



pluralages

Vol. 8, N°2, FALL 2018



Who? decides

Strengthening the
partnership between
seniors, families
and practitioners
in the context of
social and health
care services



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in Social Gerontology

*Integrated Health
and Social Services
University Network
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Pluralages is published by the Centre for Research and Expertise in Social Gerontology (CREGÉS) of the CIUSSS West-Central Montreal, which has two university designations in the health and social services sector, including that of university-affiliated centre in social gerontology. This magazine aims to inform the public and raise awareness around social issues associated with aging by, among other things, presenting the research initiatives and expertise of CREGÉS members through thematic and post-conference issues. Pluralages also aims to promote and foster ties between communities involved in research, teaching, intervention and advocacy on issues important to seniors. Issues related to aging are presented through the lens of social gerontology and include topics such as the heterogeneity of aging, the social and public recognition of seniors, experiences of social exclusion as well as solidarity, political concerns, the strategic directions of the State, and public policy in response to the aging population and its needs. Pluralages is published in French and English, in print and electronic versions. The authors are entirely responsible for the articles published herein; the CIUSSS Board of Directors and management may not be held liable for their content. The articles may be reproduced, provided the source is mentioned.

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The CREGÉS annual conference: Who decides? Strengthening the partnership between seniors, families and practitioners in the context of social and health care services

Shared decision-making ensures that interventions are adapted to the complexity of older adults' health conditions, in accordance with their values and preferences. Concretely, shared decision-making is one of the core components of the patient-centred approach¹ advocated by a number of national organizations, including the College of Family Physicians of Canada. In Quebec, this approach is also a cornerstone of the Plan stratégique 2015-2020 developed by the Ministère de la Santé et des Services sociaux (MSSS).²

This type of decision-making process requires the commitment of the person receiving care and at least one health professional, as well as the caregiver,³ if applicable. The process implies a sharing of information and joint efforts to reach a consensus on the best option to put in place under the circumstances. It is designed to empower individuals and reduce their feelings of helplessness.⁴

The participation of older adults in decision-making processes is viewed from a broad perspective and is part of an effort to preserve their autonomy in daily life.⁵ Older adults would like to better understand the care required for their condition and to be in a stronger position vis-à-vis health professionals. International scientific studies show that many older people still report a lack of knowledge and information, notably with regard to their chronic health conditions.⁵ Caregivers, too, have insufficient knowledge resulting from limited contact with health care professionals⁶ and are often unaware of the many of services available to them.^{7,8,9} The challenges of navigating the system affect the health and well-being of caregivers, increasing their stress and feeling of isolation.¹⁰

In Canada, shared decision-making takes a variety of forms, depending on the province or territory.¹¹ The practical application of shared decision-making depends not only on political will, but also on the willingness of health care professionals and the public to get on board.¹¹

The issues around older adults' decision-making in our health and social services system are complex. How can we support dialogue in order to reinforce the partnership among older people, families and service providers? What are the challenges and opportunities in shared decision-making? What are the rights and responsibilities of each individual?

These were some of the key questions addressed at the annual conference held on May 18, 2018, in Montreal, by the Centre for Research and Expertise in Social Gerontology (CREGÉS) of the Integrated Health and Social Services University Network (CIUSSS) of West-Central Montreal. The event was attended by 250 participants—roughly 60 via a webinar, an effective and popular way to reach our target audience at the regional, provincial and national levels. ➤

The conference, which was open to the general public, targeted older adults and their caregivers, managers in the health and social services network, community group representatives, researchers and students. A training activity endorsed by the Ordre des psychologues du Québec, the Ordre des travailleurs sociaux et des thérapeutes conjugaux et familiaux du Québec (OTSTCFQ), and the Faculté des sciences infirmières at the Université de Montréal, was facilitated by Rose-Marie Charest, a speaker at the conference and director of the Ordre des psychologues du Québec from 1998 to 2015. Ms. Charest graciously shared her personal experiences in the area of decision-making within the health and social services system.

The conference program included presentations by researchers and research-practitioners who coordinate the development of leading practices in three areas of expertise (mistreatment, palliative care, caregiving), and students at CREGÉS. The topics were focused on decision-making and partnerships among older adults, their loved ones and service providers.

Four **main presentations** were made by experts from the academic milieu and practice settings (social gerontology, psychology, social work, sociology and medicine):

- **Mélanie Couture (CREGÉS)** explored: 1) the key elements in shared decision-making; 2) the ways in which caregivers interact with the health care and social services system; 3) information and support challenges tied to decision-making; and 4) the usefulness of decision aids.
- **Sarita Israel (CREGÉS)** considered how societal attitudes toward older adults can affect shared decision-making. In addition to discussing ageism, she examined the

key elements involved in decision-making around care and services for older adults in situations where the person is either capable or incapable of providing consent (e.g., in cases of cognitive impairment).

- **Isabelle Van Pevenage, Zelda Freitas, Patrick Durivage and Pam Orzek (CREGÉS)** discussed issues related to decision-making in end-of-life care.
- **France Légaré**, a guest speaker and the **Canada Research Chair in Shared Decision-Making and Knowledge Translation**, presented her findings from studies aimed at promoting shared decision-making in home-care teams.

A panel discussion on challenges, opportunities and priority measures aimed at promoting shared decision-making within the health and social services system allowed a variety of stakeholders to share their perspectives (an ethics consultant, a home-care support team manager, caregivers, service users).

Information booths and a **student poster competition** generated a lot of interest among participants. Attendees, speakers, panel members, exhibitors and students also had several opportunities throughout the day to ask questions, exchange views and network.

Highlights of the conference and this special issue of *Pluralages*

The articles in this issue of *Pluralages*, published by CREGÉS, summarize the presentations and studies of the conference speakers, two of the panel members, and the winner of the student poster competition. ➤



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The conference and these articles are aimed at raising awareness and informing stakeholders who are concerned about the decision-making of older adults in the health and social services system. More specifically, these initiatives provide an opportunity to recognize the challenges around decision-making in the system, to identify possible solutions to support dialogue and promote partnerships, and to better understand the repercussions of actions on the decision-making power of older adults.

By sharing their knowledge and reflecting on the issues together, the conference speakers, panel members and participants were able to identify the main decision-making challenges in our current health and social services system. Several participants noted: 1) a culture that is sometimes ageist and paternalistic, which can impede access to information, as well as attitudes that are perhaps well-intentioned, but are not always conducive to informed decision-making; 2) the fact that older adults do not have many choices, given the lack

of available resources and services; 3) the fact that few measures have been put in place to identify older adults who would like to obtain assistance in decision-making.

At the same time, participants noted that government bodies have shown a desire to improve informed decision-making. Several professionals wish to share information and believe that they should support people in their decision-making process rather than taking charge. Managers and service providers have a role to play in improving communication in order to support informed decision-making aligned with the values and preferences of older adults and their loved ones. It is also essential to include caregivers in the decision-making process, ensuring that they are able to make choices regarding their role, whether this means evaluating their needs and extent of their involvement, or obtaining access to support services. ➤

In May 2018, a few days before the conference, the Ministère de la Santé et des Services sociaux (MSSS) announced its intention to support shared decision-making by publishing a reference framework for a partnership approach among users, loved ones and healthcare and social services professionals.¹² This framework aims to “guide users, loved ones, service providers and managers at the Ministère de la Santé et des Services sociaux (MSSS) and within the health and social services system in adopting a partnership approach and in specifying parameters for the development of this approach.” [Translation] We encourage the application of this framework in order to reinforce the partnership among older adults, families and practitioners within the health care and social services system.

Acknowledgements

The conference and this publication were made possible thanks to financial support from the Canadian Institutes of Health Research, the Fonds de recherche du Québec – Société et Culture, and the MSSS (support fund for the university-affiliated centre in social gerontology).

The publication of this issue of *Pluralages*, and the organization of the conference to which it is devoted, are the result of hard work and collaboration on the part of several individuals and teams to whom we express our warm thanks.

Happy reading!

Mélanie Couture, Gabrielle Legendre
and **Julie Beauchamp**
On behalf of the editorial team

3. Charles, C., Gafni, A. & Whelan, T. (1997). Shared decision-making in the medical encounter: What does it mean? (or it takes at least two to tango). *Social Science & Medicine*, 44(5), 681–692.
4. Davidson, L. (2005). Recovery, self-management and the expert patient perspective. *Journal of Mental Health*, 14(1), 25–35. doi:10.1080/09638230500047968
5. Holm, A.L., Berland, A.K. & Severinsson, E. (2016). Older patients' involvement in shared decision-making—A systematic review. *Open Journal of Nursing*, 6(3), 170–185. doi:10.4236/ojn.2016.63018
6. Khabarov, D., Dimitropoulos, G. & McGillicuddy, P. (2015). Qualitative study: Exploring the experiences of family caregivers within an inpatient neurology and neurosurgery hospital setting. *National Association of Social Workers*, 40(4), 290–297. doi:10.1093/hsw/hlv057
7. Armstrong, M. (2000). Factors affecting the decision to place a relative with dementia into residential care. *Nursing Standard*, 14(16), 33–37. doi:10.7748/ns2000.01.14.16.33.c2737
8. Borreani, C., Bianchi, E., Pietrolongo, E., Rossi, I., Cilia, S., Giuntoli, M., ... Solari, A. (2014). Unmet needs of people with severe multiple sclerosis and their carers: Qualitative findings for a home-based intervention. *PLoS One*, 9(10). doi:10.1371/journal.pone.0109679
9. Park, M., Butcher, H. K. & Maas, M. L. (2004). A thematic analysis of Korean family caregivers' experiences in making the decision to place a family member with dementia in a long-term care facility. *Research in Nursing and Health*, 27(5), 345–356. doi:10.1002/nur.20031
10. Wiles, J. (2002). Informal caregivers' experiences of formal support in a changing context. *Health and Social Care in the Community*, 11(3), 189–207.
11. Légaré, F., Stacey, D., Forest, P.G., Couto M.F., Archambault, P., Boland, L., ... Giguère, A.M.C. (2017). Milestones, barriers and beacons: Shared decision-making in Canada inches ahead. *Zeitschrift für Evidenz, Fortbildung und Qualität im Gesundheitswesen*, 123–124, 23–27. doi:10.1016/j.zefq.2017.05.020
12. Ministère de la Santé et des Services sociaux. (2018). *Cadre de référence de l'approche de partenariat entre les usagers, leurs proches et les acteurs en santé et en services sociaux*.

