Occupational Therapy and Participatory Research: A Partnership Worth Pursuing

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This paper argues that participatory research is an approach to developing knowledge that can make significant contributions to occupational therapy. One project, working with older adults in Toronto to organize a new seniors’ organization, is used to illustrate the ways in which this approach is participatory and how it can be understood as research. Other examples of participatory research from the occupational therapy literature are then presented. These include research among occupational therapists and research with participants who are typically clients of occupational therapy services. The examples are used to illustrate the conceptual links between client-centered, occupation-based occupational therapy and participatory research. Challenges of adopting a participatory research approach in occupational therapy are discussed, although many of these can be addressed through open discussions with participants. The paper concludes that participatory research is an approach to research that should be pursued more actively in occupational therapy.

planning group and link with seniors across the new city, 2) organizing a consensus conference that brought together older adults from across the city, and 3) planning action following the conference.

The result of the organizing effort is the newly formed Toronto Seniors Council, an organization with membership consisting of older adults and people interested in issues related to older adults in Toronto. The organization has a link with Toronto City Hall, but is independent from the local government. It addresses issues of importance to older adults in the city, including housing, retirement homes, and user fees for recreation services. It also has special funding to undertake a program entitled “Senior Friendly,” the mandate of which is to provide education and increasing awareness to business and service organizations about the ways in which their services can be made more accessible to older adults.

Throughout the research process, substantial learning took place for all participants through regular meetings and reflective discussions. This learning represents an important outcome from the process, in addition to the creation of the Toronto Seniors Council. Learning occurred in relation to the challenges of dealing with diversity, the various ways in which people engaged in the process of organizing, the importance of evaluation, the value of having a clear purpose, and the usefulness of funding to undertake such a process.

This example of one participatory research project stimulates a number of questions related to the nature of participatory research and how it links with occupational therapy. First, what makes participatory research participatory? Second, what makes it research? Finally, how does this example, and others in the occupational therapy literature, illustrate the fit between participatory research and occupational therapy? What are the challenges associated with participatory research? Although there is some participatory research described in the occupational therapy literature, it has not been an approach widely adopted within the profession to date. The purpose of this paper is to describe the nature of participatory research, and to demonstrate that participatory research can contribute to knowledge development in occupational therapy.

What Makes Participatory Research Participatory?

Participation is obviously a vital component of this approach to research. How then is participation conceptualized?

The intent of participatory research is that the participants in the research will have a role more extensive than that typically accorded subjects of research trials. People are not involved simply as sources of data, which will be collected and analyzed by a qualified researcher. Rather, they are involved in the research process from the point of defining the problem, determining the research questions, planning and conducting data collection, and analyzing and sharing results (Barnsley & Ellis, 1992; Smith, Willms, & Johnson, 1997).

A component of most participatory research is the action that is taken as a method of gaining new information. Participants are involved in planning and evaluating actions to address issues of importance to them, so that knowledge is gained through the process of acting to improve or address the issues. Although there are some forms of participatory research in which action is not the primary purpose (e.g., participatory evaluation), the intent of most participatory research is that changes will occur while knowledge is generated through the process.

In the research with the Toronto seniors, participation of the group was essential to the process from its earliest days until the point of analyzing and sharing the results. We spent almost 1 year together before agreeing on and defining the project that we would undertake. The project and the research questions were formulated together. In participatory research, the research process incorporates an action–reflection process to develop knowledge. In most cases, not only is the input of participants sought throughout the process, but also participants have much control over the research process, most commonly in partnership with someone with skills and knowledge in research methods.

A number of authors have suggested ways to conceptualize participation on continuous scales. These include the work of Arnstein (1971), who developed an eight-rung ladder of citizen participation, from manipulation to citizen control. A similar continuum was developed by Pretty (as cited in Steeghs and Talen, 1994), to describe community participation in sustainable development initiatives. Other authors suggest strategies to measure community participation (Rifkin, Muller, & Bichmann, 1988). From a participatory research perspective, these approaches provide a means to consider whether or not participation of community members in research is meeting the ideal of having participants involved in decision-making from the early stages of a project’s development.

