



pluralages

VOL. 1, NO. 2, SUMMER 2010



SOCIAL GERONTOLOGY FOR THE **21ST CENTURY**



Centre de recherche et d'expertise
en gérontologie sociale

Centre de santé et de services sociaux
Cavendish

Centre affilié universitaire

summary

editorial

Taking new paths:
Wandering off before finding our way forward! _____ 3

The many faces of CREGÉS
The VIES team:
Tackling aging, social exclusions and solidarity _____ 4

grounded practices

Voices from the front lines:
Cutting-edge programs in movement _____ 7

Jog your mind: A community program for
intellectual vitality _____ 10

applied research

Research Results
Socially isolated older adults
Not so "at risk" after all _____ 12

A balancing act: Serving elderly people with
severe mental illness _____ 14

Emerging research
Seniors: From observers to actors in a study on
Social participation _____ 16

Volunteerism in palliative home care
for the elderly _____ 18

knowledge sharing

Question marks
Autonomy and aging: Loss (PALV) or gain (GALV)? _____ 19

Recent publications _____ 21

Call for papers
Rethinking aging, renewing practices _____ 22

citizen's forum

Turning words into action
Working together to improve the quality
of life of Montréal's seniors _____ 23

For crying out loud
Volunteering gives a sense of meaning to one's life _____ 25

A spoonful for Dad... _____ 26

CREGÉS' training sessions
Aging and challenges in intervention _____ 27

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Pluralages is published by the Centre de recherche et d'expertise en gérontologie sociale (CREGÉS) of the CSSS Cavendish – Centre affilié universitaire (CAU). This magazine is designed to inform the public and raise awareness of social issues surrounding aging by, among other things, presenting the research initiatives and expertise being developed by members of the CREGÉS. *Pluralages* also aims to promote and foster ties between the research, education, practice and citizen action - for and by seniors - communities. Issues related to aging are presented through the lens of social gerontology, touching on such themes as diversity in aging, social and citizen recognition of the elderly, experiences with social exclusions and solidarities, political concerns, State directives and public policy targeting the aging population and its needs.

Pluralages is published in French and English, in print and electronic versions. Please feel free to contact us for a paper copy in your preferred language.

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Taking new paths:

Wandering off before finding our way forward!

The concepts of old age and aging are undergoing an unprecedented transformation in a number of societies. The aging process is diversifying, manifesting itself differently from one person to the next. Chronological age no longer automatically signals old age, as we can see today in those who are 65 and older.

Our social institutions have established mechanisms to address multiple forms of aging (for example, prohibiting age-based job discrimination), but they simultaneously erect barriers—barriers that generate or reproduce conditions of exclusion, or simply fail to eliminate them. A multitude of opinions and new ideas are fuelling public debate and discussion and leading to the creation of new alliances.

For now, we want this issue of *Pluralages* to take stock, present some aspects of these discussions, and touch on a variety of social issues linked to aging such as social participation, activity, community involvement and volunteering, isolation and social ties, the preservation of mental health and accessibility of transportation (which of course enables people to remain active and be socially involved).

The articles in this issue, for the most part, pose questions about our attitudes to the old and our vision of aging. They invite comparison, between our perceptions and seniors' daily experience. In short, the contributions to this issue of *Pluralages* raise the following questions: How can we ease the process of aging in contemporary society? How should we address the issue of aging while keeping in mind that this is only one leg on the journey of life, a fully fledged life stage that is enriched by our younger years and that leads into the future? What can we do to promote and enhance the diverse nature of aging?

Apart from reflecting on these questions, we want to take some new paths, let ourselves wander, so that finally we can arrive at some ideas for practical solutions that will increase our chances of aging, instead of the established way, in a way that corresponds to our values, life choices and aspirations, regardless of our gender, cultural or ethnic background, sexual orientation, and all the other characteristics that define us.

Please note that this issue also features the first piece in a new column: *From Words to Action*, for people who are involved in community groups and associations. It will be a space that gives a voice and visibility to community action by and for seniors.

Please join us and contribute your thinking to this process of reflection. <



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The many faces of CREGÉS

The VIES team: Tackling aging, social exclusions and solidarity

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A presentation by the VIES research team¹

Since 2005, the Centre de recherche et d'expertise en gérontologie sociale (CREGÉS) at CSSS Cavendish, a designated university-affiliated centre, has been home to a large joint research team known as VIES, which is funded by the Fonds québécois de recherche sur la société et la culture. There are several such teams across Québec working to further knowledge in various research areas using multidisciplinary approaches and practices that favour partnerships with the community. We believe their contributions are essential in that they allow research to be anchored in the real-world experiences of the population, and particularly, for the VIES Team, the experiences of the elderly, their family members and friends and those who work with them day after day².

The VIES team is made up of 42 researchers, researcher-practitioners, students and other stakeholders whose interests lie in the various forms of social exclusion and solidarity experienced by the elderly. Their work constitutes the fifth axis of research at CREGÉS, and cuts across the other four. As such, much like CREGÉS, the VIES team focuses on 1) *the multiple ways of aging and how*

they are socially represented, 2) older peoples' social and living environments 3) practises for and with older people, and 4) public policy on aging and the social involvement of the elderly, by analyzing them through a lens that draws attention to cases of inequity and social exclusion, but also to solidarity.

The various expressions of exclusion

Analyzing the experiences of elderly people through the lens of exclusion enables us to question social structures. Similarly, taking this approach inevitably leads to the identification and anticipation of potential solutions to lessen our

The seven dimensions of social exclusion	
Symbolic exclusion	Corresponds to negative representations and images of elderly people (e.g. vulnerable, dependent, incompetent), as well as the diminishing of their place and roles in society. This dimension of exclusion contributes also to their invisibility.
Identity-based exclusion	Refers to an identity reduced to a single membership group, which implies that the person is perceived solely or almost solely through the minute prism of age, thereby excluding the multiple determinants of his or her identity: gender, origin, culture, sexual orientation, religious beliefs, etc.
Socio-political exclusion	Takes the form of restricted access to participation in society and the spheres of influence, decision-making and politics. The elderly may experience a lack of collective or individual power and political weight.
Institutional exclusion	Implies the total or partial denial of access, for the elderly, to social and health protection measures and policies implemented by social and political institutions. This dimension of exclusion is equally associated with the standardization of practices that disregard the diversity of needs and experiences among elderly people and their loved ones.
Economic exclusion	Characterized by the absence of access to the income, material resources and capital required to meet one's basic needs.
Territorial exclusion	Refers to reduced geographic freedom, confinement to isolated spaces such as the home, and loss of control over one's living environment. This dimension of exclusion may be attributed to the physical limitations of certain elderly people, but also, for example, to poorly adapted or inaccessible public spaces or public transportation.
Exclusion from significant social ties	Defined as the absence or loss of social networks, or rejection from or abuse by such networks.



society's deficiencies in accounting for all of its members and their diversity³.

On the basis of its research, the VIES team defines social exclusion as: *"a process of non-acknowledgment and deprivation of rights and resources of certain segments of the population [in this case, the elderly] that takes the shape of power dynamics between groups with divergent visions and interests. Such processes result in inequities and, eventually, to isolation from society in seven dimensions [...]"*⁴. (Refer to table on facing page).

In adopting a multifaceted view of exclusion, the VIES team naturally speaks of exclusion in the plural, highlighting the collective nature of these exclusions as well as the social, political and economic factors that support them. The team also portrays elderly people as active participants in social spheres and not as *passive, dependent people*.

Diversity in experience and in aging

We must stress that the VIES team does not view the elderly as one large excluded, homogeneous group. On the contrary, it has witnessed great diversity in their experiences and their resistance to situations of exclusion⁵. Certain cases of exclusion are nonetheless inextricably linked in some way with "age exclusion" due to the value placed on youth and qualities typically associated with youthfulness: beauty, performance, speed, efficiency, creativity, etc. On the other end of the spectrum, negative and stereotypical images of elderly people and aging abound. For example, the aging population is presented as a burden on society and a threat to or a weight on government money.

Occurrences of inclusion and exclusion are complex⁶. Any person may be excluded at some point in his or her life for reasons having nothing to do with age, such as poverty, sexism, racism or sexual orientation. However, these processes may become more prevalent as a person gets older. Take, for example, a wealthy gay man who has been living relatively



openly with his partner for several years. The new experiences tied to his aging, such as residing in a healthcare facility, may give rise to new sources of discrimination or exclusion. Being a woman also usually implies a certain degree of social inequality. As a woman gets older, the chances that she will end up living in poverty increase, which thus accentuates the differences in living conditions between elderly men and women⁷.

The VIES team's work contributes to the observation and analysis of the complex nature of the situations experienced by people, in which a range of cases of inclusion/exclusion, advantage/disadvantage and power/weakness intersect. They also draw attention to the wide

array of living experiences and social standings among the elderly.

