

“HER WORLD GETS SMALLER AND SMALLER WITH NOTHING TO LOOK FORWARD TO”: DIMENSIONS OF SOCIAL INCLUSION AND EXCLUSION AMONG RURAL DEMENTIA CARE NETWORKS

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ABSTRACT

The purpose of this research was to critique the nature of rural dementia care from the perspectives of persons with dementia, their family caregivers and home care providers through a social inclusion/exclusion lens. A critical gerontology approach within a human rights framework (Townsend, 2006) was used. Three rural dementia care networks were included consisting of persons with dementia (n=3), spouse caregivers (n=3), adult children (n=9), grandchildren (n=2) and home care providers (n=3). Thematic analysis (Lubrosky, 1994) revealed three overarching inclusion/exclusion themes. Members of the dementia care network were being denied and afforded opportunities with respect to: (i) experiencing quality relationships among network members; (ii) having a voice in dementia care decisions; and (iii) participating in care, social, and work activities. This study contributes evidence that challenges the myth of the idyllic nature of rural places. Findings revealed the diversity of lived experiences within dementia care network members who described both positive (e.g., close community ties, life-long work opportunities) and negative (e.g., stigma of dementia, dangers of rural setting) aspects of the link between living in a rural setting and living with dementia.

INTRODUCTION

This paper will challenge the assumptions about the idyllic nature of growing old with dementia in rural communities. A critical gerontological perspective is used to examine ways in which place (rural), political, economic, and social issues contribute to social inclusion and exclusion at the micro level through the experiences of rural dementia care networks. Dementia care networks include persons with dementia, their family and friend caregivers, and home care providers. Living with dementia in a

rural setting is a double jeopardy; both the rural setting and the symptoms of dementia present additional challenges that contribute to social exclusion of dementia care network members.

Much has been published on the wide variation in how ‘rural’ is defined (du Plessis, Beshiri, Bollman, & Clemenson, 2002; Pitblado, 2005; Williams & Cutchin, 2002). For the purpose of this paper, the Canadian Home Care Association’s (CHCA, 2008) definition of rural was used in this study: “settings with small populations, low population densities and/or relatively large distances from major urban centres” (p.10). Although many Canadian rural communities are experiencing declining populations, they are also experiencing a faster growing proportion of older adults than in urban areas due to a combination of the out-migration of youth, aging in place, lack of in-migration, and the attractiveness of some rural communities for retirees (McCracken et al., 2005; Ramsey & Beesley, 2006). Indeed, 33% of older adults reside in predominantly rural regions, with proportions of older adults increasing as the distance from urban centres increases (Dandy & Bollman, 2008).

In addition, the 9.9 million Canadian baby boomers (Foot & Stoffman, 2004) are entering the age of greater risk of being afflicted with dementia. The most widely used definition of ‘dementia’ (Robillard, 2007) is acquired impairment in short- and long-term memory, associated with impairment in abstract thinking, judgment, and other disturbances of higher cortical function, or personality changes (American Psychiatric Association, 1995). In 2008, there were 480,000 people with dementia (one new case every 5 minutes) and this number is estimated to be 1,125,200 by 2038 (one new case every 2 minutes) (Alzheimer Society of Canada, 2010). Informal care will also increase as care shifts away from care facilities to communities. The annual Total Economic Burden is expected to increase substantially from \$15 billion in 2008 to \$153 billion by the year 2038 (Alzheimer Society of Canada).

A major challenge facing the Canadian health care system is the need to deliver cost-effective and efficient health care services in rural areas (CHCA, 2008). Rural persons with dementia and their caregivers experience: (i) difficulty accessing available services, (ii) lack of health care services and providers, and (iii) inconsistency of care providers who often lack the skills necessary to provide quality dementia care (Forbes & Hawranik, in press). Home care, although often lacking in rural areas (Forbes & Edge, 2009), is the largest component of community-based services and the fastest growing sector of the health care system (VON Canada, 2008). Canadian home care is defined as “a range of health and support services received at home with costs being entirely or partially covered by a national/provincial/territorial health plan. These services enable clients incapacitated, in whole or in part, to live in their home environment” (Canadian Institute for Health Information [CIHI], 2004, p.2). Core home care services include: maintenance, rehabilitation, long-term supportive care, acute care substitution, and end-of-life care (CIHI, 2004). In Ontario in 2008, 67% of home care was provided by personal support workers (PSW) and homemaking unregulated personnel and 27% by nurses (Ontario Home Care Association, 2008). With the aging of the population worldwide, the looming dementia care crisis (Forbes & Neufeld, 2008), and the additional challenges in caring for rural family members with dementia, further qualitative research is needed to critically examine the experiences of dementia care networks using a social inclusion and exclusion lens.

