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Chapter - *Shifting Focus: Agency and Resilience in a Self-Management Program for People Living with Dementia*

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## **Shifting Focus: Agency and Resilience in a Self-Management Program for People Living with Dementia**

*That's part of the benefit of going through a course like this. It really helps you work through your feelings about what's happening. It's huge. [Program Participant]*

*You're not just listening to someone talk about it. You're participating and it's making you think. I think that's the biggest thing I've gotten out of this course is the fact that it makes you think and bring those ideas that have been floating back there forward. [Program Participant]*

The definition of dementia, as a set of conditions characterized by a decline in cognitive abilities that interfere with daily life (Alzheimer Society of Ontario <http://www.alzheimer.ca/en/on/About-dementia/What-is-dementia>), clearly and definitively positions dementia within narratives of decline. While the reality of dementia cannot be ignored, the social construction of dementia within narratives of risk and decline has a clear impact on people with dementia (Baldwin, 2008; Mitchell, Dupuis, & Kontos, 2013). The current discourse and attitudes toward people with dementia continue to marginalize them as assumptions are quickly made about their capabilities (Bartlett & O'Connor, 2010; Beard, 2004; Harman & Clare, 2006; Menne, Kinney, & Morhardt, 2002). However, with earlier diagnosis, many more people living with dementia are actively advocating, speaking out, and staying well longer (Bartlett, 2014a, 2014b; Barlett & O'Connor, 2010; Camp, Skrajner, & Kelly, 2005; Clare, 2002).

Assumptions about their capabilities results in people with dementia becoming defined by levels of risk to their own safety and the safety of others (Clarke, Wilkinson, Keady, & Gibbs, 2011). Clarke and colleagues argue that judgements and decisions for people living with dementia "...move from a private, internal dialogue about 'what is best for me' to an open public/professional debate about 'what is best for him'" (Clarke et al., 2011, p. 12). As dementia becomes a defining characteristic of someone's identity after diagnosis (Baldwin, 2008; Mitchell, Dupuis, & Kontos, 2012), and actions and behaviours are attributed to dementia, decisions by people living with dementia increasingly become viewed through a lens of risk, with care partners (i.e., family members or friends) and service providers often seeking to keep the person "safe" (Clarke et al., 2011). These areas of everyday life become contested territories or contested risk (Clarke et al., 2011). For example, everyday activities such as going for a walk, using the stove, and going to the store become constructed within a discourse of risk—that is, the possibility of a negative event occurring (Clarke et al., 2011). While the person with dementia may wish to continue to participate in these activities, others such as family and professional care providers may discourage such "risk-taking". As such, the focus in policy, care, and interactions is on the deficits of people living with dementia, managing risk, and decline (Bailey et al., 2013).

What has been less examined, however, is the concept of resilience. An ever-growing body of literature suggests that many people with dementia continue to be resilient, live well and find purpose and meaning in their lives (Beard, 2004; Harman & Clare, 2006; Harris, 2008; Menne, Kinney, & Morhardt, 2002). Harris (2008) has suggested that using a framework of resilience can help illuminate potential risk and vulnerability factors but also the individual strengths, social networks, and other community resources for people with dementia. However,

resilience for people with dementia applied as a concept has been almost completely neglected in the literature (for exceptions see Clarke et al., 2011; Harris, 2008).

This chapter focuses on resilience, along with notions of citizenship and location of expertise, examined and demonstrated through a participatory action research project to develop a self-management program for people with dementia. We provide a project overview including information on key concepts that have guided our process such as social citizenship (Bartlett & O'Connor, 2010) and Authentic Partnerships (Dupuis et al., 2011). We then discuss shifting focus in three main areas: 1) the concept of self-management as a challenge to traditional discourses in dementia, including describing the program itself and how the program focuses on the agency of people with dementia. 2) the development of the program using a social citizenship approach; and 3) the learning approach of Dialogue Education (Vella, 2008) that is embedded within the program, and how this approach challenges the location of responsibility and risk expertise.

## **Project Overview**

In 2012, funding was received from the Canadian Institutes of Health Research for a multi-year participatory action research project working with people with dementia to develop a self-management program for people with dementia. The intent of this project was to take existing knowledge about living well with dementia and translate it into a learning program for people with dementia. Throughout this project, people with dementia and care partners, including family, service providers, and facilitators, were engaged in the program's development. Three people with dementia were part of our research team, and 20 people with dementia were involved in the three advisory hubs as well as over 20 care partners. These groups met monthly for one to two years to provide input and feedback on the curriculum development. The program, called *Taking Control of Our Lives*, developed by two of the authors (K. Hickman & E. Wiersma), was based on an iterative process of consultation and engagement with the advisory hubs and research team. An environmental scan, consisting of a literature review, review of existing resources, and interviews and focus groups with Alzheimer Society staff and people with dementia, was conducted at the start of the project.