Solidarity as a response to exclusion

Out of the concept of exclusions inherently arises that of inclusion, which constitutes an objective rather than a course of action, and solidarity would appear to be a good means to achieving that end. According to the VIES team, solidarity is *"a driver of social change in line with a political logic rather than a supportive logic. Manifestations of solidarity are founded on a collective willingness to take action to resolve the day-to-day problems faced*

continued on page 6 »

by individuals through an acknowledgment of the other and his or her differences, needs and abilities.”⁸ In this way, this view of solidarities is as collective in nature as that of exclusions. Each individual is a social player who influences the production of situations of exclusion and the building of solidarities.

« The members of the VIES team firmly believe that redefining a public arena that is more inclusive must be done with, not for, the excluded. »

The work of the VIES team: A few concrete examples

Several studies have shown that certain problems associated with adulthood appear to become “invisible” as a person ages. This invisibility—which one can perceive, for example, in social interactions (or lack thereof) in public spaces⁹—means that when elderly people facing this problem begin needing social or healthcare services, they end up either neglected or confined to “ghettos” of poorly adapted services. Domestic violence is often overlooked by those working with elderly women¹⁰. Elderly people with mental illnesses can end up living at home without assistance if they have been deinstitutionalized, or in old age residences with inadequate services when they begin to show signs of severe incompetence¹¹. Such situations create a great deal of insecurity and tension for the other residents¹². Elderly immigrants have a lot of trouble obtaining the information they need to access long-term care and services. Without adequate support, these people and their families go through a multitude of exclusions¹³. These findings underscore the importance of pursuing our investigation into elderly communities experiencing particular cases of institutional and identity-based exclusions, hence our interest, for example, in aging people who use end of life palliative home care services¹⁴.

Lastly, it should be noted that the VIES team’s research also examines acts of solidarity by elderly people through volunteering¹⁵ and social and political involvement¹⁶. They provide a brief overview of a rich and diverse body of research. Numerous other projects are underway that are looking at issues associated with aging that are as critical as those listed herein.

The role of the elderly in the VIES team and in research

The members of the VIES team firmly believe that redefining a public arena that is more inclusive must be done with, not for, the excluded¹⁷. Not only do these researchers have the power to transform the social and political spheres, but they have a responsibility to do so, and to re-examine the conditions for conducting research¹⁸. Research generates knowledge, an instrument of power. It is important that this knowledge be created collectively in order to enhance the distribution of power. The elderly community’s involvement in research is therefore a fundamental objective.

Partnership is the cornerstone of this team, and that on which it was founded. Not only does its research aim to answer the questions put forth by various partners¹⁹, but it requires their active participation, by means of various forums and committees, to define, conceptualize and execute projects and to convey the findings. As such, we are currently working to establish an elderly partnership forum. This, along with the VIES team’s numerous other projects, will no doubt be the subject of articles appearing in upcoming editions of *Pluralages!* <

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19. Partners of the VIES team include: CASS Cavadish-CAU, the Table de concertation des aînés de l’île de Montréal, the Alliance des Communautés Culturelles pour l’Égalité dans la Santé et les Services Sociaux (ACCESSS), the provincial association of homecare workers, the Conseil des aînés de Notre-Dame-de-Grace, Mêmes déchaînées. Others such as the Association des retraités de l’enseignement (AREQ) and the Conseil des aînés, are collaborating on special projects.



Voices from the front lines: Cutting edge programs in movement

In the inaugural issue of *Pluralages* we described part of the twenty-year history of the Cutting-edge services (CES) at CSSS Cavendish, and the challenges of developing expert teams that not only provide services based on best practices, but that engage in research, knowledge sharing, and partnership development.

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In this second issue we bring you a dynamic portrait of where things are at today. The five Cutting-edge teams – Mental Health and Ageing, Palliative Home Care, Prevention-Promotion in Health and Ageing (PPHA), the Caregiver Support Centre, and the Elder Abuse Consultation Centre of Quebec – are all engaged in new projects and innovative ways of envisioning their services. While all the teams are facing the ongoing challenges of working within a merged establishment with a new structure, all show signs of dynamism, new visions, and new methods of collaboration.

The majority of Cutting-edge services are also intimately aligned with the larger program of PALV (Loss of autonomy linked to aging), a program found in each CSSS in Quebec which provides services to older adults with a physical or cognitive impairment.

The following is an account of some of the changes that are occurring in the Cutting-edge teams, told in part from the workers themselves. We have chosen to highlight in this issue the palliative and mental health teams, as these teams

are among the most rapidly evolving.

Evolution

For evidence that things are changing, one has to look no further than the nascent palliative care program. What began as an initial research project in 1998 has evolved into a Cutting-edge practice that is over time becoming a comprehensive Cutting-edge service including presentations at conferences, the development of trainings, and further research projects.

The Palliative Home Care Program, with its emphasis on a psychosocial homecare model, emerged in contrast to most palliative programs that focus on a biomedical model in institutional settings. The team believes strongly that it is important to look beyond pain management and towards a holistic picture of the dying individual. According to Zelda Freitas, one of the founders of the palliative team, the goal of the program is to remain grounded in psychosocial practice. "I think our role as a team is to help people with their struggle at the end of life", says Zelda. "The palliative care approach is looking at the family and the person who is dying as a unit of care. What are their needs individually and as a whole?"

While the team is focused on individual and family needs, it is also focused on developing practitioners' expertise. Patrick Durivage, also one of the pioneers of the palliative team and currently the leader of the Palliative Cutting-edge practice, explains that one of the goals of the team is to help

practitioners feel more comfortable with palliative care intervention. Patrick emphasizes the necessity of "allowing people to use their psychosocial skills" and to talk with dying patients and their families about all the aspects of what they are going through.

During the early years, Zelda and Patrick were also working hard to share their original perspective at conferences, to learn as much as they could about palliative care in Quebec and Canada, and to get more research off the ground. The extra hours paid off, and the establishment has officially recognized palliative care as a Cutting-edge service in development. Patrick cites this as one of their recent successes: "The establishment recognizes that palliative should be part of the Cutting-edge service; that's something we're proud of." While the struggle for recognition has been challenging at times, both Zelda and Patrick feel that there is an increased interest and energy around palliative care.

The efforts of the palliative team are also bearing fruit in research and knowledge sharing. They have embarked with researcher Karen Nour on a variety of projects ranging from the examination of practitioners' perspectives on palliative care, to a survey of what other health care agencies in Quebec are offering in terms of palliative services. Zelda emphasizes that "the whole research aspect answers the questions of how to improve our practice, focusing in on best practices."

continued on page 8 »

It is not only palliative care that is developing in new directions. The mental health Cutting-edge service is also in the process of implementing an exciting new vision that brings them out of an initial specific focus on mental health and the elderly, and towards a new emphasis on the interrelation between mental health and all the other aspects of the client's well-being throughout their adult life so that they age with less related problems. This change in philosophy towards a "lifespan" approach does not mean that older adults are being sidelined, but that the prevention-reduction of complications relating to mental health problems as people age is becoming a primary focus.

The mental health Cutting-edge service, now called Mental Health and Ageing, which developed in the late 1990s, was originally intended to provide specialized services to an underserved population that was experiencing chronic difficulties. From an initial research project on risk behaviors, the team was able to identify which clients would most benefit from specialized mental health services using a homecare model. According to Nona Moscovitz, who helped develop this service and is now Mental Health Program Manager, *"we started to look at who the target population was, how to identify their needs", and what were the referral numbers.*" This initial foray into identifying clients at risk not only set up the basis for a homecare based program focusing on psychosocial risk behaviors, but became the preamble to a tool that is now central to the team's practice, the Psychogeriatric and Risk Behavior Assessment Scale (PARBAS).

In addition to implementing this new way of working and thinking about mental health, the team has been buoyed by the success of its on-site trainings. Training on the use of their psychogeriatric screening tool has proven popular (as well as their training on Mental Health and Older Adults), and they are looking towards elaborating new research around this tool. The mental health homecare model

(providing services directly in the clients home, if needed), an innovation in a field focused largely on a medical and ambulatory model, remains an anchoring force of the team's new structure. The model is being adapted to place more emphasis on the adult lifespan of the individual. Alan Regens-treif, Coordinator of the Mental Health Cutting-edge service, explains that the team *"now has the opportunity to work with our population starting at the age of 21 years, so that as people age they do so with fewer ill effects relating to their illness, secondary effects of their medications and unhealthy lifestyle habits"*.

Cutting-edge teams. *"I could envision a training on caregiving for people with mental health problems"*, says Alan, while musing about the future.

