



# pluralages


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## HETEROGENEITY OF AGING: BODIES, IDENTITIES AND SOCIETY



Centre de recherche et d'expertise  
en gérontologie sociale

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## The heterogeneity of aging

*This new issue of Pluralages features articles related to the second research pillar of the Centre for Research and Expertise in Social Gerontology (CREGÉS), titled Heterogeneity of Aging: Bodies, Identities and Society. The work of the CREGÉS team has, for a number of years, been focused on multiple ways of aging. The title of the first grant application submitted by the VIES team in 2003 reflected this pluralistic view: Viellissements, exclusions sociales et solidarités (Ways of aging, social exclusion and solidarity).*



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*It is essential to take into consideration elements such as socioeconomic background, gender and ethnicity in order to properly understanding aging.*

The CREGÉS team has consistently sought to break with the notion of “being old” as a main defining characteristic—a one-dimensional view that erases the many differences between groups and individuals. It is essential to take into consideration elements such as socioeconomic background, gender and ethnicity in order to properly understanding aging. This stance does not, however, prevent researchers from looking at elements of homogeneity: sometimes groups of seniors are more alike than they are different.

Over time, members of the CREGÉS team have turned their attention to different aspects of heterogeneity, including sexual orientations, stem cell procedures and living environments. But their central interest in diverse experiences of aging has remained constant: it is part of their DNA.

This pluralistic vision of aging is increasingly accepted, both by the scientific community and the general population. It is common nowadays to distinguish “young-old” seniors (young retirees who are active and generally in good shape) from “middle-old” and “oldest-old” seniors whose lives are more likely to be marked by disability and illness. Although these distinctions are reductive, a number of authors believe they offer a more accurate and subtle notion of aging.

Values and norms have significantly evolved in recent decades, creating far more openness and individual freedom. We have rid ourselves of numerous social frameworks and constraints that formerly structured our lives. However, other requirements have taken their place. The popularity of anti-aging creams, plastic surgery and sexopharmaceutical products show the extent to which an ideology of eternal youth and exclusion of aging have become powerful social norms. ➤

Along with our emphasis on the individual comes an excessive sense of responsibility. Whereas before our fate was determined by the context in which we were born, today we have to create our own life story and plan our own biography. We consequently shoulder an increasingly heavy burden of responsibility—that of our life path, our successes and failures, and finally, the manner in which we age. There is an immense pressure to “live well”—in other words, to live in good health and independently—that tends to ignore the many social and environmental factors influencing our lives.

The idea behind this collection of articles is to make researchers and practitioners more aware of the wide range of notions, theories, norms, practices and experiences shaping this last stage of life.

We hope that this issue of *Pluralages* will offer ideas and information to feed complex, multi-faceted debates on aging—a social construction that is deeply rooted in an inevitable biological decline.

Happy reading!

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# Understanding caregivers in research on aging

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**Interview with Jean-Pierre Lavoie, an institutional researcher at CREGÉS for 10 years before he retired.**

IVP: Over the course of your career, you've worked extensively on issues related to the caregivers of older people. Could you explain how their identity has evolved through the act of caregiving? This is, in fact, the subject of your thesis<sup>1</sup>.

J-PL: When I compare the interviews I carried out in the 1990s for my thesis with more recent interviews of baby boomer caregivers, conducted with Nancy Guberman, I can see a clear evolution. In my thesis, I talked about how my respondents were uncomfortable with the term "caregiver." My original question was: "What kind of care are you giving to your parent?" They would respond, "I'm not giving care." So I reformulated the

question: "What are you doing for your parent or loved one?" Then they opened up a lot.

For these individuals, taking care of a parent was part of their role as a spouse or daughter. I've been struck, over the past 20 years, by how many women (this seems to be a dominant trend but not the only one) have gone from feeling uncomfortable about the term "caregiver" to actually claiming it.

IVP: They're self-identifying as such.

JPL : Yes: "I am a caregiver." Identities and filial relationships have been redefined.

IVP: How about conjugal relationships?

JPL: That's different; the trend is less marked amongst spouses. There's also the question of age. Female identities have become more complex and filial obligation doesn't have the same force or meaning as 20 or 30 years ago. Women have increasingly been telling me, in very clear terms, that they have a multi-faceted identity—as spouses, mothers, workers and sometimes grandmothers.

IVP: Our identity is more divided.

JPL : Yes, more divided. Our identities are more complex and pluralistic, and women have to try to reconcile all of these ➤

identities. It's a more complex task than before, because the hierarchy of roles is not as clear.

IVP: And there's less obligation.

JPL: There's certainly not the same degree of obligation. In my thesis, I described situations where women would agree to stop working and stay at home. I felt that some of them regretted that decision. In my more recent studies on baby boomers<sup>2</sup>, many individuals felt more than regret; they felt a sense of injustice and anger. They were indignant about having to stop working, for both economic and identity-related reasons. This difference can also be attributed to the

Now messages about caregivers carry a certain weight. In my thesis I demonstrated a kind of "de-commodification" of family ties between adults. When you have children, there is always a degree of practical obligation: you have to do things for them, prepare meals, do housework. But relationships between adults are becoming "de-commodified"; they are becoming more recreational and emotional. The instrumental aspect isn't necessarily there.

This dematerialization of ties of solidarity has also affected other generations. In my study on values and norms<sup>3</sup>, I noted a growing reluctance among seniors to have their children help

a dependant.

IVP: Caregiving implies dependence.

JPL: It's a bit like illness. Dependence is shameful. However, when you receive an old age pension and guaranteed income supplement, you're depending on the state.

IVP: It's an anonymous form of dependence.

JPL: The moment it becomes a right, you're no longer dependant. For most people, receiving a pension is perfectly normal; it's an obvious right. I don't know many people who feel embarrassed about cashing in their pension cheque, although the same might not be true if they were cashing in a social assistance cheque. When we're entitled to a service, it reduces the feeling of dependence. Receiving a pension means you're not dependant on your family or friends; you become independent. In defining this right, the government has allowed us to become autonomous and independent.

In my research, I've met seniors who hated the fact that home support workers made them feel like they were receiving a privilege or a gift. "You're lucky to have this . . ." When you say things like that, you're re-establishing a tie of dependence and you're undermining the

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*In my research, I've met seniors who hated the fact that home support workers made them feel like they were receiving a privilege or a gift. "You're lucky to have this . . ."*

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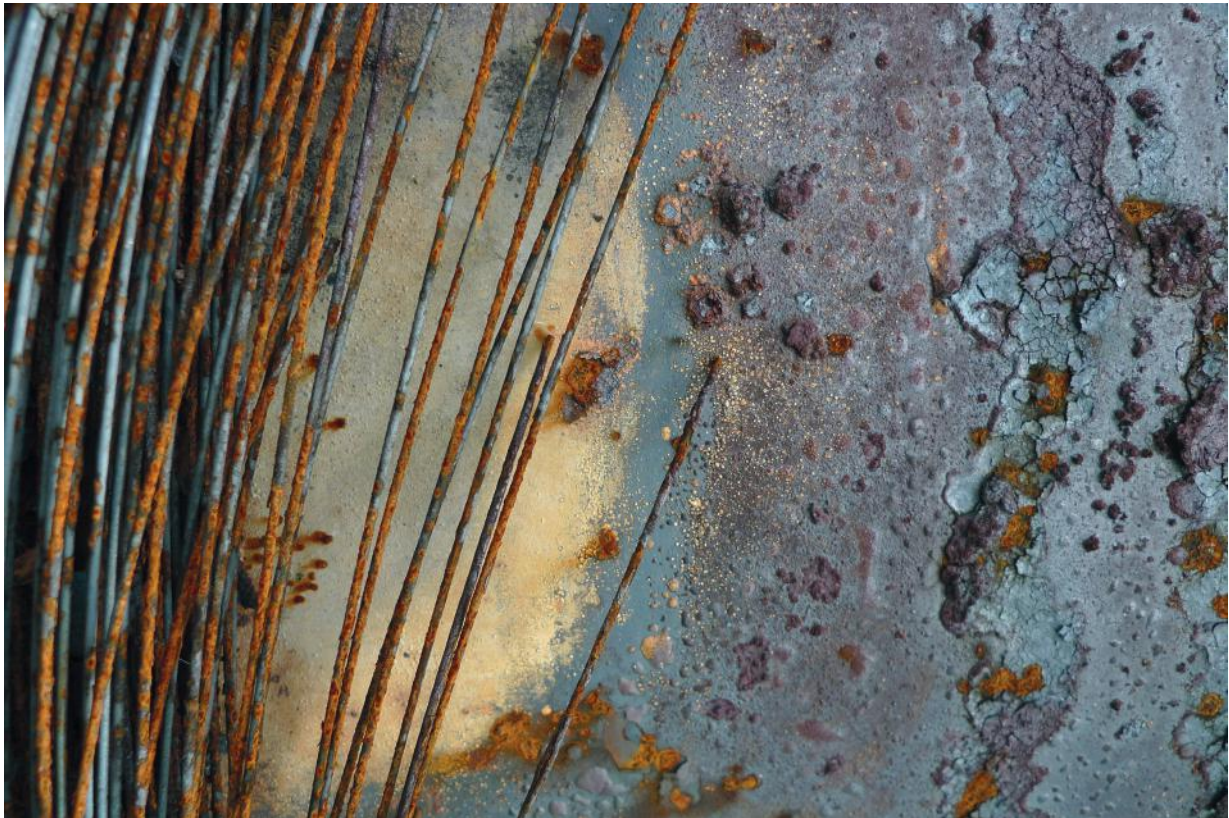
fact that the baby boomers were the first generation of women to juggle motherhood and a career.

IVP: But if you don't label yourself a caregiver, you're not entitled to support services.

JPL: I think the label has been imposed to an extent by the research community and policymakers. We're the ones who started using it. If we hadn't talked about it 60 years ago, the term wouldn't have much resonance today.

them in a material, concrete way. We want to see our children. We love and adore them, and we want to spend time with them. But if they systematically prepare our meals, dress us in the morning, bathe us . . . for a lot of people this is a form of dependence and loss of autonomy, with a corresponding loss of dignity. Parents don't want to have that type of relationship with their children. It also affects their identity. For elderly parents, it means taking on the identity of





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person's dignity. In the study on baby boomers, home support workers complained that their clients saw home care as a right. But if you read the Act Respecting Health Services and Social Services, it is a right.

IVP: Home support workers are also in a difficult position, because they see people who don't even have the basic service. It's a vicious circle: "The woman next door doesn't even have this."

JPL: It's also a way for workers to assert their authority.

IVP: OK. But some workers might feel really bad about not being able to provide all the services the person needs, so they get

around it by saying, "Consider yourself lucky." Perhaps it's a way for them to avoid cognitive dissonance: "I can't offer the services I'm supposed to offer."

JPL: Then why not say something like, "You're right, Madam, you should have a lot more services than what you're getting, but unfortunately, it's impossible for us to provide them to you in the current context. And yes, you have the right to be upset."

IVP: It restores the person's dignity. Coming back to the identity of caregivers . . . for me, one way to interpret the fact that people are claiming this label is because they want their role to be recognized. It's like homemakers,

whose work is invisible and unrecognized. "I'm doing this job, but nobody recognizes the value of what I'm doing!" People think if they don't claim this role, their work and usefulness will remain invisible.

JPL: It is more subsumed in their role as daughter. It's not natural or normal to change your mother's diapers, give her a bath and or stay up all night because she can't sleep. My life is being turned upside-down, but it's not necessarily my role. Why did the government support me when I had kids, but not when I'm taking care of my aging parents?

