project initiation, we explore alignment with just the first three key principles identified by Israel et al. (2008): collaborative, equitable partnership; an empowering process; and co-learning among all partners. We further consider issues related to research ethics review, as they presented a challenge to enacting PAR principles in meaningful ways. Our reflexive process involved writing reflexive notes throughout the project initiation process and engaging in group discussions and collective reflexivity, as well as collectively reflecting on issues during writing of the article.

Project Development

We began with the assumption that social connectedness, social engagement, and social inclusion are issues of importance to older adults, based on previous research showing interconnections between social isolation and exclusion and poor health and quality of life (Cloutier-Fisher & Kobayashi, 2009; Masi, Chen, Hawkley, & Cacioppo, 2011; Statistics Canada, 2007). In fact, social isolation itself is a strong predictor of mortality among older adults (Holt-Lunstad, Smith, Baker, Harris, & Stephenson, 2015). In line with PAR, however, we sought to use a process that would enable understanding of these issues from the expertise and experiences of older adults themselves (Kidd & Kral, 2005). According to Duran and colleagues (2013), the initial step of PAR is forming a partnership with a community, defined as a group of people with a shared identity such as geographical location or culture. After identifying a research funding opportunity, the lead author reached out to three researchers (C.M., D.L.R., and C.D.) and two community partners (M.S. and one other) who had an interest in promoting inclusion and connectedness among older adults and in working in collaborative ways with older adults; we refer to these members as the "initial team." We were interested in implementing a PAR process with residents of a seniors' apartment building to address issues of connectedness and inclusion, based on needs that we perceived within local apartment buildings. We defined a seniors' building as any building with a resident age requirement of 50 years or older. We aimed to identify a seniors' building whose residents were interested in working together on issues of connection, engagement and inclusion, and engaging as co-researchers to address questions and shared issues that were significant for them (Kidd & Kral, 2005). We further hoped to work with residents on the grant proposal so that their input would begin in the initial phases of solidifying the aim and designing the study.

We initially sought a partnership with residents of a rent-geared-to-income apartment building that the

community partners had interacted within, where building residents appeared to experience a range of factors that could contribute to social isolation, including low income and disability. Building strengths were also apparent, such as affordability, access to local services, and a large community room for activities. We met with a housing manager and with an external professional who was doing community development work in the building, gaining more details about the building and its residents. This process took place over a 2 month period, and although we were not able to meet with residents prior to the submission for funding, we obtained a letter of support from the housing manager, outlining her organization's interest in collaborating on the project. We also recognized that a partnership with building residents might or might not develop and that other options might need to be pursued. Fenge (2010) has framed PAR as a "chicken or egg" situation; before a project can begin, funding needs to be applied for, and application for funding is often led by an "outsider" researcher, a process potentially counter to participatory methodologies. Despite our best intentions, this is the process that occurred.

In the absence of solidifying a building and collaborating with its residents, we developed the proposal in as open a way as we could, clearly stating that aspects of the objectives, methods, and outcomes could not be pre-specified and would be co-created with the building residents. We planned to work in a participatory way with this community to define issues, plan, take action, reflect on action (Baum, MacDougall, & Smith, 2006), and evaluate the outcomes and process of the project. Methods would involve regular resident meetings to develop and execute the project; creating strategies aimed at promoting social connectedness and implementing select strategies; and collecting data before, during, and after the project to support implementation and evaluation, all of which would be discussed and modified by the PAR group of residents and partners. After receiving notification of our funding success, we again met with the initial building manager to discuss a few buildings under the manager's purview. Small community development projects were underway in all these buildings; at this point we decided not to pursue partnerships with any of these buildings, thinking that having two similar projects running in the same building could be overwhelming to residents and that combining our project with an ongoing project would mean that we were not involved in the beginning phases of collaborations, thereby limiting our ability to understand the entire PAR process. We then reached out to managers or owners of an additional six seniors' apartment buildings; one manager of a non-profit seniors' building agreed to a meeting. After gaining permission from the apartment building Board of Directors, the building manager invited building residents to attend a meeting with the initial team, by speaking with residents at one of the building coffee times and likely speaking individually with other residents. Approximately 15 residents attended this initial meeting, in which we described the project and the PAR approach, and the residents related the wants, needs, and strengths in their building. A few days after the meeting, one resident let us know that several residents were interested in working with us. We began meeting with the residents every two to three weeks to develop and implement the project.