Collaboration

The collaborative spirit expressed by Alan and Patrick can be felt throughout the Cutting-edge teams. This is perhaps in part due to the fact that all five Cutting-edge leaders have been working together, with researcher Michèle Charpentier, on a research action project looking at social exclusion in practice. This joint project has allowed the leaders a forum to look in detail at complex case studies and to

« This collaborative energy [...] is also concretizing in other ways: the training in palliative care and caregiving, the joining of PPHA with the PALV program, increased mentoring, and the increased effort among Cutting-edge leaders to understand each others' areas of expertise. »

Along with this new philosophy comes a new name, from Mental Health 60-plus, to Mental Health and Ageing, as well as a new emphasis on a bio-psychosocial approach that looks at the relationship between mental health problems and other illnesses. According to Alan, the new vision *"is not only looking at mental health, but the globality of a person."* Nona emphasizes the fact that this new model provides a new perspective of the clientele: *"we are able to see clients in different life stages, what their experiences are and see how they are ageing it's been a healthy shift for us, because you can't change what has already happened in someone who's presently older, but you can try to offer them a more comprehensive service"*.

The team is also looking to develop new research and new trainings, in particular in collaboration with other

discuss not only social exclusion but the links between each team's practice – for example the frequent co-existence of mental health problems and abuse, or the prevalence of caregiving issues throughout numerous situations.

This collaborative energy, or cross-fertilization between teams, is also concretizing in other ways: the training in palliative care and caregiving, the joining of PPHA with the PALV program, increased mentoring, and the increased effort among Cutting-edge leaders to understand each others' areas of expertise. While there is a need for each service to maintain their particular expertise, the coordinators also understand that they benefit from their collaboration

According to Norma Gilbert, coordinator of the PPHA Cutting-edge service, these efforts at collaboration have pro-



duced noticeable results: “*Beforehand there was a certain isolation, because the programs themselves are kind of unique. Now I feel like part of a team, and I like that.*” The same sentiment is echoed by Alan and Patrick who talk of “*breaking the boundaries*” between the Cutting-edge teams.

Not only are the Cutting-edge services emerging from their silos, but the links between researchers and practitioners are enjoying a new dynamism. New links between researchers and practitioners are being formed, with projects such as *Frontline Practitioners working with older adults with severe mental illnesses research* (see page 13 in this issue), and *Beyond the weekly bath: Building 21st century community-based care policy and Participation or social exclusion of disabled persons: The role of homecare services*.

Synergy

While the foremost concern of the Cutting-edge teams is to respond to the needs of the clientele and staff of

the CSSS Cavendish, the innovative practices and research being developed are not only benefiting a small population; they are being shared and taken up in other health and social service settings across Quebec, Canada, and internationally.

The Caregiver Support Centre’s recent publication *Counseling with Caregivers: A guide for professionals* has been sold throughout Quebec and Canada, as well as in some pockets of Europe. Similarly, the CARE Tool, a caregiver assessment tool that was developed by a team of Canadian researchers (Nancy Guberman, Janice Keefe, Pamela Fancey, and Lucy Barylak) has been integrated into various organizations in Quebec, Canada, the United States, and in Europe.

The Elder Abuse Consultation Team is also solicited throughout Canada and worldwide for its trainings and consultative services in the detection and intervention of elder abuse and

conjugal violence. They have presented at conferences and given trainings in destinations as varied as Vancouver and Barcelona.

The PPHA team’s training on their memory workshop is in demand from various agencies throughout Quebec. The *Jog your Mind program* (see page 10 for a specific account of this program), whose current research project is being conducted by professor Sophie Laforest, is proving to be as dynamic as the already-implemented programs *I’m Taking Charge of my Arthritis* and *The Fall Prevention Program*.

Over the past two decades, the Cutting-edge services of the CSSS Cavendish have developed a winning formula that combines the needs of the population with innovative practices, research, and community partnership. We will continue to learn about specific projects and accomplishments that have emerged from this synergy in future issues of *Pluralages*. <<

Jog your Mind

A community program for intellectual vitality

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Changes in memory functioning is a significant source of worry for seniors, even for those experiencing normal cognitive aging. For seniors, intellectual functions are a crucial element for the maintenance of their autonomy and quality of life. However, intellectual aging has for a long time been looked at with a fatalistic belief that the accompanying deficits are inevitable. However, research on brain aging in recent decades has demonstrated that even at an advanced age, a brain that is regularly stimulated can maintain its ability to restructure itself in a positive way.¹ Memory training programs, concentration, and other intellectual faculties may improve both

the cognitive performance of healthy seniors² and their subjective perception of that performance³. It has also been demonstrated that a change in lifestyle, most notably in physical activity, can have a positive effect on seniors' cognitive performance⁴, and these effects can still be measured after several months, even years after the end of a program.⁵

Activities that promote intellectual vitality are now considered a promising strategy for healthy, active aging. Programs that are presently available usually target the maintenance and stimulation of memory from a clinical perspective and are offered by professionals. Until now,

and can be led by practitioners and volunteers who have participated in a training session.

Program development

Jog your Mind is intended for seniors who are worried about cognitive changes related to normal aging. It is not meant for seniors with Alzheimer's disease or any other type of dementia, since experts have stated that learning-based memorisation programs can make these people feel frustrated.⁷

Several steps were required to build the program:

1) a literature and research search for existing best practices;

« The program was inspired by the experiential approach of Kolb, which emphasizes the active participation of seniors, the sharing of personal experiences, and the practical application of strategies in daily life. »

there have been very few programs that combine cognitive training with the promotion of a healthy lifestyle while simultaneously focussing on the many determinants of cognitive vitality.

It is within this optic that the CSSS-CAU Cavendish prevention/promotion in health and aging (PPHA) team developed the Jog your Mind program⁶, ensuring that it is both cost-effective and can be easily implemented in senior's organisations. Although mainly targeting the community milieu, it could nevertheless also be implemented in residences for seniors, day centres, and municipal recreational services. The ten-session program is designed to be offered to groups of 5-15 seniors, requires very little mate-

2) validation by experts on its scientific content, implementation feasibility, and the pragmatic aspects of animation; and

3) testing with groups of seniors in order to adjust the program's format and content. Consisting of ten sessions of two hours each, the program combines stimulation and health promotion following a multifactor approach. Many topics are covered: name recall strategies, the brain oxygenating benefits of exercise, healthy eating to help one think better, the impact of stress on the memory, and many others.

The program was inspired by the experiential approach of Kolb⁸, which emphasizes the active participation of seniors, the sharing of perso-



nal experiences, and the practical application of strategies in daily life. Each topic is covered in four steps: 1) Experimentation: the participants do an activity or take part in a reflection on the topic; 2) Sharing and analysis: in a group, the participants share the results of their activity and analyze the experience; 3) Conceptualisation: the group leader helps the participants draw general conclusions and explains the concepts; and 4) Application: the participants are invited to propose concrete applications of the concepts for their daily lives.

A project for and with the community

The program was tested in the spring of 2007 with 83 seniors, divided into four French and 2 English groups. The participants ranged in age from 60 to 90 years of age, were mostly women (85%), and came from a diverse socio-economic background. The education level varied from average to high. The participants were enthusiastic about the program; several organisations had waiting lists (the rate of participation exceeded 80%). It seems they found the program interesting, relevant and well-adapted, and it responded to their needs. The primary benefit they mentioned was the reinforcement of confidence in their cognitive abilities. We noted that half of the people enrolled were worried about their memory, thus the program did respond to a population need.

Following the promising testing results, the workshop manual was fine tuned and is available through the CSSS-CAU Cavendish. As well, an optional training session for group leaders was created to provide counsel and support for program implementation.

Program evaluation

A team of CSSS Cavendish, Université de Montréal, and Université de Sherbrooke researchers has received financing from the Canadian Institute of Health Research (CIHR) to evaluate the effects of Jog your Mind. A study is being conducted from 2009 – 2013 with 288 seniors who will be



followed for one year to: 1) verify the short-term effects of the program in a community setting on their attitude, their knowledge related to cognitive vitality, their practice of healthy lifestyle, (mnemonic strategies, physical activity, as well as intellectual functions (memory, attention); 2) verify the effects of the program eight months later; and 3) conduct a follow-up on the process to document diverse variables related to the implementation, the population, and the response of the organisations. <

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SOCIALLY ISOLATED OLDER ADULTS

Not so ‘at risk’ after all

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Social isolation has been studied widely in a variety of disciplines including philosophy, sociology and psychology. Despite its prevalence in a diverse body of literature, social isolation has largely been considered as a risk factor and as a problem associated with aging. This problem-focused discourse has led to a series of studies, interventions and programs aimed at addressing or preventing social isolation among older adults. While researchers and theoreticians have devoted decades of writing and research to social isolation, the voices and perceptions of older adults have been strikingly absent from the literature.

Background

My interest and confusion about social isolation emerged from my front line experiences as an *intervenante de milieu*, a position created in part to combat social isolation among older adults living in subsidized housing units. Through this work I began to question my mandate and how I classified older adults as socially isolated. I also questioned the assumption that social isolation is inherently ‘bad’ and that because it is ‘bad’ it must be broken down in order for an older person to have an optimal quality of life. I realized the social isolation ‘risk factors’ in the academic literature, such as gender, childlessness, living alone, marital status, poor health, culture and poverty were not accurate indicators of my clients’ social isolation. For instance,

I had met older adults who lived alone, had minimal social networks, and were of low-socioeconomic status, yet were highly functional, content individuals.