All of the attempts to define and measure community participation are limited in that they attempt to measure in a static way a process that is dynamic. For example, in the Toronto seniors’ project the participation levels of different members of the group and the community as a whole varied over time. Different tasks required different numbers of people. Preparing funding proposals required fewer people
than attending the conference, yet both tasks were essential to answer the questions.

Participatory researchers, by virtue of their desire for meaningful participation, would want to avoid manipulation and tokenism, and the use of measures such as those described above may at least provide cautious against that. Further, the continua may stimulate thinking about the various ways that community members can become involved in a participatory process.

Clearly then, meaningful participation of community members is an important component of participatory research. However, its participatory nature is not what defines it as research. Community organizing and community capacity building, for example, describe many of these same aspects of participation, without describing the work as research. The next section will explore the ways in which research is understood from the perspective of participatory research.

**What Makes Participatory Research Research?**

Research has been defined as “the systematic investigation into and study of materials, sources, etc., in order to establish facts and reach new conclusions” (Thompson, 1996, p. 863). Willms (1997) describes research in terms of its roots in French, “to look at again,” so that research “should be understood as a process of rediscovering and recreating personal and social realities” (p. 7). These definitions are very broad and could encompass many types of inquiry.

Participatory research is based on the premise that knowledge can be developed in many ways. Park (1993) describes three types of knowledge relevant to participatory research: instrumental, interactive, and critical knowledge. Instrumental knowledge is produced through research based on a positivistic paradigm, where that which is observed is argued to be separate from the observer, and the observations are conducted in an unbiased manner. Although instrumental knowledge is important, researchers now argue that it is not sufficient as a means to understand the world (Jiggins & Roling, 1994; Park, 1993).

Interactive knowledge is based on the connections and relationships between people. Park suggests that interactive knowledge is derived “from sharing a life-world together—speaking with one another, and exchanging actions against the background of common experience, tradition, history, and culture” (Park, 1993, p. 6).

Finally, critical knowledge is described as arising from a process of reflection and action in attempting to resolve human problems. It is at the heart of questions that cannot be answered by positivistic research. For example, while technology using instrumental knowledge is capable of developing modes of communication that allow people to interact without having face-to-face conversations, it is critical knowledge that can be useful in understanding the limitations of applying this technology at the level of individual and community cohesiveness. Critical knowledge is developed through the process of reflection on issues and action to resolve them, which in turn results in further reflection and knowledge development (Park, 1993).

The Toronto seniors’ project involved knowledge development of all three types described by Park (1993). For example, to acquire funding for our organizing conference, we used demographic data, collected through an instrumental approach, to demonstrate the importance of the older adult population in the city. Further, we used a traditional anonymous evaluation form to have conference participants provide us with feedback about the conference process. Interactive knowledge, learning through discussion, was demonstrated at the consensus conference itself. Participants attended the conference if they had an interest in seniors’ issues, but they did not necessarily come to the event with a specific expectation of the need for a new seniors’ organization or how it should be structured. Rather, the response to the research questions in part came out of the interactions among participants at the conference itself. Finally, critical knowledge through action and reflection represented the major way in which knowledge was gained throughout the project. We made decisions as a group to move forward, assign people to take on tasks, and then evaluated the results of those decisions at future meetings. For example, early in the process it was identified that we needed to conduct outreach to seniors and seniors’ groups across the city. We arrived at a final list of over 400 seniors’ organizations through a lengthy process of identifying some organizations from existing lists, making telephone calls to a number of groups and organizations, and using word of mouth. We faced challenges in reaching out to groups based on different languages. We went through a number of iterations and additions to the list, by using a strategy, reflecting on its effectiveness, developing a response to the reflection, and implementing a new outreach strategy.