It's not a question of shirking your responsibilities. ➔

Support workers would often complain to me that caregivers ask for too many services: "They don't want the responsibility; they hand it all over to me." The vast majority of these workers had not been caregivers themselves, but even if they had, they still had the same attitude. So I would draw a parallel by asking them, "Do you have children? Do you feel responsible for their education?" "Yes." "OK, then what are you doing here at work? Shouldn't you be at home teaching your kids? If you're responsible, then you're the one who should be teaching them." "No, we're not trained for that. We send them to school, because we know they'll get a better education there." "So how is that different from a caregiver who finds that a home support worker or nurse is better equipped and trained to do the job?"

It's important to recognize that caregivers have a strong sense of responsibility. You want to make sure that the person providing care to your mother will do so more effectively than you. You most likely don't have training as an aide or nurse, because you probably weren't attracted to that type of profession. Caregivers feel just as much responsibility toward their parents as home support workers feel toward their children. But when a task becomes too difficult or complex, we hand over the reins to an expert or at least

someone who is trained to do the job properly.

The Saguenay-Lac-Saint-Jean school board has been toying with the idea of getting rid of lessons and homework for elementary schoolchildren. Where is the resistance coming from? Parents. Because lessons and homework allow them to see what their children are doing at school, what they're learning and how they're progressing. It's a monitoring mechanism.

Support workers say that caregivers are offloading their responsibilities, but these same workers also complain about caregivers constantly watching over them. That is exactly what we do with our children. We check their homework and lessons. That's how we monitor their progress. And if the child is having difficulty at school, we go and talk to the teacher.

We can't reproach caregivers for doing the same thing. When a task is complex, you don't take it on yourself; you get someone to do it for you. It's a great way to show your sense of responsibility.

Except in the case of a medical event such as a stroke, the caregiving role is also assumed gradually. People's first reflex is not to call the CLSC. They're able to manage the shopping and paperwork, because it's not too challenging and they do the same

thing for themselves. But then at some point, they find they're doing everything in the house and start to feel overwhelmed.

They might be instructed to give injections. "But I'm not a nurse!" There are people who can't give injections. You have to respect that; not everyone is the same. When you push someone to do something they don't feel capable of doing, you're asking them to go beyond their responsibilities. The person will feel very bad, especially if something happens. "I knew I couldn't do it; it was too much for me."

**IVP: Where are we headed? Both caregivers and workers are overworked, and workers are blaming caregivers. There are fewer and fewer services...**

JPL : In fact, there are more services. Budgets are increasing and so is the number of home care support services. Over the past 10 years, the average number of services per user has increased. In the late 1990s, around 8% of evaluated needs were satisfied. Today 10% of needs are met. The number of services has increased since 2004, but so has the number of clients and needs. They're continually raising admission criteria for seniors' residences, which means that people who are increasingly incapacitated with growing needs are finding themselves at home. ➤

IVP: So the increase in services is not actually meaningful.

*JPL : The number of services per user has risen from 22 to 31—a 40% increase. Clients' needs have probably not increased to the same degree. An increase from 8% to 10% is not much to boast about. The way things are going, the increases are still very slow, despite all the promises.*

*And we haven't yet seen the biggest increase in needs, because baby boomers are still young. When they reach the age of 80 or 85 . . . The difference is that they are very articulate and are accustomed to voicing their opinions. We'll certainly have a more vocal group of seniors. The future will be very different to the current situation.*

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1. Lavoie, Jean-Pierre (2000). *Familles et soutien aux parents âgés dépendants*. Paris, L'Harmattan.
  2. Blein, Laure, Jean-Pierre Lavoie, Nancy Guberman et Ignace Olazabal (2009). « Vieilliront-ils un jour? Les baby-boomers aidants face à leur vieillissement ». *Lien social et politique*, 62, p. 123-134.
  3. Guberman, Nancy, Jean-Pierre Lavoie, Eric Gagnon et al. (2005). Valeurs et normes de la solidarité familiale : statu quo, évolution, mutation? Report presented to the Fonds de recherche du Québec – Société et culture as part of the program "Action concertée sur les impacts démographiques et socioéconomiques du vieillissement de la population," 101 p.

# How people with Alzheimer's experience their disease

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***In this article, we present some results of our research on how individuals with Alzheimer's experience their condition in the early stages<sup>1</sup>. The aim of this study, conducted within a phenomenological sociology theoretical framework, was to listen carefully to patients' perspectives in order to understand their experience of the situation<sup>2</sup>. This approach allowed us to avoid analyses based on lack of awareness, anosognosia or denial and, as we shall see, to depart from common, one-dimensional portrayals of Alzheimer's disease<sup>3</sup>.***

Our empirical data is based on interviews conducted with 27 individuals who had received a diagnosis of early-stage Alzheimer's disease (MMSE>20). The sample was created through the CMRR (memory research and resource centre) of Lille University hospital. The patients interviewed (11 women and 16 men) ranged in age from 52 to 92 years. They were mostly upper middle-class, but just over a third of the sample (N=10) included former

blue-collar workers, employees and farmers. Most of the patients were living with a spouse (N=17) or child (N=4), and six were living alone (including three in a retirement home).

This article is divided into three sections. In the first, we describe one of the surprises of this research—namely that for many of the patients interviewed, Alzheimer's disease did not appear to be as dramatic as one

might imagine. In the second section, we offer a typology of the various ways in which patients defined their current situation. Finally, in the third section, we show that, in order to understand these experiences, it is essential to situate them in the interpersonal context in which they occur. >

## ALZHEIMER'S DISEASE: LESS DRAMATIC THAN ANTICIPATED

What was most striking about our interviews was the fact that patients with Alzheimer's disease did not appear (or at least not always) to attach as much importance to their disease as we might have imagined. Many of our interviewees described the disease as a matter of secondary concern. They were very forthcoming about their various activities and interests (past and present), but spoke relatively little about their disease, even though that was the ostensible reason for the interview. When describing their health, they would focus more on symptoms than on the disease itself. For example, they would mention memory loss, difficulty situating themselves in time and space, forgetting words—difficulties that were clearly observable in certain interviews. When we asked them to describe more specifically how they felt about the diagnosis, they gave varied responses. Some accepted and took ownership of their disease, even using it sometimes to justify strange behaviours. Others, in contrast, seemed either indifferent to their diagnosis or angrily rejected it.

Respondents tended to describe the seriousness of their disease in relative terms, thus giving it less weight in the interviews. These statements took a variety


of forms. For example, memory problems were described as a "slight inconvenience," or were interpreted as a "lack of attention" or "poor concentration." Patients also compared these symptoms with other health problems they considered more serious, or other far more difficult ordeals in life such as the death of a spouse, a child's health problems or the sudden loss of a job. Patients would also say things that would distance them from "real" Alzheimer's patients, typified by the old, senile patient who is "out of it" and no longer recognizes his or her loved ones.

Another surprise from the interview data is related to the tone of many interviews which, rather than being dramatic, were quite serene or even positive. Of course, everyone's experience is different, and many of our interviewees' accounts were tinged with sadness and suffering. One woman seemed completely bored. Others regretted the loss of their abilities—for example no longer being able to drive or to go out without getting lost. Others expressed concern about the future, uncertainty about how quickly their disease would progress, and fears about completely losing their mind. However, there were far fewer statements reflecting suffering or discomfort than we had anticipated; in the vast majority of cases, the interviewees seemed content with their current lives.

## VARIOUS DEFINITIONS OF THE SITUATION

As noted above, many of the interviewees described the seriousness of their disease in relative terms. We realized, on closer examination, that their statements needed to be seen in relative terms as well.

From a temporal viewpoint, respondents' tendency to downplay the seriousness of the disease in the present contrasted with their initial reaction to the diagnosis. Although we were not able to systematically gather these types of statements, they showed that the diagnosis was often experienced as something violent and painful ("a shock," "an up-percut," "a meltdown"), because the patient immediately associated the disease with the stereotypical image of a "senile old person."

Respondents' tendency to describe their disease in relative terms was particularly pronounced in a portion of the interview sample. We therefore decided to push our analysis further and to outline a typology of interviewees' experiences of Alzheimer's disease at the time of the study. We were able to distinguish two main ways of defining the situation, which we characterized as "doing without" or "making do with" the disease, depending on the degree to which the individuals felt their 

memory loss had a major impact on their identity and present life.

Those who preferred to “do without” the disease experienced their memory loss as something of relatively little concern: they felt that the memory loss was mild, did not have much of an impact on their life and did not really change who they were—to the point that they even questioned the diagnosis of Alzheimer’s disease. This was the case for Mrs. Lilas, a former pediatric nurse, aged 84, who did not appear to be overly concerned about the disease (“I feel like I don’t really have it”), which was not very present in her life (“I know it’s there, in a dark corner. But it doesn’t make me suffer, so I just live with it.”)

Then there were those who opted to “make do with” the disease, who somehow appropriated it, accepted it as part of who they were, and recognized that it was having (or would have) an impact on their life<sup>4</sup>. These “making do with” statements fell into three distinct categories: “coping with observed losses”; “facing the disease” and “learning from the disease.” In the “coping with observed losses” category, the disease was seen in terms of loss: a loss of former abilities, a loss of certain activities that could no longer be carried out, and a loss of autonomy. Patients accepted these losses to varying degrees

and were still able to derive joy from life. In the “facing the disease” category, there was an element of worry and struggle: struggle against the disease in an attempt to stall its progress (through exercises or participation in clinical trials), and a struggle to keep up regular activities and preserve their autonomy. Finally, in the “learning from the disease” category, the attitude was one of discovery: the disease was seen as an opportunity to re-prioritize and live life to the full.

### PUTTING EXPERIENCES OF THE DISEASE IN CONTEXT

Our interviews reflected a full gamut of emotions—from very negative to ambivalent to very positive. To understand this range of experiences and the degree of well-being expressed in most of the interviews, we had to resituate our interviewees in their interpersonal (family) context, which were potentially a source of insecurity and suffering or, on the contrary, of protection and contentment.

Some interviewees described a family situation that did not allow them to adjust well to their Alzheimer’s disease, either because they felt cut off from their family members, or because their relationship with caregivers (notably their children) was a source of mutual incomprehension.

Other interviewees described a family environment in which loved ones were overbearing, which they found very destabilizing. They felt they had to follow a pace of life that was out of sync with their own—a phenomenon we refer to as “temporal disjunction”—and they also felt their autonomy was threatened, because their loved ones tended to do things for them and anticipate the progression of their disease, at the risk of accelerating it in a kind of self-fulfilling prophecy.

When the family environment is both protective and supportive of the person’s autonomy, patients with Alzheimer’s adapt to their disease. Couples are able to strike a “balance” in their daily interactions; loved ones learn to intervene when necessary without making patients feel they are completely incapable of doing anything.

Another interpersonal context conducive to a positive experience of the disease is a strong presence of loved ones who take charge of many aspects of the patient’s life and build a sort of protective cocoon around him or her. Unlike the patients described above, these patients accept their dependence through a process of letting go, which happens as the disease progresses. One of our interviewees (a former accountant, aged >



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82) noted how much the presence of his wife was important to him: today he is no longer interested in much, but is happy to defer to her.

This study points to a gap between the experiences of patients with mild Alzheimer's disease and common representations of the disease. Our interviews paint a very different, far less dramatic portrait of Alzheimer's disease than the usual very negative portrayals. This does not imply that we should simply replace these negative portrayals with positive ones. Rather, we should recognize that Alzheimer's is far from being a homogenous disease

category when it comes to individual experience.