-
1. Weston, W. W. (2001). Informed and shared decision-making: The crux of patient-centred care. *Canadian Medical Association Journal*, 165(4), 438–439.
 2. Ministère de la Santé et des Services sociaux. (2015). *Plan stratégique du ministère de la Santé et des Services sociaux du Québec 2015-2020*.

Choosing while thinking of others: Caregivers situation when interacting with the social and health care system



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A caregiver may be defined as “A friend or family member who provides significant ongoing or occasional support, in a non-professional role, to a person who is incapacitated” [Translation].¹ It is important to recognize that behind this informal and unpaid role, in which caregivers do the best they can to meet the care recipient’s needs, are emotional and family ties. In the context of significant cognitive impairment, caregivers are not only responsible for carrying out various tasks; they must also make decisions with the care recipient in mind, since the latter can no longer clearly express his or her values and preferences. What are the realities of caregivers who are required to make all kinds of decisions in interaction with the social and health care system? ➤

DECISION-MAKING IN THE CONTEXT OF CAREGIVING

For caregivers, decision-making involves weighing the costs and benefits regarding available options, keeping in mind both the interests of their aging loved one and their own needs.² This is a multi-stage process, since one decision often leads to another. In addition to making common daily-life decisions, caregivers have to make more substantial decisions, such as choosing a new living environment or end-of-life care.²

Caregivers' level of involvement in decisions concerning their loved one depends on family dynamics.² Many caregivers report not knowing what role they should play or what other people expect of them.² Some consult with the older adult in order to clarify his or her values; others attempt to guess through non-verbal cues or simply exclude the person from the decision-making process. Caregivers' perception of care recipients' decision-making capacity will influence the degree to which the latter are involved in the decision-making process.² When the care recipient's cognitive challenges are perceived to be too great, some caregivers prefer to make decisions on their behalf, without consulting them.

Decision-making can be difficult, given the different values of the individuals involved, including the caregiver, the older adult and other family members.² Some see decision-making as a burden that conveys negative emotions such as regret, doubt, guilt and disappointment. They are aware that others may view the decisions they make in a negative way.² That is why it is important that caregivers have access to support from professionals within the social and health care system.

PARTNERSHIP AND DECISION-MAKING WITHIN THE SOCIAL AND HEALTH CARE SYSTEM

When it comes to care-related decisions, caregivers expect to work in partnership with professionals in the social and health care system. They also expect these professionals to recognize their expertise and needs.³ More specifically, they believe that these professionals should provide information, assess their needs, offer support, and unite and guide everyone involved.⁴ They can also promote the inclusion of the older adult in the decision-making process, despite his or her cognitive impairments.⁴ In reality, many caregivers report that their needs are unmet in terms of information, discussions regarding values and needs, and decisional support.²

Many admit being unfamiliar with the workings of the social and health care system, and are disappointed that professionals do not have the time to support them or provide comprehensive explanations.² Some caregivers also report feeling pressure to accept options that they do not view as optimal.⁴

According to ministerial orientations, caregivers are considered partners in the social and health care system.¹ This partnership approach seeks to maximize care efficiency by ensuring that services match needs and are offered in a timely manner.⁵ Legally, this type of partnership remains difficult to apply. In reality, care recipients have the power of self-determination, even if they are affected by cognitive impairment. According to the Act Respecting Health Services and Social Services, only the care recipient has the right to access information in his or her care record, and to help develop an intervention plan. There is nothing in the legislation allowing a caregiver to be officially involved in this way.

The Act states that caregivers may accompany care recipients to appointments, provided the latter agree. Only when adults of full age are recognized as incapable does the role of "representative" truly exist for the spouse or close relative. ➤



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In short, older adults must be involved in making decisions that concern them.

Despite confidentiality constraints, actors in the social and health care system are required to collaborate with caregivers and listen to their concerns. The Quebec government's 2015-2000 mental health action plan states that "The Code of Ethics of physicians, like that of other healthcare professionals, stipulates that they are obliged to collaborate with the patient's loved ones or with any other person who shows a significant interest in the patient" [Translation].⁶ However, in the same document, the government recognizes

that "some practitioners refuse to listen to the patient's loved ones—a behaviour they justify on the basis of confidentiality. Yet listening does not in any way infringe on the user's rights" [Translation].⁶ Caregivers therefore have the right to insist on collaborating with social and health care professionals, according to the law and preferably with the consent of the older adult.

HOW CAN CAREGIVERS BECOME PARTNERS?

The participation of caregivers seems to depend in large part on the role assigned to them by the older adult and social and health care professionals.

In a partnership approach, caregivers' expertise should be valued through open discussion, power-sharing and interventions focused on both the social and clinical aspects of the situation.⁷ Nonetheless, within this approach, caregivers must engage in a process of reflection to identify their own needs and understand the role of each partner, in order to get their viewpoint across and to receive support in the decision-making process.

The first stage of reflection involves identifying the decision to be made and its implications in terms of values and preferences. Decision-making tools are clinical tools structuring the ➤



decision-making process on an individual basis or in partnership with other people involved.⁸ This type of tool provides information on available options, helps to clarify what is most important for the individual(s) involved, and allows perspectives and preferences to be shared.⁹ Some tools are geared towards making specific decisions while others are generic. For example, the Decision Aid for Caregivers: Choosing a Living Environment for a Relative with Dementia (DAC-CLERD) is used in a one-hour meeting with a social and health care professional in order to help caregivers select a suitable living environment for a loved one with dementia.⁸ The Ottawa Personal Decision Guide is a generic decision-making tool that helps to identify the following elements¹⁰: 1) the decision to be made; 2) available options; 3) benefits and risks; 4) decision-making needs; 5) knowledge and values; 6) support; 7) certainty and 8) planning next steps based on identified needs. There is also a version of this tool specifically designed to include the older adult in the decision-making process.¹¹

The second stage of reflection involves assessing one's knowledge of the social and health system in order to: 1) identify the right partners to carry out social and clinical interventions, and to support

the decision-making process and 2) exert one's power and rights. The partners will likely vary according to the caregiver's identified needs (information or support). For issues related to the older adult's condition, it is most appropriate to consult with doctors and professionals within the social and health care system, given the medical factors involved. Older adults must be included, since they have the right to access information in their file. It is also possible to obtain support from community organizations specialized in the older adult's condition (e.g., the Alzheimer Society of Canada, the Elder Mistreatment Helpline, Caregiver support - L'APPUI, etc.) or in providing assistance to caregivers. These organizations have an important role to play within the social and health care system, offering prevention, assistance and support programs, as well as activities to promote health, raise awareness and advocacy.

CONCLUSION

Caregivers can sometime find it psychologically challenging to make decisions related to their role, and tensions in relationships may arise. They expect to be supported by social and health care professionals, but this assistance is not always available. Caregivers can improve their interactions with the system by using

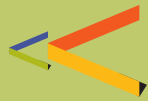
decision-making tools that clarify their needs and perspectives, so they can better communicate them to the other individuals involved in the decision-making process. These tools, along with support from social and health care professionals, can also help to include the older adults in the decision-making process, whether or not the latter is affected by cognitive impairments. Caregivers should consolidate their knowledge of the social and health care system in order to fully understand their rights and the most appropriate partners to contact in case of need. Efforts should also be made within the system to train social and health care professionals in shared decision-making and support structures for caregivers.

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1. Ministère de la Santé et des Services sociaux. (2003). *Chez soi : le premier choix. La politique de soutien à domicile.*
 2. Garvelink, M.M., Ngangué, P.A.G., Adekpedjou, R., Diouf, N.T., Goh, L., Blair, L. & Légaré, F. (2016). A synthesis of knowledge about caregiver decision making finds gaps in support for those who care for aging loved ones. *Health Affairs*, 35(4), 619-626. doi:10.1377/hlthaff.2015.1375
 3. Lavoie, J.-P., Guberman, N., Bickerstaff, J., Blein, L. & Olazabal, I. (2009). Les aidantes baby-boomers revendicatrices et des professionnels coïncés. Les enjeux d'une reconnaissance. In I. Olazabal (Ed.), *Baby-boom et baby-boomers au Québec. Trajectoires sociales et parcours de vie* (pp. 207-228). Québec: Nota Bene.
 4. Couture, M., Ducharme, F. & Lamontagne, J. (2012). The role of healthcare professionals in the decision-making process of family caregivers regarding placement of a cognitively impaired elderly relative. *Home Health Care Management and Practice*, 24(6), 282-290. doi: 10.1177/1084822312442675 >

5. Nolan, M., Grant, G., Keady, J. & Lundh, U. (2003). New directions for partnership: Relationship-centered care. In Nolan, M. (Ed.), *Partnerships in family care: Understanding the caregiving career* (pp. 257-291). Maidenhead: Open University Press. Press, pp. 257-291.
6. Ministère de la Santé et des Services sociaux. (2015). *Plan d'action en santé mentale 2015-2020 – Faire ensemble et autrement*.
7. Magnusson, L., Nolan, M.R., Hanson, E., Berthold, H. & Andersson B.-A. (2001). Developing partnerships with older people and their family carers: The Äldre Väst Sjuhärads model. *Quality in Ageing*, 2(2), 32-38. doi:10.1108/14717794200100015
8. Couture, M. & Ducharme, F. (2012). Choosing a living environment for a relative with dementia: Developing a decision-aid for family carers based on a systematic review of qualitative studies. Proceedings of the 27th International Conference of Alzheimer's Disease International. Italy: Medimond Editore.
9. International Patient Decision Aid Standards Collaboration. (2005). *Criteria for judging the quality of patient decision aids*. Retrieved from http://ipdas.ohri.ca/IPDAS_checklist.pdf
10. O'Connor, Stacey & Jacobsen (2015). Guide personnel d'aide à la décision (Ottawa) (GPDO). Institut de recherche de l'Hôpital d'Ottawa & Université d'Ottawa, Canada. Retrieved from <https://decisionaid.ohri.ca/francais/gpdo.html>
11. O'Connor, Stacey & Jacobsen (2015). Guide personnel d'aide à la décision pour deux (Ottawa) (GPDO). Institut de recherche de l'Hôpital d'Ottawa & Université d'Ottawa, Canada. Retrieved from <https://decisionaid.ohri.ca/francais/docs/GPDOx2.pdf>