Social Inclusion and Exclusion

Social exclusion is defined as “the dynamic process of being shut out, fully or partially, from any of the social, economic, political and cultural systems which determine the social integration of a person in society” (Walker, 1997, p. 8). Within a human rights framework (Townsend, 2006), measures of exclusion typically incorporate dimensions such as individuals’ lack of accepted levels of material well-being and of social benefits (Burden & Hamm, 2000), lack of opportunity to have a voice in their community (Cook, 2008), lack of engagement in meaningful social relationships, lack of participation in civic activities, lack of access to formal services (Cook, 2008; Pantazis, Gordon, & Levitas, 2006; Scharf & Bartlam, 2008), and lack of fair representation in decision-making that affects their health,

and in subsequent program and service delivery and evaluation (Commission on Social Determinants of Health, 2008). Although relevant to rural settings (Commins, 2004; Innes & Sherlock, 2004; Philip & Shucksmith, 2003), the concept of social exclusion has primarily been studied in urban settings (Scharf & Bartlam, 2008).

The lack of empirical evidence relating to social exclusion of rural older people and specifically those with dementia (Innes & Sherlock, 2004) contribute to the perpetuation of idyllic myths that highlight: (i) the integration of rural older people with close and supportive family and friend networks; and (ii) the supportive nature of rural communities (Wenger, 2001). On the contrary, Keating, Dosman, Fast, and Swindle (2008) and Statistics Canada (2005) have revealed that rural older adults are not as embedded in strong networks of family and friends as previously thought and the differences between rural and urban residents are smaller than expected in terms of social engagement and isolation from family, friends, and helping others. Our own research (Hawranik et al., 2008) has revealed that rural communities are often seen by health care providers as settings in which family and friend support networks are available and willing to assist with dementia care needs, a view not shared by rural family caregivers. Rather, rural caregivers report having no remaining energy to socialize, as well as feeling isolated from others.

Another common myth is that rural older people have fewer service needs because they are healthier and more satisfied with life than their urban counterparts. However, evidence from several sources (e.g., Canadian Institute for Health Information, 2006; Mitura & Bollman, 2003) report that rural older adults experience poorer socio-economic conditions, lower educational attainment, exhibit less-healthy behaviours, and have higher overall mortality rates compared to their urban counterparts. This misconception may be related to the disparity between objective measures of health status and rural older adults' subjective accounts that emphasize the more positive aspects of rural life (Scharf & Bartlam, 2008), perhaps due to their sense of stoicism, self-sufficiency, independence and pride (Eales, Keefe, & Keating, 2008; Forbes et al., 2008). Clearly, further critical, in-depth exploration of the experiences of rural dementia care network members using a social inclusion and exclusion lens is needed.

PURPOSE

The purpose of this research was to critique the nature of rural dementia care from the perspectives of the dementia care networks, that is, persons with dementia, their family caregivers and home care providers, through a social inclusion/exclusion lens within a human rights framework (Townsend, 2006). The aim was to determine how best to support dementia care networks that strive to enhance the well-being of persons with dementia in rural settings and to illuminate the care work of unpaid caregivers and paid care providers.

METHODOLOGY

Design

This study utilized a critical gerontology approach which sheds light on the nature in which the lives of older people with dementia, their family caregivers and home care providers are either advantaged or disadvantaged by prevailing socio-political and economic structures. By focusing on social exclusion, the varied and often hidden nature of disadvantage experienced by persons with dementia and their caregivers is illuminated through hearing their voices (Scharf & Bartlam, 2008). A critical gerontology approach also assists in challenging taken for granted assumptions, and distorted views and myths in relation to rural ageing (Phillipson & Scharf, 2005).

This paper describes the secondary analysis of data that were collected for a larger critical ethnographic study titled "Client-Caregiver-Provider Relationships in Home-Based Dementia Care: A Critical Analysis" (Ward-Griffin, McWilliam, Forbes, Kloseck, & Bol, 2006). The original study

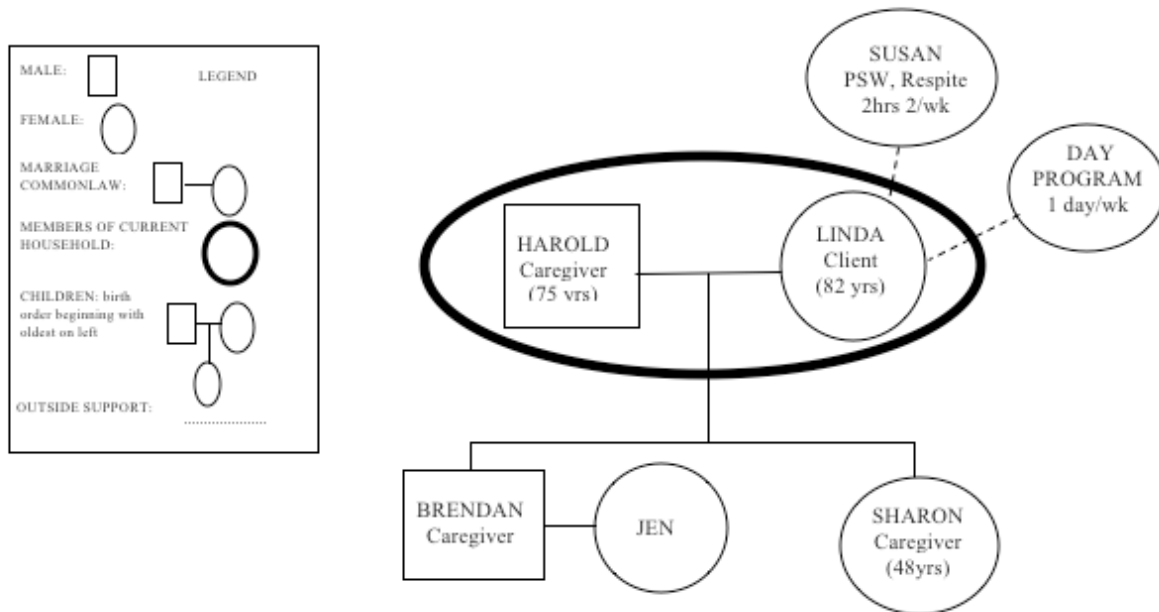
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examined values, beliefs, relationships and the experiences of providing/receiving care in the home using multiple in-depth interviews over time, participant observation and focus groups. Prior to initiating the study, ethical approval was obtained from the Research Ethics Board at The University of Western Ontario. Signed and assent consents were obtained from all participants according to recent ethical guidelines (Fisk, Beattie, & Donnelly, 2007).