Reflection

Building Collaborative, Equitable Partnerships

Within PAR, processes must be developed to enable partners to share control over all phases of the process, from project conceptualization to implementation to application of findings, to the extent that they wish to be involved (Israel et al., 2008). Building trust and rapport is an important means of promoting partnership sustainability in participatory projects (Jagosh et al., 2015). Engaging partners also involves getting to know the setting, culture, and people (Cargo & Mercer, 2008). There is a "pre-context" of factors, including previous experiences, that can impact trust building within participatory partnerships (Chughtai & Myers, 2017; Jagosh et al., 2015). In the current study, the existing relationships between the first author and community partners and among the academic partners promoted rapport and trust within this part of the team. In hindsight, spending more time developing partnerships within this initial team, learning about each other's strengths, and discussing our approaches and project expectations may have assisted the PAR process. In addition, it seemed that residents viewed the university as a reputable organization and had not had negative experiences of research that could lead to mistrust. We identified trust issues between and among community members, in that within the first few meetings it was apparent that some residents felt mistrust of the building management, as well as of other residents, issues that have major implications for the success of a project that aims to build connectedness. Issues of trust seemed to impact discussions of what was possible to achieve within the project, including whether residents could establish a resident committee that could support connections and whether communication could take place in an open and sincere way. During the first meetings, we attempted to create an atmosphere for trust building, including encouraging all voices to be heard and discussing ways to respectfully disagree within meetings. Further, we were aware we did not know what it means to be an older person and to live

in the physical and social culture of their building and, therefore, we worked to learn about these topics through taking tours of the building and asking questions. In other ways, our initial team and building residents seemed to have shared understandings, stemming from our shared experiences of living and engaging in the same city, that we discovered through discussions of city places and events. We also recognized that although we felt we had something to offer an apartment building community, residents might not want or need what we could offer. Similar to Smith, Bratini, Chambers, Jensen, and Romero (2010), we came from a position of wanting to "help", while also feeling that this was a patronizing standpoint. Our initial team aimed to help older adults build connectedness and decrease isolation, and as such, we were seeking a building with residents who had "need" in these areas. Alongside this aim, we considered that people often do not want to be labelled as "in need". As a result, we were intentional in communicating that we wanted to identify a building with residents who were interested in cultivating social connectedness, as opposed to having difficulties in social connectedness. In our initial meetings with residents, we discussed building strengths and listened closely to what residents saw as their strengths, issues, and needs. During this period, we were also reflexive about the possibility of being seen as working for the building manager, which could counter our aim for resident co-leadership.

Part of building trust and rapport, as well as gaining and maintaining access to a research site, relates to framing the research topic in a way that relates to the community's conceptualization of the topic (Bondy, 2013). In these first meetings with residents, it appeared that they understood social connectedness as occurring within group social activities, such as coffee time. In response, we attended to these preferences, through validating their perspectives, while also seeking additional ways of understanding social connectedness to allow multiple perspectives of residents to be heard. Some residents did share alternative views to the more predominant perspectives, including preferences for one-to-one interactions rather than groups and for creating spaces for shared activities.

During the first meetings, we were actively attempting to establish a participatory process in which the residents were positioned as co-researchers. Discussion in the first meetings focused on understanding PAR and what it could look like within their community, fostering a positive and respectful environment, and collaboration between initial team members and residents. We stated that our PAR process could include research to explore and understand social connectedness in the building, followed by taking action. The residents, however, seemed ready to take action right away, wanting to organize, for example, exercise classes and music events. We were encouraged by this engagement of the residents in the process and saw that an information-gathering phase could occur later. Some of the researchers among us felt that it was a useful "trade-off" to make, leading us to reflect on whether we were viewing the residents as fully equal partners who could direct the process with us. To a certain extent, we were acknowledging and letting go of our pre-conceived agenda. In addition, given that we had obtained funding prior to forming a partnership with the building residents, our initial team held control in terms of setting the general focus of the project and having access to resources. To attempt to bridge this gap in power and create a more equitable partnership (Israel et al., 2008), we started the process in the PAR stage of reflection, by describing the project and asking residents to reflect on our invitation to join us, in the context of their own strengths, needs, issues, and wants. Our intention was to leave decision-making power with the residents, and starting with our first meeting with the residents, all communications were directly with them and not through the housing manager. In fact, the residents held and continued to hold power to "make or break the project" (Reeves, 2010, p. 321); we needed their permission to schedule meetings and to enter the locked door of the building. One resident acted as an informal gatekeeper in communicating to other residents about meetings and encouraging residents to attend.