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The impact of ageism on the participation of older adults in decision-making regarding health care and social services



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This article looks at how ageism affects the decision-making process around healthcare and social services provided to older adults in cases where the person concerned is either capable or incapable of providing consent. Violation of older persons' rights, although subtle at times, is unfortunately quite frequent in the decision-making that concerns them. It is a complex issue that stems from the inherent challenge of respecting an older adult's autonomy when there is a perceived need for protection by family members and/or healthcare practitioners. In addition, there are specific issues related to the comprehension of the rights of incapacitated persons in the provision of healthcare and social services. ▶

AGEISM, VIOLATION OF RIGHTS AND OLDER ADULT MISTREATMENT

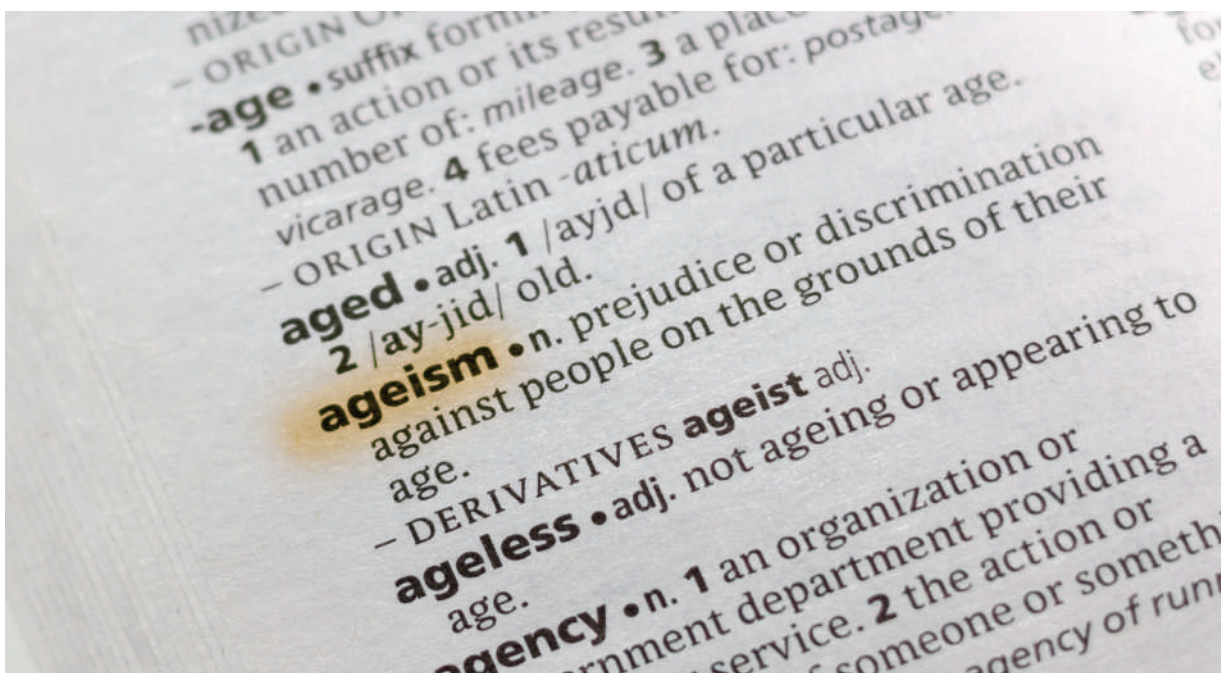
Ageism is a process whereby people are stereotyped and discriminated against because of their age—a process similar to racism and sexism.¹ We live in a society that celebrates performance, youth and beauty, which negatively affects our perception of aging. Negative stereotypes are conveyed in a variety of messages, some more subtle than others. The representation of aging in certain ads reinforces the notion that although this process is inevitable, we need to hide or fight against its signs and related conditions: wrinkles, pain, high blood pressure, digestive issues, incontinence and sexual dysfunction.

These negative messages are also conveyed in the use of common expressions that imply that aging is synonymous with deterioration or the loss of physical and/or mental capacity. For example, the expression “s/he has aged” refers to someone who has lost their vitality, and “having a senior moment” refers to a lapse of memory. Ageist attitudes can lead to discrimination or exclusion based on a person’s age. If, for example, we are convinced that as people get older, they find it more difficult or even impossible to learn new things, we might deny them learning opportunities.

Similarly, if we believe that as people get older, they experience cognitive impairments that prevent them from making informed decisions, we risk putting in place practices

that exclude older adults from the decision-making processes that concern them. It is therefore not surprising that some older adults deny or hide their health problems or their loss of certain abilities in order to avoid negative comments or behaviours. Ultimately, this type of reaction could affect their willingness to accept care and services related to their loss of autonomy. Ageism can without a doubt, negatively impact the health and well-being of an older adult.

Ageism is the normalization of a tendency to undervalue older adults, leading to a failure to recognize their competencies, knowledge and rights. This is why ageism can legitimately be considered a form of mistreatment. ➤





What is older adult mistreatment? “Mistreatment is a single or repeated act, or lack of appropriate action, occurring within any relationship where there is an expectation of trust, which causes harm or distress to an older adult, whether the person deliberately wants to cause harm or not.”

(Definition inspired by the World Health Organization² and cited at p. 15 of the *Plan d’action gouvernemental pour contrer la maltraitance envers les personnes âgées 2017-2022*,³ the notion of “intentionality” was added).

Violation of rights is a type of mistreatment that occurs when there is an infringement of individual and social rights and freedoms, such as preventing an older adult from participating in decision-making processes that affect his or her life, or failing to respect the person’s decisions.

Whether intentional or not, this form of mistreatment often gives rise to physical and/or psychological consequences. Consistent isolation and exclusion from decision-making processes can result in a growing sense of insecurity, anxiety and even confusion when having to make a decision. In certain individuals, this anxiety can lead to depression and suicidal ideation or destructive behaviours.

Mistreatment is a single or repeated act, or lack of appropriate action, occurring within any relationship where there is an expectation of trust, which causes harm or distress to an older adult, whether the person deliberately wants to cause harm or not.

(Definition inspired by the World Health Organization² and cited at p. 15 of the *Plan d’action gouvernemental pour contrer la maltraitance envers les personnes âgées 2017-2022*,³ the notion of “intentionality” was added)

The psychological consequences of mistreatment can also lead to self-neglect. In turn, self-neglect can result in temporary or permanent physical deterioration, increased morbidity and premature mortality, including active or passive suicide. It is clear that in order to prevent potentially devastating consequences of mistreatment in the context of healthcare and social service delivery, we must be aware of the elements that influence decision-making processes regarding older adults.

WHAT ARE THE KEY ELEMENTS IN ANY DECISION-MAKING PROCESS?

Typically there are three parties involved in decision making around the provision of healthcare services: (1) the older adult; (2) a significant person (family, friend or caregiver); and (3) the healthcare worker. Each of these parties will have their own perspective regarding the following elements:

- 1. The older adult’s cognitive and physical capabilities.** An accurate understanding of the older adult’s capabilities depends on whether the person consents to an objective assessment of his/her health status and needs.
- 2. Acknowledgement that there is a problem or need.** If the older adult and/or significant other do not recognize the existence of a problem, they are less likely to seek an assessment or accept any services offered.
- 3. Perception of risk or a need to protect.** The older adult plays a key role in requesting and accepting help. Family members may have different perceptions, but even if they feel there is a risk and request services from a healthcare provider, the older adult can refuse an intervention in whole or in part. ➤

4. **Trust in the person who identifies the problem.** Typically, if the older adult has a good relationship with the caregiver (child/spouse) s/he will be more open to discussing a problem and accepting the proposed assessment or services. However, if the relationship is strained, the person will be more likely to refuse. A parent in a situation of loss of autonomy may interpret a child's concern as a desire to "get rid of me" rather than to provide necessary help. Trust in a health professional will similarly affect the older adult's acceptance or refusal of care. An older adult who has not had much contact with the healthcare system may be more responsive to professionals who are traditionally held in high regard, such as doctors or nurses, as opposed to social workers or other professionals with whom the person is less familiar.
5. **Perception of the potential impact of a decision.** When proposing a care plan, the healthcare worker must take into consideration the impact of any decision on the older adult and on those who provide support. Options and concerns should be addressed with the older adult and caregiver/significant other in order to ensure that they make informed decisions. For example, a healthcare worker who identifies a conflict in the caregiving relationship should propose services that maintain the involvement of the caregiver/significant other in the care plan, but also reduce and/or prevent additional stress and tension.
6. **Access to and comprehension of the information required to make a decision.** Partial information or information that is not clear may cause confusion and inhibit the decision-making process.
7. **Exclusion of the older adult from the decision-making process.** If the older adult is only presented with the preferred options of his or her caregiver/significant other, and does not agree, s/he may refuse services and be denied other, more appropriate options. For example, family members may see placement in a residence as the best way to deal with a parent's loss of autonomy, and may not mention available homecare options. The parent may refuse to relocate without knowing that s/he has other options.
8. **Knowledge of rights.** Knowledge about who has the right to decide, and under what conditions, is key to an inclusive decision-making process. Families and older adults are not always aware that older adults have the right to be present during discussions about all decisions that concern them.
9. **Understanding the responsibilities and limits of legal mandates and powers of attorney.** Legal mandates set out obligations and constraints, as well as the conditions for their application. Homologated or official mandates—for example, in the case of incapacity—are intended to ensure the protection of incapacitated older adults and to safeguard their autonomy and rights. In practice, however, these mandates are often interpreted as being valid even if they have not been homologated, and the mandatary assumes full legal authority to act on behalf of the older adult with or without his/her knowledge.
10. **Source of the request for service.** It is not uncommon for healthcare providers to receive requests for service from concerned family members, especially in >

cases where older adults do not realize they have impairment or a need. Sometimes older adults reluctantly agree to be evaluated by a healthcare worker. It is important that the latter inform family members of their obligation to respect the wishes and rights of the older adult.

