Capacity development in participatory action research

Mary Lou Kelley and Margaret McKee

Capacity development in long-term care homes through participatory action research

The purpose of this chapter is to propose and illustrate an integrative framework that can be used to guide participatory action research in order to develop palliative care programmes within long-term care (LTC) homes for elderly people. The framework consists of participatory action research (PAR) as an overarching approach, capacity development model, and four practice principles: cultural competence, empowerment, relational ethics, and partnerships (See Figure 4.1). Based on five years of experience conducting PAR with LTC homes in Ontario, Canada, the authors offer this framework as a resource to guide the work of other researchers and long-term care homes who wish to develop palliative care programmes. The authors have also used PAR to develop palliative care capacity in rural and First Nations communities, indicating that this approach has applicability beyond long-term care homes (Kelley et al., 2011; Prince and Kelley, 2010).

Importance of palliative care research for long-term care homes

The urgency to provide palliative care services in LTC homes in Canada is growing because up to 90% of all residents now live in care homes right until death (Wowchuk et al., 2007). Residents today have a high burden of chronic and terminal disease and high rates of Alzheimer's disease or related dementias (Wowchuk, 2006) that create care challenges due to communication, functional, and behavioural problems (Sachs et al., 2004). Frequent causes of death are: pneumonia, coronary artery disease, congestive heart failure, cancer, and stroke (Reynolds et al., 2002).

Given these characteristics, it is not surprising that almost fifty percent of residents die within the year in Ontario long-term care homes, with most residents dying within two years of their admission (Palliative Alliance, 2010). Common end-of-life symptoms, such as pain, incontinence, fatigue (Reynolds et al., 2002), constipation (Casarett et al., 2001), shortness of breath, restlessness, and agitation (Ley, 1989), indicate a need for palliative pain and symptom management. Dying residents would benefit from a palliative care approach that addresses not only physical symptoms but the
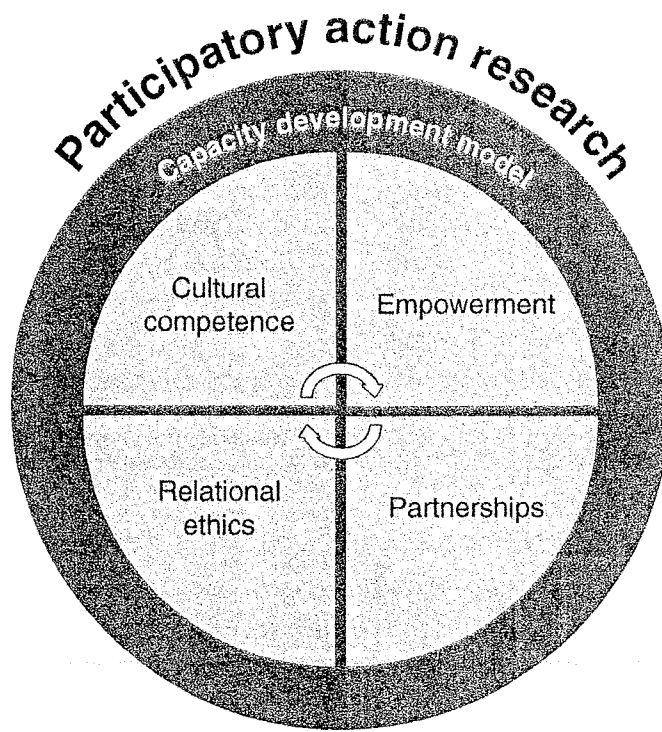
Fig. 4.1 Framework for participatory action research.

psychological, social, and spiritual issues at the end of life: issues of loss and grief, and practical end-of-life/death management concerns of residents and their families (Ferris *et al.*, 2002). Despite the need and benefits of palliative care for residents in long-term care, formalized palliative care programmes are rare in these settings.

Having a palliative care programme is currently not mandatory for LTC homes in Ontario and palliative care programmes do not have dedicated funding within long-term care homes (Ministry of Health and Long Term Care, 2007). This means that long-term care homes that wish to offer palliative care programmes must do so through developing capacity within their existing human and financial resources. Implementing the framework presented in this chapter offers long-term care homes a strategy to develop palliative care programmes using a process of capacity development.