## **Agency and Self-Management**

Self-management of chronic disease refers to the ability of individuals to protect and promote health in daily life (Bahrer-Kohler & Krebs-Roubicek, 2009)—in essence, resilience in response to living with a chronic condition. Although self-management programs have been slow to be adopted in dementia care (as an exception, see Martin et al., 2013; Mountain, 2006), research exploring the experiences of people with dementia demonstrates that despite the changes experienced in dementia, individuals are able to find ways to navigate changes and continue to live well with a diagnosis (Clare, 2002; Harman & Clare, 2006; Harris & Durkin, 2002; Mason, Clare, & Pistrang, 2005), developing innovative strategies and drawing on personal resources and social support to adapt to their cognitive challenges (Clare, 2002; Phinney, Chaudhury, & O'Connor, 2007; Preston, Marshall, & Bucks, 2007; Van Dijkhuizen, Clare, & Pearce, 2006). People with dementia find ways to maintain and preserve a sense of self (Clare, 2002; Harman & Clare, 2006; Harris & Sterin, 1999). Nonetheless, managing life with dementia is complex (Pearce, Clare, & Pistrang, 2002; Steeman, Godderis, Grypdonck, de Bal, &

De Casterlè, 2007) and people with dementia are much more likely to manage well when they have adequate information and resources to support them (Dupuis et al., 2008). Self-management programs aim to give people the information, tools, and support to live well with a chronic condition. In addition, a group environment provides emotional support and the opportunity to learn from peers (Keyes et al., 2014; Ward et al., 2012). Thus, as they are coming to terms with their diagnoses, maintaining a sense of self, and continuing to live well, there is a need to ensure that this kind of support is integrated into services designed for people with dementia.

While traditional self-management approaches focus on the individual, we have understood individuals as situated within a social context, and that agency and structure are always intertwined and shifting and changing (Giddens, 1984). As such, a social citizenship lens not only enables a greater understanding of the agency of the individual, but also of social structures, how these impact an individual, and how individuals can be agents of change within social structures (Bartlett & O'Connor, 2010).

### ***Shifting Focus: From Support to “Taking Control of Our Lives”-- The Program Approach***

The self-management program is intended to be delivered by Alzheimer Societies in Canada and other organizations sharing similar roles. The eight-week program involves weekly sessions, each two hours in length, and is designed for people with early dementia. Each topic in the curriculum is approached in a similar manner:

- Providing knowledge about the topic;
- Sharing of personal strategies and/or experiences related to the topic;
- Opportunities to try out new ideas; and
- Identifying strategies that each individual participant wants to try, and developing an action plan to put a strategy in place.

This approach enables participants to examine each topic in relation to their own experiences and to identify, where applicable, strategies they want to use in their lives. In essence, participants are building a toolkit of strategies and resources they can draw on as needed.

Participants can choose to attend the program on their own, or to bring a care partner. If care partners participate, they have their own sessions separate from people with dementia where they cover the same information as the group of individuals with dementia, with an emphasis on how they can support self-management and resilience for people with dementia.

### ***The Curriculum of Taking Control of Our Lives***

The program is divided into 4 segments: Week 1: Getting Started, Weeks 2-4: Foundational Skills, Weeks 5-7: Topic Specific Skills; and Week 8: Staying Well.

Getting started The first segment of the program introduces participants to the program and the way the curriculum will be explored. One of the first discussions is about personal meanings of the term ‘self-management’ with the goal of developing a common understanding among participants. The Getting Started component also includes a discussion of dementia and the changes associated with dementia, enabling participants to explore the changes they have noticed in themselves, and includes information on memory aids and strategies.

Foundational Skills The group then moves into the development of Foundational Skills. These skills are essential to building resilience and preparing participants to move on to the Topic Specific Skills component. The Foundational Skills includes modules on: Adapting to Change, Communication, and Finding Meaning and Purpose. The order of each of these three modules is decided on by the group.

‘Adapting to Change’ includes exploring the cognitive, physical, emotional and motivational changes that can occur with dementia. Participants explore ways to adapt, in particular, through a discussion of resilience and an exploration of what resilience might look like in the face of these changes.

Another foundational skill is ‘Communication’ which includes understanding the changes participants have noticed in their own abilities to communicate, exploring how to have difficult discussions with others, and finding one’s own voice by speaking up for one’s needs.

The foundation skill of ‘Finding Meaning and Purpose’ includes exercises aimed at building and maintaining a positive attitude, and finding meaning and purpose within one’s own life.