In contrast, I had worked with other older adults who suffered from intense feelings of social isolation and loneliness, despite being financially privileged and surrounded by extensive social networks. Consequently, my need to explore and make sense of the phenomenon of social isolation inspired my Master of Social Work thesis¹ and the following research questions:

- 1) How do older adults make sense of and view social isolation?
- 2) How is social isolation experienced in older adults’ everyday lives?
- 3) What types of strategies are adopted (if any) to protect them from experiencing the ill effects (if any) of social isolation?

Findings

Two men and four women from diverse backgrounds (one Anglophone, four Francophones and one Polish-born French speaking immigrant) ranging in age from 62-91 participated in this phenomenological qualitative study. All of the participants lived alone in a rent-geared-to-income apartment complex for autonomous older adults in Montreal and each of them had been identified as socially isolated by their service providers.

Combatting social isolation with purpose

Individual experiences of social isolation were subjective, fluid and mediated by the participants’ social agency and

identities. Some of the participants identified as being socially isolated across their life course while others associated their current social isolation to experiences of loss, conflicts and rejection brought on by age. Most striking was that regardless of the origin or subsequent causes of social isolation, the participants not only coped with but resisted social isolation through purposeful activities. Although none of the participants were gainfully employed, all engaged in a number of self-initiated purposeful activities. For example, the women enjoyed their daily domestic duties and self-care activities:

« *Solitude but I enjoy that. The floors, I have to keep washing those white cupboards, but you know that suits me to a ‘T’.* » Anglophone woman, aged 76 years

« *Je change souvent, à tous les jours je change de vêtements, de look aussi, les bijoux ça rentre en ligne de compte. Ça fait que j’aime ça, ce n’est pas pour les autres, c’est pour moi.* » Francophone woman, aged 72 years

Compared to the women, the men took pleasure in purposeful activities occurring primarily outside of the home. For example, both men volunteered their time to “take care” of their neighbours by doing odd jobs, cooking and delivering meals.

Importance of ‘loose ties’: Negotiating the risk of relationships

The maintenance of ‘loose ties’ also protected the participants from the ill-effects of social isolation². Casual relationships or ‘loose ties’ were valued

because they permitted a low-risk connection with others. For instance, the participants spoke of remedying bad days by simply having neighbours speak kindly to them (saying “hello”) and through their informal conversations in non-threatening common spaces, such as the laundry room:

«Well, I have some bad days. I get up and I'm tired, my bones are sore and I feel blue but on those days the only thing I can do to help myself is go out and sit on those benches in the summer. If it's winter I'll go down and see if one of those people I know is in the laundry room. No, I feel fairly reclusive and I feel very comfortable being alone and with what little entertainment ...as long as these people say hello and they look fine, happy but also friendly that's what matters to me, is that you're showing a type of friendship, well actually that helps better because these people don't want me or someone like me going to visit them».

Anglophone woman, aged 76 years

Close relationships were feared because they were considered too great of a risk. However, the participants had adopted strategies to minimize risks they associated with intimate relationships (i.e., being rejected or becoming the subject of gossip):

« C'est ça je parle avec les gens que je rencontre parce que eux aussi ont des chiens puis eux autres aussi ils sortent à peu près la même heure, c'est drôle à dire eh, à peu près la même heure, on se rencontre, on se parle, 'comment ça va?', titi, tata, mais je ne parle pas de ma vie personnelle ». Francophone woman, aged 76 years

Overall, the participants had negotiated with themselves a level of intimacy in which they felt comfortable and connected to the world.

Practice and Policy Recommendations

Recognizing the value of 'loose ties'

The importance of the participants' 'loose ties' raises questions about the

types of questions service providers are asking older adults in their assessments. Measures that capture social isolation may not be capturing the types of relationships that are valued by older adults. Rather than counting a person's number of regular contacts and activities, perhaps asking “Where do you go to feel connected to the world?” or “Where are the places you enjoy going to feel integrated into society?” may be better questions to obtain an accurate portrait of what types of relationships are valued by older adults. Overall, this study highlights the need for improved communal spaces and low-risk social activities that encourage the formation and maintenance of 'loose ties'.

Reframing what is considered a purposeful citizen

The positive benefit the participants obtained from purposeful activities emphasizes the necessity of maintaining a sense of purpose in old age. Writings dating back over 50 years posit that an individual's self-concept is directly related to participating in social roles yet our society has done little to provide substitutes for older people whose roles have been lost or reduced. Opportunities extending beyond the paid labour market are necessary so that older people have spaces where purpose can be preserved other than in the safety of their own homes. Moreover, the overwhelming positive reaction received from the participants regarding their participation in this study demonstrates the importance of providing opportunities for older people to feel they are still able to participate in “real world” projects and make valuable contributions to their community.

Challenging notions of aging well

The participants spoke of their personal experiences with social isolation as a preferred choice, yet when they externalized and were asked to speak about social isolation as a concept, they employed pathologizing terms:

“They would probably look dower, not warm, not friendly and thinking too

much about themselves”. Anglophone woman, aged 76 years

Even though being alone was viewed as a choice and solitary activities were enjoyed, the participants were uncomfortable self-identifying as socially isolated. Feeling ashamed about having a limited social network is not surprising considering the political rhetoric promoting social networks and value-laden ideas of what constitutes aging well³. For instance, Rowe & Kahn suggest that successful aging involves remaining active, socially engaged, and having a positive outlook on the future⁴. Older people who do not fit this homogeneous mould of aging well and who choose a solitary lifestyle risk believing they have somehow 'failed' the aging process and are left feeling invisible and embarrassed about their lifestyle choice. This research project raises critical questions concerning the types of relationships that are valued by older adults and the necessity for older people to maintain rich social networks. This is not to refute that being socially isolated is problematic for some older people; however, it should not be considered an inevitable, hopeless aspect of old age that needs to be 'combated' by a service provider. Overall, the findings suggest the image of aging well must be adapted to combat the stigma associated with social isolation to better reflect the heterogeneity of a contemporary aging population- who may not be so 'at risk' after all. <

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A BALANCING ACT :

Serving elderly people with severe mental illness

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Today, practitioners working with elderly people with disabilities are increasingly faced with a clientele suffering from a combination of physical limitations and serious mental health problems. This situation can be attributed to the simultaneous occurrence of three phenomena: an increase in longevity in people with mental health problems, which means a greater proportion of this group lives long into old age; significant growth in the elderly population; and, due to deinstitutionalization policies implemented since the 1960s and 1970s, an increasing number of people with mental illnesses living outside of institutions and using the same services as the general public.

Many wonder about the ability of the province's health and social services network to meet the needs of this ever-expanding clientele. In reality, their



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services are organized into programs which could be termed silos. There is a mental health program that traditionally targets the under-65 adult population, and there is an age-associated loss of autonomy program that focuses primarily on services for people with reduced physical mobility and, more and more, reduced mental capacity as well. But what happens when healthcare professionals receive clients presenting both problems? How do they handle these cases? Who should they be referred to? What issues and challenges are they faced with? What solutions have they found?

These questions led to a study involving 26 healthcare practitioners and five managers who were either interviewed or took part in two focus groups¹. Though the majority of participants hailed from four health and social service centers (CSSSs), representati-

ves from hospitals, geronto-psychiatry teams, community organizations and the Agence de la Santé et des Services sociaux de Montréal also contributed.

"A Balancing Act" effectively sums up the experience of practitioners working with older people presenting both physical disabilities and serious mental illnesses. They are frequently faced with dualities that carry over to every aspect of their work. They have to provide services to a clientele with problems that are two-fold. On one hand, they are dealing with people with a long history of psychiatric illness (schizophrenia, bipolar disorder, personality disorders, etc.). These clients are familiar with mental health services even though many of them do not receive ongoing treatment. For the most part, members of this group have developed adaptation strategies, but these begin to falter when a physical disability



comes into play. On the other hand, many clients seek out help for a recent problem, particularly major depression. Many of these people have not been diagnosed and are very reticent to use available mental health services, making it difficult to reach and to treat them.

Beyond the diagnosis, there exists another duality in practitioners' perceptions of this clientele. The first, or "therapeutic," perception focuses on the disabilities or weaknesses of clients, who are treated as patients. From this standpoint, a great deal of emphasis is placed on maladaptive behaviour, most notably in terms of personal hygiene and dangerousness. Another perception, the "humanist" perception, focuses more on the unique nature of these people, their particular life stories and their inner strengths—"They're survivors," says one social worker. Though some may favour one approach over the other, both perspectives tend to co-exist within most practitioners. This dual vision can lead to problems, as each is associated with a different approach to caregiving, which can be difficult to reconcile.