Research has documented that organizational culture in LTC homes is a major barrier to the provision of palliative care (Foner, 1995). One aspect of current culture is that front-line unregistered care workers—called personal support workers (PSWs) in our province—who provide 80% of direct resident care, have minimal palliative care training and little input into resident care planning (QPC-LTC Alliance, 2010). The early findings of our research indicated that PSWs viewed giving care to dying people as an important part of their work which gave great meaning to their lives (QPC-LTC Alliance, 2010). They talked about the development of family-like bonds with residents and expressed their commitment to provide highly personalized care, especially at end of life (Sims-Gould *et al.*, 2010). At the same time, PSWs reported having problems communicating their perceptions of resident care needs with registered nursing staff and felt that they had little personal control or influence over their work (QPC-LTC Alliance, 2010). Over the past three years, using this framework and

engaging PSW's in PAR has resulted in them feeling more confident in their competencies and more valued for their care for dying residents by other staff within the organization. Qualitative data presented later in this chapter illustrate PSWs' increased sense of empowerment.

Introduction to the project

The purpose of our five-year research, which commenced in 2009, was to improve quality of life for people who are dying in LTC by creating formalized palliative care programmes that can be sustained within the LTC home environment beyond completion of the project (see www.palliativealliance.ca).

Capacity development (Kelley, 2007) was chosen as the model for the research as we view LTC homes as relational and geographic communities. We adopted the Canadian Hospice Palliative Care model of care to guide our vision of a comprehensive palliative care programme (Ferris et al., 2002). We developed an alliance of partnerships as resources for LTC capacity development, including four homes as study sites, 31 researchers with a wide range of methodological and palliative care expertise, and 43 community organizations that could assist LTC homes to deliver aspects of palliative care. Alliance members also disseminate the findings of the research to their stakeholder groups.

For our research, PAR was chosen as the overarching approach most appropriate to develop LTC capacity in palliative care. Participatory action research is an approach of action research that has an orientation towards action and change. A distinguishing issue is the degree to which the researcher maintains control of the research process. The degree of participant involvement varies on a continuum from: researchers consulting the community's views (least involvement); to designing the study and then collecting data with the help of the community; to the community working closely with researchers; to total participant control (most involvement) (Kemmis and McTaggart, 2000; 2005). Our research embraced the highest degree of participant involvement, with LTC staff becoming members of the research team and participating in all aspects of project decision making and execution. We chose PAR because research on capacity development has demonstrated that changes in organizational culture and practice are most sustainable when these changes are planned and executed by those most directly involved.

We will now describe the components of the framework we used for conducting this research and illustrate each component with examples from this research.

Participatory action research approach

The goal of PAR is to create social change while generating theoretical and practical knowledge. It differs from more conventional research methodology in three ways: in its understanding and use of knowledge; its relationship with research participants; and, the introduction of change into the research process (Hockley et al., 2005). Methodologically, the participants collaborate on all aspects of the research process and control research activities in the field setting (Cashman et al., 2008). Knowledge is co-created by the researchers and participants through a reflective spiral of activity: identifying a problem;

planning a change; acting and observing the process and consequences of the change; reflecting on these processes and consequences; and re-planning, acting, observing, and reflecting (repeating the cycle) (Kemmis and McTaggart, 2000; 2005). Throughout the research, the change process and its outcomes are documented.

In our research, a PAR approach is appropriate because our goal is to change processes of care for dying residents and develop palliative care programmes. Using PAR recognizes the expertise of LTC home staff, residents, and families and promotes integration of the LTC communities' values and practices into palliative care. The LTC staff are co-researchers and they participate in creating and implementing all interventions. Meetings of the LTC palliative care teams are attended by the researchers and are used to generate knowledge. The knowledge created includes practical strategies for providing palliative care in LTC, as well as a greater theoretical understanding of the capacity development process that may be applicable to LTC homes nationally and internationally.

As long as the purpose and principles of PAR are respected, the research can use any form of data collection that researchers and participants determine are relevant for their study. In the project, our environmental assessment included: surveys, interviews, and focus groups, observations, document reviews of resident care records, and organizational analysis. We gathered data from residents, families, volunteers, and staff performing all roles within LTC, and community partners. We sought data about perceived quality of life and care, organizational culture, staff sense of empowerment, knowledge of palliative care, current care practices, communication, and relationships within the LTC home. Gathering multiple forms of data was appropriate since our goal was to 'get the story right'. Having multiple types of data and multiple sources of data enabled a more complete understanding and thus provided greater rigour in the research.

