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Supported Empowerment for Individuals with Developmental Disabilities and Dementia

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Abstract

This qualitative case study explored the experiences of individuals who have developmental disabilities and dementia. The findings of the study identify two social processes: one of marginalization and the other of supported empowerment. The process of marginalization depicts how dementia affects people as they incur multiple losses in ability, home, and community. In spite of losses, the findings illustrate how these individuals can maintain their selfhood with good health support, decision-making, self-agency, and autonomy. The study generates a theory of supported empowerment grounded in the data and micro-practices that can support people to continue living meaningful lives.

As a result of improved living conditions, surgical procedures and medical care, people with developmental disabilities are living longer (Alzheimer's Society, 2004; Cooper & Holland, 2007). Approximately 55,000 Canadians with developmental disabilities (not including those living in institutions, in the Territories, and on reserves) are 45 years of age and over (National Advisory Council on Aging, 2004). As they age, they will be predisposed to dementia, because, unfortunately, the prevalence of dementia is roughly four times higher among people with developmental disabilities than in the general population and even higher for those with Down syndrome (Alzheimer's Society; Cooper & Holland).

The most common form of dementia is Alzheimer's disease, a deteriorating brain disease with an ultimate prognosis of death (Evans, 2008). Median survival estimates in the general population after the onset of dementia range between 3.33 to 10.7 years depending on type of dementia, age of onset, sex, ethnicity, disability, and presence of comorbid conditions (Helzner et al., 2008; Larson et al., 2004; Wolfson et al., 2001; Xie, Brayne, & Matthews, 2008). Studies conducted with people with developmental disabilities primarily focus on those with Down syndrome predisposed to dementia of the Alzheimer's type. These studies indicate a survival range from 3 to 10.5 years (Prasher, 2005) but accompanied with a higher prevalence and earlier onset of Alzheimer's. Twenty-five percent or more individuals with Down syndrome over 35 show clinical signs and symptoms of Alzheimer's disease; this percentage increases with age and varies between 54.5% and 75% in those aged 60 and over (Janicki, McCallion, & Dalton, 2002). In the general population, Alzheimer's peaks after age 80 with a prevalence rate of 35% to 40% (Janicki & Dalton, 1997).

People with both developmental disabilities and dementia often lack access to services such as in-home supports and fall through the cracks (Chaput, 2002; Forbes, Morgan, & Janzen, 2006). The dual diagnosis necessitates negotiating between different government agencies or departments—funding and services related to dementia often fall under Health, while those for people with developmental disabilities fall under Social Services. In addition, family caregivers may themselves be aging and in declining health, precipitating out-of-home placements (Buhr, Kuchibhatla, & Clipp, 2006; Forbes et al.; Smale & Dupuis, 2002). However, transitioning to a nursing home can pose severe problems, including loss of community connections and serious threats to quality of life (Manji, 2004). As well, health care professionals generally lack the skills needed to support these individuals, leading advocates to question the appropriateness of nursing homes, especially when individuals are relatively young (aged 35 to 50) at the onset of dementia and able to enjoy several more years of community living (Manji, 2002; Sparks, Temple, Springer, & Stoddart, 2000).

This article is based on a study of a unique, community-based group home for people with developmental disabilities and dementia. The large detached family bungalow is situated in a newer and affluent neighbourhood. Apart from its extra-wide driveway, it is no different externally from any other home in the street. The internal design is barrier-free accommodating wheelchairs and other equipment needed to support activities of daily living. The open living space and the interior decor, lighting, and temperature control are designed to keep the person with dementia relaxed and calm. The reason why this facility was selected for this study was that it represented a new model and was known for its approach to empowerment. It's small size allowed a "much more personal" environment, "tailored to the people that live there." A low consumer-to-staff ratio (5:2 during morning and dinner peak times and 5:1 at night) facilitated individualized support, consumers' freedom of movement within the home, and a low-stress ambience. The trained staff provided 24-hour person-centred support in an empowerment model that enabled consumers to continue living meaningful lives; lives in which their desires for participation were encouraged with choice, their personal aspirations were achieved, and where engagement with others was nurtured.

The study generated a theory of *supported empowerment*, grounded in the data, which offers a social model and micro-practices to support this population. Policy considerations that prevent premature placement in nursing homes, enable aging in place, and maintain a participatory life in community are recommended. Suggestions are made for ways of supporting individuals in their own homes and transforming practices in other settings.