Although some interventions are generalized, since all practitioners stress the importance of ongoing monitoring of their elderly clients' conditions and of ensuring that the necessary services are made available (case management), they fall under two different approaches: The first favours referring patients to mental health professionals, adhering to the treatment plans they prescribe—especially medications—and the adoption of appropriate behaviours, particularly with respect to personal hygiene and diet. The second focuses chiefly on guiding or assisting the elderly person, providing emotional support and forging social ties with the client. Once again, though numerous healthcare professionals tend to opt for one over the other, they typically waver between the two. This ambiguity or fluidity indicates a fundamental problem within the treatment process.

In fact, this issue is at the centre of a perplexing ethical debate: how does one reconcile the safety and security of elderly clients, the importance of instilling the greatest sense of well-being (in

keeping with the notion of beneficence), and clients' autonomy? Many practitioners are acutely aware of this dilemma and feel helpless when confronted with it. In addition to this challenge, the elderly person's refusal to seek help through services and to follow prescribed treatments is another challenge in a therapeutic approach. A more humanist approach can be hindered by clients' resistance to establishing a relationship or conversely, by over-solicitation and dependence. The problems experienced by practitioners cannot, however, be attributed solely to the strategies and actions of older people suffering from severe mental illness. The political and institutional context in which they work renders their job particularly challenging.

As mentioned above, the province's health and social services network is structured around programs. Elderly people with physical limitations and severe mental health problems fall between the cracks, as they are overlooked in mental health policies and by programs concerning age-associated loss of autonomy. Consequently, stakeholders almost unanimously point to a shortage of adequate resources to address this two-fold problem, including accommodations, home care services, crisis centres and social activity programs -- and therein lies the problem of referrals to CSSSs and the network as a whole: Should these clients be referred to mental health services or to services for elderly people with disabilities?

Furthermore, services from one "silo" will often turn these clients away, pointing them in the direction of the other "silo" and thereby creating a ping-pong effect among a highly vulnerable clientele. As a result of the challenges posed by this clientele, many healthcare professionals feel so ill-equipped or unsupported that they refuse to see them at all. These structural constraints are compounded by a variety of irritants associated with the organization of work, namely an excessive workload and insufficient time to properly address these clients' numerous problems, performance indicators that do not account for the complexity of these cases and leave little room for multidisciplinary teamwork

and case discussions—which are vital in order to exchange ideas on various dilemmas and difficulties encountered during interventions—and inadequate expertise and training.

In so outlining the problems of treating elderly people with both physical disabilities and severe mental illness, practitioners have painted a clear picture of a population that is facing social exclusion. These clients are subject to a double stigma because of their age and their mental health problems. They are effectively invisible in health and social services policies and, to a number of healthcare professionals, constitute burdensome and uninteresting cases. The absence of specialized services and facilities, the lack of adequate resources dedicated to this clientele, and the denial of services from two silos that continuously "pass the buck" invariably lead to this clientele's exclusion by public institutions.

Confronted with such difficulties and considerations, healthcare professionals have put forth a series of action proposals touching on virtually every topic raised during the interviews and focus groups. From the outset, they stress the importance of combating stigmatization, educating the public and the professional milieu on health, and increasing this group's visibility by addressing their needs in public policy on mental health. These proposals call for greater access to professional healthcare, home care, transportation, and supportive care and attention services, and for the development of specialized resources in terms of both accommodations and community services, even though some point to a risk of ghettoization. Lastly, in order to optimize their practice, many healthcare professionals are asking for greater opportunities for knowledge transfer and training. We will see if their voices will be heard... <<

1. This article covers the main findings of the study *Identifying Issues, Challenges, and Concerns for Community Frontline Practitioners Working with Older Adults with Severe Mental Illness*, directed by Annette Leibing and Jean Pierre Lavoie, in collaboration with Alan Regenstein and Nona Moscovitz. This research was funded by the Canadian Institutes of Health Research (CIHR).

Seniors: From observers to actors in a study on social participation

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PROLOGUE

This sketch is an inside look at a study commissioned by four organizations¹ on the social participation of seniors in the Québec City region, which has been underway since early 2008. The study emerged following the development of a conceptual model on healthy aging, a component of which is social participation. Two phases of the study have been completed so far: a review of the literature and a consultation with focus groups.

Scene 1

Characters: Elena (68) and Roger (74)
Two friends, Elena and Roger, are taking a walk in the park. When they come to a bench, Elena suggests they sit down because she wants to show Roger an article she has in her bag.

Elena: Roger, look what I've borrowed from my daughter who works at the public health institute. It's about the social participation of seniors.

Roger: Social participation? Sounds pretty racy to me!



Elena: Enough with your little jokes already. You said yourself a while ago how much you like volunteering with the children in the school near you. It makes your life meaningful, you said. Do you think that's what they mean by social participation?

Roger: Yes, Elena, sure it is. I really feel useful when I help Karim with his English homework, and he makes me laugh so much, that little one. And you're being just as useful when you help your 92-year-old mother.

Elena: That's exactly what this article says. That social participation can mean all kinds of things.

Roger: Elena, don't you think that it's a little strange to study something that has so many definitions?

Elena: Hmm, yes, I was thinking the same thing. But, you know, that's what's going on right now: everyone's talking about what seniors can do for our society. We've got to work longer, help our children and our parents, have interesting pastimes, do volunteer work . . . not to mention defending our rights with this shaky pension system we have. It's a pretty big job, all that! At the same time, I'm happy that things have changed a bit, and that I'm healthy enough to do lots of things like see my grandson, sing at demonstrations to protest that last budget . . .

Roger: It's hard to say. Is it right or wrong to say that seniors should be socially involved?

Elena: I know, Roger, it's complicated. That's why we've got to keep infor-

med and talk about these things. There are studies that have shown that social participation, like volunteering with a group, is good for your health. Is that a good reason to recruit more seniors as volunteers? Is this what social participation is really about?

Roger: I don't know about this, Elena. So much the better if my involvement is good for my health, but that's not why I'm a volunteer! Hey, lend me that article so I can read up on this a little more.

Elena: I've got a better idea: let's go to a talk that's being given by two people who are working on the study.

Scene 2

Elena and Roger go to a public lecture organized by the Conférence régionale des élus of Montreal concerning the social participation of seniors. The talk is being given by Émilie Raymond and Andrée Sévigny.

Andrée Sévigny (*addressing the audience*): As we can see, many factors influence the social participation of seniors. For example, accessibility of the spaces in which activities are held is a central issue for people with reduced mobility. People's socio-economic situation is another crucial concern. Our work may indeed lead to the development of more equitable social policies.

Roger (*murmurs to Elena*): I tell you, it takes money to volunteer, especially if you want to be «social» with the other volunteers. You have fun together, so you want to extend the pleasure and go out to eat after.

Elena (*murmurs to Roger*): Shhh, Roger, it's the other speaker's turn.

Émilie Raymond (*addressing the audience*): In the study, we identified around 30 actions designed to stimulate the social participation of seniors that have already been evaluated. The

projects were varied, including community gatekeepers for outreach to isolated seniors, and a group of women activists called the Raging Grannies.

Elena (*murmurs to Roger*): Hey Roger, that's my gang!

At the end of the talk

Andrée Sévigny (*addressing the audience*): Do you have any questions or comments on the presentation?

Roger (*gets up and approaches the mike*): Hello everyone. I'd like to know if you have examples of projects that have been done in Québec to help seniors who want to become socially involved. I think there are lots of examples, for example, the golden age clubs, seniors' steering committees, and retirees associations, like my retired teachers association.

Émilie Raymond: Thank you for your question sir. I have to tell you that we didn't include any Québec projects in the literature review because we were looking for activities that had been formally evaluated and we didn't find any from here. But you're not the only person to raise this, so we decided to continue our study by focussing on what is happening in our region in the area of the social participation of seniors: What people think about it, what's being done, what could be improved or changed. If you like, you can sign up for a focus group. We're organizing a dozen of them, with seniors and with people who work with seniors.

Scene 3

Elena and Roger are riding on a bus. They decided to follow up on the speaker's invitation and signed up for a focus group on the social participation of seniors. They're on their way to the meeting.

Roger: We'll be there in three stops. Thanks Elena, for bringing me to the

lecture the other day. It's made me want to say what I think about being socially involved.

Elena: Did you think about what you want to say to the group?

Roger: I'm going to tell them what I do for others and how I get more out of it than I give. It's mutual, you know? For me, that's what it means to be involved in your community.

Elena: For a man who was so mixed up just a few days ago, you sure seem to have thought a lot about this! It's the opposite for me; I'm more confused than before. Before, I thought social participation meant being committed to a cause, but now, I'm not sure. If some people are happy simply to go bowling Friday night and see their friends, who am I to say that that isn't a way to be socially involved?

Roger: Don't worry, Elena, I'm sure that talking about it with others in this group will make everything clearer. And anyway, it's just a start. This has made me want to take it further.