The depth and richness of the data also allowed us to appreciate the complexity of change that would be required to achieve our goal of implementing palliative care programmes. The data allowed the researchers and staff to identify multiple interventions encompassing the physical, social, psychological, spiritual, and practical aspects of palliative care as well as targeting changes for residents, families, direct care staff, and managers. Many interventions involved direct care staff, while others were implemented by managers or with community partners. Staff prioritized and gradually began to implement and evaluate the interventions using established organizational approaches to quality improvement, such as using plan-do-study-act cycles. Researchers also collected process and outcome data in conjunction with the LTC staff. As an example, the personal support workers (PSWs) generated the idea of providing 'comfort bags' for families of residents who were dying that consisted of toiletries, activities (such as crossword puzzles), and informational pamphlets on end-of-life issues. In a series of palliative care team meetings, the content, timing, and method of offering the comfort bags was modified until staff were satisfied with the result. Researchers participated in these discussions and documented the transformation of the intervention over time.

In PAR much is outside the control of the researchers because research progress is dependent on the participants, and the work occurs in a field setting that is subject to

many internal and external forces that can interrupt plans (Kemmis and McTaggart, 2000; 2005; Prince and Kelley, 2010). Managing environmental impacts becomes an important part of the research process, and researchers must remain flexible. In our project, the LTC homes have coped with new regulatory legislation and requirements, a new electronic charting system, as well as changes in senior management which temporarily took their focus away from the palliative care project. Our project expectations needed to adapt to these realities and, whenever possible, synergies with other requirements were identified. For example, the new legislation mandated that LTC homes provide palliative care education and develop a pain management programme. The researchers identified how developing the palliative care programme could support the homes to meet these requirements.

In PAR, knowledge transfer to all stakeholders and participants is embedded in the process (Kemmis and McTaggart, 2000; 2005). Throughout our project, the first dissemination of research findings was always to the LTC staff participants which also helped to ensure that our interpretations were correct. This was done via organized presentations, workshops, and meetings. Subsequently, conference presentations have included our LTC partners as authors and presenters. Long-term care staff prepare articles for the project website, newsletters, and author manuals for the tool kit. This has the benefit of ensuring that the language and presentation of our research findings meets the needs of the primary audience, that is, staff of other LTC homes.

The focus of PAR is social change; such change may take a long time and maintaining participants' motivation is very important (Kemmis and McTaggart, 2000; 2005; Prince and Kelley, 2010). In our five-year project, researchers focused on creating quick benefits for the staff, such as meeting their requests for palliative care education. Research staff built personal relationships with the staff by spending time in the LTC homes; personal relationships enhanced engagement in the project. Researchers attended monthly meetings with the staff in the LTC homes and maintained ongoing email communications and telephone contact. As the project progressed over time, staff observed progress in creating the palliative care programme which served to sustain their motivation.

Researchers in PAR function as facilitators and catalysts in a change process that is controlled by the participants. This catalyst role is also consistent with the model of capacity development that requires changes to be generated from within the community and not imposed by external people or organizations. This next section describes four phases of the capacity development model created through previous research in rural communities (Kelley, 2007; Kelley et al., 2011) and adapted for use in this research, since we view LTC homes as geographic and relational communities.

Capacity development model

Capacities are the collective capabilities found within and among people, organizations, and community networks and society (Norton et al., 2002). From this perspective, we viewed LTC homes as communities that have the capacity to tackle their problems through collective problem-solving. Capacity development requires a long-term investment as it involves holistic change and is slow (Bolger, 2000). In our project,

the researchers were committed to five years of involvement because they understood a major culture change would be needed for staff and LTC homes to fully embrace a new identity and role as providers of palliative care.

Capacity development promotes change from within each home and does not impose solutions from outside (Morgan, 1998). It focuses on: existing strengths and empowerment; the use of bottom-up, community-determined agendas and actions; and, processes for developing competence (Raeburn *et al.*, 2006). Our project offered resources to support this internal change process; for example, research assistants, graduate students, and money to purchase staff time for programme development. One PSW in each LTC home immediately joined the research team as a staff liaison, to guide and assist in the project. The capacity development model, depicted below in Figure 4.2, guided the PAR used to implement the four phases of developing palliative care for LTC.