Despite our intentions to shift decision-making power to the residents, they continued to look to initial team members for project direction and to complete tasks. We continued to respond that our aim was to plan and do the project together. The residents' perspectives seemed partly based on their original conceptions of how research happens, aligned with more traditional researcher-driven models. Over time, these questions dwindled, and the residents seemed more comfortable in their roles as partners. We served as facilitators of the PAR process and project meetings, which felt appropriate given our familiarity with the method and our facilitation skills; however, we also actively sought resident participation and ways to transfer ownership of the project to residents, such as asking for resident input and for resident volunteers. Residents took on roles such as setting up the space for meetings and assisting in an interview for a research assistant. We also tried to relinquish or step back from particular roles and allow residents to step in to plan next steps or next meetings. However, such efforts were not fully successful. For example, residents rarely took the initiative to plan next steps, but were willing to do so when directly asked. In addition, as we sought to

elicit information about strengths and needs related to social connectedness and sense of community, the residents identified that only certain people come to building social events, and that they did not know why. We attempted to collaboratively devise an approach to learn more about the perspectives and preferences of other building residents; in practice, once an initial team member suggested doing a survey of building residents, people attending our meetings immediately agreed and did not seem interested in exploring other options.

Enabling Empowerment

Within PAR, enabling empowerment involves increasing sense of control and mastery and enabling participants to address issues affecting their lives (Blair & Minkler, 2009). In this project, we sought to identify areas that residents wished to change, but had not, and to create a space to begin a dialogue to enable them to address issues. We initially needed to negotiate with gatekeepers (Board of Directors and building manager), rather than with residents, placing the residents in a potentially disempowered position. Gatekeepers can help or hinder access and the research process, depending on how they value the research and their relationships with the people to whom they provide access (Reeves, 2010). In this case, the gatekeepers appeared to value the project and provided access, and residents became engaged and interested in discussing their needs and wants. As we began our dialogue, we wanted to engage with and hear the voices of as many residents as possible. Similar to Reynolds (2018) and Reeves (2010), who discussed boundaries regarding who was "allowed" to participate, contribute to decision making, and benefit from a community project, we found informal boundaries in place as we engaged with building residents. A group of approximately 10-15 residents began to meet with our initial team; the voices of those absent were not heard. There seemed to be an intangible boundary between who attended meetings and who did not, in that the attendees seemed to be part of a group that met regularly for coffee or other activities. These residents expressed a desire for more involvement with other building residents, and uncertainty about why other residents did not join activities, suggesting areas for exploration as the project continued.

Similar to the participants in Reynolds's (2018) study, the residents we initially engaged with described the boundaries that existed in the community, in that residents who did not attend were different in some way, such as being younger and employed full time, not having English as a first language, or not being interested in joining the others for social activities. Since the project inception we have been aware of potential boundaries within the building, potential "in groups", and the potential difficulties other residents may have in breaching the boundaries of groups. We have sought to bridge the gaps, through discussing how to engage with other residents during meetings, discussing our perspectives on social connectedness, and deciding as a group to implement a building-wide survey as a starting point. These issues are key to any community project but even more so to the current one, with its focus on building social connections. We identified that in our future work on the project, we would need to attend to how social connectedness is understood in this building, whether we are engaging all residents who wish to be engaged, and the barriers to social engagement that may be in place for a range of residents.

Engaging in Co-learning

In PAR, learning occurs for all parties, and requires openness to new ideas and challenging pre-conceptions (Kidd & Kral, 2005). During this initial stage of forming and beginning a partnership, we gained understandings of partnership development within PAR. We initially wanted to develop a partnership with a building with residents who were lacking in social connectedness and sense of community; a challenge was in determining whether a building had needs in these areas, in the absence of in-depth knowledge of the various buildings in the city. We first thought about factors that are linked to social isolation such as income (Statistics Canada, 2007), and hypothesized that a rent-geared-to-income building or a building in a lower-income area of the city might provide such an opportunity. As it turned out, we made connections within a building that did not meet this criterion, prompting us to examine our pre-conceptions about who would be a suitable partner for this project. We saw how partnerships contain many elements, including rapport, common interest in an issue, and willingness to work together, which must be considered simultaneously, being conscious of whether certain elements are being prioritized unnecessarily.