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1. This study, carried out in the CeRIES sociology research centre (Université Lille 3), was funded by the Fondation de Coopération Scientifique pour la Recherche sur la Maladie d'Alzheimer et les Maladies Apparentées. This article summarizes the initial results, which are presented in more detail in Chamahian, A. & Caradec, V., *Vivre "avec" la maladie d'Alzheimer. Des expériences en rupture avec les représentations usuelles de la maladie. Retraite et Société* (forthcoming).
  2. Cotrell, V., Schulz, R. (1993). The Perspective of the Patient with Alzheimer's Disease: A Neglected Dimension of Dementia Research. *The Gerontologist*, 33(2), 205-211.
  3. Ngatcha-Ribert, L. (2012). *Alzheimer : la construction sociale d'une maladie*. Paris : Armand Colin.
  4. Baszanger, I. (1986). Les maladies chroniques et leur ordre négocié. *Revue Française de Sociologie*, 27(1), 3-27.





# Participating in clinical trials: masculinity, stem cells and heart disease

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***One of the ways to understand the many trajectories of aging is to focus on individuals who have, for a variety of reasons, enjoyed privileged access to health care and are therefore able to envisage an aging process that would not otherwise have been possible. This article is based on interviews conducted with men aged 53 to 77, living in a major Canadian city, who suffered serious heart incidents and subsequently took part in a clinical trial program involving the use of stem cells. As a result of their participation in this program, these men have new hope for the future, are able to make concrete plans and can entertain the possibility of aging "in good health."***

Given that a heart damaged by a heart attack cannot be repaired, because the tissue is scarred, mechanical devices (cardiac stents, bypasses) and medications (e.g., beta blockers) are used to keep the organ minimally functional. Heart transplants are a possible, although less attractive alternative, because of serious risks, including complications arising from immunosuppressive

therapy. There is also a shortage of donors. Although the number of myocardial infarctions has diminished in recent years (the reduction has been more marked in Western Canada than in the Maritimes and Quebec), it is estimated that more than 500,000 Canadians are currently living with heart disease, with 50,000 new patients diagnosed each year<sup>1</sup>. Despite all the available

treatment modalities, only 50% of patients who have suffered a heart attack survive five years after the event.

Another possible solution is an operation using autologous stem cells (taken from the patient's body) in order to regenerate muscle tissue. This procedure avoids thorny ethical issues (strong opposition >

to the use of embryonic stem cells) and immunological problems (no immunosuppressive therapy is required, because the patient is his/her own donor). Unfortunately, some 100 clinical trials conducted worldwide on the use of stem cells to treat cardiac patients have yielded mixed results. Some patients enjoyed improved health compared to participants in the placebo cohort, while others saw no change. These trials have nonetheless demonstrated the safety of these procedures. They also show the tremendous potential of this type of medical technology, since tests on animals have produced positive results and trials on humans have been moderately successful<sup>2</sup>. However, a recent article<sup>3</sup> reached devastating conclusions for proponents of stem cell procedures.

After analyzing a number of discrepancies in publications on stem cell procedures to treat cardiac patients, the authors showed that the studies reporting the most positive effects also had the highest number of discrepancies in their results. Bearing these uncertainties and discrepancies in mind, our article presents the rationales given by people with serious heart disease for participating in experimental stem cell trials.

## AGREEING TO TAKE PART IN A CLINICAL TRIAL

The patients in our study showed great confidence in medicine from the start of their participation in the protocol.

*I really believe in it. I'm convinced this is the science of the future. I think we'll all be able to heal ourselves with this. Right now they're working on specific diseases, but maybe one day they'll be able to cure cancer with this. Anything's possible. I believe this is just the beginning.* (Patient 10)

The interviews showed that most patients, with a few exceptions, were not aware of this technology before participating in the protocol. The patients generally stated they were keen to participate, as the following account shows:

*I had one chance in two of getting better afterwards. Those seemed like good odds to me. I made my decision as soon as he told me about it, without hesitation.* (Patient 10)

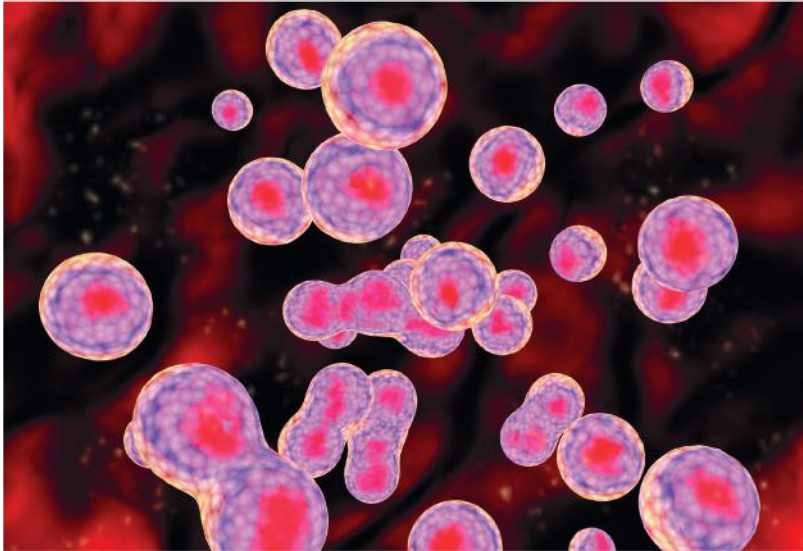
Most of the participants obtained information about the procedure from the consent form. None mentioned using the Internet. Some asked family members or acquaintances to help them decide whether or not to participate in the protocol. The daughter of one patient worked in the medical field and the neighbour of another had

successfully participated in a similar clinical trial.

The clinical researchers involved in the trials told us that almost all the patients agreed to participate. The interviews revealed three reasons for this positive response: 1) the apparent simplicity of the process; 2) the absence of ethical issues associated with their participation (compared to embryonic stem cell procedures); 3) the fact that no foreign tissue or substance would be introduced into the patient's body. This resolved the problem of immunosuppression and minimized potential concerns related to identity, contamination and pollution—what Waldby and Mitchell term transcorporeality<sup>4</sup>. One of the researchers interviewed noted:

*. . . when the doctor is trying to convince a patient and says "No, no, that's not a stem cell. A stem cell, [that's] you, in your own body, in your bones, that's a stem cell, and we're going to take it out, and put it back into you." So, after you say that, they will say, "No problem at all." Most people would say that.* (Researcher B, 2011)

Another motivation was the hope this innovative procedure gave to a person suffering from a potentially fatal disease. It was literally a "technology of hope"<sup>5</sup>: *So, I mean, I knew it was for the good, not for the bad. So I said, "Why not? I'm in this >*




decision.

*"My brother said, 'Claude, do it!' You'll get much better follow-up care than if you don't."*  
(Patient 6)

This extensive, personalized care undeniably eased patients' concerns. Although the participants rarely used the emergency services offered through the protocol, the fact that these services were available reassured them and gave them a feeling of security, which probably influenced their post-operative health, regardless of whether or not they received a transplant. Paradoxically, this enthusiasm contrasts with their very infrequent visits to hospitals and other health care establishments prior to their heart attack.

#### THE FIGURE OF THE DOCTOR

Many patients saw their surgeon as a charismatic star, a saviour and an expert. At the same time, some patients reported not seeing their surgeon often on account of his importance, status and many responsibilities. This confirmed his skill and reinforced patients' confidence in his abilities. Their confidence in the protocol and stem cell therapy was therefore linked to their faith in medicine and the professionalism of its representatives.

*When your back is up against they wall and they offer you things . . . They're the doctors, not me. I used to be a* 

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*position right now; what do I have to lose?" So I said, "Yeah." The next day there was an ambulance downstairs and—zoom!—they took me in.* (Patient 8)

In addition, as noted in the literature, the operation is without major risks for the patient. Patients got the same message from the medical staff who recruited them to participate in these clinical trials:

*There was no mention of anything, no complication, danger or things like that. If there was, I wasn't told. There was more positive than there was negative, you know. So the danger was 2% and the rest was 98%. I think it's worth it; even 5% or 10%, it's still worth it.* (Patient 8)

Only some patients expressed doubts about the validity of this type of surgery. They were not sceptical about the procedure itself, but rather about the health care system. The following

patient believed the hospital was developing a bone marrow bank, like certain establishments that run their own blood banks—but without patients' consent:

*They had to take a bone marrow sample and I thought it was to create a bank for themselves, because a lot of people are suffering and need bone marrow.* (Patient 4)

The inclusion of ongoing care in the research protocols, such as regular post-operative follow-up care for two years, was another incentive for patients to agree to participate in the trial before meeting with the medical team and surgeon. Their participation in the study would ensure long-term follow-up care and an availability of resources in the health care system that is rarely seen in other departments, and is certainly not the norm for the general public. This argument came more from loved ones and others who influenced the patient's

mechanic, so I know if something needs to be repaired right away or not. But you're the doctor. You know what you're talking about. I'll just follow what you say. (Patient 2).

### ADVANCING SCIENCE

Patients' confidence in the protocol, medicine and science in general was bolstered by their feeling that they were pioneers helping to advance science. Some patients noted that they were contributing to something bigger than themselves:

*It's a new study. I'm a firm believer in research. If people hadn't done experiments with Aspirin, we wouldn't be where we are today. By participating, I can make a small contribution to this research. (Patient 10)*

Another patient confided that his participation in the clinical trial had been the most important event of his life.

### FROM INDESTRUCTIBILITY TO VULNERABILITY

#### COMING TO TERMS WITH THE ILLNESS TRAJECTORY

The trajectory of chronic heart disease starts with a heart attack which, for most patients, came as an unexpected, unpredictable shock with no warning signs. It marks the start of a sometimes painful awareness of another body, a "sick" body.

That is why patients develop hypotheses around the possible causes of their heart attack. For example, some interviewees pointed to stress and "having too much on the go" as a major cause. Another patient thought he was "invincible" before his heart attack. The men in our sample were, for the most part, former casual workers, labourers and factory employees who were proud of their ability to carry out demanding manual work. After their heart attack, they found themselves forced to adopt an attitude of "care of the self," in Michel Foucault's terms<sup>6</sup>, and

*my heart, it would be something else. At a certain point, the machine just doesn't work anymore. (Patient 6)*

#### POST-OPERATIVE REPORTS: ACTIVITY AS A SIGN OF A REGENERATED MALE BODY

Although patients knew they would not necessarily be getting a stem cell transplant during their participation in the clinical trial, the vast majority believed that they had indeed been transplanted. The conclusion for most interviewees was "I feel good, therefore I got a transplant":

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*Patients' confidence in the protocol, medicine and science in general was bolstered by their feeling that they were pioneers helping to advance science.*

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to see their body in a new light. The trajectory of their disease involved looking back on their past and their attitude towards physical activity and productivity.

Using the metaphor of a machine allowed them to see their heart attack as a mechanical breakdown and the operation as a repair job. Machines have a limited life span and can stop working if they are not properly maintained.