Sample

Participants were recruited from the South West-Community Care Access Centre (CCAC), in Ontario, Canada that currently serves a jurisdiction of 22,000 square kilometres with a population of just under one million people; 30% of whom live in rural areas (South West-Local Health Integration Network, 2006). Organization administrative leaders and case managers (n= 200) oversee the work of 1470 full-time equivalent home care providers delivering in-home care to approximately 16,000 clients at any one point in time (McWilliam et al., 2008). The CCAC case managers and four in-home provider agencies assisted with recruitment of persons with dementia and their family caregivers. Once they agreed to participate, their home care providers were approached to also participate. Our secondary analysis included 18 interview transcripts and field notes from three rural dementia care networks at several time points over 19 months.

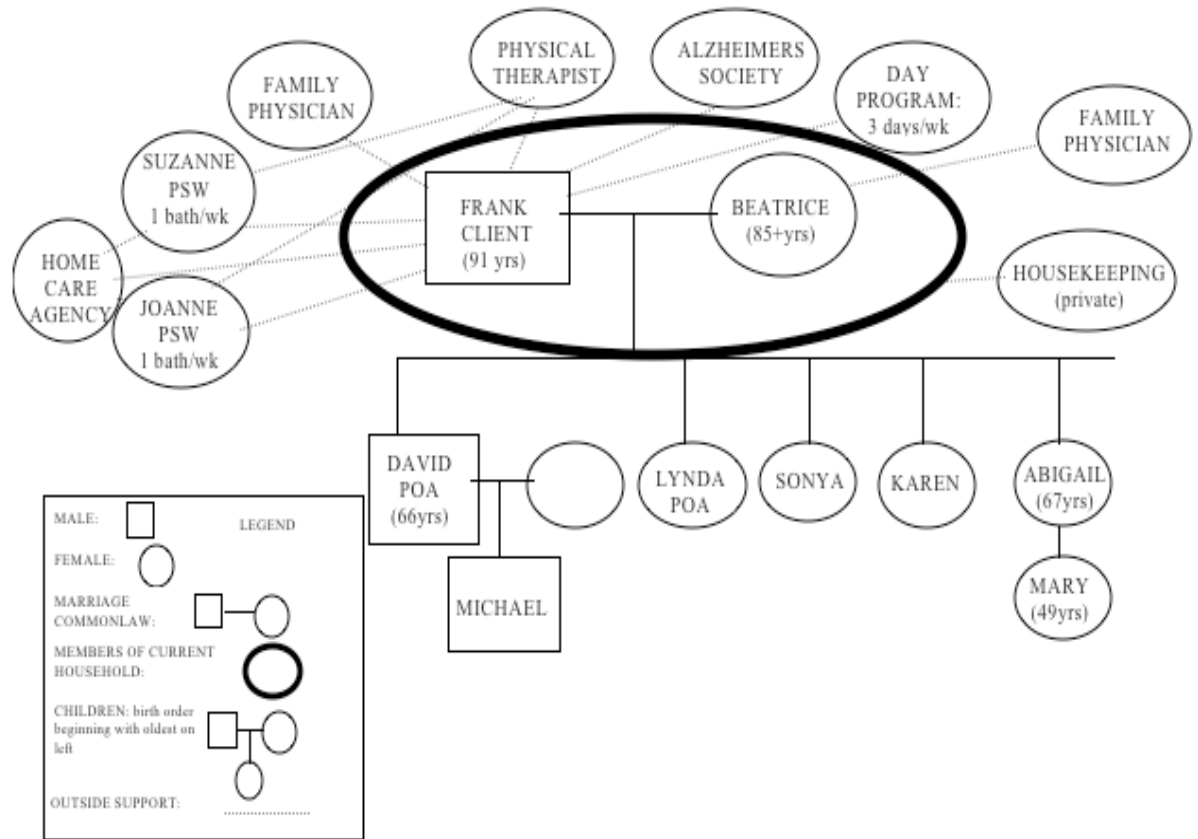
Figure A: Ecomap of Network One



The three networks included persons with dementia (n=3), spousal caregivers (n=3), adult children (sons=2, daughters=7), grandchildren (grandson=1, granddaughter=1), and personal support workers (n=3). An ecomap of each of the networks can be found in Figures A, B, and C. All names are pseudonyms to protect the identity of the participants.