Kelley's capacity development model is essentially a theory of change that depicts a 'bottom-up' community change process to develop palliative care programmes in four sequential phases:

Phase 1. Having sufficient antecedent conditions to begin the change process.

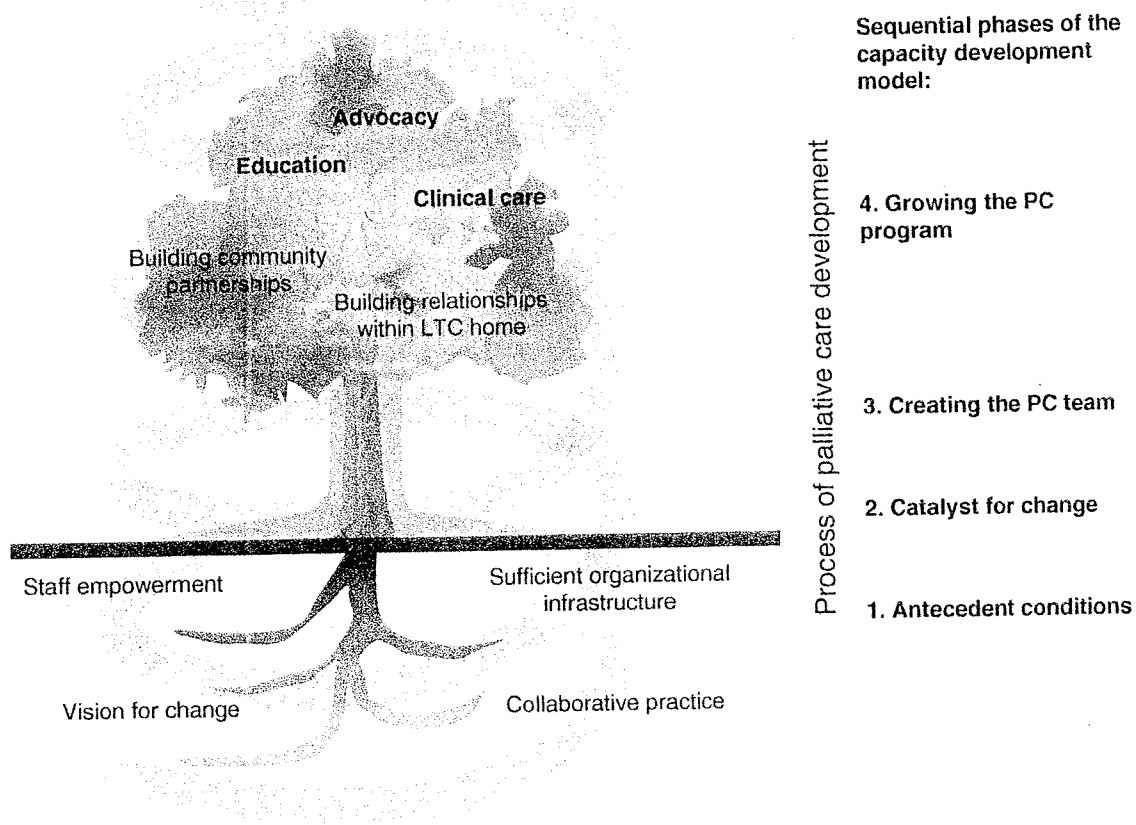Phase 2. Experiencing a catalyst for change.

Fig. 4.2 Capacity development model for long-term care.
Adapted with permission from Mary Lou Kelley, Developing Rural Communities' Capacity for Palliative Care: a Conceptual Model. *Journal of Palliative Care* (Autumn 2007), **23**(3): 147, copyright © Institut universitaire de gériatrie de Montréal, 2007.

Phase 3. Creating a palliative care team.

Phase 4. Growing the palliative care programme.

This model was applied to build capacity in the LTC home. Using PAR, the phases were initiated sequentially by the LTC home staff, but the overall development process was dynamic and non-linear, shaped by internal and external forces. At each phase of the model, there were strategies to guide the LTC staff to manage challenges such as lack of resources, internal resistance to palliative care, and bureaucracy. Research interventions in the LTC home respected enabling factors identified in the model: being focused on the whole organization; educating providers; working together; internal leadership; and participants taking pride in their accomplishments. Ultimately, by implementing the model, the LTC home staff created a comprehensive palliative care programme that provided clinical care, education, and advocacy; built relationships within the LTC home; and made strong community partnerships with outside expert resources (QPC-LTC Alliance, 2010). We next describe the implementation process that occurred in the PAR research.

