# $\label{eq:AGING} A \text{GING IN RURAL NEW BRUNSWICK:} \\ End of Project Report for the new brunswick heath research foundation^1$

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#### Introduction:

The number of Canadians 65 years and older makes up nearly 14% of the total Canadian population and the proportion of seniors could nearly double in the next 25 years (Statistics Canada, 2007a). In addition, much of the informal care provided by the children of aging parents (or by other close family members) is in a state of transition. This 'natural' support system has represented an invaluable resource. While it is still the main source of support in Canada for seniors today, the changing mores and demographics indicates that change is impending. This will inevitably represent a decrease in the availability of this resource. Nonetheless, keeping seniors in their own private living arrangements for as long as possible is the most cost- effective strategy for families and government, when compared to more institutionalised arrangements (Chappel et al., 2009). To keep seniors at home means that care must be adequate in its content, nature, organisation, and delivery. The current study examined care for seniors in rural New Brunswick and the dilemmas it presents, particularly from the perspective of elders themselves.

### Methodology:

Employing life histories as part of the overall methodological approach, the Psycho-Social Ethnography of the Commonplace (P-SEC) was used to conduct this research (Gouliguer & Poulin, 2005). P-SEC is a qualitative feminist methodology developed specifically to study the psychologies and sociologies of marginalised groups (e.g., Gibson, O'Donnell, & Rideout, 2007; Poulin, Gouliquer, & Moore, 2009). In other words, this methodology is used to study the influences of the social relations of power or ruling (Smith, 1987) on the lives of the more marginalized in society. As such, P-SEC borrows from three different theoretical perspectives: feminist standpoint epistemology (Harding, 2004), institutional ethnography (Smith, 1987; 2004; 2005), and schema theory (Bem, 1993; Rumelhart, 1991). Twenty-two seniors 65+ years and older living in rural New Brunswick were interviewed. Five were men and 17 were women. Their age ranged from 67 to 95, with an average of 80 years old. All but two lived in their own homes. About half (45%) were married, about half widowed (45%) and the remaining few individuals (10%) were divorced. On average, they had four siblings and four children. In terms of language and culture, four were Francophone and the rest Anglophone. The interviews, which averaged nearly two hours each, produced 1000 pages of transcribed text. Following the P-SEC methodology, the data were analysed first thematically using a qualitative computer analysis program to help organize the data.

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To understand how the institutional structuring (i.e., social relations) of 'care and services' shapes the marginalised rural elders' social reality, we identified and coded the data for 'Organisational Moments' (OMs)(Gouliquer & Poulin, 2005). OMs are defined as common. recurring events that serve to meet the needs of an institution while complicating the lives (thoughts & activities) of the marginalised group. Thus, the analysis of an OM represents a number of steps. First, we identified the specific complications that resulted from the way care and services were delivered to the aging individuals. Complications arise when there is a disjuncture between organisations' ideologies and practices and the needs of the individuals whose actualities are shaped by those organisations. Second, we used schemata, a concept from cognitive psychology, to identify how elders understand and made sense of the complications linked to the OMs, which recurred in their commonplace reality. Linking the complications, the schemata and the organisational moments illuminated how government policies (i.e., relations of ruling) intersected with the everyday realities of seniors and influenced their thought processes (Khayatt, 1992). Most importantly, investigating schemata revealed the strategies that the elders employed to reconcile, resolve, and/or cope with the complications that resulted when their needs were not served by organizational practices and policies. Insights, therefore, were gained regarding the influences of the organization of care and services in the lives of aging individuals living in rural NB.

In summary, we utilised abridged life-history interviews and focused on elders' common realities of aging in the rural NB context. Thus, this study provides detailed and rich information regarding how care is socially organised in rural contexts of New Brunswick.

# Findings:

Forty-three thematic codes emerged from seniors' interviews. The five themes selected for this report were the most prevalent during the interviews (e.g., participants talked about them most frequently and at greater length). The themes were: Cost of Health and Home Care, Inadequate Services, Inflexible Care Services, Institutional Restrictions, and Reliance on Informal Care.

- 1. Many Participants talked about the high Cost of Health and Home Care and the financial challenges this entailed. Some discussed the strain of dealing with the added expenses needed to pay for home care services if they did not qualify for government-sponsored care. Many participants also mentioned the financial strain associated with medical expenses such as testing strips for blood sugar levels. Due to the financial burden for supplies, participants devised strategies to lower these costs. However, this often was associated with an increased health risk. Participants also expressed anxiety over being unable to pay for home care services if they should become unwell or unable to care for themselves. In summary, this theme spoke to the precarious financial situation in which rural NB elders live.
- 2. The theme of Inadequate Services refers to participants' concern with the government budgetary cuts in the domain of health. The participants felt that the number of hours of care they received were insufficient. For example, some elders had to remain in bed for longer periods of time, as they needed assistance to get out of bed. Some also spoke of tasks, such as cleaning, cooking, and/or bathing that went undone given the lack of services available. Participants had to either go without these services, or use informal care, whether paid or unpaid, to make up for the lack of services. Participants also noted a need for but an absence of night care, thereby increasing risks such as falling. Many participants expressed their hesitancy over reporting these inadequacies to their service providers/care managers out of fear that they would lose the services they currently were receiving.