Participatory research assumes that all of these types of knowledge are valid, and in fact that research should be conceptualized broadly to encompass all three of these types of knowledge development. In participatory research then, the goal is to gain new knowledge that is useful to the group, and to do so in a way that is in the hands of the people who need the knowledge. Many ways of gaining knowledge are acknowledged as useful. The term research is as broad as the dictionary definition, not excluding but also not limited to the dominant understanding of research.
Traditions of Participatory Research

Participatory research has been described here as a singular approach to research. Participatory and qualitative research are considered distinct although related approaches (i.e., participatory research is sometimes described as a form of qualitative research [Reason, 1994]) and some argue that qualitative research such as critical ethnography is a form of participatory research. Although there is significant overlap in their assumptions related to knowledge, and in their critique of positivist assumptions, participatory research is not necessarily limited to qualitative methods. Quantitative methods have been used in participatory research as well.

Similar to qualitative research, there are also different traditions of participatory research. In qualitative research, researchers might describe their work as ethnography, phenomenology, or grounded theory. Even within those broad areas, there are distinctions of different types. The same is true for participatory research. The most commonly described approaches to participatory research include action research (Gilmore, Krantz, & Ramirez, 1986), action learning (Marsick & O’Neil, 1999), participatory action research (Smith, Willms, & Johnson, 1997), and feminist participatory research (Maguire, 1987).

Action research has its roots in organizational development (Brown & Tandon, 1983). It typically occurs within single organizations, is based on a consultancy model, and generally maintains existing power structures (Franklin & Morley, 1992). Action learning has evolved from action research to focus on issues that occur in broader community contexts, rather than focusing on a single organization (Gray, 1989). In action learning, a significant amount of time may be involved in developing an understanding of underlying problems, and identifying the interested stakeholders before action to address the issues can begin (Franklin & Morley, 1992). Participatory action research has its roots in education and development initiatives, and generally involves people who are oppressed or face inequities in access to information and knowledge (Brown & Tandon, 1983). It is explicit about the notion of knowledge as power, and has an empowerment component (Fals-Borda, 1991). Feminist participatory research is grounded in the feminist movement and its associated political action (Mies, 1991). Maguire (1987) demonstrates the need to ensure accessibility of knowledge development to women, to ensure gender equity issues are raised as valid issues for study, and that women are involved in participatory research processes and also benefit from the changes that occur as part of the participatory research.

The field of participatory research can sometimes be quite confusing since the same words are sometimes used for different traditions. It is not the purpose of this paper to describe the details related to the similarities and differences among the various traditions. However, it is important to acknowledge that the different traditions exist, in the same way that other research approaches have different traditions.

In occupational therapy, there has been little application of any one tradition of participatory research to develop new knowledge in our field. It is therefore most useful to consider the overall value of participatory research to occupational therapy. Once participatory research becomes more readily accepted in occupational therapy research, consideration of the applicability of the different traditions will be warranted.

Previous Participatory Research in Occupational Therapy

When I undertook to do a literature search, I identified nine citations in occupational therapy literature where participatory research was used. The focus of some of these projects has been on occupational therapists as participants in the research, where the research centers on understanding occupational therapy practice or professional development. The remaining projects involved occupational therapists working in partnership with people who traditionally are our clients. The projects identified will be briefly presented, to illustrate how participatory research can contribute to occupational therapy knowledge development.