Since the project inception, the academic researchers, community partners, and building residents have developed their understandings of other aspects of PAR. The academic researchers had implemented PAR methods previously, and expanded their knowledge and skills regarding the approach, including learning how to communicate about research paradigms in lay terms and enabling equitable relationships and empowerment as described in the previous sections. The community partners were not familiar with PAR as a

methodology; however, their work and perspectives aligned well with PAR core concepts such as collaboration, capacity building, and sustainability. They have gained further understanding of participatory research, such as how it can be used to evaluate outcomes, and the language that can be used for organizational reports. We questioned our ability to help the residents understand the project that we were proposing, and unsurprisingly found that residents had knowledge of more traditional research approaches but were not familiar with projects in which participants played a key role in development and implementation. We discussed PAR processes in our initial meeting with residents, but it is only by engaging in the process together that residents have been able to understand how PAR can be enacted.

Research Ethics Review Considerations

We identified tensions related to conducting PAR while adhering to research ethics guidelines and review processes that are not designed for participatory processes. The Tri-Council Policy Statement on the ethical conduct of research involving humans (TCPS-2) guides research ethics in Canada (Canadian Institutes of Health Research, Natural Sciences and Engineering Research Council of Canada, & Social Sciences and Humanities Research Council of Canada, 2014). University research ethics boards (REBs) work to apply these guidelines; however, limited information about participatory approaches to research is included in the guidelines. Our university ethics board has an evolving knowledge of PAR processes and has worked with us to develop ethics procedures for this project. As this project began, we discussed the project several times with ethics board officials to resolve two key issues: whether we needed ethics approval in place as we contacted potential partners to invite them to participate in the project, and whether we needed ethics approval and the formal consent of building residents for ongoing project meetings, in which we engaged building residents as co-researchers.

Need for Ethics Approval Prior to Contacting a Potential Community

The TCPS-2 states that some research development activities do not need REB review, such as contacting and discussing potential research projects with individuals or communities to establish research partnerships, before designing the research itself (Canadian Institutes of Health Research et al., 2014). Particularly for community-based collaborative research, discussions need to take place to determine research questions and methods and the means of addressing community through the research. Our REB agreed that we did not need ethics approval at this stage, as we were not collecting specific participant data, and the communications and discussions focused on sharing information and answering questions. However, we did seek REB approval to conduct these meetings, a step that benefitted our subsequent conversations with ethics officials at our university, as it allowed them to become familiar with the project and opened dialogue that facilitated the amendment process later on.

Need for Ethics Approval and Participant Consent for Ongoing Project Meetings

The TCPS-2 recommends a dynamic and ongoing consent process, and recognizes that "the emergent nature of many qualitative studies makes the achievement of rapport with participants and feelings of interpersonal trust crucial to the generation of questions considered important or interesting by both parties, and to the collection of dependable data" (Canadian Institutes of Health Research et al., Chapter 10), often requiring considerable time. The guidelines further state that preliminary activities that do not require REB review can include note taking, diary writing, and observation long before the researcher formalizes a research project, with the caveat that researchers must seek consent from individuals to share material from this phase. Khanlou and Peter (2005) point out that researcher and participant roles are blurred in PAR, making it unclear how informed consent should be obtained, and suggest that the initiator of the research should engage community members in dialogue that could itself constitute informed consent (Khanlou & Peter, 2005). With these ideas in mind, we approached our university REB regarding consent for project meetings. Initially the REB requested that we obtain written, informed consent from building residents at the start of each meeting, because of the potential demands of the project on participants, and to ensure ongoing consent. After further discussions regarding the residents' position as co-researchers who may contribute to project development, data collection and analysis, and sharing findings, the REB determined that we did not need ethics approval or participant consent to use information that was shared in project meetings, based on the premise that the residents were co-researchers and could eventually be co-authors on publications or presentations. We also felt that asking the residents to complete consent forms, as typical research participants, particularly in the early stage of the project, seemed counter to developing an equitable partnership. We therefore began our project meetings without obtaining formal, written consent, but with an openness that this was a research project, that we hoped to share findings widely later, and that the residents would share control of the project with us and contribute in