EPILOGUE

Elena and Roger, and over 100 others, participated in a focus group on the social participation of seniors. The results of this second phase of the study will be available in the next few months. Next, a third phase may be organized, which will make it possible to work with groups and associations who want to get their users or members to think about ways of encouraging social participation. We too, want to explore the subject further. <

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Volunteerism in palliative home care for the elderly

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Every year, 75% of deaths in Canada are attributed to the elderly population, and it is estimated that this number will increase by 33% by 2010¹. As the population ages, medicine is keeping pace, making it possible to prolong the lives of terminally ill patients². As a result, society is faced with the questions surrounding the appropriate use of healthcare resources for elderly persons nearing death³. Currently, only 15% of Canadians have access to palliative or end-of-life care programs, and the demand for end-of-life care for the elderly will only increase over time⁴. In light of these trends, it is becoming ever more important to consider the active participation of all partners, including volunteers. Traditionally, volunteers have played a vital role in the delivery of palliative and end-of-life care⁵.

Despite the large number of volunteers working in healthcare establishments, advancing home care volunteerism appears to be more problematic. Consequently, a process should be undertaken to better understand the factors that further or hinder volunteerism in the field of end-of-life home care for the elderly.

With a view to contributing to the development of knowledge in this field, an exploratory study (a pilot project) was conducted in a region of Québec where the proportion of home deaths is higher than the provincial average (8.2%). Applying qualitative research methods, this study consisted,

in part, of interviews with various stakeholders, including six elderly people who are in the end-of-life stage and who receive home care services from a CLSC, eight family caregivers who provide end-of-life home care to the elderly, eight healthcare professionals (family doctors, nursing staff, social workers, visiting homemakers and case aids), and nine volunteers involved in the delivery of end-of-life home care to this clientele. The findings of this pilot project were used to develop and carry out a study that is presently underway. Funded by the Canadian Institutes of Health Research (CIHR), the project — entitled *L'étude dynamique des facteurs facilitant ou contraignant le bénévolat auprès des aînés en fin de vie qui vivent à domicile*—is being carried out in four different regions across Québec. Using the same methodology as that applied during the pilot project, data is being collected through semi-structured interviews. Forty-five of the 64 interviews scheduled have been carried out, and the qualitative analysis of that data is in progress.

In keeping with the results of the pilot project, the preliminary results of this study reveal the various factors that promote or hamper volunteer participation in end-of-life home care for the elderly. Nonetheless, the results also illustrate the importance of stepping back from a dichotomous (and static) viewpoint in which a single factor is seen as facilitating participation, or the reverse, preventing it. Essentially, volunteer participation in home care for the elderly will be facilitated by the volunteer's and his or her organization's ability to strike a balance between: 1) The capacity to build trusting relationships with elderly patients

and their families while maintaining a certain degree of distance (i.e. the volunteer is "like family", but is not family); 2) The existence of basic rules to govern volunteers' interventions that also provide considerable flexibility in the care they can deliver; 3) The existence of basic rules to guide the actions of professionals from the CSSS network that leave them enough latitude to work together with the volunteers; and 4) The presence of relationships that are formed without clear-cut rules and largely spontaneously, as well as of those that use official communication channels and are governed by a fixed set of rules.

It is hoped that the findings of this study will serve to gain a more thorough understanding of the dynamic of integrating volunteer activities with the actions of others who dispense end-of-life care services to the elderly, while upholding the underlying values and the nature of volunteer work. <<

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QUESTION MARK

Autonomy and Aging

Loss (PALV) or Gain (GALV)?

Michèle Charpentier

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The Obsession with Loss Affects Representation and Services

In this second Question Marks column, I want to examine — or, dare I say it — denounce our obsession with seniors’ loss of autonomy; it dominates and colours the conversation to the point of determining how we name and conceive of health and social services addressed to seniors, for example: services for age-related loss of autonomy (known by the French acronym PALV, for *perte d’autonomie liée au vieillissement*). This is not a trivial concern. Words are not neutral; we use them to represent our world, they structure our thinking and convey a message, which, when disseminated over a long period of time in many contexts, conditions our individual and collective actions. Not only is the emphasis on loss rather than seniors’ strengths and assets scientifically biased and misleading in principle, but it doesn’t match how the seniors we meet in our practice and research define themselves, even those living with disabilities and the extremely elderly.

The data are clear and conclusive: today’s seniors have more formal education, more resources, enjoy a longer life expectancy and better health.¹

So it is false to claim that seniors are the main cause of rising health costs. Many experts and reports demonstrate that the increases are rather due to technological innovations, equipment upgrades and drug costs.² We’re not



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denying the existence of health-related inequality, or the challenges facing seniors with physical, social, psychological and cognitive problems. Our intent is rather to denounce the emphasis on loss and incapacitation, which leads to

a negative and truncated representation of seniors, who are then seen as a burden to their close relatives and friends and to society. Too often, and indeed, paradoxically, the biomedical

continued on page 20 »

paradigm guiding our interventions, which is based on the assessment and measurement of functional autonomy loss, is used to justify cutbacks and service reduction for seniors who are, in fact, dealing with losses (and also gains) associated with aging.

Autonomy despite the losses associated with aging

Our entire team is committed to deconstructing the traditional negative conceptions of old age that associate it almost exclusively with the loss of physical and cognitive capacity, fragility, dependence, and illness. This vision contradicts seniors' own images of themselves and their experiences of aging, in which their independence and emotional, psychological, spiritual, social and even physical assets are of key importance.

Older people simply do not view and define themselves as individuals with diminishing autonomy. Countless personal stories and comments gathered in the course of our research and intervention confirm this. Someone who comes to mind is Ms. H., 92, who lives in a residential centre and insists: «I'm still pretty spry for my age»;³ another is Ms. Josette, a 91-year-old single woman who, despite her fractured hip that must be tended daily, still lives at home and asserts «I'm still standing,» meaning that despite being less mobile, her independence is still a central factor in her self-image.⁴ These examples corroborate a colleague's (Grenier)⁵ findings from qualitative research conducted with older women service users, which refutes the notions of «fragility» and «loss of autonomy» as they are articulated in the health and social services system. Assets and strengths related to old age should be highlighted more, which would reinforce the empowerment of older members of society.

In favour of new names for seniors' services

Rather than simply criticize, something for which researchers are often reproached, here are some proposals that more closely reflect how we view

seniors and the services to which they are entitled. I think it's time we came up with names and acronyms more suited to the 21st century, and less likely to stigmatize older citizens who at some point in their life trajectory and, as they get older, will likely require some services. Maybe someone will hear me. . . Who knows?

So, instead of PALV, SAD (French acronym for soutien à domicile or home support) or MAD (maintien à domicile or home support), I suggest a less negative formulation. How about Services aux personnes âgées: SPA? It's clear, simple, carries no negative connotations, and it's modern. In a more professional vein, our seniors' programs could be known as SAGE: Services d'aide (ou d'accompagnement) en gérontologie (gerontology support services). I can already feel a wave of increased respect and appreciation.

I am open to other suggestions, there's certainly room for creativity. But PALV—for persons with age-related diminishing autonomy—that I can't take. <<

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RECENT PUBLICATIONS

SOCIAL SCIENCE & MEDICINE

Volume 70, n° 10, Mai 2010, Pages 1501-1508

Using the life course perspective to study the entry into the illness trajectory: The perspective of caregivers of people with Alzheimer's disease

**Normand Carpentier
Paul Bernard
Amanda Grenier
Nancy Guberman**

Résumé

The research community is showing increasing interest in the analysis of the care trajectory of people with chronic health problems, especially dementias such as Alzheimer's disease. However, despite this interest, there is little research on the initial phases of the care trajectory. The fact that the first symptoms of dementia are generally noticed by those surrounding the elderly person suggests that the recognition of the disease is intimately linked to interactions not only amongst family members but also amongst friends, neighbours and health professionals. This study focuses on the period beginning with the first manifestations of cognitive difficulties and ending with the diagnosis of Alzheimer-type dementia. Interviews with 60 caregivers in Montreal, Canada were used to reconstruct how older people with Alzheimer-type dementia enter into the care trajectory. Our methods consisted of the analysis of social networks, social dynamics and action sequences. Our findings are presented in the form of a typology comprised of 5 pathways of entries into the care trajectory that are structured around the following four principles of the Life Course Perspective: family history, linked lives, human agency and organisational effects. We believe that analyses of the initial phases of the care trajectory, such as this one, are essential for the application of effective early detection and intervention policies. They are also central

to informing future studies that seek to understand the care experience in its entirety.

Keywords: Recognition processes; Life course perspective; Social network

ANTHROPOLOGY AND MEDICINE

Volume 17, n° 2, 2010 (Special issue, in press)

Inverting compliance, increasing concerns: Aging, mental health, and caring for a trustful patient

Annette Leibing

Résumé

Why, after 40 years of intensive research, is adherence to treatment still an issue? This paper suggests a possible solution to an apparently unsolvable problem: reconceptualizing adherence. To understand how adherence can affect key personnel in any western health system, this study focuses on community nurses working with older mental health patients in Québec. When they spoke about adherence, nurses presented an idealized image of the nurse-patient relationship, namely, the caring nurse and the trustful patient. However, this idealization cannot be reduced only to questions of power and paternalism. By reconceptualising adherence as a 'matter of concern', health professionals and researchers alike might come to understand individual care situations within a broader notion of conflicts in patient care.