There is a complex balance between the obligation to respect the older adult's autonomy and a perceived need for protection.

Healthcare workers can be of great assistance in such situations, ensuring that the necessary evaluations are carried out to assess the older adult's needs. They can provide information regarding options and local resources. Above all, they can offer support to the older adult and caregivers or significant others, and ensure that the person's rights are respected, regardless of his/her level of incapacity. It is not always clear to older adults and their caregivers or significant others how incapacity is assessed, and who can make decisions.

WHAT IS INCAPACITY?

Incapacity is confirmed in medical and psychosocial assessments. These assessments establish:

1. **Type of incapacity.** Is the person unable to plan, accomplish the tasks of daily living, or manage property, money and investments?
2. **Extent of the incapacity.** Is the incapacity partial (the person is able to make some informed decisions)—or total (the person cannot make informed decisions, exercise their rights, or manage their affairs)?
3. **Prognosis.** Is the incapacity temporary or permanent?

It is important to note that even if an assessment attests to the incapacity of an individual, the latter is still considered capable until s/he is legally declared incapable by a judge. The person has a right to refuse a competency assessment, except in cases of immediate danger to self or others, or when the assessment is ordered by a court.

Regardless of the degree of incapacity and legal representation, individuals retain the fundamental right to consent to or refuse care, which can include medical assessments, tests, treatment and placement, even if such care is necessary to sustain life. This right must be upheld unless there is a court order, or if consent is impossible to obtain in the context of a life-threatening emergency.

The assessment of consent to care is carried out by a professional who is able to judge whether the person understands their illness or condition and the treatment proposed. According to the criteria established in the *Nova Scotia Hospitals Act*⁴, this evaluation verifies the person's understanding of the nature and purpose of the proposed treatment, the risks associated with the treatment, and the risks of refusing treatment. The assessment also considers whether the person's current state or illness could affect their capacity to consent to care.

Where it is ascertained that a person of full age is capable of providing consent to care, the person's wishes must be respected, even if s/he has a legal representative. Where it is ascertained that a person of full age is incapable of providing consent to care required by his/her state of health, consent is given by the person's mandatary, tutor or curator. If the person of full age is not so represented, his or her spouse may give consent. If the person has no spouse or the spouse is prevented from giving consent, consent may be given by a close relative or a person who shows a special interest in the person of full age (Article 15).⁵ ➤

Ultimately, if we want to ensure older adults' well-being and the appropriate delivery of care and services, we must consult them as far as their capabilities permit, and aim for a decision-making process that protects their choices, dignity, security and rights.

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1. Butler, R.N. (1975). *Why Survive? Being Old in America*. New York: Harper & Row.
 2. World Health Organization (2002). *The Toronto Declaration on the Global Prevention of Elder Abuse*. Retrieved from http://www.who.int/ageing/projects/elder_abuse/alc_toronto_declaration_en.pdf
 3. Ministère de la Famille. (2017). *Plan d'action gouvernemental pour contrer la maltraitance envers les personnes âgées 2017-2022*. Retrieved from <http://publications.msss.gouv.qc.ca/msss/fichiers/ainee/plan-action-maltraitance-2017-2022.pdf>
 4. Hospitals Act. Chapter 208 of the revised statutes, 1989. (2016). Retrieved from <https://nslegislature.ca/sites/default/files/legc/statutes/hospitals.pdf>
 5. Civil Code of Québec, chapter CCQ-1991. Retrieved from <http://legisquebec.gouv.qc.ca/fr/showdoc/cs/CCQ-1991>



End-of-life care at home, decision-making and caregiver grief: multiple issues and perspectives



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There are a number of conditions that can facilitate a person's choice to die at home. The presence of family members and /or friends is central as is access to palliative homecare, and certain adaptations made to the home environment. The presence of one or more caregivers who have the desire and ability to support the end-of-life patient at home is essential.¹ Undeniably, the experiences of end of life caregivers are extremely diverse, since they are influenced by numerous factors such as available resources, their shared history with the patient, family dynamics, the type of disease and its duration, to name just a few.

Patients who wish to die at home must be supported by their families/caregiver as well as be able to rely on the presence of an interdisciplinary healthcare team ,which can include physicians, nurses, social workers, psychologists, occupational and physical therapists, personal support workers and other allied health care providers. These teams will assist patients and their loved ones in coping with the disease and in making often difficult decisions. They play an important role during the trajectory of the illness, by providing support during illness and during the bereavement process. In this article, the authors present some critical decision-making moments in an end-of-life context, and demonstrate through the use of examples, of how an interdisciplinary team can play a pivotal role in caregivers' experiences in end of life care.

SOME CRITICAL DECISION-MAKING MOMENTS

As a person nears the end of life, a number of questions arise. The atmosphere is emotionally charged—for the person who is ill, for his or her family and friends, and for the care team.

Here are a few areas in which questions arise.

The time of **diagnosis** is an understandably critical moment for the patient and their loved ones. The time, place and health care provider's use of language are important elements that will affect the patient's and his or her caregiver understanding of

the diagnosis, treatment options and prognosis. If the health care team has a clear understanding of the situation, they will be able to ask the right questions and make informed decisions. For the health care team, some of the questions that might arise are: "When do I deliver the news about the illness?" "Should we speak to the patient alone or ask that there is with someone else present?" "What is the best way to communicate the diagnosis and discuss treatment options when the disease is deemed incurable?"

Some examples of questions related to **treatment options** are: What treatments will respond best to the patient's

illness? Do we know what the patient's preferences are? How can the team ensure that all issues related to these treatment options are properly understood by the patient? When should palliative care be introduced?

Loved ones may also have many questions and decisions to make in terms of their caregiving role. Do they want to become caregivers? Do they know what this role will involve in terms of the daily physical and emotional tasks and consequences? Are they prepared to take on responsibilities such as helping to ensure that medication and other therapies are administered?² >



Another issue relates to the **place of care**. Do the patient and caregivers want the team to monitor the situation at home? If this is their decision, is the necessary support (formal and informal) available? Do the patient and caregivers mutually agree? Are they prepared for the transformation of their home into a hospital like setting? When the patient is nearing the end of life, will he or she still feel that being home is the best option? Research shows that without the presence of caregivers, dying at home is practically impossible.¹ Are loved ones emotionally prepared to go through this experience of supporting a dying patient? The media and public policy often report that people want to die at home.³ However, in 2013, only 11% of Quebecers died at home and this percentage was even lower for the oldest population segment: only 9% of those aged 80 and older died at home (INSPQ, unpublished data).

There are also questions regarding issues around **advance medical directives**, a written statement made by persons of full age capable of expressing their will, in which they indicate the medical care they accept or refuse in the event that they become incapable of providing consent. This approach to advance care planning is not well known by the general public. Health care providers may not

be aware that their patient may have written directives. Another possible issue is regarding the different interpretations of these directives and the fact that providers need to mitigate the possible conflicts that could arise as a result.

Understandably these are just some examples of questions that occur and decisions that need to be made. Undoubtedly the patient is at the center of these concerns; however caregivers and support teams also play a role at these decisive moments.

GRIEF AND THE HEALTHCARE SYSTEM

Often, in end of life care, the health care team is focused on the patient during disease and pain management rather than on the needs of the caregiver. Caregivers likewise receive little support when the person dies and they enter a period of grief. In 2002, the World Health Organization declared that caregiver/family support is an integral part of the delivery of palliative care, both during the disease management phase and the period following the patient's death.⁴

During the management of end-of-life care, one of the questions health care providers may ask themselves is how they can influence the caregiver's experience of grief? What can

they do so as not to negatively impact the bereavement process?

Bereavement: definition(s)

There are several definitions, models and conceptualizations of grief and bereavement. However, as a general rule, the grieving process is seen as all of the reactions and emotions a person may experience following the loss of a loved one.⁵ Bereaved individuals frequently face all kinds of reactions and feelings, ranging from shock and disbelief to sadness, anger, ambivalence, guilt and relief. Although these emotions might seem contradictory, it is not rare for them to occur at the same time or to accumulate in the months following the loss. "The experience of grief is universal, but the manner in which individuals experience and react to it is highly variable and is influenced, among other things, by culture and personality" [Translation]⁵

Grief may also be categorized in different ways, depending on how it manifests itself. Hanus describes grief as "normal," "difficult," "complicated" or "pathological." The first refers to the most common type of grief, experienced by people who do not have a particular disorder. "Difficult" grief is when bereavement manifests in the usual way, but is more intense and prolonged, >

especially on a psychological level, but also in terms of the person's behaviour or physical health. Grief is "complicated" when a psychological pathology, already present prior to the loss, worsens following the death. And "pathological" grief is when pathology not present prior to the death, suddenly emerges. Hanus notes that, "People experiencing difficult grief require psychological support. Those experiencing complicated or pathological grief require care" [Translation].⁶

Although grief is a painful experience, some studies estimate that 60% of people generally do not need any specific professional support. Then there are those who might need more support than that provided by friends and family, for example, from support groups or individual counselling. Studies show that approximately 30% of grieving individuals find themselves in this situation. Finally, about 10% of people experience "problematic" grief and require more intense professional support.^{7,8}

Factors influencing the grieving process

As mentioned earlier, the experience of grief is influenced by a person's culture and personality. However, these are not the only factors that influence the grieving process. After conducting a literature

review and working with a group of researchers and clinicians with an expertise in palliative care, our team identified 53 factors that could influence a person's grief experience.⁹

Here we will focus on factors related to caregivers' experience with the healthcare system. Studies tend to pay little attention to the role that support teams and the healthcare system more broadly play in the grieving experience. Here are 17 factors that should be taken into account:

- The experience in the period between the emergence of symptoms and the diagnosis
- Symptom management
- The quality of services provided
- A Do-Not-Resuscitate order
- The relationship between the caregiver and health care providers
- Consistency within the support team
- Spiritual support
- Bereavement follow-up
- Home care support
- The period between the diagnosis and the time of death
- The quality of information provided
- Satisfaction with care
- Advance medical directives
- Availability of practitioners
- Possibility of respite care
- Referral to external resources
- Psychosocial support

The healthcare system, decision-making and the experience of grief

The manner in which practitioners interact with patients and their caregivers and families will affect the grieving process.