Prior to initiating the PAR research, researchers assessed each LTC home's antecedent conditions for change through a comprehensive environmental assessment (Phase 1 of Kelley's model). Antecedent conditions for change are: collaborative practice; sufficient organizational infrastructure; having a vision for change; and staff sense of empowerment. Understanding these conditions for LTC homes required the researchers to understand current values, attitudes, and practices related to palliative care and to identify strengths, gaps, facilitators, and barriers to change. Researchers conducted surveys, interviews, and focus groups with staff in all roles, residents, families, and community partners. Observations and reviews of resident care records and policy were also completed. These data were summarized by the research team.

Initiating the PAR involved creating a catalyst for change (Phase 2 of Kelley's model) in each LTC home. Researchers shared the findings of the environmental assessment with Alliance members, long-term care home managers, staff, and families to build common understanding of current capacity and identify goals for change. A strategic planning session was held with LTC staff in each home to discuss their own data and plan the palliative care programme. The staff vision for change laid the foundation for creating a palliative care team to implement a new palliative care programme. The research team continued to work with the LTC staff as facilitators or catalysts for change by organizing meetings, providing resources, advocating with managers, and teaching new skills.

An inter-professional palliative care team was created in each home, uniquely structured to the homes' wishes (Phase 3 of Kelley's model). Each LTC palliative care team then created their palliative care programme (Phase 4 of Kelley's model) incorporating interventions in the five categories identified in the capacity development model: clinical care, education, advocacy, building relationships internally within the LTC home, and building community partnerships with people and organizations to assist them in providing palliative care. Each LTC home identified their unique priority interventions to be implemented and evaluated together by researchers and staff. At the time of writing, 23 interventions are completed or underway, such as new pain assessment protocols, new palliative care policy, staff and family education

programmes, and new partnerships with hospice volunteer visitors. The interventions are being shared throughout the Alliance via bi-annual meetings and at the end of the project the most successful interventions will be included in a tool kit for LTC homes developing palliative care programmes. The model thus outlines an incremental process for PAR where the right resources are provided at the right time when they are most applicable.

Our developing understanding of how a researcher 'does' PAR and 'capacity development' is addressed in the next section of the chapter, with examples from the research.

The four practice principles of participatory action research

In our project, we achieved change while respecting the philosophy of PAR (Kemmis and McTaggart, 2000; 2005) and capacity development (Kelley, 2007) through adopting four practice principles in our work: cultural competence, empowerment, relational ethics, and partnerships. These practice principles have evolved from the core values of social work, the professional discipline of the authors (CASW, 2010).

Empowerment

In our research we defined empowerment as the state of feeling you have with the control over your own destiny. In the workplace it includes the ability to think, behave, take action, and control your work and decision making in autonomous ways (Palliative Alliance, 2010). Our environmental assessment data indicated that while PSWs have the most intimate knowledge of the needs of their dying residents and their families and do the majority of the day-to-day care, they do not perceive themselves to have much influence in care planning and decision-making (QPC-LTC Alliance, 2010). It was thus clear from the beginning of this research that empowerment of the PSWs was key to the development of palliative care in LTC. We also knew that the success of the PAR process depended on PSW investment in the process of organizational change. The researchers' focus was on the PSW experience, making an explicit statement that we valued their experience and knowledge. Engaging the PSWs in the research as experts and advisors was contrary to the usual knowledge hierarchy where the more educated nurses and physicians are more respected.

In a focus group we conducted in the third year of this research, the PSWs talked about how their involvement in the research led them to trust their own instincts and knowledge: 'We've learned things just by experience alone. There's nothing wrong with being confident and saying those things.' They talked about having discovered a sense of voice: 'Being able to voice those things because we always felt like we weren't allowed to before', as well as a strong sense of professional identity: 'We're not registered, but we're still professionals.' They told us they were speaking up more regularly and more confidently with registered nursing staff, and were seeing communication barriers and professional silos beginning to break down.

Personal support workers now saw themselves as 'in the driver's seat' and recognized that: 'As a PSW I am sitting in the front seat of that change right now. I feel empowered by it.' One of the PSWs said that 'Before this [research] started happening I felt like I

was at the bottom of the healthcare totem pole. Now I am a little bit okay with saying that I may be near the bottom but I am a stable base . . . right?' Another PSW said: 'We're not the bottom. We're the front line.' This reframing of their position as 'the stable base' or as 'the front line' expressed their growing sense of identity, pride, and power.