Conceptual Framework

The study used a social (rather than a biomedical) model of disability. As critical theorists have pointed out, medical interpretations of dementia tend to ignore the social, economic, and political relations inherent in aging (Estes, Biggs, & Phillipson, 2003; Payne, 2005). The social model of disability emphasizes that systemic barriers including negative attitudes exclude individuals with disabilities from society (Dunn, 2006). For example, traditional interventions tend to increase dependency on professionals, perpetuate stigma, limit consumer control, and segregate individuals from mainstream communities (Dunn, 2006).

The social model advocates for social rights and full inclusion; programs are based on independent community living principles, which increase self-determination and minimize dependence (Pedlar & Hutchinson, 2000). Central to this approach is the concept of *empowerment*: "processes whereby individuals achieve increasing control of various aspects of their lives and participate in the community with dignity" (Lord & Hutchison, 1993, p. 4). The goal of empowerment is to enable individuals to overcome barriers that obstruct self-fulfillment and, in so doing, to improve their world (Neuman & Kreuger, 2003; Payne, 2005). Empowering occurs at the micro-, mezzo-, and macro-domains of society (Lord & Hutchinson, 2007), and affects both process and outcome. Its hallmarks include raising awareness, eliminating stereotyping, activating resources, building capacity and mutual support, and facilitating community integration, freedom of choice, and autonomy (Nelson, Lord, & Ochocka, 2001). To attain empowerment, an individual must have the opportunity to express needs, make choices, and participate in the community (Nelson et al.). A one-size-fits-all solution is inconsistent with the practice of empowerment (Boehm & Staples, 2002).

Method

The project described here was an exploratory, qualitative case study of four consumers with developmental disabilities who lived in a small modern home specializing in dementia support. Approval for the study and consumer participation was given by the Wilfrid Laurier University Research Ethics Board, Waterloo, Ontario.

The study used an emergent and interpretive methodology to analyze the experience of the consumers and views of the stakeholders (Creswell, 2007). The data was collected and analyzed by the first author. Preliminary discussions with key informants established that consumers in this study would be unable to participate in one-on-one interviews. Therefore, the researcher drew insights from consumers by conducting unstructured observations of discrete behaviours that occurred in the residential facility, such as the way the social setting was constructed and used, the way people behaved, and the way people interacted in the space (Mulhall, 2002). Direct observation of all consumers consisted of 150 hours at the home during a 6-month period. Observation sessions ranged from 3 to 8 hours in length and were arranged so as to capture diverse aspects of the consumers' daily life.

Observation data was collaborated with interview information from stakeholders closest to the consumers; family/friend caregivers, direct-care staff, and administrators. Each stakeholder participated in one in-depth audiotaped interview lasting between 1 and 2 hours. A semi-structured interview format enabled the stakeholders to share what they deemed to be significant in their perspectives (Patton, 2002) and describe the consumers' experience of service before moving to the home, the fit of the current service, and options for good practice models.

Results from observations and interviews were further compared with reviews of daily consumer log notes completed by staff in the home. These notes covered periods when the researcher was both present and absent from the home. Concrete citations supporting general themes already uncovered in the data were noted.

Participants

Data was obtained from 16 participants consisting of 4 consumers residing in the home and 12 stakeholders being families or close friends akin to family currently active in their lives, their direct-care staff, and agency administrators involved in the operations of the home. All stakeholders were identified and recruited through the agency. The consumers (identified pseudonymously here as Donna, Jenny, Jim, and Rose) were in the early to end stages of dementia; a diagnosis of dementia was confirmed by staff reports based on medical opinion. Table 1 illustrates the characteristics of the study participants.

Table 1. Characteristics of Participants in the Study

Participant Category	*Age Range*	*Gender*	*Years in Residence*	*Status*
Consumer	49–59 yrs	1 m 3 f	1–5 yrs	1 lived in supported independent living; 2 in group homes; 1 in family home.
Family/Friend Caregiver	30–80 yrs	1 m 3 f	N/A	1 parent; 1 sibling; 2 friends
Direct-Care Staff	≥ 18 yrs	4 f	9 mos–6 yrs	2 full-time; 2 part-time.
Administrator	30–60 yrs	1 m 3 f	N/A	1 Executive Director; 1 Manager; 1 Supervisor; 1 Person-Centered Planner.

Data Analysis

After each interview and field observation session, the researcher recorded in a journal her general impressions that arose during the discussion with the participant and the writing of field notes(Creswell, 2007). This journal itemized the major themes that she initially identified and also included reflections on any researcher bias that may have been evoked during the research process.