Here are some concrete examples:

1. Informing loved ones of imminent death

It is never easy for healthcare teams to announce the imminent death of a patient. These are emotionally charged moments—for the patient, caregivers and families and practitioners alike. The latter would like to postpone this moment, to continue to find hope in treatments, to not give the impression of "giving up." However, if they wait too long to announce the news, there will be very little time to prepare for the inevitable separation. It is difficult for patients and their caregivers/families to know that they have just a few hours or days before death. Healthcare teams need to take into account the fact that they may need time to let the news sink in. It is not rare for care teams to wait until the last minute to announce an imminent death when they could have advised the patient and family sooner. Although some studies have shown that a long and difficult disease can have a negative impact on the grieving process, others report that a short time lapse between the >



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announcement of death and the patient's passing may also have a negative effect. It is therefore up to health care teams to realize that, paradoxically, they can actually help caregivers by providing a difficult diagnosis early on in the process.¹⁰

2. Providing access to palliative care

Announcing an imminent death is also important insofar as it allows the patient and family to have access to palliative care which is focused on providing

optimal pain management and preserving quality of life. For loved ones, it can be a relief, or at least reassuring, to see the patient in good hands. It will also affect their experience of grief. It is comforting to know that a caregiver passed away "as peacefully as possible."

3. Providing quality information to the patient and loved ones

The efficiency and quality of communication between care teams and caregivers/families

can also have a positive impact on the grieving process. Conversely, poor or insufficient communication can lead them to feel guilt or regret following the death. "If I'd known he was going to pass so quickly, I'd have done this or that"; "If we'd been aware of his or her condition, we'd have asked for support from a specialized team." These regrets do not facilitate the grieving process.¹¹

4. Information on advance medical directives

Information on advance medical directives is also an important factor in the grieving process. For caregivers/families, it is reassuring to know there is a procedure in place so they do not have to carry the burden of this crucial decision on their own. It is important for both the care team and the caregiver(s) to make these wishes known and to start a discussion around end-of-life care. For example, caregivers can advise ambulance attendants that the patient does not wish to be revived. It is never easy to make this request, but if it has been discussed beforehand, the psychological burden and impact on the grieving process will be lessened.¹²

These are just some of the decisions faced by care teams which could have a major impact on caregivers' grieving experiences. It is important to attend to these factors, >

knowing that the impacts are often “forgotten” or neglected by practitioners.

CONCLUSION

End-of-life decision-making is always difficult and complex. The manner in which decisions are made will have either a positive or negative impact on caregivers’ grieving process. During this process, the support of interdisciplinary health care teams is essential, both for patients and their caregivers/families. Communication between the end-of-life patient, his or her caregivers, and the health care team is a major factor in the experience of dying and grieving.

To answer one of the key questions at this conference—“Who decides?”—our response is that end-of-life decision-making is a responsibility shared by the patient, his or her caregiver/family, and the interdisciplinary teams providing support. The latter must create favourable conditions to support patients and their caregivers/families in this difficult and complex decision-making process.

2. Phillips, L.R. & Reed, P.G. (2009). End-of-life caregiver’s perspectives on their role: Generative caregiving. *The Gerontologist*, 50(2), 204-214. doi:10.1093/geront/gnp116
3. Ministère de la Santé et des Services sociaux (2015). *Pour une meilleure qualité de vie. Soins palliatifs et fin de vie. Plan de développement 2015-2020.*
4. World Health Organization. (2002). *National Cancer Control Programmes. Policies and Managerial Guidelines.*
5. Bourgeois-Guérin, V., Van Pevenage, I., Lachance, J., Blondin, R.A. & Marquis, A. (2018). L’expérience du deuil chez les personnes âgées : la fréquence rime-t-elle avec l’aisance ? In Billette, V., Marier, P. & Séguin, A.-M. (Eds). *Les vieillissements sous la loupe. Entre mythes et réalités* (pp. 213-220). Québec: Presses de l’Université Laval.
6. Hanus, M. (2006). Deuils normaux, deuils difficiles, deuils compliqués et deuils pathologiques. *Annales médico-psychologiques*, 164(4), 349-356. doi:10.1016/j.amp.2006.02.003
7. Aoun, S. M., Breen, L. J., O’Connor, M., Rumbold, B. & Nordstrom, C. (2012). A public health approach to bereavement support services in palliative care. *Australian and New Zealand Journal of Public Health*, 36(1), 14-16. doi:10.1111/j.1753-6405.2012.00825.x
8. Hanus, M. (2009). Les deuils au grand âge. Études sur la mort, 135(1), 89-97. doi:10.3917/eslm.135.0089
9. Van Pevenage (forthcoming). Grief Factor Caregiver Cartography (GFCC): A promising tool to help social workers support caregivers.
10. Sentilhes-Monkam, A. (2006). L’hospitalisation à domicile et la prise en charge de la fin de vie : le point de vue des patients et de leurs proches. *Santé publique*, 18(3), 443-457. doi:10.3917/spub.063.0443
11. Vannotti, M. & Vannotti, M. (2009). Soins pour la famille ou avec la famille ? *InfoKara*, 24(3), 141-146. doi:10.3917/inka.093.0141
12. Mack, J.W., Cronin A., Keating, N.L., Taback, N., Huskamp, H.A., Malin, J.L., ...Weeks, J.C. (2012). Associations between end-of-life discussion characteristics and care received near death: A prospective cohort study. *Journal of Clinical Oncology*, 30(35), 4387-4395. doi:10.1200/JCO.2012.43.6055

1. Lamontagne, J. & Beaulieu, M. (2006). Accompagner son conjoint âgé en soins palliatifs à domicile : les éléments influençant l’expérience des proches aidants. *Nouvelles pratiques sociales*, 18(2), 142-155. doi:10.7202/013292ar



Implementating shared decision-making in home care teams: From 2017 to the present



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When older adults begin to lose their autonomy, they and their informal caregivers have to decide on an appropriate living environment. To ensure that they make an informed choice, a shared decision-making approach is both helpful and necessary. Naturally this approach involves several stakeholders and areas of expertise.

Since 2007, we have been conducting research on the implementation of shared decision-making in home care teams. Taking into account the challenge of this process when several stakeholders and areas of expertise are involved, our team has developed a conceptual model for an inter-professional approach to shared decision-making.

As we build on our findings, we aim to implement the model on a wider scale and possibly adapt it to other contexts as well. ➔

THE NEED AND CHALLENGE

As the population ages, older adults who are losing autonomy must choose a living environment adapted to their needs. According to 2016 figures, 18.4% of Canadians aged 75 years and older are living in a residence (we define a residence as having at least 10 rental units, of which at least one was not subsidized; it did not only admit residents requiring long-term care or high levels of health care; and it had at least 50% of its residents who were 65 years of age or older).¹

It is important to underscore that moving to a public or private care facility is not the only option. Staying at home with additional help may also be an option. Staying at home with additional help may also be an option. The Canadian Institute for Health Information estimates that, across Canada, one in five seniors who were admitted to residential care could have delayed or even avoided this move if all of their options and preferences had been taken into account.² In Quebec, the Ombudsman has indicated that “all possible choices should be presented at the same time, and on an equal footing, so that an informed decision may be made.”³ [Translation] However, according to a recent survey of people receiving services from

home care (HC) teams, the older the patients, the less involved they are likely to be in choosing housing options aligned with their values and preferences.⁴ It is therefore both relevant and necessary to implement shared decision-making in situations where older adults need to make a decision about housing adapted to their loss of autonomy.

In the case of older patients who are losing autonomy, shared decision-making extends far beyond the patient-clinician dyad. It involves: a) the older adult (the patient), who is the expert on his or her values and preferences; (b) the person’s caregiver(s) who help(s) to coordinate the informal care they provide with the formal care delivered by HC professionals; and (c) the HC team, consisting of social workers, nurses, occupational therapists, dietitians and unregulated personnel (e.g., daytime and night-time personal care assistants, social services technicians). Given the many different stakeholders and areas of expertise involved, shared decision-making may seem inherently complex, and a less inclusive approach may appear easier to implement.

OUR INNOVATION: IP-SDM CONCEPTUAL MODEL

The conceptual model⁵ for an inter-professional shared decision-making approach (IP-SDM) is a new shared decision-making model. It recognizes the respective roles and expertise of several stakeholders, whether they are part of the “patient team” (the patient and informal caregivers) or the professional healthcare and social services team. The model also recognizes that the role of the coach in the decision-making process (a person who supports the patient) and of the initiator (a person who identifies the health problem and the fact that a decision needs to be made) are not specific posts: they may be played by any actors on the “patient team” or on the team of healthcare professionals.⁵

We developed this conceptual model between 2007 and 2012. We first validated it with stakeholders (patients, caregivers and healthcare and social services professionals delivering primary care in Quebec and Ontario⁵), followed by individuals providing home care (HC) services out of a health and social services centre (CSSS) in Quebec. We also co-created an IP-SDM decision guide to assist older adults with a loss of autonomy in making housing decisions.⁶ We then developed a training ➤