The PSWs also discovered their power as a group: 'If we stick together . . . what are they going to do, fight all of us? It's something that we believe in so strongly that we are sticking together!' They talked about forming a PSW network with the idea of having regular meetings to problem solve together. Finally, they talked about how being empowered had made them better PSWs, happier and more purposeful; and they talked about how this had transformed their workplace: 'You're coming into work more empowered, happier . . . you bring that to this building, to these people.'

However, empowerment also came with some risks for the PSWs. With their newly-discovered sense of voice came a rebalancing of power in the institutional hierarchy which they experienced as both exciting and risky. They expressed worry that they might inadvertently overstep the mark and that their new found solidarity might meet with retribution. Their vulnerability in the organization thus surfaced as an ethical issue for the researchers and participants to problem solve together.

Relational ethics

Relational ethics is the second practice principle and is vital to managing the unfolding dynamics of this capacity development process. A relational ethics stance calls attention to the interpersonal nature of the PAR research contract, and the ongoing need for maintenance of that interpersonal contract through continuous dialogue and joint problem solving about all aspects of the research. Relational ethics requires human engagement, mutual respect, embodiment of lived experience, and creation of an ethical environment for action (Bergum and Dossetor, 2005). It is an ethic of action that focuses on *how* we treat one another and ourselves rather than *why* we act. For research, the usual way of thinking about ethics approvals (where participants and researchers agree in advance on all the details, and then 'sign off' on de-contextualized consent documents) is not appropriate. Instead, we need to think about consent as a dynamic process of ongoing collaboration and working out of details as they unfold in real time and in real place.

A relational ethical stance means researchers and participants are both experts. The researchers bring their knowledge, contacts, and networks. The participants, their deep knowing of the community they represent, and their aspirations for the research. Together they forge a partnership where areas of moral concern are negotiated as they arise, through mutual learning and accommodation (Bergum and Dossetor, 2005).

Cultural competency

Culture implies the integrated pattern of behaviour that includes thoughts, communications, actions, customs, beliefs, values, and institutions of a social group (NASW, 2001; Prince and Kelley, 2010). We include cultural competency as the third practice principle of PAR because researchers will commonly be working within a social group whose experience and perspectives are different to their own. In our project, we understand

LTC as a unique culture with rules, constraints, customs, and patterns of interaction and communication that are understood best by the people who work there.

For researchers to successfully engage in a new culture requires the same sensitivities one would need to engage in professional practice with any unfamiliar culture: self-awareness and a commitment to understanding our own personal, cultural, and professional values; respect for and appreciation of multicultural identities; and gaining appropriate knowledge and skills to understand and behave respectfully in the culture (NASW, 2001). Our experience as professional social workers and PAR researchers tells us that successful engagement is facilitated by an attitude of curiosity about cultural differences, genuine willingness to learn, and openness to authentic dialogue.

Being culturally competent in LTC means appreciating the ecology of constraints within which the staff work. There are so many things over which they have no control: governing legislation and funding, union contracts, professional scopes of practice, and health system dynamics such as the shortage of acute care beds or changes to home care provision. Cultural competence means acknowledging that LTC staff members are themselves the experts on their culture, and taking time to learn from them. It also means that we have to earn their trust, and we do this by safeguarding our commitment to joint decision making and safety for all participants. The culture change they are trying to make can only be successful if it is grafted onto their culture and ecology of constraints.

Partnerships

When thinking of capacity building as a set of skills, resources, and knowledge held within a whole network or community of partners, not just within one individual or LTC home, then a key strategy in capacity building is the development of new partnerships. Partnerships are perhaps one of the most important things researchers have to offer in PAR, that is, a network of people and resources that can help participants achieve their vision of becoming palliative care centres of excellence.

In our research, the Quality Palliative Care in Long Term Care Alliance (QPC-LTC Alliance, 2010) was created as a partnership of LTC homes, researchers, and community organizations. Alliance partners (for example the Alzheimer's Society, or hospice volunteers) bring an infusion of palliative care knowledge and expertise from the wider community into LTC. They help break down the institutional silos that have marginalized LTC homes and made them resource-poor. They place LTC homes back in the wider community. These partnerships will last long after the research is over, and should help sustain LTC culture change into the future. Indeed, one of the strategies for making culture change sustainable after completion of the research is to make partnership-building a core strategy in PAR. This is the rationale for developing the researcher, LTC home, and community partner alliance at the outset of the project.