Topic Specific Skills Once again, participants determine the order of topics based on personal needs and interests. Three skill areas are explored: Building and Keeping Connections; Emotional Wellness, and Safety, Independence and Decision Making.

Within the ‘Building and Keeping Connections’ area, three aspects of connections are explored: meanings of stigma and having conversations about stigma; inclusive spaces, including what constitutes an inclusive space and how to create inclusive spaces; and the importance of connections. The latter explores how relationships can change and grow over the dementia journey.

The topic of ‘Emotional Wellness’ explores positive and negative emotions experienced after receiving a diagnosis of dementia, issues of grief and loss, and trying out practical ways of managing stress.

The ‘Safety, Independence and Decision Making’ module has participants examine their own definitions of safety and risk and what is important to them. Participants also explore decision making within the context of safety and risk.

Staying Well The final week is focused on ‘Staying Well’. Here, participants examine strategies to keep themselves healthy as well as practical tips for working effectively with health care providers. Participants reflect on their learnings and experiences during the course of the program, and discuss ways to maintain positive changes in their lives.

Instead of simply being recipients of support, the program encourages participants to reflect on their current situations and experiences, celebrate and share the approaches they’ve used to manage their current circumstances, learn new approaches from peers, and proactively develop plans to build their capacity to live well with dementia.

### ***Shifting Focus: From Service Provision to Service Development--Engaging People with Dementia with a Social Citizenship Lens***

This program was developed using the lens of social citizenship (Bartlett & O’Connor, 2010), which transforms our views of people with dementia from a person to be cared for to a person with agency. It moves us to think beyond person-centred care to view people as active

agents, and is embedded within rights-based discourse (Bartlett & O'Connor, 2010). People with dementia were integral to our work and were considered equal partners. They had equal voice as contributing members of the team to shape major decisions and actions in the project.

We supported social citizenship in our process through an Authentic Partnership approach (Dupuis et al., 2011). The Authentic Partnership approach is a framework that guides key stakeholders, including persons living with dementia, to work collaboratively, to make shared decisions, and to promote social change, equality, empowerment, and a sense of enhanced well-being for all. It involves working *with* others, not *for* others (Dupuis et al., 2011). Using an Authentic Partnership approach requires putting away people's assumptions about dementia, valuing the perspectives of all involved, and working interdependently instead of independently. More importantly, the Authentic Partnership approach fundamentally recognises that for a partnership to thrive, everyone's perspectives and contributions must be valued. This is demonstrated in particular by the advisory hubs, which provided input into program development but also became a source of support and friendship. They provided opportunities for members to feel a sense of accomplishment and of being heard through opportunities to share their experiences, perspectives, and opinions on the program.

There are three guiding principles that need to be in place in order to mobilize Authentic Partnerships - a genuine regards for self and others, synergistic relationships, and a focus on the process. A genuine regard for self and others is a strength-based perspective, which focuses on recognizing and enhancing the personhood of all those involved in the partnership. This includes recognizing and upholding human rights, valuing and being valued, knowing others and being known, fostering others' growth and development, and being truly open to others' experience. A synergistic relationship focuses on interdependence and reciprocity, shared mutual learning, building trust, and openness to others' perspectives, opinions, and ideas. It recognizes that we are often stronger when we harness the group's collective abilities and strengths. Focusing on the process allows for new learnings to emerge throughout the process, and not just at the end. When we honour this principle, we view learning as an ongoing, never ending process. This principle requires openness to "unlearning" and new learnings, flexibility, and patience. Throughout the process of any partnership, opportunities for regular self and group reflection and dialogue are integral to the partnership's success.

The content and objectives of the program were determined by advisory hub members. There were opportunities for the members to review, try out, and provide feedback on parts of the curriculum; they provided important direction in the structure of the program including the length of the program and duration of sessions, as well as the role of care partners in the program. This iterative process was intensive and took a significant amount of time, but was important in operationalizing the principles of Authentic Partnerships. Throughout this iterative process of engaging the advisory hubs in the curriculum development, we focused on understanding the process of engagement, what worked, and what didn't work, and how we could learn to better listen to and learn from them.

### ***Shifting Focus: From Passive Learner to Learner-Knower-Teacher and Challenging the Location of Expertise***

The self-management curriculum was firmly rooted in Dialogue Education™ (Vella, 2008), an adult education approach reflective of Paulo Freire's critical pedagogy that posits that education is a form of liberation and is a political act (Freire, 1968; Kincheloe, 2004). Much

adult education is delivered using traditional didactic methods with the teacher as authority, yet we know that adults learn best when they are fully immersed in the learning process, when past experiences are the basis for learning, and when learning is meaningful and relevant to the learners' lives (Freire, 1968; Knowles, 1973). Paulo Freire (1968) advocated for an approach to education that was dialogical in nature, where learners are decision-makers exploring new ideas and determining how these fit with their experiences rather than being passive recipients of information. Within the Dialogue Education™ framework for education, learning is designed to be responsive and accountable to the needs of learners and is facilitated in a respectful and safe way so that learners are both challenged and supported in the process (Global Learning Partners [GLP], 2015a). This leads to transformative, lasting learning (GLP, 2015).