*There was no reason for my heart to give out. I don't know why it happened. But it doesn't bother me too much. If it wasn't*

*As long as I feel good and have a lot of energy, I won't lose any sleep over whether or not I got the transplant. I think I probably did, because you don't feel better just like that—unless I wanted so badly to get better that I really believed the placebo was my stem cells. (Patient 10)*

Some patients experienced improved health in the medium term, and felt more physically independent than before their heart attack. The following excerpt clearly illustrates how intensely one patient enjoyed carrying out his former >

activities:

*I work 10 hours a day, every day, no problem. I think I feel even better than before my heart attack. I'm not afraid of challenges and I stay fit. I'm still working 70 hours a week. (Patient 10)*

However, for the vast majority, post-operative rehabilitation involved getting used to "not being able to do anything anymore," especially when the patient was used to being very active on the job or at home: *For me, there's no middle ground. So I've learned to slow down, but sometimes when I slow down too much, that's not good . . . I don't do anything. (Patient 7)*

Some patients became depressed immediately after the operation because of changes in their lifestyle and physical capabilities. One had to stop working in the freight transportation industry, while another found himself unable to open a jar of food: *I was feeling pretty depressed for a while. I couldn't open a jar of peanut butter! I wondered what was going to happen. (Patient 4)*

Other participants kept up their previous activities, but adjusted them according to the limitations of their no longer indestructible body. A lack of bodily awareness was replaced by a search for balance:

*It didn't change my pace of life, because I still do the same things. I still work just as hard as*

*before, but not as fast. I'm still in construction. Before it would have taken me six hours to raise a platform; now it takes me three days. I get tired, so I sit down and take a break. I don't run like I used to. (Patient 5)*

Mowing the lawn, preparing for trips to the cottage or vacations in Florida, and doing jobs around the house were all stereotypically masculine roles:

*I still shovel the snow. I asked Dr. N. about it, because everyone was telling me not to do it anymore. (Patient 6)*

## CONCLUSION

The accounts of the men we interviewed showed huge confidence in the experimental stem cell procedure. The authority of the surgeon and his team, as well as the apparent simplicity and safety of the procedure, eased any uncertainties associated with the protocol. The accounts presented a desire not only to regenerate the damaged organ, but also to rebuild a masculine identity closely intertwined with physical activity and work.

(DAMASCENE): weighted regression and meta-analysis. *BMJ*, 348. Repéré à doi: <http://dx.doi.org/10.1136/bmj.g2688>.

4. Waldby, C. et R. Mitchell (2006). *Tissue Economies: Blood, Organs and Cell Lines in Late Capitalism*. Durham : Duke University Press.
5. Leibing, A. et V. Tournay (dir.) (2010). *Les technologies de l'espoir, La fabrique d'une histoire à accomplir*. Québec : PUL.
6. Foucault, M. (1978). *The History of Sexuality*. Trans. Robert Hurley. New York: Pantheon Books.

- 
1. The Heart and Stroke Foundation (2014). Statistics. Retrieved from <http://www.heartandstroke.com/site/c.iklQLcMWJtE/b.3483991/k.34A8/Statistics.htm>.
  2. Noiseux, N. et al. (sous presse). The Current State of Stem Cell Therapeutics: Canadian Approaches in the International Context. *Canadian Journal of Cardiology*.
  3. Nowbar, AN et al. (28 avril 2014). Discrepancies in autologous bone marrow stem cell trials and enhancement of ejection fraction



# The Multiple Paths to Retirement Incomes: A closer look at the challenges faced by Canadian women and immigrants

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*Across industrialised countries, governments have been actively implementing reforms to tackle multiple challenges afflicting various pension schemes, such as increased volatility in financial markets, lower economic growth, and lengthier lifespan. As evidenced most recently by the gradual rise in the retirement age to 67 for both the Guaranteed Income Supplement (GIS) and the Old Age Security (OAS), Canada has not escaped these international trends. The introduction of pension reforms combined with the risk of having to face further reforms represent an important source of concern for future and current retirees. Most media stories focus on the tension between younger and older citizens and, as illustrated by the wave of protest triggered by Bill 3, whether workers are covered by a company pension plan or not. Often forgotten amidst these feature stories is the continued experience of poverty among current retirees, which is the focus of this contribution. >*

Until recently, growing old implied living in poverty for most citizens. In 1951, two-thirds of Canadian retirees earned less than \$1000 a year<sup>1</sup>. Adjusted for inflation, this figure represents roughly \$9000 in 2014. The growth and expansion in social policies that followed World War II included substantial improvements in the coverage and generosity of pension policies. First, the introduction of a universal OAS in 1952 and, subsequently, the GIS for poorer retirees in 1967 guaranteed income to older Canadians regardless of their previous participation in the labour market. Second, the creation of the Canadian Pension Plan and the Régie des rentes du Québec in 1966 provided a universal mandatory earnings-related scheme covering all Canadian workers. As a result of the maturation of these public programs, Canada is considered to be one of the most successful countries – alongside Scandinavian countries – in alleviating poverty amongst older citizens.

This outcome has been highly contested recently because there are many seniors who “squeak” barely ahead of the poverty line employed in these comparative assessments. The location and interpretation of the poverty line is a topic of lively discussions<sup>2</sup>. According to recent comparative figures published by the Organization for Economic Cooperation and Development

(OECD), Canada continues to rank amongst the best performers in the world when it comes to alleviating poverty amongst seniors, here defined as individuals being aged 65 and above. However, it is important to note that Canada’s poverty rate reached 7.2% in 2010, an increase of two percentage points since 2007<sup>3</sup>.

The successful picture fades rapidly when we analyse the retirement incomes of Canadian women and immigrants. Still today, they face higher risk of poverty with women being twice as likely as men to rely on the GIS while immigrants having been in Canada for more than 20 years depend on the GIS three times more than Canadian born<sup>4</sup>. Using 2004 figures, the combination of

were tied in with the full time work of a husband, generations of women failed to “gain” pension rights. Even though women benefit from higher education levels and have much higher participation rates in the labour market than a generation ago, they still face higher risks of having interruptions in their careers and they are more likely to hold part-time and precarious positions. These outcomes reflect multiple socio-economic factors such as women spending more time on caregiving activities and the persistence of discrimination in the labour market. The long-term effects of these labour market outcomes is lower pension income originating from the Canada Pension Plan/ Québec Pension Plan and private pensions.

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*The introduction of pension reforms combined with the risk of having to face further reforms represent an important source of concern for future and current retirees.*

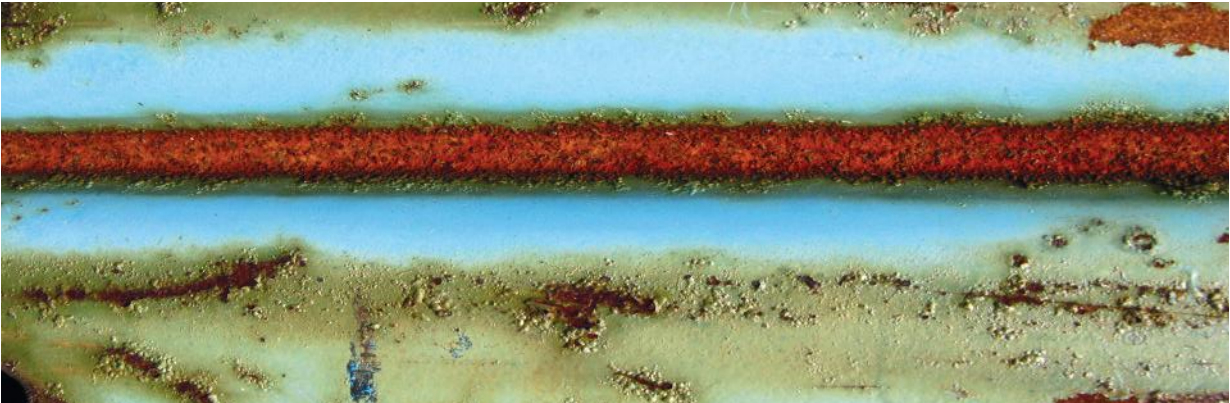
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gender and immigration on retirement income is troubling. The median pension outcome for Canadian born men stood above \$25 000 while it was barely above \$10 000 for immigrant women<sup>5</sup>.

The roots of this outcome lie with the design of the Canadian pension system. Designed originally with a traditional breadwinner model, where social benefits

Also, women tends to live longer than men. This has an important impact in the long run since both GIS and OAS are price indexed. This means that overtime there is a growing income gap between individuals in the labour market who benefit from continuous, albeit small, real wage growth, which is not the case for poor seniors. Over the course of a twenty year retirement ➤





period, this can result in a 15% gap between the wage of a median worker and older retirees.

face more barriers to enter the labour market than previous generations of immigrants.

Immigrants face even more risks of poverty in Canada. First, programs have well-established residency tests. The OAS requires 40 year residency to obtain a full benefit. For example, if an immigrant moved to Canada at age 35 in 1979, this person would obtain \$5074 in 2014 instead of \$6765 for a Canadian born citizen earning retirement income less than \$71 594. The GIS is not accessible to those who have not resided in Canada for at least 10 years. Second, those who emigrate to Canada in mid career do not have the opportunity to establish long contribution periods to the CPP/QPP and private pension schemes (although contributions to public schemes in the country of origin covered by an agreement between both pension agencies can result in higher public benefits). Third, many immigrants have a very precarious attachment to the labour market. This is particularly true for the post 1970 immigrants who

Without negating the importance of other pension related issues, including the declining access to company pension plans, the important disparities faced by poor Canadian retirees deserve far more attention in the media and the public sphere.

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1. Bryden, Kenneth. (1974). *Old Age Pensions and Policy-Making in Canada*. Montréal : McGill et Queen's University Press.
2. Milligan, Kevin. (2008). The Evolution of Elderly Poverty in Canada. *Canadian Public Policy*, 34(s1), 79-94.
3. OCDE. (2013). *Pensions at a Glance 2013: OECD and G20 Indicators*. Paris : OCDE.
4. Marier, Patrik et Suzanne Skinner. (2008). The Impact of Gender and Immigration on Pension Outcomes in Canada. *Canadian Public Policy*, 34(s1), 59-78.
5. *Ibid.*



# Shiva at SAPA

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## APRIL 1998

As part of my Master's degree in social work, I am completing an internship at the CSSS Cavendish, in the autonomy support program (today known as SAPA: Program for Support of the Autonomy of Seniors). A few weeks before the end of my internship, I get a call from a caregiver who tells me her husband, whom I visited at their home for several months, has just passed away. As a young intern, I feel slightly awkward in offering her my condolences. She asks me to pick up the equipment loaned by the CLSC as soon as possible, since she will be sitting shiva at the family home. I quickly contact the occupational therapist in charge of the file, who does not seem at all surprised by this request.

That afternoon I bump into my internship supervisor, Lucy Barylak. She has been informed of the file and suggests I attend the shiva for the deceased client. Intrigued, I accept, although I know nothing about Jewish customs related to death and mourning. My supervisor will guide me.

The following day, she invites me to come and talk to her about it.

She tells me about shiva, the seven-day mourning period. When I ask why it lasts seven days, she explains that "shiva" means "seven" in Hebrew. During this week, mourning must be observed by seven categories of loved ones: father, mother, brothers and sisters, sons and daughters and their spouses, and the spouse of the deceased. All will gather, preferably at the home of the deceased, to honour his or her memory and receive visitors.


When we arrive at the home of my deceased client, I realize how strange it is to return to the place where I conversed with him just a few days ago.

I go to knock on the door, but my supervisor holds me back. We must simply enter without making too much noise; the door will remain unlocked for the seven days. During this period, the bereaved family members will be focusing on their loss and mourning; they should not be considered hosts. It is up to friends, neighbours and other family members to bring food over the

course of the week.