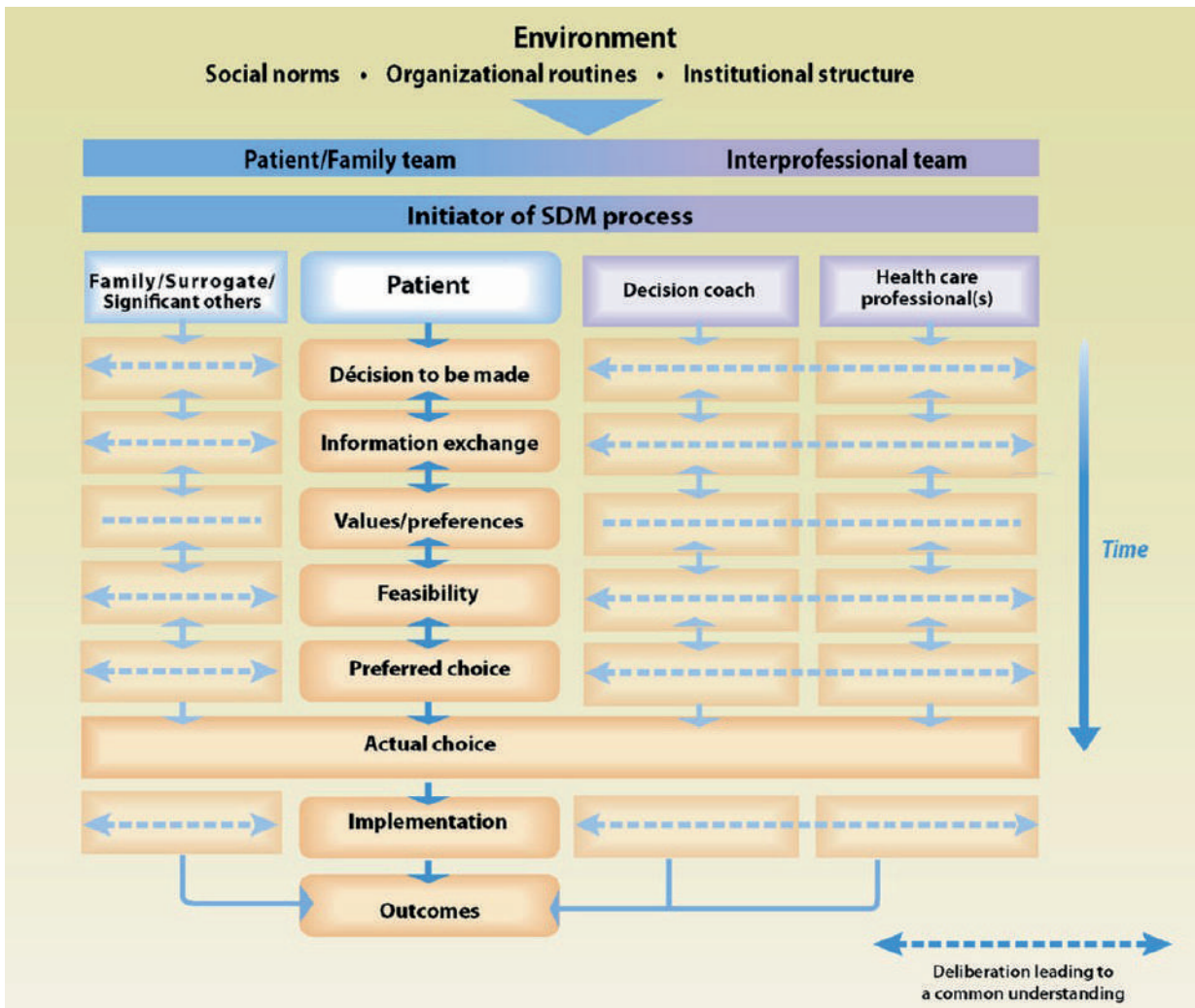


Figure 1: Conceptual model for an inter-professional approach to shared decision-making⁵

program for professionals in the HC teams aimed at facilitating their use of this guide and supporting the implementation of the IP-SDM model. At this stage of the project, we conducted a first pilot study with HC teams in Quebec and Alberta.⁷

From 2014 to the present, we have completed two clinical trials during which we implemented shared decision-making in 32 health and social services

centres (CSSS) in Quebec. Through these trials we sought to validate our hypothesis that providing HC team professionals with the appropriate tools and training would increase the proportion of older adults with loss of autonomy and their caregivers who play an active role in making housing decisions.^{8,9} Over the course of these trials, we trained close to 500 professionals in HC teams and gathered data on over 300 people

aged 65 years and older who were competent to make a decision, and over 600 caregivers of people aged 65 years and older who were no longer capable of making a decision. ➤

RESULTS OF THE CLINICAL TRIALS

1. Participation of patients/caregivers

The first clinical trial was conducted between 2014 and 2016 in 16 CSSSs. The results showed that compared to no intervention, dissemination of the decision guide combined with training the HC teams increased the proportion of older adults with loss of autonomy who played an active role in housing decisions by 12%.⁸

The second clinical trial has been underway since 2015 in 16 CSSSs affiliated with nine integrated (university) centres (CISSSs and CIUSSSs) within the health and social services network. It compares the effects of the passive dissemination of the decision guide (i.e., without any interventions or structured activities) with dissemination accompanied by training for HC teams. Our forthcoming results will show whether the training increased the active participation of older adults (with loss of autonomy but still capable of decision-making) and caregivers supporting older adults (with loss of autonomy and incapable of decision-making) in deciding about housing options.⁹

2. Consistency between the preferred and actual role of patients/caregivers

The results of the first clinical trial showed that dissemination of the decision guide combined with training the HC teams increased the match between the preferred and actual role in decision-making about housing played by the caregivers of older cognitively-impaired adults by 14%.⁸ In demonstrating that shared decision-making better met the expectations of actors in the "patient team," these results are even more significant in light of the fact that patients aged 65 and older are generally less exposed to shared decision-making.⁴

The results of the second clinical trial will show whether a similar effect occurs when we compare exposure to the decision guide only, or exposure to the guide combined with training.⁹

3. Acceptance by professionals in the HC teams

The training was much appreciated by professionals in the HC teams who participated in these two clinical trials: 75% found it excellent and 23% found it satisfactory.

The health care providers who received training in the second clinical trial felt that it increased their level of confidence

in helping older adults and their caregivers participate in the decision-making process. It also made them more confident about adopting an IP-SDM approach and using the decision guide. On a scale of 1 to 10, the training increased their level of confidence by approximately two points.

These results suggest that despite the number of actors and areas of expertise involved, the implementation of an IP-SDM model in HC teams does not make their usual clinical practice more burdensome. On the contrary, the professionals on the HC teams underscored the "tool's simplicity" and its "potential to be implemented in practice."

FURTHER REFLECTIONS...

SIMPLIFYING A COMPLEX REALITY

Based on the assumption that shared decision-making around housing for older adults with a loss of autonomy is already a complex process, we succeeded in implementing the IP-SDM model and received positive feedback on the practicality of the approach and simplicity of the decision guide. We believe one of the keys to this success is the fact that our research process is aligned with recommendations on developing and evaluating >

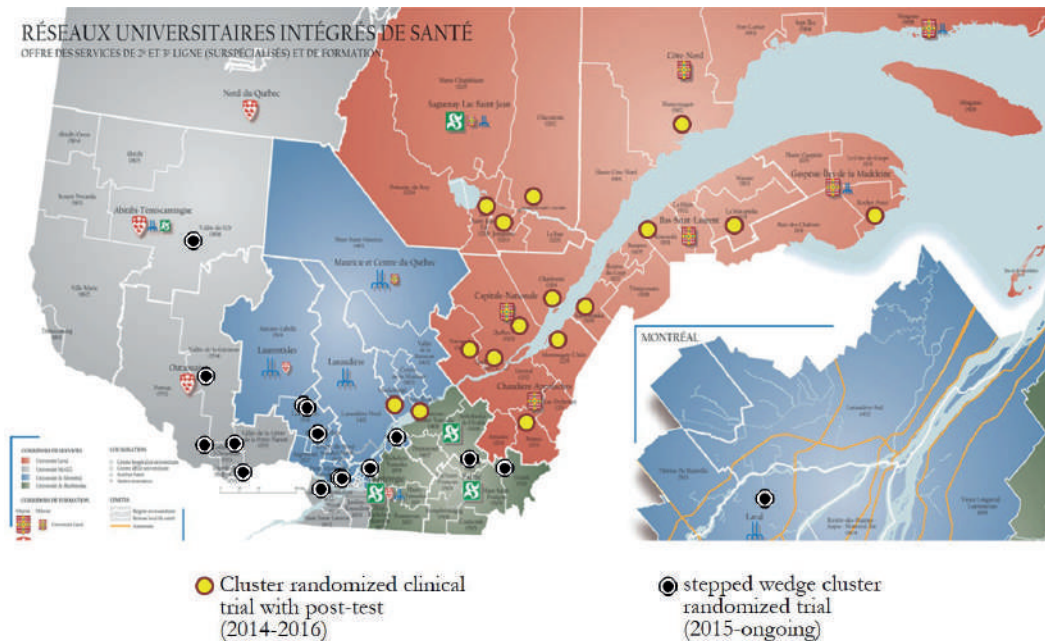


Figure 2: Location of HC teams involved in the clinical trials

complex interventions in health-care and social services¹⁰: our intervention (the decision guide and training) is rooted in a conceptual model and was progressively fine-tuned according to shortcomings, barriers and possible solutions identified during our validation of the model and feasibility study.

However, the professionals on the HC teams also noted that the intervention seemed less effective in complicated cases, such as older adults with cognitive impairment or dysfunctional families. There was likely little representation of such cases among the older adults and caregivers recruited for our two clinical trials. In fact, the HC professionals in both studies were free to choose older adults and caregivers based on

our eligibility criteria. Clearly tools that focus on more complicated decision-making scenarios need to be developed.

AN INTERVENTION COMPATIBLE WITH SEVERAL ORGANIZATIONAL CONTEXTS AND ACCEPTED BY HEALTH PROVIDERS

Despite the diverse organizational settings, the intervention was successful in the 16 HC teams involved in the first clinical trial, and we are expecting promising results for the 16 teams involved in the second clinical trial. Although the 32 HC teams were largely made up of social workers, they operated in different ways. For example, we observed that the degree

of inter-professional integration varied: in some teams, all providers attended the same administrative meetings, regardless of their profession. In other teams, administrative meetings were organized by profession and channels of communication were more formal. We also observed that personnel changes affected all of the HC teams, but to varying degrees.