The principles and practices used in Dialogue Education™ are based on six key elements of how adults learn (GLP, 2015b). These elements include relevance, safety, immediacy, engagement, respect, and inclusion. Each of these is carefully attended to in both the design and facilitation of the *Taking Control of Our Lives* program, creating a rich learning environment.

Using this approach, the person with dementia in the program is positioned in three ways—as learner, knower, and teacher. These three roles of learner-knower-teacher effectively challenge the location of expertise, moving it from external to the person with dementia, often rooted in a biomedical model (Baldwin, 2008), stigma, and assumptions, to internal, based on the capabilities and strengths of the person with dementia. Positioning people with dementia as learners, knowers, and teachers, and building on their capabilities and strengths can increase self-confidence and enhance resilience.

Learner Growth, as a key concept of social citizenship (Bartlett & O'Connor, 2010) underpins our positioning of people with dementia in the *Taking Control of Our Lives* program as learners. Learning does not assume a location of expertise external to the person as the capabilities and skills of the learner are important as s/he engages with the material presented (Knowles, 1973; Vella, 2008). Positioning people with dementia as learners challenges traditional tragedy discourses and narratives of decline (Baldwin, 2008; Mitchell, Dupuis, & Kontos, 2013) as people with dementia are seen as capable of learning, growing, and incorporating new skills into their daily lives.

Knower A key aspect of adult learning theory and of Dialogue Education™ in particular is that learners are the experts in their own experiences, and that any type of learning should always recognize and build on the experiences and skills of the adult learner (Knowles, 1973; Vella, 2008). Dementia culture is primarily biomedical (Baldwin, 2008; Mitchell, Dupuis, & Kontos, 2013), and as such, the person with dementia's experiences can be discounted in favour of expert approaches (Baldwin, 2008). Through this project and this program, we consider people with dementia as knowers of their own experiences. People with dementia have held multiple roles throughout their lives and we acknowledge their expertise in a variety of areas, both in living with dementia and beyond. Thus, we relocate the expertise from the biomedical realm to the person with dementia as the knower bringing a variety of expertise to the process. Through this, we challenge social position, and implicitly and explicitly acknowledge the experiential expertise of people with dementia as privileged. The curriculum, as such, is built on people's experiences and expertise, and opportunities are presented for people with dementia to share this information.

Teacher The predominance of a biomedical model presupposes that unless a person's experiences fit within this model, they are discounted (Mitchell, Dupuis, & Kontos, 2013). Because of these assumptions, people with dementia are rarely placed in the role as teacher despite the growing body of literature on the importance of peer support (Keyes et al., 2014; Mason, Clare & Pistrang, 2005) and on people with dementia in leadership and activism roles (Bartlett, 2014a, 2014b; Camp, Skrajner, & Kelly, 2005; Lorentzon & Bryan, 2007). In fact, much of the literature acknowledges that a key aspect of peer support is the sharing and learning that occurs among people with dementia (Mason, Clare, & Pistrang, 2005; Ward et al., 2012). Dialogue Education™ suggests that learners should be engaged with each other, and that learning does not happen from “teacher” to learner unidirectionally, but when people engage with each other. Within the program, people with dementia are sharing skills, tips, and strategies for living well with others, and when questions arise, the facilitators turn this over to the group for collective problem solving. Understanding that people with dementia have much to teach others is a key underpinning of this program, consistent with social citizenship (Bartlett & O'Connor, 2010). This re-positioning creates agency and builds resilience for people living with dementia.

## **Conclusions**

Throughout this chapter, we have demonstrated, in practical terms, how participatory action research, through the development of a self-management program for people with dementia, shifts discourses from a biomedical, risk-based discourse to resilience and agency, focusing on how people with dementia continue to live well. The importance of not only developing services to support living well, but of engaging people with dementia in the development of these services, is an additional way to shift the location of expertise from traditional “experts” (that is, service providers) to people with dementia. Using Freire's (1968) underlying values that education is a political act, along with Dialogue Education™ where people are positioned as learners-knowers-teachers, also serves to shift the expertise from traditional experts to people with dementia. Using concepts of agency and resilience through self-management, rights and social citizenship through our process of program development, and relocation of expertise through Dialogue Education, we have demonstrated how one project—the development of *Taking Control of Our Lives*--a self-management program for people with dementia, can challenge traditional discourses in dementia.



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