whatever ways they chose. After several meetings, we did ask meeting attendees to sign a consent form, granting permission to share information that was discussed at project meetings within publications and presentations. We sought consent at this point for several reasons: we had built rapport and trust with the residents and introducing paperwork was not likely to damage our relationships; we felt that not all residents would choose to be co-authors on future work, and would likely not consider themselves to be full co-researchers, but rather project partners; and that journal requirements related to ethics approval might differ from the university perspective. We will continue to seek consent as "a mutually negotiated, ongoing process between researcher and participant" (Smythe & Murray, 2000, p. 330). Methods to manage all of these aspects of consent will include consent forms for specific purposes such as surveys, seeking informal, oral consent, and continuing a dialogue about if, and how, to share information. We have found that research ethics approval is an ongoing process as the project evolves, and that amendments to ethics documents are a required part of the process.

Implications and Conclusion

In this article, we reflexively examined the initiation of a PAR process with older adults. We aimed to support implementation of PAR processes in ways that exemplify key participatory principles, by describing the challenges that we faced and some approaches that we took. Several key learnings stem from our reflections. First, initiating PAR with communities and developing relationships over time is in tension with funding calls that researchers and practitioners respond to. The initial stage of this project has highlighted that it is possible to engage in PAR that starts with a researcher-led idea. There is a need to build flexibility into initial project objectives and design to enable the project to evolve and new questions to form beyond the bounded project. Equitable partnerships in this instance may take longer and require greater intentionality to establish. Second, attending to issues of trust amongst collaborators and opening a space to develop trusting relationships is needed to form collaborative relationships. The nature of relationships and levels of trust/ mistrust may be revealed over time; mistrust needs to be taken into consideration and, if possible, addressed, in order for a PAR project to progress. Third, implementation of PAR principles can operate on a continuum, rather than a dichotomy, in which principles are implemented to the greatest extent possible. This process requires ongoing reflexivity regarding what is happening and how principles can be better integrated into a given project. Next, creating equitable partnerships can be hindered by assumptions held by co-researchers about their potential role in research, understandings that are likely influenced by larger social conceptions of traditional research. We found that a balance between information sharing and simply "jumping in" to a project, with reflexivity, was an effective approach that enabled all involved to learn through direct experience. Finally, PAR principles of equitable partnerships and empowerment are balanced against REB interpretations of participants as being vulnerable and needing protection. When applying PAR approaches, an ongoing dialogue with REBs is necessary, to enable understanding of the approach by all parties and to ensure that research ethics procedures do not work against implementing PAR principles. Further development of ethical and publishing guidelines that address PAR approaches are needed.

Reflecting on the beginning stages of a PAR process with older adults has provided some key insights into the challenges and potential useful strategies that can be applied to future work that embraces a PAR approach. In fact, our own team has benefitted from reflecting in this way as we continue our work with this community. We hope that this information can help researchers and others to achieve the full potential of PAR, which is to address issues of concern by collaboratively and equitably working with the people most affected.

References

- Baum, F., MacDougall, C., & Smith, D. (2006). Participatory action research. *Journal of Epidemiology and Community Health*, 60(10), 854–857. doi: 10.1136/jech.2004.028662
- Baur, V., & Abma, T. (2012). 'The Taste Buddies': Participation and empowerment in a residential home for older people. *Ageing & Society*, 32(6), 1055–1078.
- Blair, T., & Minkler, M. (2009). Participatory action research with older adults: Key principles in practice. *The Gerontologist*, 49(5), 651–662. doi: 10.1093/geront/gnp049
- Bondy, C. (2013). How did I get here? The social process of accessing field sites. *Qualitative Research*, *13*(5), 578–590. doi: 10.1177/1468794112442524
- Canadian Institutes of Health Research, Natural Sciences and Engineering Research Council of Canada, & Social Sciences and Humanities Research Council of Canada (2014). Tri-Council policy statement: Ethical conduct for research involving humans, December 2014. Retrieved 20 March 2018 from www.pre.ethics.gc.ca/eng/policypolitique/initiatives/tcps2-eptc2/Default/
- Cargo, M., & Mercer, S. L. (2008). The value and challenges of participatory research: Strengthening its practice. *American Review of Public Health*, 29, 325–350. doi: 10.1146/annurev.publhealth.29.091307.083824
- Chughtai, H., & Myers, M. D. (2017). Entering the field in qualitative field research: A rite of passage into a

complex practice world. *Information Systems Journal*, 27(6), 795–817. doi: 10.1111/isj.12124