Participatory Research With Occupational Therapists

Three initiatives in the literature clearly focus on the profession of occupational therapy itself. The first was a project focused on gaining better understandings of occupational therapists’ clinical reasoning. Mattingly and Gillette (1991) report on the incorporation of action research into a project that was originally designed to be a qualitative study. The project involved the occupational therapists who were the focus of the study as collaborators in the analysis process. The clinicians were not involved in the definition of the research problem or design. However, collaborative analysis allowed the clinicians to reflect on their practice and these reflections were an essential component of the analysis process. Analyses were often conducted through group sessions where clinicians would together observe a videotape of an occupational therapist involved with a client. The group would then go through a process of interpreting the clinical reasoning process. A multiplicity of perspectives was thus brought forward, and Mattingly and Gillette (1991) note that “a more complex story was developed that integrated many of the particular stories the therapists had told.”
practising in isolation from other colleagues working with similar clients. The goal of the project is to develop strategies that enable occupational therapists to use research findings. Four groups of occupational therapists are participating in the project through discussions using the Internet. An initial report on the project indicates that significant challenges were faced in relation to accessing the technology of the project (Egan, 2002). Although the project was based on previous research with clinicians in practice, the clinicians participating are not included as co-investigators and the investigators will analyze the online conversations. It is not clear whether the participants will be a part of the analysis process, although that would be expected in participatory research. The results of this project are yet unknown, but its implementation demonstrates the potential for professional knowledge development using technology to bring clinicians from remote areas together.

Participatory Research With Community Groups

Participatory research strategies have also been reported in research with people in communities who would typically be clients of occupational therapists. Such research has included children with disabilities and their parents, adults with physical disabilities, adults with mental illness, and older adults.

Parents of Children With Disabilities

Law (1997; Law, Haight, Milroy, Willms, Stewart, & Rosenbaum, 1999) engaged in a participatory process with parents of children with physical disabilities. The purpose of the project was to work with parents to identify environmental situations that presented challenges to their children. Since there was no identified parents’ group with whom she could work, she used a focus group process with parents of children with disabilities to begin to explore issues related to environmental supports and barriers. These focus groups helped in the development of an interview guide for a series of qualitative interviews with parents of children with physical disabilities identified through the local children’s treatment center. At the end of the interview stage, participants came together to discuss the results, and organized themselves into a parent support and advocacy group. A number of policy suggestions were developed out of the project itself, and the parents’ group continues to meet and work to improve the community for children with disabilities. The research process did not involve parents in the problem definition and research design stage because there was not an organized group of parents to contact. However, through the collaborations conducted...
Throughout the process in developing the interview format and sharing results, a participatory action research process evolved. Efforts derived from the project continue to be undertaken through the parent advocacy group.

**People With Physical Disabilities**

In another example, Stewart and Bhagwanjee (1999) describe a process of group development using participatory research to evaluate a self-help group for people with spinal cord injuries. The group began as one facilitated by an occupational therapist to meet the expressed needs of people who were attending a hospital outpatient clinic and who were experiencing stresses related to their discharge from rehabilitation. After 18 months, the group members began to reflect on the group’s function and structure, and a participatory process was undertaken to evaluate the group. Together, group members designed a questionnaire, and also engaged in important reflective discussions as the questionnaire was developed. As a result of this process, the group assumed collective ownership for the group, and new responsibilities in its management. The therapist’s role became that of invited consultant. This project demonstrates how participatory research can be used as a vehicle for empowerment. However, it also demonstrates the power that the therapist facilitating the group held in designing the process as one that was participatory. It is an irony in this situation that by using participatory methods, the clinician in partnership with the group members worked through a process that resulted in her having a less active role in the group. The group needed the therapist to be willing to forgo that control for the evaluation to be undertaken and the results used to reshape the group’s structure and processes. The project involved participatory evaluation, with involvement of all group members in all stages of the evaluation process. The results of the research led to significant changes in the group’s structure and process, but as is common in participatory evaluation, action was not a major component of the evaluation itself.