Keywords: adherence, trust, caring, older mental health patients, community nurses, matters of concern.

LIEN SOCIAL ET POLITIQUES

62 – Automne 2009, pages 123-134

Vieilliront-ils un jour ?

Les baby-boomers aidants face à leur vieillissement

**Laure Blein
Jean-Pierre Lavoie
Nancy Guberman
Ignace Olazabal**

In Quebec, baby boomers are increasingly becoming carers. In interviews about their experiences as carers, we asked them about their perceptions of old age and aging, to find out specifically what they have to say about their own aging, what they are doing to get ready for it and what this means in terms of demands on health care and, specifically, public services to help and assist them in an aging process that they want to be radically different from that of their own parents.

Keywords: baby boomers, care-giving, aging, ageism, social services <<

Nouvelles pratiques sociales (NPS)

Vol. 24, n° 1 (Autumn 2011)

Dossier :
Seniors: Rethinking Aging, Renewing Practices

Editors :
Michèle Charpentier and Anne Quéniart

Our society is aging. We're hearing it all the time; about the threat it represents. Yet people are now living the increasingly numerous years comprising «old age» in better health, and this is giving rise to multiple forms, paths and experiences of aging. In opposition to the dominant, simplistic and negative discourse, and while acknowledging the reality of persisting inequality and social exclusion, it is reasonable to consider aging anew. In this issue we propose to question our concepts of aging and seniors' civic participation in light of current plural realities: increased life expectancy, changes in retirement, modified relationship to time and other people, intergenerational transmission, new forms of social commitment and grey power. Numerous social issues and problems are still very present and affect aging trajectories: isolation and crumbling social networks, especially in old old-age, economic insecurity—particularly affecting old women who live alone—expanding privatization and barriers to care and services. We want to know: who are the older members of society today, these seniors of the 21st century, and, above all, what place does society reserve for them?

This last question involves social recognition and the consideration of older people's situations and needs. It would seem to be important to examine the answers provided/proposed for and by seniors. In the tradition of NPS, we want this issue to revisit the social discourse about seniors as well as reconsider the related social practices and interventions of our public, private and community-based organizations. This is the reflexive exercise in which prospective authors are being invited to participate.

Articles may come from a variety of disciplines (social work, sociology, anthropology, etc.), present findings from research conducted in Québec or other countries, or propose theoretical thinking and critical analysis on current and emerging practices. The call for papers is thus international

in scope. More specifically, contributions should address one of the three following thematic areas: The first theme is the paths of aging and pluralism of retirement perspectives; the second is seniors' civic practices and forms of social commitment; and the third theme is intervention practices with fragile or vulnerable seniors, often, those who have reached «old old-age.»

Manuscripts should be submitted via e-mail before November 15, 2010, to *Nouvelles pratiques sociales* (nps@uqam.ca).

Authors with questions about this special issue can contact one of the two editors:

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Reminder: The article presentation guide is available in the journal and you can also consult it on our website at <http://www.nps.uqam.ca/appel/guide.php>; however, we want to stress that no article should exceed 35 000 characters, including spaces, notes, bibliography and tables.

WORKING TOGETHER TO IMPROVE THE QUALITY OF LIFE OF MONTRÉAL'S SENIORS

An accessible city and practical transportation alternatives

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The purpose of the Montréal Steering Committee on Seniors (MSCS, also known by its French acronym, TCAÎM) is to provide a structure for coordinated action with seniors' organizations in Montréal to improve the quality of life of seniors, while simultaneously building solidarity with people of all ages. It is a non-profit organization comprising over 55 member groups and 15 partner institutions. The MSCS strives to highlight the economic, social and cultural contributions of seniors, with a special focus on seniors in the city's different ethno-cultural communities. Also, by working with decision-making bodies at the local and regional levels, it hopes to foster the planning and implementation of policies and programs that will improve seniors' living conditions.

Since September 2007, the MSCS has led a coordinated regional process to adapt transportation services to the particular needs of the population's senior members. This initiative is supported by a city-wide committee of partners: Société de transport de Montréal (STM), Ministère des Transports du Québec, Bureau du Taxi et du remorquage de Montréal, Ministère de la Famille et des Aînés, Coalition pour le maintien dans la commu-

nauté, Conférence régionale des élus, Office des personnes handicapées du Québec, and the Regroupement des usagers du transport adapté et accessible de Montréal. If the issue of transportation is of ongoing concern to seniors organizations, it is because access to transportation services, and mobility, in its broadest sense, have a major impact on access to health care, food security and social participation. When we consider seniors' access to a vehicle or to assistance from a relative or friend, or their physical and financial capacities, there is no such thing as equal opportunity when it comes to getting around the island of Montréal. For example, not everyone is able to drive, or even to climb stairs, walk, hear, see, communicate, etc.

The MSCS published an overview of the situation in January 2009. The report, a product of concerted action, is entitled *Seniors' Mobility and Transportation in Montréal: Addressing Issues Facing an Aging Population* (available on the website at www.tcaim.org in complete—French only—or summary version—French and English).

Like the rest of the Montréal population, seniors prefer the car as a primary means of transportation. The next choice after the car is public transit, followed by walking. Taxis, para-transit and volunteer transportation services are used less frequently. However, a «means of transportation» cannot necessarily be equated to «mobility.» Having access to a means of transportation means being able to get to it, climb on or into and get

off of or out of it, being eligible for it, able to pay for it, able to understand the instructions, etc. The principle of accessibility must be promoted systematically because, as demonstrated by the MSCS study, there are multiple factors related to the level of response concerning mobility needs. For example:

- Physical condition (problems with vision, hearing, walking, etc.).
- On the Island of Montréal, 101,190 seniors stated that they have at least one disability; in other words, 40% of those aged 65 or older.
- Available options (driver's licence, help from family or friends, access to a vehicle or public transit, etc.).
- On the Island of Montréal, over one in two seniors (52%) do not drive.
- Financial resources:
- 28% of Montrealers aged 65 or older live below the low-income cut-off (LICO) level.
- Perceived safety:
- Many seniors will not use public transit or walk out of fear of falling or of being mugged or assaulted.

Seniors, particularly in Montréal, are a diverse group with multiple needs. Those most at risk of having insufficient access to a means of transportation are undoubtedly seniors who, in addition to having a disability, live alone and are poor. That being said, as people get older, the functional

continued on page 24 »



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and cognitive skills necessary for the use of different means of transportation, whether a car, public transit or walking, are such that getting around on one's own is increasingly difficult. The report clearly shows that there is no single answer to the problem of mobility for seniors in Montréal. In fact, a plethora of initiatives have already been implemented or are in the process of being implemented by the different partners.

We're happy to present some of the actions being planned or already underway:

- The STM recently set up a shuttle bus service for seniors in seven Montréal neighbourhoods – the Navettes Or. In the sectors of Montréal-Nord, Saint-Michel, Rosemont, LaSalle, Rivière-des-Prairies, Mercier-Est and Hochelaga-Maisonneuve seniors now have the use of a minibus that travels through those areas outside rush hour periods, with stops placed strategically for older persons.
- The STM is also pursuing its efforts to increase accessibility:
 - total replacement of the existing fleet with low-platform buses;
 - renovation of Metro stations through the installation of escalators and elevators (including Lionel-Groulx and Berri-UQAM); and
 - refitting Metro cars according to principles of universal accessibility.
- The City of Montréal is gradually increasing the time allotted to pedestrians to cross the street. It also plans to prioritize snow removal of sidewalks.
- The Ministère des Transports du Québec (MTQ) is implementing measures for Montréal taxi drivers in which all drivers must complete seven hours of training about the transportation of people with functional limitations.

Despite all these measures, numerous challenges remain. Priorities include the development and consolidation of medically-motivated volunteer trans-

portation services. Up till now this type of service has mostly been provided by community groups with limited resources, volunteers and financial means. The demand for this service has multiplied tenfold due to the ambulatory shift and the policy of keeping seniors with diminishing autonomy at home, and community groups have reached the limit of what they can do. For low-income seniors who do not have any close relatives or friends to help them or who cannot get around any other way, this user-friendly reasonably priced service is essential.

Clearly, the quality of seniors' lives will not be improved without the creation of practical transportation alternatives that meet actual needs. This requires ongoing concerted action by all concerned stakeholders. The MSCS continues to lobby specific stakeholders and to work in concert with them to fulfill this mission. More than ever, we must make Montréal a more welcoming city for seniors and as a result, a more welcoming city for everyone! <<

Volunteering gives a sense of meaning to one's life

Claire Lachance

Volunteer and proof-reader

It must have been serendipity when, in 1975, at the age of 35, I started going to a residential senior care centre to visit my mother's best friend, her confidant of over 40 years. At first, with my rather introverted nature, I was afraid of change, and especially, of any special responsibilities that made me stand out from the crowd. I set aside one afternoon per week to visit this 65-year-old woman, and over time began to like caring for others and making them happy. I developed the fairly essential skill of being a good listener and a commitment to helping less able people who were gradually becoming more dependent. Learning about illness, aging and, especially, death—which frightened me terribly—became the main impulse for me to continue along this important path. I had finally discovered my mission down here on Earth!