At the end of the study, the researcher noted themes of significance in the field notes and interview transcripts and checked these across the respective journal entries. She compared the coded themes from each source of the data (i.e., documents, interviews, field notes) to each other to find evidence of triangulation and divide into units of information (Lincoln & Denzin, 2008). The final organization of the units of information resulted in a number of themes and sub-themes that were coded using a qualitative data analysis computer software product QSR NVivo 1.3 (QSR International Pty Ltd., 2000). NVivo is designed to generate a table of categories, themes, and sub-themes from across rich-text qualitative data. All divergent and convergent perspectives from the multiple data sources were included in the findings to develop a theoretical framework for understanding the consumers' experiences.

Findings

The study identified two social processes: marginalization and supported empowerment. The process of marginalization—"death by reduction"—depicts how dementia affected consumers as they incurred multiple losses in three areas: ability, home, and community. An administrator coined the expression "death by a thousand reductions" to describe this experience.

Loss of ability entailed profound losses in mental and physical well-being, including a progressive decline in skills and ability to care for oneself, solve problems, and stay safe. Individuals experienced seizures, memory loss, confusion, fluctuating moods, fear, and grief. Loss of ability was sporadic, insidious, and variable for each individual. A direct-care staff said:

> She knew she wanted to stand up. She kept trying to stand up. She would yell at you to help her stand up. And then she would get scared halfway through and sit back down, and push herself to the back of the chair….I knew she was walking yesterday, and I knew she was walking earlier this morning. But for some reason she couldn't get up. She was forgetting how to walk.

Loss of home was characterized by being unable to live independently, having insufficient resources to live in their own home, and being faced with inappropriate alternatives for living. As dementia progressed and needs became more complex, lack of home support resources necessitated moving to a nursing home. However, recognizing that there are variations between nursing homes, the stakeholders noted that these facilities have high patient-to-staff ratios and lack the expertise in supporting people with developmental disabilities; they often do not have social stimulation and are disconnected from significant friends and family. As an administrator stated:

Table 2. Major Category: Death by Reduction

Loss of ability	*Loss of home*	*Loss of community*
Mental decline	Supported independent living	Diminished participation in community activities
- Seizures	Family home	Shrinking social networks
- Fear	Group home	
- Confusion	Nursing home	
- Forgetting		
- Fluctuating moods		
Physical decline		
Dying and death		

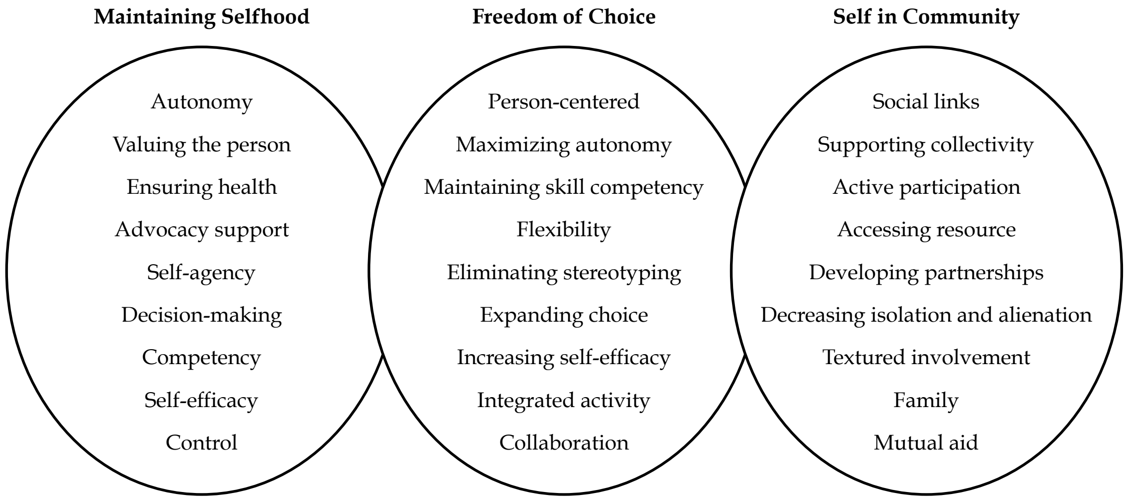

Figure 1. Elements of empowerment found in the social process of supported empowerment for people with developmental disabilities and dementia.

> She didn't make any connections with anybody else that lived there, and she wasn't encouraged to. If she didn't have family or staff dropping in to visit her from [name of group home], then I don't think she ever would have gone outside.

As for loss of community, stakeholders said that as a result of cognitive decline, consumers began to opt out of social activities they had enjoyed previously. Donna's family caregiver explained, "She used to go to the mall and walk around, now she doesn't even want to go out of the house; [or] go in the van."