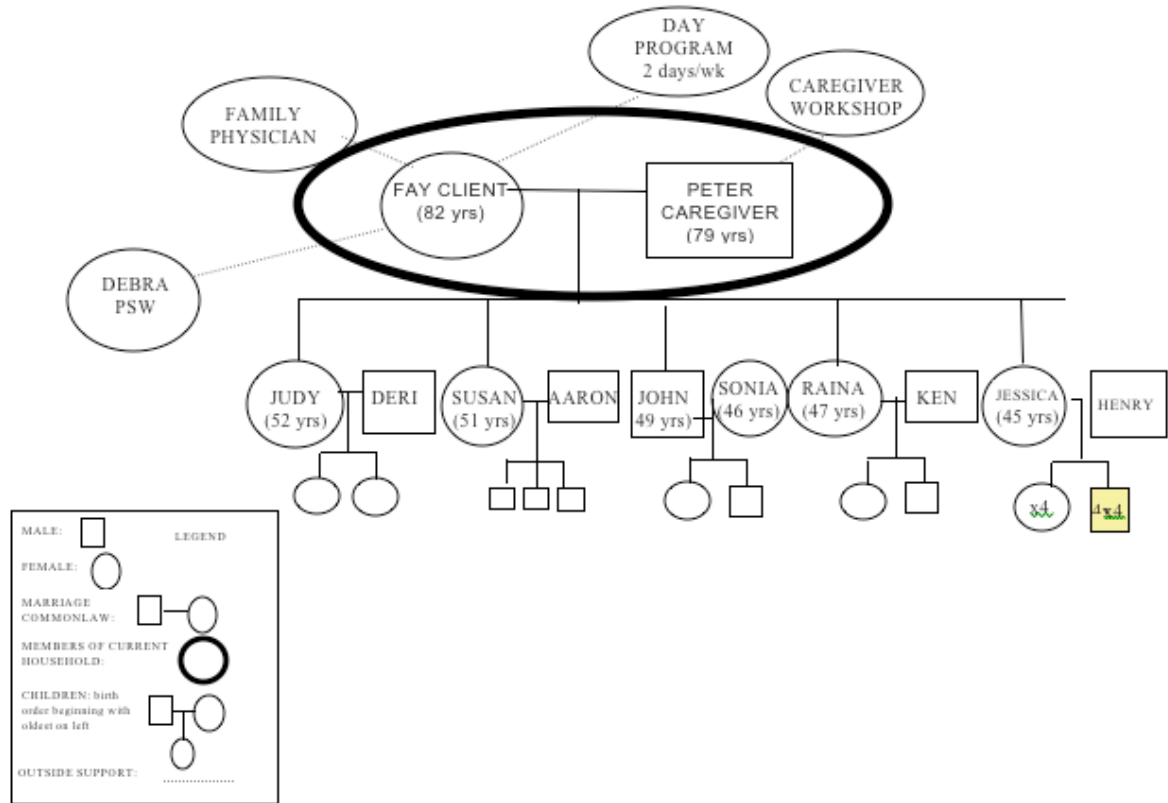
Network One was the smallest network. Harold and Linda lived on the family farm which was located approximately two kilometers from their daughter, Sharon, who lived in the nearest village. Brendan, their son, who owned a farm nearby, and their nearest neighbour was approximately two

kilometers away. Harold, at 75 years of age, still farmed with son Brendan. Susan, their PSW, visited Linda two hours twice a week in order to give Harold some respite from his caregiving duties (Figure A).



Network Two included Frank and Beatrice who lived in a two-storey farmhouse, surrounded by fields of corn. Their wood stove provided not only heat for their home but was also used for cooking. Their daughter, Abigail and granddaughter, Mary lived on the same property in the original family home. Frank worked in his rural community until the age of 85 at which time Abigail took over but continued to involve her father whenever he was available. The other three daughters and son lived about 1-2 hours drive away. The closest urban centre was approximately 40 kilometers away. Two PSWs were involved with this family, each visiting once a week to help Frank with his bath (Figure B).

Similarly, Network Three was large. Peter and Fay immigrated from Holland as newly weds and built their family home, a bungalow, on an acreage about a 15 minute drive from the city limits. Jessica, a daughter with 8 children, and their son Johnny lived about a 15 minute drive from their parents, while the remaining three daughters lived between 1-2 hours drive away (Figure C).

Figure C: Ecomap of Network Three

Data Analyses

Transcripts from the participants' personal interviews were coded using Lubrosky's (1994) thematic analysis. Main ideas and topics that had the most meaning to participants were identified by the analysis team and coded using key phrases that emerged from the data. The codes were grouped into themes (a higher conceptual level) and sub-themes. By comparing and contrasting the coded data, sub-themes, themes, interrelationships and patterns were revealed. To ensure rigor and trustworthiness, members of the analysis team independently conducted the primary coding analysis. These preliminary conceptualizations were shared with the research team as a whole for development and refinement of the themes and patterns, to ensure that the conceptualizations reflected the data presented by the study participants and to encourage the emergence of multiple perspectives around the interpretation of data. The data from these three networks provide opportunity for a rich, deeper of understanding how relationships are negotiated and supported in the context of rural, home-based dementia care; such understandings may well resonate with other care recipients and providers in similar contexts. Data were stored and managed using Nvivo 8 software.