**Adults With Mental Health Issues**

Participatory projects that involved work with adults with mental health issues were identified in three citations found in the occupational therapy literature. Cockburn and Trentham (2002) describe a project conducted within the context of a cooperative program designed to provide meaningful work for people who had had involvement with the mental health system. After 3 years of operating as a small co-op, members of the group began evaluating the group’s history and possible futures. A research proposal was developed to conduct a qualitative study involving document review and semi-structured interviews. Members of the group were involved in all stages of the research project, from proposal development, ethics review, data collection, analysis and reporting results. However, challenges were faced throughout this process, including dealing with the need to seek ethics approval for a project in which the co-investigators were also the subjects, and the decrease in participation of members of the group during the data analysis stage. Although it may not be uncommon for fewer people to be engaged by data analysis, it is a source of concern when the results had such potential to influence the future of the cooperative.

Corring (2001) describes two participatory research projects that involved consumers. The first explored the concept of client-centered practice from the perspective of consumers of mental health services. Coresearchers, who had themselves been consumers of mental health services, collected data with other consumers contacted through local consumer/survivor agencies. Coresearchers and those interviewed were engaged in the analysis of the data collected, which in turn resulted in suggestions for action to address the issues. Despite its participative nature, this project began as Corring’s own graduate research project. It is not clear that the research question would have come from the co-investigators if it had not been for her initial interest in this area. The second project involved a consumer/survivor group, a family network group, and local mental health service agencies. There were challenges associated with identifying the focus of the research in its initial stages. In part, it appears that this was related to the project’s initiation by a planner from the district health council and the executive director of a local mental health consumer/survivor agency, rather than from consumers themselves. The project eventually explored the quality of life issues facing consumers and their families. Qualitative data collection involved focus groups that were co-facilitated by the researcher and a peer of the participants. The results of the research were used to advocate for new services in the local community. Again, this project’s initial stages do not fit the ideal of what is described in the participatory research literature. The purpose of the research was itself contested by the different stakeholder groups, and had to be negotiated among them, rather than coming from them initially.

Townsend, Birch, Langley, and Langille (2000) describe efforts to examine a research unit operating within the context of a mental health clubhouse. The study questions focused on identifying the “challenges and opportunities for people with mental health problems to advance their empowerment through the occupation of research” (Townsend et al., 2000, p. 24). Although institutional ethnography was used to conduct the examination of the research unit, a number of the findings from the project...
relate to participatory research because of the participatory nature of the research unit itself. The researchers noted that research can be an occupation that takes many forms, and that can engage participants who are clubhouse members, staff, and other researchers. At the same time, the analyses identified challenges associated with power inequities, and the importance of the research being used in a critique of social structures. While this project gained significant insights about participatory research, it did so through an ethnography that involved participant observation rather than the cycle of action and reflection typically described in the participatory research literature. However, it also demonstrates the links that can be made between participatory and qualitative research.

**Older Adults**

The final set of participatory research projects described in the occupational therapy literature involves older adults in the research. The Toronto seniors organizing project described at the beginning of this paper is one of three that were identified. In another, a group of older adults engaged in participatory research to develop a curriculum for health professional students related to health promotion and older adults (Carswell, 1995). In the project, a group of 12 older adults worked with the investigator (an occupational therapist) and a community health promotion coordinator to develop an interview questionnaire to collect information about seniors living in the community. The group members administered the questionnaires and analyzed the data in order to develop the curriculum. The outcome of the research process was a curriculum that focused on key issues related to health and aging. The process that was used to develop the curriculum involved the older adults in a process of collaboration and dialogue that resulted in learning, and they reported improved health at the end of the project itself. However, the older adults did not initiate the project; rather they were recruited to participate in the process. It is not clear how much control they had in designing the questionnaires, but they had significant input into the development of the curriculum that resulted from the project.