We introduce ourselves to the family. Men and women are sitting on low stools. Loved ones have to sit close to the ground in order to feel their sadness more profoundly—they are literally "brought low" by grief. It is normal for them not to get up when visitors arrive.

Sometimes, mourners do not want to talk. Visitors must respect this silence, knowing that their mere presence is a source of comfort. When it comes time to leave, visitors see themselves out. They are not accompanied to the door, since they are not "invited" by the family.

Before leaving the home, I notice that all the mirrors are covered in sheets. My supervisor tells me that during this period, loved ones should not be concerned with their physical appearance in order to focus on their feeling of loss and to engage in a profound spiritual reflection. Other traditions may also be observed, depending on the individual. For example, people may refrain from bathing or wearing new 

clothes, and men may refrain from shaving.

After we leave, the rabbi comes to the house and assembles the family members to pray.

## JUNE 2014

It has been 15 years since I ended my internship and began my career in palliative home care. I wonder whether my Jewish colleagues still practice the same customs when a loved one passes away. I ask some of my colleagues to share their personal experience.

the Jewish tradition, cremation is not permitted.

My colleague then recounted her memories of the first Jewish burial she attended. She was ten years old at the time. She clearly remembers the atmosphere, the sadness of the family and the profound meaning of the event.

For her, shiva is a very important time. She realized this when one of her own family members passed away. This mourning period allows people to get together and talk about the deceased to keep his or her memory alive.

mourning, unexpected visits can give meaning to the experience and are a form of recognition of the loss. It is important to be accepting, since we are not all comfortable with the idea of death, mourning and sorrow. It is true that shiva can create a certain pressure, given the constant focus on the bereaved family. It can be exhausting, when one is in mourning, to have to attend to others.

Shiva takes place during the first week of mourning. The family should not participate in celebratory events for the first month. A few months later, the tombstone is unveiled at the cemetery. This is a small, private ritual where the family gathers around the tombstone. It is also a way to remember and honour the deceased. This ritual takes place during the first year after the person's passing away.

To see whether Jewish traditions around death and mourning had changed over the years, I also spoke to some younger Jewish colleagues. For them, shiva is an enduring tradition, but some find sitting shiva to be painful and tiring. They feel the ritual is too social, leaving loved ones too little room to mourn, which undermines the purpose of the ritual.

Colleagues remarked that the format and length of the ritual have changed. Nowadays, some families opt for a private shiva >

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*Nowadays, some families opt for a private shiva to which only family members are invited; the general public may not attend.*

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I meet up with a colleague who is keen to share her perspective on Jewish funeral and mourning customs. She notes that, in general, many religious rituals are still present in the community. She says that following a death, a person must stay near the body at all times to recite prayers. Once the death certificate has been obtained, the corpse is sent to the funeral home. There is a special ritual to prepare the body, which is wrapped in a winding sheet. The coffin is closed during the religious service. The burial takes place very soon after the death, sometimes even the following day. In

In addition to visiting, people can send cards, or bring sympathy gifts and food. It is not considered appropriate to send flowers.

For my colleague, shiva is a distraction, a kind of "pillow" that softens the impact of the loss. This period allows loved ones to gradually come to terms with their new reality. It is also a time of forgiveness, allowing family members and friends to renew their ties.

When I asked whether the presence of strangers could cause a certain malaise for some people, she replied that, during



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to which only family members are invited; the general public may not attend. Some families sit shiva over a shorter period—for example, two or three days. However, the majority of families still respect the seven days of shiva. For many, it is important to preserve this religious tradition, which is adapted to individual religious beliefs and family traditions.

In conclusion, shiva is still very present in the Jewish community, across all generations. Based on my experience and the accounts offered by my colleagues for this article, I encourage interns and practitioners to attend their

clients' shiva, knowing that the presence of others is a source of comfort to grieving families.

For more information on the topic, the author recommends the book by Rabbi Lamm, which explains all of the rituals around death in the Jewish tradition, from death until the end of mourning.

This article does not describe all of the rituals associated with death in the Jewish community, but rather offers perspectives on certain rituals offered by Jewish practitioners at SAPA. The goal is to raise awareness around this reality in order to

offer support with sensitivity and understanding.

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Lamm, M. (2000). *The Jewish Way in Death and Mourning*. États-Unis : Jonathan David Publishers.

The Resource for Jewish mourning. (2014). *Shiva*. Retrieved from <http://www.shiva.com/learning-center/what-to-bring-or-send/flowers-and-jewish-mourning/>.

Palatnik, Lori. (2001). *ABCs of Death Mourning*. Retrieved from [http://www.aish.com/jl/dam/ABCs\\_of\\_Death\\_Mourning.html](http://www.aish.com/jl/dam/ABCs_of_Death_Mourning.html).

# Jews and old age

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*To perpetuate itself, an ethnic group must be supported by a strong collective memory that is carefully passed down from one generation to the next. This collective memory essentially consists of places of memory—founding moments, historical figures, symbols, myths, customs and manners of speaking. In ancient societies, especially those without writing, it was the responsibility of elders to preserve and transmit this memory to younger generations through ritual events or ceremonies, in accordance with tradition. This collective memory intersects with historical memory in literate societies, which are codified. Collective memory and historical memory are more pronounced in some groups than in others.*

The memory of persecutions is generally a reason for these two types of memory to be revived within the population in order to foster unity. Jews, in this regard, are a perfect example. A people whose history and law (from the Torah) have been intertwined since Antiquity, Jewish people hold elders in the highest regard as those able to mediate between past and present. Old age is seen as a virtue and the elderly are particularly cherished, both within the community and family.

Since Biblical times, Jews have considered old age a blessing, a gift from God that only the just deserve. The advanced old age of the founding fathers in Judeo-Christian mythology (Abraham, Isaac, Noah, Moses and, especially, Methuselah) was considered worthy of admiration. Today it is understood that these

venerable ages are mythological rather than real, but they still carry a significant metaphorical weight.

Over the course of Antiquity, Jews developed a unique perspective on aging. Two and half thousand years later, they still see aging in a positive light. Unlike the current Western tendency to perceive seniors as old people rather than elders, the Jewish tradition has always treated them with affection. Rabbi Menachem Mendel Schneerson sums up well the divine quality of longevity: “The Torah considers old age a virtue and a blessing. Throughout the Torah, ‘old’ (zakein) is synonymous with ‘wise’; the Torah commands us to respect all elderly, regardless of their scholarship and piety, because the many trials and experiences that each additional year of life brings yield

a wisdom which the most accomplished young prodigy cannot equal.”<sup>1</sup>

Respect for elders is characteristic of many nomadic, illiterate societies, but also of sedentary pastoral and agrarian societies. This veneration is found in traditional societies whose legitimacy is derived from the government of a council of elders and the power of oral transmission. As we can see in the first books of the Torah and, more specifically, in Genesis (the Jews’ founding myth), God grants the privilege of dying “old and full of years” to all who obey the law. Respect for the divine commandments guaranteed a long life. With the succession of patriarchs, however, life spans were reduced: whereas Adam lived to the age of 930, Joseph only lived to 110 years. Starting with Abraham (who died at the age of 175), >

the lessening of God's grace became truly evident, as the Biblical story gradually replaced mythological life spans with real ones. Georges Minois notes a turning point in the perspective on the elderly as Hebrew and then Jewish society was increasingly influenced by the rapidly expanding Greek culture. The latter was fundamentally ageist, especially towards the end of its peak<sup>2</sup>. Max Weber implicitly notes that the decreased appreciation of old age among Jews was related to the shift from a

In fact, traditional societies that practice ancestor worship (according to a cyclical intergenerational logic, ancestors are given the same treatment as the living) generally venerate their elders. With modernity, ancestor worship has fallen into disuse. In Europe and North America, where individual worth is measured in terms of social utility, respect for the elderly tends to diminish as technology and laws advance, and as history and the transmission of memory lose their social pre-eminence<sup>5</sup>. Jews can be seen as an excep-

the Hassidic Jews in Outrement and the Mile End, whereas in reality the latter are an ultra-orthodox minority and do not represent the majority of members of this so-called ethnocultural community. The main distinguishing feature of the majority of Montreal's Jews is that they are seen as belonging to the city's anglophone community. There is a French-speaking minority, born in Morocco and other parts of North Africa, and there is also an orthodox community distinct from Hassidic congregations. The vast majority of Jews, who are moderately observant—whether they are of Ashkenazi, Sephardic or Eastern origin—blend into Montreal's general social fabric, even more so because both older and younger generations are generally from Quebec.

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*The countless places of memory in the Jewish collective conscience are aimed at preserving the unity of the group, and the reference to the elderly and ancestors is a link between present, past and future.*

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society based on the authority of the council of elders to one based on the authority of a military state (which, by definition, was younger)<sup>3</sup>. The close association between age and wisdom in the first sacred books was challenged by the observation that evil people often lived longer than those who were righteous. Under the influence of Hellenism, Jews during the Period of the Kings did not accord as much importance to elders. But this was simply a hiatus, since respect for the elderly would return in the Diaspora<sup>4</sup>.

tion in Western societies, since for them the past and collective memory continue to be vital. Very old individuals, who in a sense represent the group's past and memory, always command respect. This is just as well, since the Jewish community is one of Montreal's most rapidly aging ethnocultural groups.

### **MONTREAL'S JEWISH COMMUNITIES**

It is important to note that Jews in Montreal, as elsewhere, do not constitute a single community but rather several<sup>6</sup>. There is a mistaken belief that Montreal's Jews comprise solely

That said, Quebec Jews, regardless of their cultural allegiance or origin, are generally strongly marked by a strong collective memory and its resulting customs, values and symbols, such as endogamy (marriage within the ethnic group), an emphasis on learning, the symbol of Israel, the importance of family and ancestor veneration. Elderly Jews are provided comfort and support by their descendants and the community. In this regard, it is worth underlining the importance of the Cummings Jewish Centre for Seniors, an undeniable model of community organization, as well as ➤



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the CLSC René-Cassin (formerly the CSS Jewish Family Services) and the Maimonides long-term care facility, recognized for its exemplary services to seniors who are no longer able to live at home. For a long time, many seniors lived below the poverty line, and a generation of seniors also experienced the departure of their children and grandchildren between the 1980s and 2000. The Jewish value of tzedakah (the religious obligation to do what is right) was therefore applied, and institutions were developed throughout the 20th century to come in aid of seniors in need, while maintaining ties with their family<sup>7</sup>.

One of the reasons the social importance of old age has persisted among Jews is no doubt, as indicated, the force of collective and historical memory. The countless places of memory in the Jewish collective conscience are aimed at preserving the unity of the group, and the reference to the elderly and ancestors is a link between present, past and future.

Since the Jewish community is becoming increasingly prosperous, the new generation of seniors—first-generation baby boomers who have already reached the age of 70—will not generally experience poverty once they are very old.

Baby boomers tend to age differently than their parents, regardless of their ethnocultural origin<sup>8</sup>. They are better informed, eat a healthier diet, are more financially secure and often want to age well. As is the case for a number of older Quebecers, many Jewish seniors spend part of the year in Florida, since retirement conditions are much better than in the past. Many, however, continue to take care of their much older parents, who often live in special seniors' residences in Côte-Saint-Luc, the municipality with the oldest population in Canada. In 2011, 28% of the population of Côte-Saint-Luc was aged 65 and over (compared to an average of 16% for the Montreal area). ➤



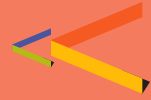
It was in Côte Saint-Luc that, in the early 1990s, the CLSC René-Cassin developed innovative leading-edge services to support seniors, through the former Institut universitaire de gérontologie sociale du Québec<sup>9</sup>. These services were originally provided in the territory served by the CLSC, but are now offered across Quebec. The Ligne Aide Abus Aînés, a provincial elder abuse helpline centralized in the CLSC René-Cassin (which receives thousands of calls from across the province each year), and the Caregiver Support Centre clearly reflect the respect for seniors within Montreal's Jewish communities. Their objective is to make life easier for seniors and caregivers in order to keep more seniors in the community.