As the years went by I became familiar with all kinds of disturbing conditions: senility, cognitive impairment, cancer, the aftermath of a stroke, multiple sclerosis and amyotrophic lateral sclerosis, and to top it all off, Alzheimer's.

I began spending time with other older women in my neighbourhood, listening to them and encouraging them, playing cards, praying together, sharing in their happiness, anguish, trials and even mourning. For everyone, moving into a residence is a major change, and eventually we must gather our courage and consider the possibility. Sometimes we end up going against our will, which makes it all the harder.

My friends gradually came to know that I was devoting my free time—between my classes and the choir—to visiting seniors in eight homes and residences. My heart won't let me say no; I've learned to listen, love and give without receiving anything in return. I find peace and serenity in fulfilling my mission, which is also rewarding and makes me feel valued. As the

«Learning about illness, aging and, especially, death—which frightened me terribly—became the main impulse for me to continue along this important path.»

demand grew, I was careful to balance my schedule to take into account my own health and personal responsibilities. I schedule my visits according to need, always beginning with people who are isolated or have been abandoned, who face long and empty days.

Here's a funny anecdote. A woman came up to me in the grocery store one day and said:

- «You're lucky, you don't work.»
- «No! I don't have time to work. With the 25 seniors I visit every month I don't have a single day free for paid work; volunteering keeps me going and voluntary simplicity costs so much less.»

I spend the money I earned when I was younger and my father taught me how to save. My mother bequeathed to me all her tricks for how to make do with nothing. I've chosen a simple lifestyle.

My 35 years of volunteering in geriatrics have been like a long love story filled with moments that taught me to develop all kinds of previously unknown facets of my character. Now I'm 70 and the time has come to «retire» from volunteering (for health reasons). But can I really do that? I don't think so.

After all these years spent with the elderly, I have not changed the attitude I adopted when I was in my thirties. The expression «old age» isn't in my vocabulary and is not part of my world view. There's a saying that I still follow: «One day at a time.» I accept reality without worrying about it. I only care about one thing: I want to keep up what I've learned from my proofreading work right until the end. I like to stimulate my brain with intellectual games. I'm thrilled to be constantly discovering new horizons.

I firmly believe in doing everything I possibly can to stay engaged and prolong my youth until my last breath, if possible. I think that a person is old when their spirit has gone. My sharp centenarian friends don't show any sign of senility; I admire them so much for their mental vitality. It is on this path that my volunteer work has led me. <

A spoonful for Dad...

Jacques Boulerice

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In the parking lot of a CHSLD, a residential and long-term care centre, a man sits waiting. In his car, he waits today as he did last Sunday, and just as he will in a week's time. He waits for one hour, sometimes longer. He waits for his significant other to finish feeding his own father, as this is something he can no longer do for himself... his frail, withering father. Faced with the question of why he doesn't help his dad, he remains speechless, a lump in his throat. His inability to answer that question is as overpowering as his inability to walk arm in arm with an old man taking his last steps. He does not know what to say. He does not know what should be done, nor how to do it. He simply doesn't know, that's all.

Perhaps it's the fear of looking into his eyes and seeing a stranger? Or maybe it's seeing nothing but his own reflection in empty eyes? Could it be the terrifying thought of words being uttered that bring back the inescapable misunderstandings time has amplified? Perhaps. But all this is as true for the daughters offering spoonfuls as it is for the sons waiting in cars. Daughters understand the tenderness of catching food trickling down one's chin, even the chins of strangers, who they often help after having finished with their loved ones'. The sons wait an hour, and another after that.

A man suffocates, choking as he awaits his wife's return. He can't breathe. He figures it's the sun turning the inside of his car into a sweltering box, despite the grey November sky. In an act of increasing futility, he adjusts and readjusts the openness of his window. Deep inside he knows he's stifling for never having learned to draw those few words out, to command them, to coax them all the way to his tongue. He never learned to bridge the gap between warm tears and cold sweats, waiting and being waited on. He can't even recite the chorus of an old tune for his father, an act that might make bearable the long silences between words interminably repeated in the smothering, humid room. Such gestures carry more weight than the dense air.

Behind the CHSLD windowpanes, on which his gaze is fixed, he imagines the scene. He sees the tiny spoonfuls between which an old man asks a woman he no longer recognizes for news of his son, over and over. She merely offers him smaller bites to keep him from choking, but it's all in vain.

And in the car, too, it's all in vain. <

AGING AND CHALLENGES IN INTERVENTION

Professional Development for Practitioners

The Centre de recherche et d'expertise en gérontologie sociale's training sessions are an opportunity to share knowledge gained from research and innovative practices with seniors. They are given by practitioner-researchers and expert practitioners who are developing cutting-edge services at CSSS Cavendish. These sessions will be useful for addressing the challenges faced by health and social services network and community-based practitioners.

Register for the training sessions listed on CREGES' schedule or contact us to set up a session in your organization. CREGES is an Emploi-Québec certified training agency.

Registration and information: 514-484-7878, extension 1603 – creges.cvd@ssss.gouv.qc.ca – www.creges.ca

DATE	THEMES	TRAINERS	PLACE
Friday October 29, 2010 9:00 – 17:00	Caregiving in the Palliative Stage : A Training for Multidisciplinary Professionals (English)	Patrick Durivage Soins palliatifs à domicile Esther Hockenstein Centre de soutien aux aidants naturels	CSSS Cavendish CLSC René-Cassin 5800 Cavendish Blvd. 6th Floor, Room 31
Wednesday November 17, 2010 9:00 – 17:00	Musclez vos méninges Promouvoir la vitalité intellectuelle des aînés Formation d'animateurs	Manon Parisien Prévention et promotion Santé et vieillissement	CSSS Cavendish CLSC René-Cassin 5800 Cavendish Blvd. 6th floor, Room 31
Friday November 26, 2010 9:00 – 17:00	L'outil « AIDE-Proches »	Nancy Guberman Chercheure associée, CREGES Centre de soutien aux aidants naturels	CSSS Cavendish CLSC René-Cassin 5800 Cavendish Blvd. 6th floor, Room 31
Friday January 28, 2011 9:00 – 17:00	Counselling de courte durée auprès des proches aidants	Esther Hockenstein Centre de soutien aux aidants naturels	CSSS Cavendish CLSC René-Cassin 5800 Cavendish Blvd. 6th floor, Room 31
Thursday February 17, 2011 13:30 – 16:30	Introduction aux soins palliatifs à domicile	Patrick Durivage Soins palliatifs à domicile	CSSS Cavendish CLSC René-Cassin 5800 Cavendish Blvd. 6th floor, Rooms 19-20-21
Friday March 11, 2011 9:00 – 17:00	Abus envers les aînés : Pourquoi dépister ?	Sarita Israël Centre québécois de consultation sur l'abus envers les aînés	CSSS Cavendish CLSC René-Cassin 5800 Cavendish Blvd. 6th floor, Room 31
Friday March 18, 2011 9:00 – 17:00	Abus envers les aînés : L'intervention, de la théorie à la pratique	Sarita Israël Centre québécois de consultation sur l'abus envers les aînés	CSSS Cavendish CLSC René-Cassin 5800 Cavendish Blvd. 6th floor, Room 31
Friday March 23, 2011 9:00 – 17:00	Jog your mind Promoting the intellectual vitality of seniors Training group leaders (English)	Norma Gilbert Prévention et promotion Santé et vieillissement	CSSS Cavendish CLSC René-Cassin 5800 Cavendish Blvd. 6th floor, Room 31
Friday April 8, 2011 9:00 – 17:00	PARBAS Application de l'échelle psychogériatrique de dépistage des comportements à risque dans les plans d'intervention individuels	Alan Regenstreif Santé mentale et vieillissement	CSSS Cavendish CLSC René-Cassin 5800 Cavendish Blvd. 6th floor, Room 31
Friday May 6, 2011 9:00 – 17:00	Problèmes de santé mentale et personnes âgées	Alan Regenstreif Santé mentale et vieillissement	CSSS Cavendish CLSC René-Cassin 5800 Cavendish Blvd. 6th floor, Room 31
Friday June 7, 2011 13:30 – 16:30	Introduction aux soins palliatifs à domicile	Patrick Durivage Soins palliatifs à domicile	CSSS Cavendish CLSC René-Cassin 5800 Cavendish Blvd. 6th floor, Room 31



JOG YOUR MIND

A PROGRAM OF COGNITIVE VITALITY FOR SENIORS
A WORKSHOP MANUAL – A GROUP LEADER TRAINING – AN ONGOING STUDY

CENTRE AFFILIÉ UNIVERSITAIRE CAVENDISH

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