FINDINGS

Three overarching inclusion/exclusion themes were identified. Members of the dementia care network being denied/afforded opportunities: (i) to experience quality relationships among network members; (ii) to have a voice in dementia care decisions; and (iii) to participate in care, social

activities, and work. Each of the themes is described and exemplar excerpts are presented to illuminate dimensions of these themes.

Theme One: To Experience Quality Relationships Among Network Members

Persons with dementia, even with severe cognitive impairment, continued to recognize the familiar faces of family members and enjoy their company.

If he [husband] has to go, he brings me to my daughter's and I'm always welcome there (laughs). She has eight young children, and the first words are always when I come in there, 'Oma did you bring Rumica?' (laughs). They want to play Rumica (laughs). We love doing that stuff too like my husband and I know Rumica and Dominos and all that. And so that works out good, really good (N3, Fay, client).

However, family relationships were different now that their spouse/parent was presenting with symptoms of dementia. The person with dementia was no longer the same grandparent, parent or spouse with whom the family members were familiar. Adjusting to the perception of her/his impatience, anger and poor judgment were not easy for the adults and particularly the children.

So I would say sometimes she [mother with dementia] got a little angry with me and she gets angry with the kids quicker. Like they do something, like you know kids they grab something, well she just grabs it right back (N3 daughter, Jessica).

Attempting to understand the difficult behavioral and mood changes of the person with dementia tended to enhance the relationships between the sisters and between the primary caregiver and daughters. Family members found it necessary to frequently get together to share their perceptions of the symptoms presented by their parent and to collectively develop strategies about how best to support the primary caregiver in his/her belief that the family home was the best place for the person with dementia. Their strong family values and beliefs became apparent through their substantive efforts to support the primary caregiver. Similar efforts were not as apparent in terms of attempting to understand the inclusion needs of the person with dementia.

In our family everybody does what they can and I tried not to think 'Oh that person should be doing more or that person should be doing more' like I just thought everybody should do what they can. If we all try to do what we can, there's a bunch of us, it's going to help my dad out a lot you know so I think it's been good. But I think that's sort of how we were raised too. That my dad was very family-oriented and family was important and you know he probably knocked that into us (N3, daughter, Jessica).

Family members described several reasons why it was important to maintain quality relationships among the dementia care network members. Love and compassion for their life-long partner and a strong commitment to marriage vows were revealed, even when their loved one was demonstrating behaviours that were challenging to manage. Family members reported a sense of abandoning their spouse or feeling like a failure when formal services were needed.

You know I really admire him [father] because he really took his marriage vows seriously. The first time he took my mom to the Day Program he felt really awful. Like he felt like he was doing something wrong. He didn't say that but I just know. One time he said to me 'I used to feel bad dropping her off, I don't feel that anymore.' But that's been over a year so it took him a long time to realize it's okay (N3, daughter, Jessica).

Family members also reported that they were pleased to be able to reciprocate the love and support their parents had provided them as children and young adults.

He [father] gave me \$125 a month. So when I finished university and graduated as an engineer I didn't have any debt! So you gotta look after the old bugger! (N2, son, David).

However, many family members found the symptoms of dementia too stressful and were not able to maintain a quality relationship with the person with dementia.

See quite frankly right now, I kind of avoid being one-on-one with my mother. Dad used to leave once in a while to go here and there, he's not allowed to do that anymore. I'd show up and mom would be there. Like twenty minutes and I'm thinking 'God I gotta get out of here' (N3, son, David).

Not understanding the reasons for the symptoms and challenging behaviour and how to manage them were particularly distressful for family members as these episodes often occurred in the evening when other family members and supports were unavailable. Trial and error strategies were implemented with varying success.

The worst part of this is she sees things. Like, there's always people. The house is full of people. The memory part, you can live with, that's easy but it's just like looking out after a four to five year old... Now after supper that's the hardest time. She wants to go home but yet she doesn't know where home is. You just get in the car - when it gets real bad, and go for a drive and then come home. And everything is okay then (N1, husband, Harold).

Incontinence was another symptom that caregivers had difficulty talking about and managing. Family members were often unaware of incontinence products and approaches that would be of assistance in preventing and managing incontinence of urine and stool. Incontinence is a precipitating factor in admission to a long-term care facility, which may be located at a distance from their rural community. Symptoms of incontinence and institutionalization may result in excluding the person with dementia from their family members and friends.

You can't talk to her [mother with dementia] about it because she says 'Oh I've always had that or I dribble a bit'. She won't use appropriate products, she uses toilet paper instead of using a pad. These are just sensitive things that are not an easy thing to talk to your father about. She did have a bowel accident at my sister's and my dad's reaction was not like 'Oh my god', it almost gave you a sense that this was not the first time. I can usually ask them questions about most things, but I feel like if I talk to them about this, especially my dad, a wall goes up a bit. It's not really something he wants to talk about (N3, daughter, Susan).