To conclude, Montreal's oldest Jewish residents generally live at home, but close to family members and community organizations. Certainly not all live in traditionally Jewish neighbourhoods like Côte-Saint-Luc, Hampstead or Snowdon; some live on the West Island and others in Laval or on the South Shore. As is the norm in the Western world, the elderly prefer to maintain independent households and to live at home. It is rare to find intergenerational families in non-Hassidic communities. Maimonides offers long-term care to those who can no longer live at home. Loved ones continue to offer regular support,

echoing traditional Jewish values regarding the elderly.

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1. Rabbi Menachem Mendel Schneerson. *The Jewish view on aging and retirement*. Retrieved from [http://www.chabad.org/global/popup/default\\_cdo/aid/1168/jewish/Growing-Old.htm](http://www.chabad.org/global/popup/default_cdo/aid/1168/jewish/Growing-Old.htm).
  2. Georges Minois. (1987). *Histoire de la vieillesse. De l'Antiquité à la Renaissance*. Paris : Fayard.
  3. Max Weber (1952). *Ancient Judaism*. Glencoe, Ill.: Free Press.
  4. "Remarking that David became feeble in his old age and was therefore no longer apt to rule, and that Solomon ended his days in a state of senile dementia, many turned towards other gods." [Translation] (Minois, 1987, p. 55).
  5. Donald O. Cowgill and Lowell, D. Holmes. (1972). *Aging and modernization*. New York: Appleton-Century-Crofts.
  6. See Pierre Anctil and Ira Robinson (Eds.) (2010). *Les communautés juives de Montréal*. Quebec City: Éditions du Septentrion.
  7. See Ignace Olazabal (2006). *Khaverim: Les Juifs ashkénazes de Montréal au début du XXe siècle, entre le shtetl et l'identité citoyenne*. Quebec City: Éditions Nota bene.
  8. See Ignace Olazabal (Ed.). (2009). *Que sont les baby-boomers devenus? Aspects sociaux d'une génération vieillissante*. Quebec City: Éditions Nota bene.
  9. Today the Centre for Research and Expertise in Social Gerontology (CREGÉS) of the CSSS Cavendish-CAU.





# Aging and domestic work: Exploring the experiences of retired Filipino domestic workers in Canada

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*They clean houses. They cook meals. They provide round the clock childcare so that parents are able to leave the household and participate in the paid labour force. Though they are not related to their employers, they are sometimes regarded as members of the family. Who are they? They are domestic workers from the Global South who provide private, live-in care for children, the elderly and persons with disabilities.*

According to a 2011 report by the Toronto Immigrant Employment Data Initiative, more than 52 493 domestic workers immigrated to Canada since the inception of the Live-in-Caregiver Program (LCP), the current national domestic labour policy<sup>1</sup>. Though domestic workers come from overseas, the vast majority are from the Philippines where migration policies structurally and socially encourage the commodification of its labour force to meet the global demand for transient, cheap, and

low-cost labour<sup>2</sup>. Approximately ten percent of Filipinos live outside the Philippines where they take on predominately low paid and physically demanding manual work<sup>3</sup>. In Canada, Filipino women represent the vast majority of domestic workers, and arrive in their prime productive years (25 to 48 years old)<sup>4</sup>. In a greying society, where health and social services are increasingly cut back and made inaccessible, domestic workers serve a pivotal role in ensuring the survival of middle class to affluent

Canadian families who are able to pay for their services.

## **A BRIEF HISTORY OF DOMESTIC WORK IN CANADA**

The need and demand for domestic work has a long history, which began during the early stages of the Canadian nation-building project. Predominately seen as undesirable work, unmarried women from the United Kingdom were recruited to address the need for domestic

labour<sup>5</sup>. Anglo-Saxon women were seen as ideal immigrants because they fit the mould of what was then considered to be the ideal settler; valorized for their future potential as wives or 'mothers of the nation'<sup>6</sup>. Postwar conditions of the early 20th century expanded the roles of women outside the household and consequently shifted the availability of domestic workers from the UK. In response, Canadian domestic work policies turned its recruitment efforts to 'non-preferred' states such as Germany, Greece, and Italy<sup>7</sup>. The turn toward women from the Global South occurred during the mid 20th century with the introduction of the West Indian Domestic Scheme which allowed women from the Caribbean to immigrate as domestic workers<sup>8</sup>.

Unlike earlier recruits from Europe, domestic workers were not offered immediate permanent residency upon arrival, or financial recruitment incentives. Instead, women from the Caribbean were subject to a high degree of restrictions, and the indignity of invasive medical screenings, which were imposed and enforced by the domestic work policy. The most drastic shift was the imposition of an extended live-in requirement which obligated employees to reside in their place of employment as a condition of receiving landed immigrant status<sup>9</sup>. The West Indian Domestic

Scheme was transformed into the Non-immigrant Employment Authorization Program (NEAP) in 1973 but revoked the right to permanent residency<sup>10</sup>. Following mounting reports of abuse and protests by social justice advocates demanding the right to permanent residency, the Canadian government introduced the Foreign Domestic Movement program in 1992. This program reintroduced the pathway to permanent residency

but only after two years of required live-in service<sup>11</sup>. Further changes were made in 1992 with the Live-in-Caregiver Program, which ostensibly sought to reform the program but placed further eligibility restrictions (such as the requirement of a grade 12 education, and official knowledge of the official language)<sup>12</sup>. The shift from the West Indian Domestic Scheme to the Foreign Domestic Movement and subsequent Live-in-Caregiver Program also >



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saw a change in its primary applicant pool with women from the Philippines representing the majority of applicants.

Research by both scholars and advocacy groups have highlighted the many problems of domestic work policy which has been characterized as modern-day slavery. Among the many contentious issues that domestic workers face are: the 24 hour live-in requirement for a period of 2 years; prevailing wage standards which dictate minimum salaries but do not account for extended and overtime work hours, which drastically lowers the actual hourly compensation; the deskilling of a very educated and professional workforce; and delayed processing times in applying for and receiving permanent residency. The last point is particularly problematic because lengthy delays in receiving permanent residency status means prolonged separation between mothers and their families in the Philippines. Taking into account the extended wait times in applications for family sponsorship, domestic workers are forced to be separated from their families for an average of five to years<sup>13</sup>.

### ISSUES OF AGING AND DOMESTIC WORK

While existing scholarship has documented, and sometimes advocated for the rights of Filipino

caregivers in Canada, existing research has focused almost exclusively on young domestic workers who are in their prime productive years. However, less is known about the aging and retirement experiences of domestic workers who have settled in Canada for several years to decades,

and have already received their permanent residency/Canadian citizenship, and have been reunited with their families in Canada. Research has shown how women's work over the lifecycle garners significantly lower income than their male counterparts<sup>14</sup>. Average earnings for a full year and full time worker show that women earn 71 cents for every dollar earned by men<sup>15</sup>. The type of work is also markedly different, with women more likely to take on caring responsibilities and labour which extricate them from the paid labour force. These disadvantages become pronounced in late life especially considering how women have been shown to live longer, and find themselves among the poorest of the poor. According to Young these realities exist in part because of retirement policies in Canada that

encourage the utilization of and investment in private pensions. As such, older women heavily rely on state funded provisions such as the Old Age Security Pension, and the Guaranteed Income Supplement which yields a maximum benefit of approximately \$14 000 CAD; an amount

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*The costs of lodging (rent), food, medicine, leisure, and family obligations forced many to continue to work in the peripheral labour market or what is colloquially known as under-the-table work.*

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that is below the low income cut off in urban (\$22 229 CAD) and rural (\$15 302 CAD) areas<sup>16</sup>. These gendered inequalities prompt questions regarding the aging experiences of retired Filipino domestic workers; a population who has and continues to have a pivotal role in the survival of Canadian middle class and affluent families.

### METHODOLOGY

In order to explore the experiences of aging domestic workers, in-depth qualitative interviews were conducted with Filipina respondents who had immigrated, and worked under the Foreign Domestic Movement program. This data was part of a larger dissertation study, which examined the aging experiences of Filipinos in the Canadian diaspora. Recruitment took place ➤

through snowball sampling, and advertisements posted in local Filipino-Canadian newspapers. The sample included participants who had different lengths of residence in Canada, but who had all immigrated under the Foreign Domestic Movement and would later receive their Canadian citizenship. Participants were asked to talk about their retirement provisions, and the extent to which these entitlements were sufficient in addressing their late life needs. The purpose of these questions was to trace how older domestic workers prepare and subsequently evaluate their retirement and transition into late life.

### THE NECESSITY BUT INSUFFICIENCY OF RETIREMENT PROVISIONS

A major finding of the study centered on the dichotomous nature of retirement and subsequent pension entitlements. The majority of participants did not contribute to private pensions schemes and received little by way of their Canadian Pension Plan/Quebec Pension Plan contributions. As such, all participants for this study received the basic Old Age Security pension, and were supplemented by the Guaranteed Income Supplement. On the one hand, participants unanimously praised and were grateful for their monthly provisions. For many, having the fixed monthly income from

Old Age Security, and the accompanying Guaranteed Income Supplement provided financial flexibility which allowed them to reduce their work hours, and/or to find more suitable types of work that were less physically demanding.

Although domestic workers were officially retired, nearly all spoke about how their entitlements were not enough to cover their basic costs of living. Some expressed shock and anxiety when they received their first retirement instalment. The costs of lodging (rent), food, medicine, leisure, and family obligations forced many to continue to work in the peripheral labour market or what is colloquially known as *under-the-table* work. When asked how they would survive with the sole financial support of the Old Age Security and Guaranteed Income Supplement, nearly all expressed doubt, fear, and worry. Even when given the maximum allotment of Old Age Security and the Guaranteed Income Supplement, most respondents discussed the need for additional income.

### ADVANTAGES AND DISADVANTAGES OF WORKING UNDER THE TABLE

Given the inadequacy of pension entitlements, retired domestic workers find themselves in situations where they must look for supplementary income. Most

participants chose to continue their work relationship with their employers; having already been accustomed to the needs of their employers and developing familiarity with their household workplace. This arrangement was particularly advantageous for domestic workers who felt that their bodies were still capable of withstanding the physical demands of the job. A few predicted that they would continue to work for their employers well into their 70s. Others, however, felt that their aging bodies were no longer compatible with the work they were hired to do.

Just as domestic workers aged, so did their employers; highlighting complications that arise when both caregiver and employer transition into their late lives. For many, working for an older client meant having to engage in more rigorous tasks such as lifting, and cleaning/bathing their employers. A few domestic workers discussed developing new strategies of communication with employers who had developed cognitive impairments.