No HC team withdrew from either of the two clinical trials, even though those involved in the second trial had to deal with major changes resulting from the passing of Bill 10, An Act to Modify the Organization and Governance of the Health and Social Services Network, in particular by abolishing the regional agencies. ➤

We think our innovative conceptual model is compatible with a number of organizational contexts and is sufficiently versatile to accommodate change, notably because the stakeholders who helped to validate the model in the pilot study came from three provincial healthcare systems (Quebec, Ontario and Alberta), each with its own organizational realities.

NEXT STEPS: WIDE-SCALE IMPLEMENTATION AND ADAPTATION

By the end of the second clinical trial, we will have acquired considerable expertise in implementing the IP-SDM model. We already know that providing our decision guide and training to HC team professionals increases the number of caregivers who play an active role in making housing decisions for an older person with loss of autonomy. We will find out whether this also applies to older adults who are losing autonomy but are still capable of making decisions, and whether the training is truly necessary. In addition, we will have contextual data for 32 HC teams in all of Quebec's regions (except for Côte-Nord and Nord-du-Québec). This important experiential knowledge and good practice in developing complex interventions will help prepare for successful scaling up of the implementation.

In parallel with our work with the HC teams, we will explore opportunities to adapt the model to other contexts, notably accompanying older adults with a loss of autonomy who are being discharged from hospital.

We also recently had the opportunity to present the decision guide and training to a group of managers of non-profit residences. Although these are not accredited residences for seniors, some of their tenants are older adults with a certain loss of autonomy whose condition is gradually deteriorating. The participants appreciated the IP-SDM approach and repeatedly stated that it was a "very good process that could be adapted to [their] situation." This exploratory workshop highlighted the fact that decision-making around housing for older adults with a loss of autonomy occurs outside clinical contexts as well.

5. Légaré, F., Stacey, D., Gagnon, S., Dunn, S., Pluye, P., Frosch, D., ...Graham, I.D. (2011). Validating a conceptual model for an inter-professional approach to shared decision making: A mixed methods study. *Journal of Evaluation in Clinical Practice*, 17(4), 554–564. doi:10.1111/j.1365-2753.2010.01515.x
6. Garvelink, M.M., Emond, J., Menear, M., Brière, N., Freitas, A., Boland, L., ...Légaré, F. (2016). Development of a decision guide to support the elderly in decision making about location of care: An iterative, user-centered design. *Research Involvement and Engagement*, 2(26). doi:10.1186/s40900-016-0040-0
7. Légaré, F., Stacey, D., Brière, N., Desroches, S., Dumont, S., Fraser, K., ...Aubé, D. (2011). A conceptual framework for interprofessional shared decision making in home care: Protocol for a feasibility study. *BMC Health Services Research*, 11(23), 1-7. doi:10.1186/1472-6963-11-23
8. Adekpedjou, R., Stacey, D., Brière, N., Freitas, A., Dogba, M.J., Desroches, S., ...Roy, L. (2017). *Improving the decision-making process with caregivers of elderly people about housing options: A cluster randomized trial*. 4e Journée de la recherche des étudiants de l'axe Santé des populations et pratiques optimales en santé du Centre de recherche du CHU de Québec-Université Laval. Communication par affiche. Québec, QC; 01-06-2017.
9. Légaré, F., Brière, N., Stacey, D., Lacroix, G., Desroches, S., Dumont, S., ...Guérard, J.P. (2016). Implementing shared decision-making in interprofessional home care teams (the IP-SDM-SW study): Protocol for a stepped wedge cluster randomised trial. *BMJ Open*, 6(11). doi:10.1136/bmjopen-2016-014023
10. Craig, P., Dieppe, P., Macintyre, S., Michie, S., Nazareth, I. & Petticrew, M. (2013). Developing and evaluating complex interventions: The new Medical Research Council guidance. *International Journal of Nursing Studies*, 50(5), 587-592. doi:10.1016/j.ijnurstu.2012.09.010

1. Canada Mortgage and Housing Corporation. (2016). *Seniors' Housing Report – Canada Highlights*.
2. Canadian Institute for Health Information. (2017). *Seniors in Transition: Exploring Pathways Across the Care Continuum*.
3. *Place en CHSLD : Le Protecteur du citoyen critique le CIUSSS de la Capitale-Nationale*. Le Journal de Québec <https://www.journaldequebec.com/2017/11/13/places-en-chsld-le-protecteur-du-citoyen-critique-le-ciuss-s-de-la-capitale-nationale>
4. Canadian web-panel. Léger <https://legerweb.com/en-ca/home.asp>

Shared decision-making in the healthcare and social services system: Challenges, opportunities and priorities



Nicole René

Member, Comité des usagers de l'Institut universitaire de gériatrie de Montréal

Chair, Comité des usagers du CIUSSS du Centre-Sud-de-l'Île-de-Montréal


Member, Regroupement provincial des comités des usagers (RPCU)



Zita Kruszewski

Clinical ethicist specialized in long-term care, CIUSSS West-Central Montreal

As part of the conference Who decides? Strengthening the partnership between seniors, families and practitioners in the context of social and health care services, **four panelists were invited to discuss challenges, opportunities and priorities with regard to shared decision-making in the healthcare and social services system:**

- **Zita Kruszewski, Clinical ethicist specialized in long-term care at the CIUSSS West-Central Montreal;**
- **Christine Touchette, Assistant Director of the Support Program for the Autonomy of Seniors (SAPA) at the CIUSSS West-Central Montreal;**
- **Mario Tardif, Coordinator of the Regroupement des aidantes et aidants naturels de Montréal (RAANM);**
- **Nicole René, Informal caregiver, member of the Comité des usagers de l'Institut universitaire de gériatrie de Montréal, Chair of the Comité des usagers du CIUSSS du Centre-Sud-de-l'Île-de-Montréal, and member of the Regroupement provincial des comités des usagers (RPCU). **

The panelists were asked to answer the following questions:

1. What are the main challenges associated with shared decision-making in our healthcare and social services system?
2. What are the main elements facilitating shared decision-making in our healthcare and social services system?
3. What measures should be prioritized in the coming years in order to promote a culture of partnership among older adults, their family and friends, and practitioners?

For this issue of *Pluralages*, **Nicole René** and **Zita Kruszewski** agreed to provide their responses in the form of short texts.

ANSWERS FROM MS. NICOLE RENÉ

1. CHALLENGES OF SHARED DECISION-MAKING

In my experience, the medical community is too often informed by a culture of paternalism with elements of ageism. It is imperative that this community move towards a **culture of partnership** with patients and families. Healthcare professionals with a paternalistic attitude choose to limit the amount of information they provide to their patients, even when the latter need it to make an informed decision (e.g., how the illness is likely progress; different treatment options and their side effects). Physicians say they're afraid that patients will not understand their explanations or might become anxious. Or they say they don't have enough time to dedicate to each patient.

An example? Recently in a hospital emergency department, I was called to the bedside of a lucid 86-year-old woman who had been waiting over 48 hours for a physician to explain why she had

fallen for no apparent reason in her room at her retirement home. Every time she was approached by a hospital staff member, she repeated the same questions: "What are my test results? Can I go home or do I have to move into a long-term care facility? When can I leave the hospital?" Instead of speaking directly to the woman, the medical staff waited for her son to visit before answering these very legitimate questions. Only then did they provide a diagnosis and give the woman permission to return home alone.

Access to services is another challenge associated with shared decision-making. Logically, it doesn't make sense to talk about shared decision-making if the context or resources prevent a decision from being respected, whether or not it is the result of a shared process. Take the example of a person who wants to stay in her home but can't, because home care resources are inadequate to meet her needs unless she has a caregiver. Another example is that of an older person waiting to find out when he can move to a safe environment (in this case, a long-term care facility) when his name is on a long waiting list.

Another challenge in shared decision-making involves **respecting the patient's wishes** in terms of care or CPR, if these wishes go against the values and preferences of family members and the medical team. These are fundamental ethical issues.

Two examples come to mind:

► In a long-term care facility, a physician refused to try a new antibiotic after the first course of treatment failed, believing that the family was seeking an overly aggressive treatment. Yet the patient was still clearly expressing his desire to live—a choice that was supported by his wife. When the patient passed away, the family filed an official complaint. ➤




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► At the request of a family member, a medical team revived a patient who had clearly expressed his desire not to be resuscitated in an official document. He also filed a complaint.

Providing **support to vulnerable individuals** is a major challenge when it comes to shared decision-making. I believe it is essential to improve the support provided to people who are alone and left to their own devices, as well as to those with mild cognitive impairment. These individuals are too often victims of the system, because nobody takes the time to explain their options to them in simple terms. You only have to spend some time in a hospital or long-term care facility to realize the degree to which service quality and respect for a person's decisions vary, depending on whether or not the person has support from others.

2. ELEMENTS FACILITATING SHARED DECISION-MAKING

Shared decision-making requires the **agreement**, **involvement** and **commitment** of professionals, patients and loved ones. In a retirement home or long-term care facility, the presence of caregivers facilitates their participation in decision-making, especially when professionals take the time to explain the role of each party in the decision-making process.

To obtain the **informed consent** of patients and their loved ones, practitioners must provide users or their representatives with all the information they need: the patient's state of health, available treatments, and possible complications, notably a loss of autonomy. Professionals must not only 

take the time to explain the ins and outs of the decision to be made; they must also make sure that the patient and his or her loved ones fully understand the situation.

Healthcare professionals must also be aware of the values and personal situation of the person concerned, especially when a health problem will lead to a loss of autonomy. Does the patient live alone or with a spouse? What is the state of health of the person with whom the patient is living? Is this person able to provide occasional or long-term assistance? Doctors should be proactive in calling on social services to intervene, rather than waiting for the patient or a loved one to request an intervention.

We also need to use proven **consultation mechanisms**. In long-term care facilities, shared decision-making is facilitated by participation in interdisciplinary meetings, where patients and their loved ones are systematically invited to discuss care plans.