In another citation, Cockburn and Trentham (2002) describe an initiative with older adults living in a seniors’ apartment building in downtown Toronto. The project began as a means to increase the capacity of the tenants in the building to respond to issues that challenged their health and quality of life. An issue related to fear of falling was identified by a tenant in the building, and in response a committee was organized to address issues related to falls. The committee chose to organize a falls prevention workshop, and a participatory research project was initiated to explore how more tenants could be engaged in the process. Eventually, the question expanded to consider how more tenants could be engaged in the building’s community events in general. One of the challenges in this project was to balance the focus on a concrete task, organizing a falls prevention workshop, with the need to engage in more abstract discussions about community participation generally. Through reflective discussion following the workshop, the group was able to identify key issues related to power imbalances between tenants and building authorities that influenced tenant participation. However, once identified, it is also challenging to move to an action phase to address such systemic issues, especially as a project is nearing its anticipated conclusion.

All of the projects described here, whether involving occupational therapists, or people who are usually clients of occupational therapy services, provide examples of the kinds of knowledge that can be gained through participatory research. Knowledge has been gained about how occupational therapists work in clinical practice and can increase their scholarly activity. Significant learning has been gained related to group development and organization, and issues specific to the people with whom occupational therapists work have been addressed. The projects demonstrate some of the conceptual links that can be drawn between occupational therapy and participatory research.

**Conceptual Links Between Occupational Therapy and Participatory Research**

Two key concepts in occupational therapy link strongly with the underlying principles of participatory research: client-centered practice and occupation. Both of these concepts have received increasing attention in occupational therapy in recent years. They provide insights into the potential usefulness of participatory research to knowledge development in occupational therapy.

**Client-Centered Practice**

Over the last two decades, client-centered practice has gained significant prominence in discussions of occupational therapy practice (Law, 1998; Sumsion, 1999). We consider it essential to engage with our clients in a partnership to name issues the clients identify as most important to be addressed, and to work with clients to select and implement interventions. At the same time, occupational therapists are working in settings where client-centered practice is an expectation of the setting, such as in schools, independent living centers, community settings, and health promotion contexts.

Law and Mills (1998) describe seven concepts of client-centered practice that are common to models described in...
the health literature. These include: respect for clients and their families; clients and families having ultimate responsibility for decisions about their occupations and occupational therapy services; provision of information, physical comfort, and support; facilitation of client participation; flexible, individualized occupational therapy; enabling clients to resolve their occupational performance issues; and focusing on the person–environment–occupation relationship (p. 9).

Although exact parallels between these concepts and those of participatory research are not present, overlap can be noted. For example, participatory research is founded on respect for the people participating in the process, and valuing their expertise. Ideally, participants are engaged in the research process from the beginning. From the examples described in the occupational therapy literature, this early participant engagement has sometimes but not always been the case. For example, the participants themselves initiated both examples described by Cockburn and Trentham (2002). In others, the projects evolved to incorporate increasing participation from the participants (Mattingly & Gillette, 1991; Law, 1997). In others, the original question or issue was initiated by the researcher (Carswell, 1995; Corring, 2001), but participants were engaged in the process once the topic was established. It is also worth noting that some groups of people with disabilities have in fact called for participatory research to be adopted more broadly (Woodill & Willi, 1992).

Participatory research, not unlike client-centered occupational therapy practice, is grounded on a relationship that is based on a partnership among all participants, including the researcher. Each participant brings to the process his or her own strengths and expertise to assist in the process of action and reflection. Law (1997) notes a difference in the relationships in client-centered occupational therapy practice and participatory research. In occupational therapy, the therapist is seen to be an “expert” and to use that expertise to facilitate solutions to client-identified problems, while in participatory research, she notes that the expert role was not useful. Cockburn and Trentham (2002) also discuss the challenges associated with expert roles, but argue that occupational therapists need to bring their expertise to the process in participatory research, and engage in explicit discussions with the participants about their potential contributions.