While some domestic workers continued to work for their aging employers, others chose to curtail their work, and engage in more specific tasks such as cooking, cleaning, or accompanying work (such as accompanying older clients who were in long-term care facilities). ➤

## INTERGENERATIONAL AND RECIPROCAL FORMS OF CARE

Another important finding is the support of the intergenerational family. Nearly all participants interviewed spoke about living with or moving in close proximity to their adult children and grandchildren. This arrangement helped to alleviate the costs associated with rent, food, medicine, and other basic and leisure necessities. The intergenerational family is thus an important source of care for aging domestic workers. This arrangement, however, is mutually beneficial since retired domestic workers also provided secondary financial contributions to the family unit. Perhaps most importantly, retired domestic workers provided intergenerational care for their grandchildren; liberating their adult children to engage and participate in the paid labour market. By taking on this intergenerational role, retired domestic workers also ensure the cultural transmission to their grandchildren.

## IMPLICATIONS FOR POLICY MAKERS AND SERVICES

The findings of this paper have major implications for policy makers and service providers. Policy makers first and foremost have the responsibility of acknowledging how gendered inequalities

develop over the lifecourse. The interviews conducted for this study are in line with existing feminist scholarship, which highlights the significant contributions that women make in the both the paid and unpaid labour market; playing a central role in the reproduction of labour.

These contributions, however, are poorly compensated and have substantial ramifications in late life, where basic state pensions are not enough to fully retire. Domestic workers for this study unanimously acknowledged how existing pensions were insufficient, and failed to cover their day-to-day activities. Young (2011) has suggested that in order to address some of these late life inequalities, measures must be taken to improve existing public pension schemes such as the Old Age Security and the Guaranteed Income Supplement; pensions which older women are most reliant on. Better compensation would ultimately alleviate the burdens of care that retired domestic workers experience in late life, and could offer better choices for those who are obligated to work under the table to ensure their survival.

The findings also have implications for service providers, who are in positions to offer and/or link retiring and retired domestic workers to valuable state resources. For instance, information

sessions and workshops on retirement planning could go a long way in helping older adults plan for their late lives. This is an important contribution given how some participants expressed initial shock when receiving their first Old Age Security cheque.

Service providers must also understand the importance and role of the intergenerational family. With the majority of participants living with (or in close proximity to) their adult children and grandchildren, it is crucial that potential interventions (regardless of whether they are individual or group-oriented; clinical or educational) acknowledge the dynamics of support within the intergenerational family, and includes the participation of adult children.

1. Kelly, P. F. et Toronto Immigrant Employment Data Initiative (TIEDI). (2011). *Profile of live-in caregiver immigrants to Canada, 1993-2009*. Toronto : Toronto Immigrant Employment Data Initiative (TIEDI).
2. Parreñas, R. S. (2001). *Servants of globalization: Women, migration and domestic work*. Stanford (Californie) : Stanford University Press.
3. Rodriguez, R. M. (2010). *Migrants for export : How the Philippine state brokers labor to the world*. Minneapolis : University of Minnesota Press.
4. Pratt, G. et Philippine Women Centre of BC (2012). *Families apart: Migrant mothers and the conflicts of labor and love*. Minneapolis : University of Minnesota Press.
5. Bakan, A. B. et Stasiulis, D. K. (1997). *Not one of the family: Foreign domestic workers in Canada*. Toronto : University of Toronto Press.
6. *Ibid.* 

7. Cohen, R. (1994). A brief history of racism in immigration policies for recruiting domestics. *Canadian Women Studies*, 14(2), 84-86.
8. Foner, N. (2009). Gender and Migration: West Indians in Comparative Perspective. *International Migration*, 47(1), 3-29.
9. Bakan, A. B. et Stasiulis, D. K. (1997). *Not one of the family: Foreign domestic workers in Canada*. Toronto : University of Toronto Press.  
  
Henry, F. (1968). The West Indian Domestic Scheme in Canada. *Social and Economic Studies*, 17(1), 83-91.
10. Hsiung, P.-C. et Nichol, K. (2010). Policies on and Experiences of Foreign Domestic Workers in Canada. *Sociology Compass*, 4(9), 766-778.
11. Cohen, R. (1994). A brief history of racism in immigration policies for recruiting domestics. *Canadian Women Studies*, 14(2), 84-86.
12. Bakan, A. B. et Stasiulis, D. K. (1997). *Not one of the family: Foreign domestic workers in Canada*. Toronto : University of Toronto Press.
13. Pratt, G. et Philippine Women Centre of BC (2012). *Families apart: Migrant mothers and the conflicts of labor and love*. Minneapolis : University of Minnesota Press.
14. Young, C. (2011). Pensions, Privatization, and Poverty: The Gendered Impact. *Canadian Journal of Women and the Law*, 23(2), 661-685.
15. *Ibid.*
16. *Ibid.*



# Ways to better appreciate the realities of LGBT seniors

Fondation Émergence

[www.fondationemergence.org](http://www.fondationemergence.org)

**Trans (trans person, trans identity, etc.):** The noun, adjective and prefix “trans” refer to a wide range of identities that people may adopt, or that may be assigned to them, when their gender identity does not fully correspond with the sex they were assigned at birth. For example, a person who has been assigned a given sex might (from childhood or later) identify with the other sex or at least not fully identify with the sex s/he has been assigned. Trans identity can therefore refer to individuals who self-identify as transsexual or transgender and, in certain cases, to those who perceive themselves as not conforming to gender norms.



*Fondation Émergence has a mission to counter homophobia and raise public awareness around the realities of lesbian, gay, bisexual and transgender (LGBT) individuals<sup>1</sup>. In 2004, the foundation began a process of reflection on the aging of LGBT people. Five years later, the organization implemented the program “Pour que vieillir soit gay” (Let’s make aging gay), aimed at raising awareness among service providers about the realities of LGBT elders. This article begins with a description of some of the life experiences and specific challenges faced by LGBT seniors. It then proposes concrete avenues for everyday action, as well as tools to ensure the well-being and inclusion of LGBT elders in society. >*

## LIFE EXPERIENCES OF LGBT ELDERS

Although LGBT individuals are now equal before the law in Quebec and Canada, LGBT elders often had difficult life experiences, marked by various forms of discrimination. An awareness of these experiences allows us to better understand some of their fears and realities.

In the West, at the end of the nineteenth century, doctors began to take an interest in homosexuality. The nascent fields of psychology and psychoanalysis considered homosexuality to be a pathology that had to be “cured” through conversion therapy, electroshock therapy and lobotomy.

A number of writings by experts were published in the late nineteenth and early twentieth century attempting to explain this supposedly aberrant behaviour and to offer solutions. Today these works are still a reference for people who condemn homosexuality and who choose to ignore more recent scientific evidence demonstrating that homosexuality is not a disease or pathology, but simply one sexual orientation among others.

It is important to remember that LGBT elders not only lived during a time when homosexuality was considered a disease by the health care and social services

sector, but was also regarded as sinful and was treated as a criminal act punishable by law.

## THE BIRTH OF THE LGBT RIGHTS MOVEMENT: THE STONEWALL RIOTS

Not until the end of the Second World War and particularly the late 1960s did gay and lesbian groups begin to form, not as closed social groups but as organizations fighting against discrimination and promoting the decriminalization of homosexual practices.

In June 1969, weary of incessant police raids on gay bars, trans-identified and gay men spontaneously demonstrated against a police raid on the Stonewall Inn bar in Greenwich Village, New York. Several riots ensued and the event was broadcast on television. The Stonewall riots were symbolic, because they represented the beginning of the fight for LGBT rights in the United States—a movement that would spread to all other Western countries. Every year gay pride parades, held in most major cities on or around June 29, commemorate the Stonewall riots.

In Canada, LGBT individuals obtained legal equality in 2005 as part of the legalization of same-sex marriage. The next step was to raise awareness in order to promote greater acceptance of

LGBT realities in various social spheres.

## WHAT IS HOMOPHOBIA?

Homophobia includes all negative attitudes that could lead to direct or indirect rejection or discrimination toward LGBT individuals or any person whose appearance or behaviour do not fit male or female stereotypes<sup>2</sup>. Often insidious, homophobia manifests itself in a number of ways, ranging from mockery to physical violence to social exclusion. Many LGBT individuals have grown up in social and cultural milieus where homosexuality was condemned. With no role models, some homosexual people even internalized homophobic prejudices and social norms, leading to feelings of low self-esteem, self-hatred and guilt. Others, in contrast, directed these negative feelings toward other homosexuals from whom they sought to distance themselves, thus becoming homophobic in turn.

## THE CURRENT SITUATION AND CHALLENGES OF LGBT ELDERS

Despite their emancipation, LGBT elders still face ongoing battles. Today they not only have to cope with the same aging-related challenges as other seniors, but their life experience, combined with other people’s ignorance about their realities ➤

*We sometimes hear the following statement: "We have no LGBT seniors in our clientele." Yet, between now and 2018 in Quebec, an estimated 210,000 LGBT seniors will have reached the age of 65 and over.*

and resulting homophobia, add a layer of complexity. A review of the literature and personal accounts sheds light on specific aspects of their reality and several recurring themes.

### RESEARCH AND TRAINING: THE INVISIBILITY OF LGBT ELDERS

LGBT elders feel they are becoming increasingly invisible in the eyes of both society and their own community. In Australia, gerontologist and sociologist Jo Harrison has observed the lack of visibility of LGBT elders in research, in the training of personnel who work with this clientele, and in the policies concerning them<sup>3</sup>. She contends that this invisibility is the result of the heteronormativity prevalent in all areas related to seniors in Australia. This invisibility was noted in all of the studies reviewed—from Australia, the United States, Great Britain, Spain and Canada<sup>4</sup>.

### DISTRUST OF THE HEALTH CARE SYSTEM

Not only do practitioners providing services to seniors show


a lack of interest in LGBT realities; LGBT elders themselves often have a negative perception of the services provided. Those from the pre-Stonewall generation are distrustful of all types of institutions, given their experiences of legal stigmatization (criminalization of homosexuality), religious discrimination (homosexuality as a sin), medical discrimination (homosexuality as a mental illness) and social discrimination (lack of recognition and exclusion of homosexuals). This distrust makes LGBT elders unwilling to disclose their sexual orientation and to seek help outside their circle of friends and loved ones, since they do not feel they are in a welcoming and safe environment. Their reluctance to seek help and services could have an impact on their physical health<sup>5</sup>.

### HIGHER RATES OF ISOLATION AND SOLITUDE

Isolation and solitude can lead to episodes of depression or abuse of alcohol and drugs (prescription or street drugs). Compared to heterosexual seniors, a higher proportion of LGBT seniors are

isolated and live alone. A study carried out in 2006 in Lambeth, a London neighbourhood with a significant LGBT population, showed that the proportion of LGBT seniors living alone was two and a half times higher than that of heterosexual seniors in the same situation<sup>6</sup>. Equally worrying are the results of a survey conducted in New York showing that the proportion of LGBT seniors living alone in that city was 80%, compared to 50% of heterosexual seniors. The same study noted that only 25% of LGBT seniors had children, compared to 75% of heterosexual seniors<sup>7</sup>.

### IMPORTANCE OF THE CHOSEN FAMILY

The fact that LGBT elders have fewer children, are more often single and are sometimes not close to their family members (brothers, sisters, nephews and nieces) reveals another aspect of their lives: the importance of friends in their social network. Friends are a substitute for the biological family and occupy a very important place in the life of LGBT seniors. A survey conducted in 2004 showed that among respondents without a life partner, 59% stated that when in need of emotional support, they would call their friends, while only 9% would turn to their biological family<sup>8</sup>. The notion of the chosen family is a new concept that should be 

taken into account by those who work with seniors.