There are several challenges in forging such partnerships. One is to overcome the institutionalized norm of 'we can do it all ourselves' and the fear and uncertainty surrounding bringing people in from the outside. Another is that potential partners from outside organizations come with different cultural norms and practices and may not know how to adapt what they do to the culture of LTC. They may be locked into existing resources and unable to imagine expanding their role or mandate. Or quite simply,

neither side may know how to make the first step. Here we see the interrelatedness of the principles in our integrative framework: cultural competence, that is, a deep understanding of the culture of LTC, and, an ethic of mutual trust between researchers and LTC participants, are absolutely crucial for these partnerships to get started and to flourish. The researchers are like cultural brokers, facilitating the transfer and integration of practices and expertise from new partners, and the building of an extended community. In our PAR project 43 different community partners have committed to supporting LTC homes in their transition to developing palliative care. Some are clinical partners, others provide palliative care education, and others serve a knowledge translation function. However, the common purpose is to build capacity for better palliative care by building community partnerships.

Our experience has been that acceptance of outside partners has increased as the PSWs have become more empowered. The more capable and assured they become in their own role, and the more empowered they are to articulate that role, the better able they are to enter any exchange as full and equal partners. An interesting example arose when there was an opportunity to partner with the local hospice volunteer organization. The PSWs were protective of the residents and did not know if they could trust the volunteers who were, after all, strangers. Furthermore, the PSWs longed to be the ones at the bedside when their residents were dying; it was not a simple matter for them to turn over these precious moments to outside volunteers. As the PSWs increasingly found their voice they were able to articulate their concerns about this proposed partnership. They could easily have let the partnership fail, but instead they were able to negotiate a mutually agreeable resolution. It was decided that the volunteers would be assigned to the PSW rather than to the resident; that way the PSWs would have more say in what the volunteers did at the bedside. It was an outcome that reinforced for the researchers how important the empowerment of the PSWs truly was to the success of the whole research project.

Conclusion

The purpose of this chapter has been to propose an integrative framework that is being used in PAR to create palliative care programmes in LTC homes. The components of the framework integrate synergistically and their values and principles complement one another. Both capacity development and PAR represent a commitment to community and participant control, and creating social change that benefits them. The practice principles of empowerment, cultural competency, relational ethics, and partnerships operationalize how we as researchers can 'do PAR' in a way that is genuine and respectful of our participants. In our experience, all the elements of this framework are equally important and reinforce one another.

While this chapter has focused on using PAR to develop palliative care in LTC homes, the authors believe that our framework could apply to any research focusing on palliative care capacity development in a defined community or organization. The four-phase capacity development model is a theory of change that is independent of any particular socio-cultural context, and builds on the local people and resources. Combined with PAR as a methodological approach, this framework thus has potential as an international resource.

References

Bergum, V. and Dossetor, J. (2005) *Relational Ethics: The Full Meaning of Respect.* Maryland: University Publishing Group Inc.

Bolger, J. (2000) *Capacity Development: Why, What and How.* Gatineau (QC): CIDA, Policy Branch; (Capacity development occasional series 1, no. 1).

CASW (2010) *Canadian Association of Social Workers: Guidelines for Ethical Practice.* Available at http://www.casw-acts.ca/en/what-social-work/casw-code-ethics (accessed 18 March 2012).

Casarett, D.J., Hirschman, K.B., and Henry, M.R. (2001) Does Hospice Have a Role in Nursing Home Care at the End of Life? *Journal of the American Geriatrics Society,* 49: 1493-8.

Cashman, S., Adeky, B.S., Allen, A.J., et al. (2008) The Power and the Promise: Working with Communities to Analyze Data, Interpret Findings, And Get To Outcomes. *American Journal of Public Health,* 98: 1407-17.

Ferris, F.D., Balfour, H.M., Bowen, K., *et al.* (2002) *A Model to Guide Hospice Palliative Care.* Ottawa, ON: Canadian Hospice Palliative Care Association. Available at: http://www.market-marche.chpca.net/chpca/marketplace.nsf/prodnum/0605ecd/$file/a+model+to+guide+hospice+palliative+care+2002-urlupdate-august2005.pdf (accessed 27 January 2012).