In spite of losses, a parallel process, "living by supported empowerment," illustrates how consumers can be empowered through elements in Figure 1 invoked by micro-practices that sustain quality of life: maintaining selfhood, freedom of choice, and self in community.

A critical aspect of maintaining selfhood is maintaining health which mitigates the effects of rapid deterioration. In the case studied, both physical and emotional health was managed by staff trained in basic healthcare such as first aid, CPR, administering medications, tube feeding, and palliative care. Staff documented and monitored medical concerns and teamed up with the community health system to effectively treat health issues. Particularly important for the emotional health of consumers was grief support; death of peers was a struggle for consumers who "keep losing their friends." According to a direct-care staff grief was supported by inclusive counselling sessions: "The people who live there participate in the staff [counselling] sessions…They know that we are all in it together, so we don't exclude them in any way."

Flexible delivery of health services according to consumer comfort facilitated seamless healthcare. Administrators and direct-care staff mentioned that health professionals made house calls when consumers were unable to go to their medical appointments or were in palliative stage. Staff, in turn, made every effort to enable the individuals to stay at home as long as possible. Even when hospitalization was necessary, the staff maintained their physical and emotional support for the individual in hospital according to a direct-care staff: "We will continue to…help the nurse…and sometimes it's just to be there to support them."

All stakeholders concurred that freedom of choice maintain individual comfort and morale. In an environment that empowers consumers to make decisions about daily living, people will exercise self-agency and sustain their autonomy. Jim exercised self-agency by choosing not to go to a vocational program each morning, or to leave at a different time. As a direct-care staff put it, "If, at 8:00 a.m., he decides he doesn't want to go but, at 9:00 a.m., he decides he wants to go, we put him in the van and we take him." Similarly, Jenny made moment-to-moment decisions about her day:

> Jenny goes in her bedroom, and a staff member follows to see what she wants to do.… [Staff] tells me that Jenny stood in her room. When staff asked her if she wanted to go to bed, she said "Nein." Then staff asked her if she wanted to go to the living room. She said, "Nein." Then staff asked her if she needed a hug. She said, "Ha!" Staff gave her a hug, and Jenny crawled into bed. Staff said Jenny had decided to go to bed early today. (Field note)

Stakeholders emphasized that person-centered, flexible support helped sustain ability and community in the home studied. For those in advanced stages of dementia, the elevated empathy that developed between consumers and support staff in the intimate, home-like setting facilitated choice.

Self in community means maintaining lively, meaningful connections and participation in a community. This is particularly important, since dementia fragments one's identity, altering how one relates to others and how others relate in return. For the consumers, belonging flowed between and within the outer and inner community. Vocational or leisure activities outside the home, whether planned or spontaneous, motivated the consumers by giving them a purpose, a sense of competency, and the satisfaction of being part of social life. Rose spent most of her day seated in her wheelchair or lying in bed. However, she was supported to enrich her life, as documented in a log about her trip to the fair:

> Rose had a fabulous time at the fair. She spent 4 to 4.5 hours there and was very alert and aware of her environment. [She] loved the comings and goings of people, the noise, and the food. Ate lots of junk food and loved every minute of it. Went to the casino and vocalized with much delight. Was assisted pulling the handle down on the slot machine. [She] laughed most of the time.

Similarly, in the inner community, consumers participated in work and leisure-related activities, interacted socially, and showed caring and affection to others. All stakeholders mentioned that staff compassion, commitment, and affection elicited consumer participation and ensured their privacy as well as their respect, dignity, and comfort. Staff used empowering discourse to raise consumer self-esteem, permitting them to feel loved, valued, and successful in interactions. Individual morale was further sustained by including family connections in the home. As an expansive team of friends, family, and service providers they collectively immersed themselves in supporting consumers. Strong bonds of mutual aid, formed in a supportive network, helped reduce the grief for all who witnessed the profoundly debilitating effects of dementia.

The strengths of this model were that staff promoted empowerment to maintain selfhood, freedom of choice, and involvement in the community. There was an active coordination of specialized medical supports and empowering processes that sustained the autonomy of the individual. However, many people maintain that any form of group home is inherently a segregated mini institution and does not depict true integration and social inclusion in the community (Pedlar, Haworth, Hutchison, Taylor, & Dunn 1999).