## FEARS ABOUT RETIREMENT HOMES

In most of the studies reviewed, over 70% of LGBT elders would like there to be dedicated LGBT retirement homes (this percentage is slightly higher among lesbians). According to a study conducted by Keogh et al.<sup>9</sup>, the desire to have exclusive retirement homes is fuelled by LGBT seniors' fear of not being able to share their life experience with other residents; fear of rejection by residents if they were to discover their sexual orientation; and fear of not receiving the same care from personnel and workers because of their sexual orientation or gender identity. These fears demonstrate the importance of creating environments that are sensitive to the realities of LGBT individuals.

## PRESUMPTION OF HETEROSEXUALITY (SERVICES PROVIDED TO SENIORS)

We sometimes hear the following statement: "We have no LGBT seniors in our clientele." Yet, between now and 2018 in Quebec, an estimated 210,000 LGBT seniors will have reached the age of 65 and over<sup>10</sup>. In a study carried out by the Centre for Research on Families and Relationships<sup>11</sup>, the vast majority

of respondents felt that professionals and workers always assume that seniors are heterosexual. The respondents also noted that this presumption of heterosexuality on the part of service providers could lead them to adopt heterosexist behaviours.

## REDUCTION OF HOMOSEXUALITY TO SEXUAL PRACTICE

It is sometimes believed that with age, the disappearance of sexuality also signifies the disappearance of homosexuality. First, it is important to remember that sexuality does not disappear with age: "Three-quarters of people aged 60 to 69 and approximately one-quarter of those aged 70 and over are still sexually active."<sup>12</sup> Second, even in the absence of sexuality, and with a policy in place stating that "what goes on in people's bedrooms is their private business," it is important not to reduce sexual orientation to its sexual expression alone.

Being gay or lesbian encompasses much more than having sexual relations with a partner of the same sex. In the absence of sexuality, the social and emotional dimension must be taken into account. Just like heterosexual couples, same-sex couples build their relationships around feelings of love and affection. Same-sex couples, consisting of two

men or two women, experience the same joys and challenges as heterosexual couples. They have their own life experience and want to be understood and recognized.

## EVERYDAY ACTIONS

In light of these recurring themes, it is important to recognize that sexual orientation and gender identity are specific identity markers just like age, sex, language and religion. Here are a few everyday actions that will make a difference to LGBT seniors:

- ▶ Show signs of openness toward LGBT seniors so they can feel more comfortable about disclosing their sexual orientation or gender identity;
- ▶ Refrain from making assumptions about a person's sexual orientation by using neutral terms such as "life partner" rather than "spouse";
- ▶ Respect an older person's choice to disclose or not disclose his or her homosexual orientation or trans identity;
- ▶ Be aware of the importance of chosen families for LGBT seniors;
- ▶ If workers or other residents display homophobic behaviour toward LGBT seniors, assist the latter in taking action. ➤



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## TOOLS TO GO FURTHER

Fondation Émergence has compiled information and awareness material in a toolkit designed to promote discussion and help people better understand the realities of LGBT seniors. This toolkit includes:

- ▶ A “proper treatment charter” to be posted in facilities frequented by LGBT seniors. This shows that the establishment adheres to the eleven principles of the charter in order to create a non-homophobic environment<sup>13</sup>;
- ▶ Video clips of practitioners working with seniors;
- ▶ A workshop animation guide;
- ▶ Information sheets on LGBT realities;
- ▶ A filmography;
- ▶ A review of studies on LGBT seniors;
- ▶ Promotional material.

All of these tools are available on the Fondation Émergence website:

[www.fondationemergence.org](http://www.fondationemergence.org).

It is also possible to order print copies of certain tools by sending an email to: [courrier@fondationemergence.org](mailto:courrier@fondationemergence.org)

The toolkit is promoted in all of Quebec’s administrative regions. It includes lectures, workshops and information booths that you may reserve by writing to: [courrier@fondationemergence.org](mailto:courrier@fondationemergence.org) ➔

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1. Personne transidentitaire : *Personne qui s'identifie comme transsexuelle ou transgenre*. Chambre de commerce gaie du Québec. (2004). Lexique LGBT sur la diversité sexuelle et de genre en milieu de travail. Repéré à [http://ccgq.ca/CCGQ-2014\\_Lexique-LGBT.pdf](http://ccgq.ca/CCGQ-2014_Lexique-LGBT.pdf).
  2. Définition inspirée de celle du ministère de la Justice. Ministère de la Justice. (2009). *Politique québécoise de lutte contre l'homophobie*. Repéré à <http://www.justice.gouv.qc.ca/francais/publications/rapports/pdf/homophobie.pdf>.
  3. Harrison, J. (2005). Pink, lavender and grey: Gay, lesbian, bisexual, transgender and intersex ageing in Australian gerontology. *Gay and Lesbian Issues and Psychology Review*, 1 (1), 11-16.
  4. Fondation Émergence. (2010). *Pour que vieillir soit gai : Recensement des études, recherches et expériences*. Repéré à [http://fondationemergence.org/utilisateur/documents/recensement\\_aines.pdf](http://fondationemergence.org/utilisateur/documents/recensement_aines.pdf).
  5. *Ibid.*
  6. Keogh, P., Reid, D., Hickson, F. et Weatherburn, P. (2006). *The needs and experiences of Lesbians, Gay men, Bisexual and Trans men and women in Lambeth. The Full Report of Lambeth LGBT Matters, London Burrough Lambeth*. Repéré à [www.sigmaresearch.org.uk/files/lambeth\\_long.pdf](http://www.sigmaresearch.org.uk/files/lambeth_long.pdf).
  7. New York State LGTB Health and Human Services Network, Herman, T., & Empire State Pride Agenda Foundation. (2000). *Building community assets: lesbian, gay, transgender, and bisexual New Yorkers and their families : state of the state report 2000*. Albany (NY) : The Network.
  8. Heaphy, B., Yip, A. et Thompson, D. (2004). Non-heterosexual Ageing: social and policy implications. Dans Centre for Research on Families and Relationships, *Shaping Futures: LGBT people growing older. Report from a seminar of 11th May 2004*. Édimbourg : The University of Edinburgh.
  9. *Ibid.*
  10. Fondation Émergence. (2013). *Pour que vieillir soit gai : Fiches d'information*. Repéré à [http://fondationemergence.org/utilisateur/documents/aines/PQVSG\\_fiches.pdf](http://fondationemergence.org/utilisateur/documents/aines/PQVSG_fiches.pdf).
  11. Heaphy, B., Yip, A. et Thompson, D. (2004). Non-heterosexual Ageing: social and policy implications. Dans Centre for Research on Families and Relationships, *Shaping Futures: LGBT people growing older. Report from a seminar of 11th May 2004*. Édimbourg : The University of Edinburgh.
  12. Wallach, I. (2013). Des mythes sur la sexualité et le vieillissement à la non-prévention du VIH/sida auprès des aînés. *Pluriâges* (4) 1, 8-12.
  13. Cette charte a inspiré le Comité régional d'orientation en maltraitance envers les aînés de Lanaudière dans l'élaboration en 2014 de la Charte de la bientraitance envers les aînés de Lanaudière.

# CREGÉS Training Calendar 2015

trainingcalendar



TITRE DE LA FORMATION	DATE & HEURE	FORMATEURS	OÙ ?
<b>Short-term counseling for caregivers</b> <i>Formation offerte en anglais – Training offered in English</i>	Mercredi 21 janvier 2015 9 h 00 - 17 h 00	<b>Pam Orzeck</b> Soutien aux proches aidants CSSS Cavendish – CAU	<b>CLSC René-Cassin</b> 5800, boulevard Cavendish <b>6<sup>e</sup> étage, salle 31</b> * 80 \$ (dîner non inclus)
<b>L'outil PARBAS</b> : Application de l'échelle psycho gériatrique de dépistage des comportements à risque dans les plans d'intervention individuels	Vendredi 23 janvier 2015 9 h 00 - 17 h 00	<b>Samia Moussalam Issid</b> Santé mentale et vieillissement CSSS Cavendish – CAU	<b>CLSC René-Cassin</b> 5800, boulevard Cavendish <b>6<sup>e</sup> étage, salle 31</b> * 80 \$ (dîner non inclus)
<b>Les soins palliatifs et l'aide au proche : une formation pour professionnels multidisciplinaires</b> <i>Formation offerte en français</i>	Mercredi 11 février 2015 9 h 00 - 17 h 00	<b>Patrick Durivage</b> Soins palliatifs communautaires pour les aînés CSSS Cavendish – CAU	<b>CLSC René-Cassin</b> 5800, boulevard Cavendish <b>6<sup>e</sup> étage, salle 31</b> * 80 \$ (dîner non inclus)
<b>Problèmes de santé mentale et personnes âgées</b>	Vendredi 20 février 2015 9 h 00 - 17 h 00	<b>Samia Moussalam Issid</b> Santé mentale et vieillissement CSSS Cavendish – CAU	<b>CLSC René-Cassin</b> 5800, boulevard Cavendish <b>6<sup>e</sup> étage, salle 31</b> * 80 \$ (dîner non inclus)
<b>Caregiving in the Palliative Stage: A Training for Multidisciplinary Professionals</b> <i>Formation offerte en anglais – Training offered in English</i>	Jeudi 26 février 2015 9 h 00 - 17 h 00	<b>Pam Orzeck</b> Soutien aux proches aidants CSSS Cavendish – CAU	<b>CLSC René-Cassin</b> 5800, boulevard Cavendish <b>6<sup>e</sup> étage, salle 31</b> * 80 \$ (dîner non inclus)
<b>Musclez vos méninges!</b> Promouvoir la vitalité intellectuelle des aînés	Mardi 10 mars 2015 9 h 00 - 17 h 00	<b>Manon Parisien</b> Prévention-promotion, santé et vieillissement CSSS Cavendish – CAU	<b>CLSC René-Cassin</b> 5800, boulevard Cavendish <b>6<sup>e</sup> étage, salle 31</b> * 40 \$ (dîner non inclus)
<b>Reconnaître et comprendre les stratégies de soins des hommes âgés aidants : implications pour la pratique et les interventions</b>	Mercredi 18 mars 2015 9 h 00 - 13 h 00	<b>Norma Gilbert</b> CSSS Cavendish – CAU <b>Yvan Provencher</b> Centre de soutien entr'aîdants, St-Hubert	<b>CLSC Benny Farm</b> 6484, Avenue Monkland <b>salles 041</b> * 40 \$ (dîner non inclus)
<b>Jog your mind!</b> Promoting the intellectual vitality of seniors <i>Training offered in English – Formation offerte en anglais</i>	Vendredi 27 mars 2015 9 h 00 - 17 h 00	<b>Norma Gilbert</b> Prévention-promotion, santé et vieillissement CSSS Cavendish – CAU	<b>CLSC René-Cassin</b> 5800, boulevard Cavendish <b>6<sup>e</sup> étage, salle 31</b> * 40 \$ (dîner non inclus)
<b>Intervention auprès des personnes âgées en soins palliatifs</b> (2 jours de formation)	Jeudi 21 et 28 mai 2015 9 h 00 - 16 h 30	<b>Patrick Durivage</b> CSSS Cavendish – CAU <b>Isabelle Van Pevénage</b> CREGÉS - CSSS Cavendish – CAU	<b>CLSC René-Cassin</b> 5800, boulevard Cavendish <b>2<sup>e</sup> étage, salle AFS</b> * 160 \$ (dîner non inclus)

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\* NB: La formation est gratuite pour le personnel, les bénévoles et stagiaires du CSSS Cavendish – CAU

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