In both client-centered practice and participatory research, it is important to acknowledge that all participants bring a certain type of expertise to the process. In occupational therapy clinical practice, clients bring expertise related to their own life experiences, their values, and their ability to identify and explain the areas of occupational performance that are most important to them. Occupational therapists bring expertise to assist them in identifying those issues, and developing strategies to address them. In participatory research, community participants bring expertise related to the issues that need to be addressed through the research process, and clear understandings of what action strategies are most feasible and realistic to respond to the issues identified. The occupational therapy researcher may have expertise related to the occupational context of the issue, and how research strategies might be implemented to address the issues. In both scenarios, I believe that there is no single “expert.” Rather, the participatory nature of both practice and research relationships leads to the acknowledgement of different types of expertise. In both cases, these need to be acknowledged, since in different contexts, some types of expertise may be associated with more credibility and power; these issues may present challenges to a successful process if they are not acknowledged. Townsend, Birch, Langley, and Langille (2000) support this idea of making power differences explicit when they note that “power inequities between members, professionals, and outside researchers need to be discussed openly if members’ empowerment is a goal” of research (p. 39).

A final distinction between client-centered occupational therapy and participatory research is the concept of individualized occupational therapy. Participatory research is seldom conducted with one individual; rather a group or community participates in the research process. Further, and more importantly though, participatory research is not intended to be “therapy” in the same way that occupational therapists traditionally work with clients. The purpose of participatory research is to generate knowledge that is useful and meaningful to participants. Heaney (1993, p. 45) notes that “participatory research is credible and legitimate when the action to which it leads brings about better conditions for life. Period.” Although underlying values in occupational therapy support the goals of participatory research, conducting a participatory research project is not occupational therapy. In fact, it could be argued that labelling participatory research as therapy would be an attempt to institutionalize participatory research to fit within a profession, rather than to meet the needs of the community with whom it is being undertaken. Participants who engage with occupational therapists in a participatory research project are not clients of the therapists; they are their research partners or coresearchers. That is not to say that research is not an occupation in which individuals might find satisfaction. Rather, it is important to make a distinction between participatory research as an undertak-
ing in partnership to achieve mutually agreed upon goals, and the therapeutic process in which occupational therapists and clients engage to achieve goals related to occupational performance.

**Occupation-Based Practice**

The other conceptual link between occupational therapy and participatory research relates to occupation itself. Therapists believe that people’s health and quality of life are strongly influenced by their engagement in roles and activities that are meaningful to them. Engagement in occupations is a key determinant of health from an occupational therapy perspective (Wilcock, 1998).

Participatory research, through its use of action as an inherent part of the research activity, has a link with the occupational therapy concept of occupation. By definition, participatory research is intended to have action as a key component. The intent is that participants will consider what issues they are addressing, and develop action strategies to address the issues. They will then reflect on the outcomes of their actions and make further decisions about next steps. This iterative process of action and reflection leads to knowledge development as well as change in communities and empowerment for participants (Smith, 1997).

The action component of the occupational therapy participatory research projects presented here vary in the type of activity undertaken as well as the ease with which the actions are discernable in the research papers. For example, Cockburn and Trentham (2002) describe a falls prevention workshop that was organized by participants. Roth and Esdaile (1999) describe a series of actions to assist the occupational therapy department to make the transition to a more scholarly focus. Law, Haight, Milroy, Willms, Stewart, and Rosenbaum (1999) and the Toronto seniors’ organizing project both involved the formation of new community organizations.

In other projects, the research activities are clear in terms of data collection and analysis. Corring (2001), for example, reports on how the participants worked with her to collect and analyse data related to client-centered practice and quality of life issues. It is less clear how the participants used the results of these research projects. Regardless, all of the projects described involve participants, whether they are occupational therapists or people with whom occupational therapists work in a process of exploring a topic. As Townsend, Birch, Langley, and Langille (2000) then note, engaging in research can itself be considered a valuable form of occupation with significant meaning to the participants.

**Challenges of Participatory Research in Occupational Therapy**

This paper makes the argument that participatory research can make significant contributions to knowledge development in occupational therapy. Challenges associated with implementing participatory research should also be acknowledged.