Foner, N. (1995) *The Caregiving Dilemma: Work in an American Nursing Home.* Berkeley: University of California Press.

Hockley, J., Dewar, B., and Watson, J. (2005) Promoting End-of-Life Care in Nursing Homes Using an 'Integrated Care Pathway for the Last Days of Life'. *Journal of Research in Nursing,* **10:** 135-52.

Kelley, M.L. (2007) Developing Rural Communities' Capacities for Palliative Care: A Conceptual Model. *Journal of Palliative Care,* **23:** 143-53.

Kelley, M.L., Williams, A., DeMiglio, L., and Mettam, H. (2011) Developing Rural Palliative Care: Validating a Conceptual Model. *Rural and Remote Health,* 11: 1717.

Kemmis, S. and McTaggart, R. (2000) Participatory Action Research. In: N.K. Denzin, and Y.S. Lincoln (eds), *The Sage Handbook of Qualitative Research,* 2nd edn, pp. 567-606. Thousand Oaks: Sage.

Kemmis, S. and McTaggart, R. (2005) Participatory Action Research. In: N.K. Denzin, Y.S. Lincoln (eds), *The Sage Handbook of Qualitative Research,* 3rd edn, pp. 559-604. Thousand Oaks: Sage.

Ley, D.C. (1989) The elderly and palliative care. *Journal of Palliative Care,* 5: 43-5.

Ministry of Health and Long-Term Care (2007) *Long-Term Care Homes Act, 2007.* Available at: http://www.health.gov.on.ca/english/public/legislation/ltc_homes/ltc_homes.html (accessed 27 January 2012).

Morgan, P. (1998) *Capacity and Capacity Development: Some Strategies.* Hull (QC): CIDA, Policy Branch.

National Association of Social Workers (NASW) (2001) *National Association of Social Workers: Standards for Cultural Competence in Social Work Practice.* Available at: http://www.socialworkers.org/practice/standards/NASWCulturalStandards.pdf (accessed 27 January 2012).

Norton, B.L., McLeroy, K.R., Burdine, J.N., Felix, M.R.J., and Dorsey A.M. (2002) Community Capacity: Concept, Theory, and Methods. In: R.D. Clementi, R. Crosby, and M. Kegler (eds), *Emerging Theories in Health Promotion Practice and Research.* pp. 194-227. San Francisco: Jossey-Bass.

Palliative Alliance (2010) *Quality Palliative Care—Long-term Care Alliance*. Available at: www.palliativecarealliance.ca.

Prince, H. and Kelley, M.L. (2010) An Integrative Framework for Conducting Palliative Care Research with First Nations Communities. *Journal of Palliative Care*, 26: 47–53.

Quality Palliative Care in Long Term Care (QPC-LTC) Alliance (2010) *Quality Palliative Care in Long Term Care: Project results*. Available at: http://www.palliativealliance.ca/project-results (accessed 27 January 2012).

Raeburn, J., Akerman, M., Chuengsatiansup, K., Mejia, F., and Oladepo, O. (2006) Community Capacity Building and Health Promotion an a Globalized World. *Health Promotion*, 21: S84–90.

Reynolds, K., Henderson, M., Schulman, A., and Hanson, L.C. (2002) Needs of the Dying in Nursing Homes. *Journal of Palliative Medicine*, 5: 895–901.

Sachs, G.A., Shega, J.W., and Cox-Hayley, D. (2004) Barriers to Excellent End of Life Care for Patients with Dementia. *Journal of General Internal Medicine*, 19(10): 1057–63.

Sims-Gould, J., Wiersma, E., Arseneau, L., et al. (2010) Care Provider Perspectives on End-of-life Care in Long-term Care Homes: Implications for Whole-Person and Palliative Care. *Journal of Palliative Care*, 26: 122–9.

Wowchuk, S.M., McClement, S., and Bond, J. (2006) The Challenge of Providing Palliative Care in the Nursing Home: Part 1: External Factors. *International Journal of Palliative Nursing*, 12: 260–7.

Wowchuk, S.M., McClement, S., and Bond, J. (2007) The Challenge of Providing Palliative Care in the Nursing Home Part 2: Internal Factors. *International Journal of Palliative Nursing*, 13: 345–50.