Abusive behaviours were particularly difficult for family members to accept and manage and often resulted in excluding the person with dementia from future similar situations, thus further isolating and decreasing their contact with family, friends and members of their community.

I know she [mother] hit one of her grand daughters who is 20. It was like wow she never would have done that before... hit her grandchildren ever, never would have done that but now it was like 'okay you're bothering me', smack! (N3, daughter, Raine).

A successful approach to managing the symptoms of dementia was to focus on the person instead of her/his symptoms. A positive verbal and non-verbal, caring, and consistent approach also contributed to an inclusive relationship.

I've had people that have never known my name. I've went there for five years - have never known my name but they recognized my face. I have a lady that actually is one that was aggressive, and she actually kicked me in the stomach. Not too long after, she went to the hospital. I stopped up to see her a few times. She never knows my name but she always recognizes me. You know, just my face and the smile I think. And a handshake, I always shake their hand always or give them a hug. I feel that's important and they like it (N1, PSW, Susan).

However, not all of the PSWs were as effective in developing quality relationships with their clients. Others saw their role as primarily providing physical care while neglecting the emotional care.

I happened to be there a few Fridays when she [PSW] gives mom her bath and washes her hair and that takes 15 minutes. I guess she is supposed to give an hour and she basically sat there. I'd say to her, like we were playing Rumica, 'Do you want to play?' 'Nope, I'll watch you play' (N3, daughter, Raine).

Other home care providers focused primarily on risk factors rather than considering the civil rights and self-determination of the person with dementia: *I make sure he's safe, because my concern mainly with him is... he is prone to falling* (N2, PSW, Joanne).

In summary, *experiencing quality relationships* among family members, friends, and home care providers was valued by most of the dementia care network members and in particular by persons with dementia. Their PSWs sometimes became a friend while others focused on the task or risk factors rather than the person. The dimensions of the theme *experiencing quality relationships* reflected their reasons for wanting to sustain relationships among the network and the effort that was required to build meaningful relationships as the symptoms of dementia became increasingly challenging.

Theme Two: To Have a Voice In Dementia Care Decisions

Often the person with dementia was excluded from discussions and decisions surrounding his/her care based on perceptions that he/she was incapable of making these decisions due to cognitive impairment. A rare example of a respectful holistic approach that valued the 'personhood' of the family member with dementia follows:

I have a lot of admiration for my dad, like he didn't make her [mother] go to the Day Program. He said that if she doesn't want to go, I'm not going to make her. So he had to really re-assure her and she said to him 'You won't make me stay if I don't want to stay?' He said 'No he wouldn't'. Now she goes two days and I think it's fine but she never seems to remember what she has done there (N3, daughter, Raine).

Enactment of positional power was also used to exclude family members in care decisions. Gender, birth order, status, income, prior relationship with the person with dementia and their caregiver all influenced decision making authority within the network. In the excerpt that follows the only son and a daughter, who had some experience as a health care provider, had power of attorney, even though another daughter, Abigail provided the majority of care.

The caseworker made the recommendation [need for placement to long-term care facility]. Lynda [sister] and I had lunch together and we said, 'What are we gonna do?' 'We could call a family meeting'. But we said, 'If you called a family meeting and everybody was against it, are we gonna still go along with it because we think that's right?' So we said, "Well, you know we'll make the decision to do it [admit to LTC]", and then met with the family after and explained to them what we did and why we did it. I think my sister, next door, she felt she should have been consulted a little more. Even

though we had the power of attorney, like every time something came along we should check with her because she had been doing the care (N2, son, David).

Other reasons for not participating in care decisions included being grateful for what was provided and not wanting to request additional services, and feeling powerless because they perceived that they did not possess the skills or qualifications to contribute to the care plan. These perspectives are commonly held by older adults.

The case manager was doing a follow up and dad said “I think they want to offer more help”, but you know there’s nothing for Debra [PSW] to do. She is done in less than an hour with mom and she’s just sitting there watching the clock. I said maybe we can ask if she can take mom for a walk. My dad said “I’m not going to tell them what they should be doing in their job”. My dad figures ‘I’m getting this for free I can’t complain about it’. My dad and lots of clients I know feel that way that they should be just grateful for what they’re getting. I find that seniors are quite a grateful population compared to what I’m going to be like when I get up there (H3, daughter, Susan)

The second theme, *to have a voice in dementia care decisions*, revealed that persons with dementia are often not included in discussions related to care decisions that affect them due to the stigma of the diagnosis of dementia. In addition, older adults, disempowered family members and PSWs were reluctant to contribute to relevant discussions because of their perception that they lacked the necessary skills to participate and/or were not provided opportunities to have a voice in dementia care decisions.

Theme Three: To Participate in Care, Social and Work Activities

In a rural community where most people know each other, the lack of anonymity may limit participation in care group activities such as support groups for caregivers, may discourage the receipt of home care services provided by individuals known to the recipient of care, or prevent attending a memory clinic located in a small community. The stigma attached to dementia that results in treating the person with dementia differently was a concern to the participants.

They had all those people come there [support group] and it was basically caregivers and kids from the caretaker. So I didn’t say nothing there about [Fay] because I didn’t want to do that. I didn’t find it appropriate to talk about it with all those people (N3: Husband, Peter).