- Cloutier-Fisher, D., & Kobayashi, K. M. (2009). Examining social isolation by gender and geography: Conceptual and operational challenges using population health data in Canada. *Gender Place Culture*, *16*, 181–199. doi: 10.1080/09663690902795787
- Duran, B., Wallerstein, N., Avila, M. M., Belone, L., Minkler, M., & Foley, K. (2013). Developing and maintaining partnerships with communities. In B. A. Israel, E. Eng, A. J. Schulz, & E. A. Parker (Eds.), *Methods for community-based participatory research for health* (2nd ed., pp. 43–68). San Francisco: Josey-Bass.
- Fenge, L. A. (2010). Striving towards inclusive research: An example of participatory action research with older lesbians and gay men. *British Journal of Social Work*, 40(3), 878–894. doi: 10.1093/bjsw/bcn144
- Holt-Lunstad, J., Smith, T. B., Baker, M., Harris, T., & Stephenson, D. (2015). Loneliness and social isolation as risk factors for mortality: A meta-analytic review. *Perspectives on Psychological Science*, 10(2), 227–237.
- 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: From process to outcomes* (2nd ed., pp. 46–66). San Francisco: Jossey-Bass.
- Jagosh, J., Bush, P. L., Salsberg, J., Macaulay, A. C., Greenhalgh, T., Wong, G., et al (2015). A realist evaluation of community-based participatory research: Partnership synergy, trust building and related ripple effects. *BMC Public Health*, *15*(1), 725. doi: 10.1186/s12889-015-1949-1
- Khanlou, N., & Peter, E. (2005). Participatory action research: Considerations for ethical review. *Social Science & Medicine*, 60, 2333–2350. doi: 10.1016/j.socscimed.2004.10.004
- Kidd, S. A., & Kral, M. J. (2005). Practicing participatory action research. *Journal of Counseling Psychology*, 52(2), 187–195. doi: 10.1037/0022-0167.52.2.187
- Masi, C. M., Chen, H. Y., Hawkley, L. C., & Cacioppo, J. T. (2011). A meta-analysis of interventions to reduce loneliness. *Perspectives of Social Psychology*, 15, 219–266. doi: 10.1177/1088868310377394
- Minkler, M., & Wallerstein, N. (Eds.). (2008). Communitybased participatory research for health: From process to outcomes (2nd ed.). San Francisco: Jossey-Bass.
- Reeves, C. L. (2010). A difficult negotiation: Fieldwork relations with gatekeepers. *Qualitative Research*, *10*(3), 315–331. doi: 10.1177/1468794109360150
- Reynolds, J. (2018). Boundary work: Understanding enactments of 'community' in an area-based, empowerment initiative. *Critical Public Health*, 28(2), 201–212. doi: 10.1080/09581596.2017.1371276

- Smith, L., Bratini, L., Chambers, D. A., Jensen, R. V., & Romero, L. (2010). Between idealism and reality: Meeting the challenges of participatory action research. *Action Research*, *8*, 407–435. doi: 10.1177/1476750310366043
- Smythe, W. E., & Murray, M. J. (2000). Owning the story: Ethical considerations in narrative research. *Ethics & Behavior*, 10(4), 311–336.
- Statistics Canada (2007). A portrait of seniors in Canada, 2006. Retrieved 15 April 2018 from: www.statcan.gc.ca/ pub/89-519-x/89-519-x2006001-eng.pdf
- Sultana, F. (2007). Reflexivity, positionality and participatory ethics: Negotiating fieldwork dilemmas in international research. ACME: An International E-Journal for Critical Geographies, 6(3), 374–385. Retrieved 2 April 2018 from www.acme-journal.org/index.php/acme/article/ view/786
- Trentham, B. L., & Neysmith, S. M. (2018). Exercising senior citizenship in an ageist society through participatory action research: A critical occupational perspective. *Journal of Occupational Science*, 25(2), 174–190. doi: 10.1080/ 14427591.2017.1402809