- 3. A further prevalent theme was that of Institutional Restrictions. Elders talked about a list of approved tasks to which their care workers must adhere. Nearly all elders mentioned two restrictions: care workers are not allowed to use ladders or stools to reach up, and they must not lift heavy objects. The implications for these restrictions are significant for elders. For example, when an elder transfers from their wheelchair to their bed or in the bathroom, home care workers are unable to help because of the lifting restrictions. Additionally, the restriction for workers not to use ladders or stools results in the home care workers being unable to complete small but necessary tasks such as changing a light bulb, or cleaning a cupboard. Elders also felt that they were not consulted in terms of their needs; only the service providers determined what work the elder required.
- 4. Another theme that emerged was that of the Inflexible Care Services. This refers to the participants' descriptions of 1) how the institutional policies dictate the length of time an individual may be absent from their home and from the provision of regularly scheduled care, or 2) who qualifies for subsidized care. Elders reported that if they left their home for too long of a period (e.g., more than 1 to 2 weeks), care services would be stopped, and they would need to reapply before services resumed. Elders feared any interruption in their care. This was significant, as they could not stay at home without the services; yet, they felt threatened by having their services interrupted or cancelled if they went away for a few weeks (e.g., visiting a child living in another province). Participants also voiced frustration over being unable to leave their home while care workers were present (e.g., to go to church, or to visit a family member). This resulted in keeping the elders from participating in various community events or to take extended trips to spend time with their children. They had to remain at home to maintain continuity of their home care services. The elders' interpretation of the care policies, therefore, resulted in an increase in their level of isolation. Participants also described being refused home care services because they were considered too mobile, in that they were able to bath themselves and walk a certain distance. Although they were able to do these things, there were many tasks that they were not able to accomplish on their own. This situation would then require them to pay out of pocket to receive care and/or services. Participants described that, although social services deemed their income too high to qualify for home care services, their income was insufficient to allow them to pay to receive the services they felt were necessary.
- 5. These previously mentioned inadequacies, costs, and restrictions to home care services give rise to another major theme; namely that of reliance on Informal Care. This theme refers to the aid that elders received from their informal care network (i.e., friends, family, neighbours, or other members of the community) to complement their formal care services. The data revealed that because of the lack of services provided, the cost of health care services, and the restrictions to the services provided, they had to rely heavily on informal care. All participants talked about needing help with household repairs, yard work, snow removal, drives to appointments and running errands. Rural elders relied mostly on family for these forms of informal care. When it was financially possible for them to do so, they paid when family members were not present or able to help. The need for informal care was most necessary for participants during times of illness or health problems (e.g. surgery, chemotherapy) that rendered them temporarily less able to care for themselves in more encompassing ways. During these periods, elders described a heavy reliance on their informal family care network to make up for the types of care that were not provided through home care services such as overnight care. For elders who did

not have family or friends to help during these periods of illness, they expressed having to devise ways of caring for themselves or hiring outside help, which was often costly.

#### Conclusion:

In summary, the multifaceted approach of P-SEC facilitated the identification of complicating institutional practices of the health care and services system for elders living in rural NB. Aging individuals expressed apprehension over becoming a burden to their family and friends if they were to rely on them too heavily for care and services. Participants often preferred to attempt to manage their situation on their own or to hire outside help rather than ask for "additional" help from their children. Many of the elders expressed that they understood the burden of caring for an elderly person because of their own experiences of caring for their partners during times of illness or death. The elderly talked adamantly about not wanting to place this burden on their children/family. Additionally, participants spoke of their families having their own lives and their own families, and not wanting to disrupt them. This fear of becoming a burden often lead the elders to indicate that they would not choose to live with their children should they ever become unable to care for themselves. They voiced that they would rather go to a care facility instead.

All elders spoke of their desire to remain living independently in their own home. Certainly, previous literature has stated that this is the most cost effective method for society (Chappel et al., 2009). This desire was complicated by elders' recognition of their increasing need for care and services as they aged or as their health declined. Elders described preparing themselves for having to leave their own homes but stressed that they would only do so as a last resort in the event that they could no longer care for themselves. A few participants expressed a willingness to live with their children, but also spoke of not wanting to burden their family. Participants employed many strategies (e.g., hiring help) to stay in their own home for as long as possible. In this context, they also spoke of concerns over their ability to cover the cost of maintaining their home or paying for a facility. Many elders expressed that if they were to lose their mobility they would be forced to leave their homes. Additionally, participants who were still living with their spouses expressed their desire to remain with their spouse. This further complicates their lives when faced with availability issues and restrictive policy dimensions when moving to an institutional care facility.