Deficits in the model were evident when some consumers continued to attend segregated programs not integrated ones. In addition, consumers were disempowered by inconsistencies in support; these inconsistencies occurred when caregivers (formal and informal) were less familiar, experienced, or trained to meet the physical, emotional, and medical needs of the individual. Inconsistent support impeded the choice of the individual, especially when caregivers disagreed about a practice. Baker and Donelly (2001) state that parental overprotection is often cited as "a hindrance to social experiences" (p. 74) and restricts the independent living choices of people with a dual disability.

Staff facilitated the principle of self-determination by using historical information to actualize prior preferences of consumers. It seemed to be an empowering tool for giving control to the individual over support planning, and decisions about day-to-day and future living. In the context of dementia, practice based on prior preferences of an individual can only be a form of implied or pseudo-autonomy (Jacques, 1997). At best, one is left ″guessing″ what the individual may like or that the individual is meaning what is being verbalized.

Another source of weakness in the model was lack of resources; deficient funding restricted consumers from participating in some activities outside the home. Administrators and direct-care staff were concerned that when staff accompanied a consumer outside the home or when needs in the home changed as more people moved into the third stage of dementia lack of resources jeopardized the quality of support staff members were able to give: "[If] we are short-staffed at the house…somebody loses out there." Additional staffing and funding was required to fully meet consumers' goals, such as living in their own home, maintaining a safe and equipped living environment (e.g., flooring, lifts), going on a one-on-one holiday with a person of her choice; or to fulfill consumers' spontaneous requests, such as going on an outing; or to meet the new needs that arise as dementia progresses.

Ultimately, although this model tried to promote inclusion and empowerment it was in a group home. The home was small and integrated into the architecture of the houses on the street. However, consumers did not live independently in their own homes. Nevertheless, the model did try to promote the choices, options, and integration of consumers with a lot of medical and support needs.

Discussion

Supported empowerment builds on theories and concepts about the social construction of disabilities. Empowerment is not an end product, but rather an ongoing process in the individual, community, and societal domains. Individuals with developmental disabilities who have dementia experience profound impacts on their mental and physical well-being, and often require ongoing flexible supports— in an empowering manner. Empowering interpersonal relations are central to this process. This study proposes that person-centered supports should include an emphasis on maintaining selfhood, freedom of choice, and active participation in the community. Such supports must be tailored to individuals, be within their control, and altered as their wishes and needs change.

Support workers, family, and friends need to be aware of nonverbal and behavioural communications in order to promote empowerment and selfhood. Listening to people who have developmental disabilities and are experiencing dementia is crucial to empowerment. Their loss of speech requires elevated empathy, so their sounds and movements can be understood so as to facilitate choices.

Coordinated and consistent health supports are needed to assist in health maintenance, and to respond to the medical events that often accompany dementia, such as seizures, pneumonia, chronic chest infections, kidney and heart malfunctions, and digestive failures. Supported empowerment promotes continued involvement in the community. Those with dementia are often institutionalized without connections to family, friends, and/or community. Maintaining these connections and community activities enables people to continue an integrated social life after the onset of dementia. Circles of support can assist in reducing isolation and alienation by facilitating a textured life (Pedlar et al., 1999), social networks, and actively involving informal supports. "Death by reduction" usually means that individuals lose their home. For the consumers in this study, living at home was not possible, due to lack of resources. All stakeholders said that government funding for homecare was barely adequate to support people in even the early stages of dementia. In one study, caregivers said they spent between 69 to 100 hours a week assisting their family member, and 80 percent had made major financial sacrifices to do so (Ministry of Health and Long-Term Care, 1999). All the stakeholders in this study found this small, specialized, innovative group home, which emphasized empowering practices, to be highly beneficial and a real alternative to a nursing home. Nevertheless, they all would have preferred to ensure people could remain in their own homes and to age in place.

If consumers are to remain in their own homes, new government programs are required. Lord and Hutchison (2007) stress that government policies must nurture social inclusion, promote independent planning, and dramatically increase funding for independent living. Governments have begun to coordinate their services more effectively and to initiate individualized funding programs (Ministry of Community and Social Services, 2006). However, agencies are advocating for a more comprehensive system so that everyone can have the option of living independently.

Meanwhile, supported empowering micro-practices should be promoted for all arrangements—independent, family and institutional homes—including 24-hour attendant services in the community. Attendant services are not necessarily empowering and staff members do not inherently know how to support individuals with developmental disabilities and dementia. This study provided some insights about best practices that employ powerful tools of listening to consumers and intentional empowering of people. The study demonstrates that even faced with the challenges of dementia, empowering support from family, friends, and staff can help people create full, rich, and meaningful lives for themselves.

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