Many of the persons with dementia had lived in the same rural community all of their lives. They farmed the land, raised their children, participated in building and maintaining their churches, and contributed to the social and economic fabric of the community. Most continued to value their involvement with their friends, neighbours, church, and social networks.

The community has been pretty helpful too. They’ve been good to them. They line dance and they bowl and there’s been ladies who pick her up for choir practice and bring her back home. So they have a good community there. Cause my mom wants to go. It doesn’t matter where (N3, daughter, Jessica).

However, maintaining their life-long social networks was not without difficulty, as their symptoms increased, their worlds became smaller.

I don’t know if they were in a museum and somebody was standing in her way and mom just shoved them out of the way... just threw them out of the way and just pushed her out of her way...like this is just such foreign behavior for her. She was always so polite

and careful what people will think or say about you. Like the scope of what you can do with her gets smaller and smaller (N3, daughter, Raine).

A couple of the participants continued to work beyond normal retirement age. Working the land and delivering the rural mail were part of who they were. As long as they were physically able, the participants carried on with these roles which appeared to enrich their lives. Receiving home care services facilitated these continued work activities.

The only time it bothers me [caregiver of 75 yrs] is in the spring when we're starting the seed, or in the fall when we're taking it off. The son and I farm together. As long as I'm home here, it isn't bad but if I go to his place, I won't leave her [wife with dementia] alone...Susan [PSW] comes on Thursdays and Tuesdays and she [wife] goes to day care on Wednesdays. So you get stuff done then (N1, husband, Harold).

The third theme, *to continue to participate in care, social and work activities* was important for all of the dementia care network members. While the rural setting presented some challenges such as the lack of anonymity and knowing most of the community members, there were also positive aspects such as the opportunity to continue working the land. Their rural routes were strong and their connections to their community remained although to a lesser extent as the symptoms of dementia increased.

DISCUSSION

Social inclusion is important in preserving the well-being of persons with dementia (Cook, 2008). When examined within a human rights framework (Townsend, 2006) and using a critical gerontology approach, dimensions of social inclusion and exclusion became apparent. The dimensions revealed in this study related to quality relationships among rural network members, having a voice in dementia care decisions, and participating in care, social activities, and work. Other researchers (Cook, 2008; Innes & Sherlock, 2004; Innes, 2009; Scharf & Bartlam, 2008) have reported similar but less developed dimensions of social inclusion and exclusion. Each of these dimensions is discussed below.

Being Denied and Afforded Opportunities to Have Quality Relationships Among Rural Network Members

There are multiple benefits of close social relationships for all members of the network and particularly for persons with dementia who derive companionship, love, and a sense of safety and support from quality relationships (Cook, 2008). All three dementia care networks in this study included family members who were committed to supporting the person with dementia to remain in the family home for as long as possible, at great sacrifice to their own daily lives. Relationships between the daughters and between the spouse caregiver and the adult children were often strengthened due to these common goals. However, maintaining their relationship with the person with dementia was often difficult due to the challenging symptoms of dementia such as hallucinations, incontinence, abusive behaviors, repetitive questioning, and wandering. The manifestation of these 'anti-social' symptoms (Blackstock, Innes, Cox, Smith & Mason, 2006), especially in public places and the fear of stigmatization often resulted in further social exclusion of the person with dementia. Friends and neighbours tended to become increasingly less involved as these symptoms progressed.

Home care front-line staff and case managers, although well-positioned to be working with family members to manage these symptoms, did not appear to have the skills, resources, funding or time to share with the family members information and resources about the disease trajectory. Rather, getting the task completed in the brief allocated time was a priority for the PSWs with little emphasis on emotional and information support. Professional and non-regulated workers have low expectations of the potential of persons with dementia to engage with others which limits their opportunities for

inclusion and social interaction (Cook, 2008). Educational programs that incorporate dementia care should be a mandatory component of home care providers' training (Mason, Blackstock, Cox, Innes, & Smith, 2005) because of the complexity and challenging aspects of the disease.

The responsive behaviours of persons with dementia that reflect resistance or abusive symptoms are too often interpreted as challenging behaviours. Instead, focusing on the meaning of the behaviours that challenge (Innes, 2009) follows more closely the person-centred philosophy of Kitwood (1997). Kitwood defines personhood as "the standing or status that is bestowed upon one human being, by others, in the context of relationship and social being" (p. 8). This definition can also be applied to persons with severely compromised cognitive function. A personhood approach requires a holistic perspective that rejects a narrow focus on cognitive abilities and recognizes the emotional, social, spiritual, and artistic dimensions of the person (Cantley & Bowes, 2004). O'Connor et al. (2007) have broadened the vision of this definition to encompass three unique but interrelated dimensions of the person-centred approach: the subjective experience of the person with dementia, the immediate interactional environment and the broader socio-cultural context. All of these levels, from the micro to the macro, need to ensure that the person with dementia's way of responding is understood, as well as the need to examine the impact social structures and processes have on the lives of those with dementia.