The costs of health care and services, the lack of adequate services in some rural areas in NB, and the restrictions on services provided essentialize the need for elders to rely on various forms of informal support (mostly family). This reliance increases health risks for both elders and their families. Furthermore, this reliance and belief of the government that an informal support networks exists rests on the assumption that all elders have a family on which they can rely. This functions to essentialize the role of the family in a number of ways, which is problematic. First, it forces elders to place the burden of care onto their family with which they may not be comfortable. As a result, the situation is anxiety provoking for all and it heightens the possibly of conflict and abuse within the family. Second, for elders without strong informal support networks, they have to personally finance their care services, which many cannot afford. Finally, the assumption that all elders have a reliable support network may force them to move to residential care facilities prematurely, which is costly to both the individuals and the government.

## Recommendations:

Since informal care (especially from family members) is still the most critical element in keeping the elders staying in their homes, government resources should be directed toward both (1) making informal care giving easier, and (2) reducing elders' dependencies on informal care.

These recommendations will serve either or both of these objectives:

- 1. The NB Government should improve the flexibility of informal caregivers' respite program. Currently, the respite care includes Day Activity Centres for Seniors, which are meant for a few hours of respite and Relief Care for overnight respite (either at the elders' home, at a Special Care Home, or at a Nursing Home). To add to the flexibility, elders and their caregivers should have a choice of using the funding to pay other people, not specified above, to stay and accompany the elders in their own home. This would allow elders to stay with people they are comfortable with and their family can trust (e.g.: neighbours, cousins).
- 2. Improving the home care services system:
  - a. The NB Government should create a governing body specifically to inspect and uphold the standards specified in their guidelines.
  - b. The NB and federal Government each should create an independent ombudsman office, where elders can lodge a complaint or a suggestion regarding care and services they receive. There should be multiple ways that elders and their family members can voice their concerns, and these ways should represent a readily and easily accessible service for help, information, and advice. It also should be a confidential and anonymous service. One of the most convenient ways to provide such a service is through the Internet. Forms that elders and their family will need can be filled and sent with a click of a button. For the elders without Internet knowledge, paper forms should be available in various public places like pharmacies, or the places where seniors socialise. A phone line that provides the equivalent information for those who are not computer savvy or mobile is also pertinent at this time. Furthermore, these bodies need to be proactive in informing elders that there are ways for them to have their voice and concerns heard without fear of retaliation. This information can be disseminated through such methods as newspaper advertisements.
  - c. Seniors input with regards to care should be solicited and reported on a regular basis. This report could be accomplished by using surveys conducted by an independent party. Even if their needs are not being met, seniors do not often report or complain, as they fear retaliation in the form of a reduction in their services. Moreover, they may not know where or how to report. This report would provide the government with the platform to be proactive and take seriously the input of the users of the system—the seniors.
  - d. Home care services standards of training should be available for both formal and informal care providers. It should include training in social skills specifically pertinent for dealing respectfully and appropriately with elders. Understanding the differences between the myths and realities of elders will reduce the stress of both the home care providers and recipients. Training should also cover the preparation of food and the planning of adequate menus, and training in daily hygiene care.
  - e. Raising the minimum wage for the home care service providers will attract more people into this challenging occupation, as well as retaining those who are already employed in this service industry. Currently, the minimum wage is set at \$11.00 per hour for home care service workers in New Brunswick, which is lower than the average wage of a janitor (\$12.55). Considering that keeping elders to stay at home

costs less than having them live in institutionalized care facilities, the additional cost of paying for the home care services should be prioritized. The short-term costs that this change demands would reduce future overall health care costs. More importantly, it would increase the quality of life for elders in the province.

- 3. Transportation is a major hurdle for elders in rural New Brunswick. Creating a more effective transportation system for elders will help keep them stay in their homes longer. With adequate transportation, elders can have better access to preventative measures (e.g., social gathering, fitness groups), and early interventions (i.e., medical check-ups) regarding their health. It is accepted knowledge that keeping elders healthy for a longer duration will save the Government in costly subsequent interventions. One of way to help with the costs and availability of transportation for NB rural elders is to have a car pool/informal taxi system that is managed provincially, where drivers (people from the community) can get reimbursement for driving elders to their medical appointments and other functions.
- 4. The government needs to develop innovative ways to help elders where the home care workers are restricted due to safety limitations imposed by the Work Safe NB. An example of this problem would be the need to change a light bulb. Currently, home care services workers are not allowed to climb to undertake particular household tasks (e.g., those needing the use of a ladder). A simple solution would be to supply government-approved two-step, wide-base, light ladder, which would be sufficient for any worker to change a light bulb. This simple measure alone would represent an important change leading some elders to remain in their home instead of having to move to a more costly residential facility.
- 5. Examine closely the implications that "safety protection practices" have for formal and informal care providers: Formal care workers are instructed not to climb on anything. However, these policies lead to either informal care workers doing the work and usually without training or knowledge of how to prevent injuries, or it leads the seniors to attempt the work themselves. In both cases, the approach to this work is without safety training or proper safety tools, both of which can lead to injury. Such will bring about increased cost for the health care system. Prevention policies and better training practices could reduce injuries and the cost associated with medical/care. These would offset the costs of training and reduce the need for hospitalisations linked to injury.