First, there may be times when participatory research should not be undertaken. If a research question or design is already in place, and investigators are not willing to have the direction of the research change, there is little point in inviting participation from other stakeholders or community groups. There are other times when the research does not lend itself to a participatory research approach. For example, when outcome measures are being tested for their reliability, validity, and sensitivity, it may not be valuable to involve clients as co-investigators in that research. However, it may be important to involve people in the process of identifying the need for new instruments or what the content of such instruments should encompass.

A second challenge sometimes described in the literature is that participatory research is time-consuming (Allison & Rootman, 1996). In fact, all research takes time. The amount of time required to conduct participatory research may depend on whether or not a relationship with a community or group exists prior to starting the research. In the Toronto seniors’ organizing project, it took 1 year of working together before formulating the research questions. If the relationship had already existed, as it did in the vocational program evaluation described by Cockburn and Trentham (2002), the time would be reduced.

A third challenge faced by participatory research relates to the role of the external researcher in the process. Although it is often acknowledged that many participatory research projects would not be undertaken without the initiation of an “outside” researcher, there are challenges associated with leadership of processes (ideally leadership evolves within the research community). King (1995) describes this as the challenge of facilitation: without facilitation from an external researcher the process might die, but if there is too much control in the hands of the external researcher, people will not be active participants of the process.

From the perspective of the researcher, there is also a need to relinquish the research agenda for the benefit of enabling the community to develop more knowledge and research skills. However, funding for this type of research may be difficult to acquire. Further, when academics participate in the research, there is a risk that participatory
research will become institutionalized, driven by demands of the organization rather than the researchers. Cockburn and Trentham (2002), for example, describe the requirement for the work co-op program research study to undergo ethics review because of the program’s location in an institutional setting. Group members initially felt that this was unnecessary, since they were the coresearchers and were essentially researching themselves. However, they turned the requirement into an opportunity to increase the project’s visibility and to advocate having a consumer on the ethics review board.

Researchers engaging in participatory research should also be prepared to have their roles change throughout the process. Depending on the expertise of the group members, multiple roles may be taken on by the researcher. For example, the researcher may act as a small group facilitator and a secretary, as well as take a lead role in proposal development or data analysis. The skills of a participatory researcher may include self-awareness, facilitation, political, intellectual, and data management skills (Reason, 1994). Some researchers, in occupational therapy and other disciplines, may be challenged to bring those skills to a participatory research project.

All of the challenges related to the role of the external researcher need to be made explicit through ongoing discussion with participants in the process. Continual attention to the relationships and roles among participants and outside researchers or facilitators is an important aspect of participatory research.

A final challenge to adopting participatory research in occupational therapy relates to the nature of the research and its ownership. If occupational therapists engage with communities or groups in participatory research, they need to be willing to share control with the participants. That may mean that the research takes a direction that may not contribute as much as the occupational therapist would like to knowledge specific to occupational therapy. As well, since the community gains the knowledge, the dissemination of findings in academic milieu may be unimportant to community members. External researchers need to be willing to share responsibility for writing and reporting results of a research project, and be prepared to share results through multiple media beyond the traditional peer-reviewed presentation or publication. Explicit discussions with all participants need to be held to ensure that all members agree on how and if research findings will be shared with a broader community.

This discussion of limitations should not be seen as discouraging researchers from undertaking participatory research. However, it does highlight some of the issues that need to be addressed by the researcher and the community or group with whom the research is undertaken. A number of these issues need to be addressed in the research partnership, in order for the research to meet the needs of the community as well as the researcher.

Conclusion

Participatory research is a legitimate approach to knowledge development that expands the notion of traditional research in a way that reflects a client-centered understanding of knowledge. Examples in the literature demonstrate the value of participatory research to knowledge development in occupational therapy. Future research initiatives can build on these initial efforts to increase occupational therapy knowledge through participatory research. It is a partnership worth pursuing.

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