Only including networks which incorporated supportive family members was a limitation of this study. Networks without family members were not included. This may be a reflection that home care programs are reluctant to provide services to persons with dementia who do not have adequate family/friend support. Home care resources are allocated primarily based on service provision capabilities and not on the needs of dementia care networks. Mason and colleagues (2005) found similar findings in Scotland. Thus, persons with dementia with inadequate or no family support are usually admitted to a more costly long-term care facility, often located at a distance, resulting in being physically excluded from their social networks and communities (Cook, 2008; Forbes & Hawranik, in press). Further research is needed to examine the experiences of those who are most vulnerable - persons with dementia without family supports.

Being Denied and Afforded Opportunities to Have a Voice

Being denied and afforded opportunities to have a voice in dementia care decisions was the second overarching theme. Many of the members of the dementia care network either experienced or contributed to the silencing of other members. Persons with dementia felt disempowered because of their exclusion from participating in decisions that affected their lives and their limited choice and control. Contributing to this are assumptions that care network members make such as people with dementia are not capable of participating in care decisions. Ultimately, their fundamental rights as citizens and human beings may be infringed (Cantley & Bowes, 2004).

As well, family members had limited choice in the type and amounts of home care services received and in who provided the care. Family members' birth order, employment status, income, and relationship with each other all influenced decisional making authority within the network. Similar findings from another secondary analysis of the same data, examined siblings/siblings-in-law relationships in home-based dementia care and revealed that gender, birth order and proximity determined how dementia care decisions were made and who provided care (St-Amant, Ward-Griffin, & Forbes, under review).

In the current study, home care case managers' assessments of persons with dementia often placed greater emphasis on risks rather than considering their civil rights and self-determination. As well, their focus was on the family caregiver's ability and willingness to provide support for their loved one, rather than on the caregiver's needs. Family caregivers' needs must be addressed as well to ensure that they are able to sustain their care work. The care planning and service provision tended to over-

ride people's own rights and desires. Front-line home support workers also reported feeling undervalued and inadequately supported and trained to provide quality dementia care. The employer should provide adequate dementia care training for new staff and ongoing mandatory in-services/workshops should be offered to ensure that the front-line providers are kept up-to-date on the best available evidence on dementia care. For all dementia care network members, the silencing of members comes about through a range of interconnected factors and processes. These occur at all levels, from the collective ideology and culture through to interpersonal and individual levels (Cantey & Bowes, 2004).

Clearly there are challenges in raising the voice of dementia care networks. Cooks (2008) recommends a strong self-advocacy movement for persons with dementia, similar to the disabled group's movement. This would have the added benefit of challenging stereotypes around dementia and overcoming the stigma related to dementia. Persons with dementia should be active participants in all relevant activities (e.g., policy, practice, and research), 'nothing about us without us'.

Being Denied and Afforded Opportunities to Participate in Care, Social and Work Activities

The third overarching theme was to have opportunities to participate in care, social and work activities. Attempting to maintain their life-long social networks in their rural communities was important to a number of the dementia care networks, while others were concerned with the stigmatism and safety of the person with dementia. While the rural landscape can offer comfort to those with dementia, it can also become a source of danger when disorientation and wandering occur in later stages of dementia.

Home care personnel have an important role to play in ensuring that people with dementia who are unable to get out and about by themselves have the support needed to engage in social relationships and meaningful activities, both in their homes and in their communities (Cook, 2008). Home care personnel themselves may be the main source of socialization for individuals living at home with dementia, thus they need the training and support to engage in meaningful activities with these individuals. Policy makers also have a role to play in promoting social inclusion through initiatives that encourage local commissioning of innovative services such as respite services (Sargeant, 2008), the First Link program (Mcainey, Harvey, & Schulz, 2008) which connects persons with dementia and their caregivers to a community of learning, services, and supports early in their Alzheimer journey (http://alzheimerott.org/first_link/index.htm), and dementia cafés which provide an informal place for persons with dementia and their caregivers to meet, share experiences, and find out more about dementia (Cook, 2008). However, it must be recognized that there are often greater barriers to providing these services in rural areas which results in fewer available service options and fewer qualified home care providers. As well, rural dementia care network members have greater distances to travel to access some of these amenities that are not available online.

CONCLUSION

This study contributes evidence that challenges the myth of the idyllic nature of rural places through a critique of rural dementia care networks using a social inclusion/exclusion lens within a human rights framework. The diversity of lived experiences within rural dementia care networks was revealed as both positive aspects (e.g., close community ties, life-long work opportunities) and negative aspects (e.g., stigma of dementia, dangers of rural setting) were identified. This suggests that the participants were realists who did not portray rural life as either 'romanticism or despair' (Blackstock et al., 2006). Home care programs and policies need to address this diversity both within rural communities and within dementia care networks. Policies and services should place person-centred approaches within the dementia care network's spatial and social context (Morgan, Semchuk, Stewart, & D'Arcy, 2003). As partners in care, the voices of those who comprise dementia care networks, including the persons with dementia, must be heard, and encouraged to participate in dementia care decisions. Home care case managers are well positioned to take a greater role in assisting members of

dementia care networks to enhance the quality of their relationships, to have a voice, and to participate in care, social, and work activities. Diminishing social exclusion and promoting social inclusion are the first steps in preserving and promoting the health, well-being, and ethic care that Kitwood (1997), we, and most rural families espouse.

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