3. PRIORITY MEASURES TO PROMOTE PARTNERSHIP

The caregivers at the long-term care facility where I do volunteer work have almost all told me that they are generally satisfied with the staff's attentiveness when it comes to making a decision about a loved one's treatment. The most common criticism is that staff members do not systematically inform them of incidents such as falls, wandering or misplacement of an important item, or when the patient's health is declining. In one case, the family only found out about the father's death the following day, after he had spent several hours in distress during the night. Fortunately, this was an exceptional case, but it was worrying nonetheless.

I am delighted that the Ministère de la Santé et des Services sociaux recently published a [reference framework for a partnership approach](#)

[among users, loved ones and healthcare and social services professionals](#). This approach seeks to "allow users and their loved ones to exert a greater influence on their health and decisions related to their care and services . . ." [Translation] (MSSS, 2018).

However, a *change in culture* takes time and we know that patients' rights are currently not being respected. We must therefore make it a priority to focus on practices that are a source of frustration and that managers would be able to change.

My experience in long-term care facilities has shown me that even if the rules state that a soiled diaper should be changed immediately—something that residents and their loved ones also request—all too often staff members refuse to take care of it, or can only do it between 4:15 and 6:00 P.M., the period during which clean clothes are distributed, along with glasses of water, nightshirts and meals. In some units, residents have 30 minutes to eat, after which time their trays are taken away, whether they have finished or not. Also, response times to calls often exceed 20 minutes.

We hear a lot of negative stories in the media, yet there are also many positive examples of kindness and generosity in the healthcare system. There are still doctors who, before prescribing a medication, will wait for you to return to your mother's bedside in order to talk about her medical history, values and wishes. A doctor once said to me, "You know, I could tell you what science has taught me, but you're the one who knows her. Only you can help me with this." Sometimes a nurse will call to tell a wife that her husband doesn't want to eat his meal or take his medication when she's not there.

We need managers who believe it is important to respect the choices of those who use the system or live in a government-run facility. If these managers exercised leadership on a daily basis, we'd all be a lot better off! ➤



From left to right: Rose-Marie Charest, Nicole René, Christine Touchette, Mario Tardif and Zita Kruszewski

ANSWERS FROM MS. ZITA KRUSZEWSKI

1. CHALLENGES OF SHARED DECISION-MAKING

Firstly, the **complexity** of clinical practice and the healthcare and social services system is a major challenge for any kind of decision-making. Both clinical practice and the system continue to become more complex. Consequently, it is challenging even for the healthcare and social services professionals who work in the system, let alone for the persons receiving the services and those accompanying them.

Secondly, having worked throughout the healthcare system for 20 years, I have observed that professionals face another important challenge: a **lack of time**. It takes time to navigate the complexity of the system and the depth of clinical practice. It is also difficult to communicate with multiple professionals and care team members, often dispersed in different areas of the system. Furthermore, with increasing workloads and a more complex professional practice, healthcare professionals and workers are often overwhelmed, exhausted and worn out.

All of this means that when they find themselves dealing with complex situations, they lack the time and energy to approach decision-making in the appropriate way, fully respecting clinical practice guidelines, ethics and the law.

Thirdly, given my professional experience, I see that there is a **lack of knowledge** with regard to medicine and healthcare, ethical principles, standards of behaviour and how decision-making should function in the context of the healthcare system. An improved understanding of ethics would improve service quality, allowing us to make sure we are respecting clients, particularly their right to make care decisions for themselves, as this is an ethical requirement.

Lastly, older adults are often confronted with **ageism**, which is based on certain assumptions—for example, equating physical frailty with loss of cognitive capacity, or the notion that older people with diminishing mental faculties are not capable of making any decisions for themselves. These assumptions are not based in fact and compromise respect for the autonomy of the person, which is always of central importance in any decision-making situation. ➤

2. ELEMENTS FACILITATING SHARED DECISION-MAKING

Respect is the fundamental element facilitating shared decision-making. All decision-making situations in the healthcare and social services system require respect for the person. We need to respect the older person as a human being, as a unique individual, and always with dignity. This concept is known as the ethics principle of respect for the autonomy of the person, and is also a legal right enshrined in the Civil Code of Québec. Care and services must always be centered on the person receiving the care and services.

This idea is so simple, yet often challenging to apply, given the complexity of medical practice and of the system itself.

Shared decision-making starts with respect among healthcare professionals and members of the care teams and, more specifically, with respect for the expertise of each professional and care team member. Due to the complexity of social and healthcare practices in our current system, quality care depends on teamwork. The team must work in a climate of respect in order to serve the best interests of the person receiving the care and services.

Information is another necessary element in shared decision-making. Clinical practice is founded on scientific principles and is based on established, professional, evidence-based practice standards and guidelines. Therefore, informed decision-making in the healthcare setting starts with professional knowledge and expertise in order to determine all the available options for the individual, based on their condition and situation. Subsequently, it is up to older adults themselves to make decisions about the care plan that is most appropriate for them, choosing among the options presented. Available care options depend on the person's medical condition and prognosis, and may

therefore be limited. It is up to the professionals involved to make sure that individuals are making free and informed decisions. To do so, they must provide all relevant information and explanations so that patients understand their options and their eventual decision.

Once again, **time** is an important element in decision-making. Free and informed decision-making is a process and, as such, can take time. The more complex and invasive the potential care options are, the more time may be required to understand a diagnosis, care/treatment options, and the consequences of treatment. If the person has cognitive deficits, the process becomes more complicated and the decision-making will involve more parties.

At this point, I would like to highlight the lack of mental health services for older adults, particularly in long-term care facilities. Besides being beneficial for general health and well-being, access to mental health services, such as timely capacity/competence assessments, can be critical for decision-making situations. Since ethically we always promote the autonomy of persons and their ability to make decisions for themselves, when there are grey areas, a psychiatric assessment for capacity/competence will help to determine the point at which the legal decision-maker/mandatory/family members start to more formally take over the role of speaking for the older adult. This assessment is, of course, necessary for any legal determination of incompetence and the formal processes for homologation of mandates and private curatorship. This is very important in terms of respecting the dignity and autonomy of the older person and combating some serious aspects of ageism, as briefly mentioned above. Furthermore, if the older person has depression and does not have access to mental health services, such as a psychologist for psychotherapy, the depression will impact the person's quality of life and will invariably affect their decision-making. ➤

The process for informed decision-making becomes much more complex when the older adult has a cognitive deficit. Depending on the severity of this deficit, family members, accompanying persons, surrogate decision-makers and/or legal decision-makers will share in the decision-making process. In the case of someone who has been assessed as incapable of consenting, a mandate or advance directive document such as a Level of Medical Intervention will help to facilitate the decision-making process on the basis of respect for the person's previously expressed wishes. However, even if the older adult does not possess such a document, we must always promote his or her autonomy. Even when an older adult is considered medically and legally incapable of consenting and there is a legal decision-maker, s/he has the right to refuse care. In Quebec, no one can force tests, medication or treatment on a person who is incapable of consenting unless they have a court order.

3. PRIORITY MEASURES TO PROMOTE PARTNERSHIP

I would like to emphasize the importance of **education**, especially education for healthcare professionals, staff members, users of the health system, their families and significant others, and the community around core ethical principles: beneficence, non-maleficence, and respect for the person's autonomy. More specifically, with regard to informed decision-making with older adults, or with persons who have lost, or are losing, their capacity for decision-making, how do we continue to respect that person and their autonomy?

Education on surrogate decision-making and the substituted judgment standard is lacking, yet essential. All shared decision-making is centred on the person—respecting that person and their wishes.

Lastly, we must promote the preparation of **mandates, advance directives and the completion of Level of Medical Intervention forms** in hospitals (an advance directives forms filled out by a person's physician after discussion). These written advance directives allow a decision-maker to be appointed for the person, and provide written instructions to facilitate decision-making that continues to respect the person and their wishes when they are not able to speak for themselves.

CONCLUSION

Through their extensive contacts with patients and caregivers, these panelists have observed a number of challenges associated with shared decision-making in the healthcare and social services system, including ageism, the complexity of the system, a lack of information, and a lack of time. They believe that certain improvements could facilitate the decision-making process of patients and families. Showing respect, obtaining informed consent, sharing information, and taking more time are all steps in the right direction. We call on managers and leaders in government and institutional settings to implement best practices and provide quality training and tools in order to facilitate shared decision-making. It is also important to highlight positive initiatives that are already in place!

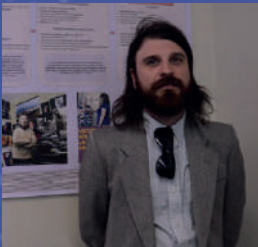
Reference :

Ministère de la Santé et des Services sociaux. (2018). Cadre de référence de l'approche de partenariat entre les usagers, leurs proches et les acteurs en santé et en services sociaux.





Older tenants and the experience of displacement in Montreal: from a threatened home to the housing committee



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I entered the poster competition held at the CREGES annual conference to share the results of the research I am conducting for my doctoral degree at INRS-UCS. My research focuses on the dynamics between ageing tenants and community-based groups, notably housing committees. These are community organizations that defend tenants' rights, educate the general public and support tenants. The majority of older adults who participated in the study had contacted a committee because of problems with their landlord. Depending on the case, landlords had allegedly tried to get the tenant to move using tactics that were either legal (eviction, repossession) or illegal (unfair rent increases, harassment). Since it is generally up to tenants to exercise their right to housing, this article examines the following question: How do ageing private renters react in the face of external threats to the occupation of their dwelling? In other words, how do they enter into contact with a housing committee, and how does mobilizing this resource affect their residential trajectory and broader relationship to the city? ➔

BACKGROUND

In 2016, the case of Pierino Di Tonno—an 82-year-old photographer who has since passed away—made the headlines in Montreal. Pierino, who had been renting an apartment in Little Italy since the 1970s, was threatened with eviction by his landlord, who also owns the adjacent Milano grocery store. Pierino and the Petite-Patrie housing committee led a campaign to boycott the store and force the landlord to abandon his project. Pierino repeatedly told the media that he did not want to be moved somewhere to wait to die; that this would be a fatal blow to him. Because of procedural problems, the rental board (the Régie du logement) ruled against the eviction in March 2016. Three months later, in June 2016, the province passed a new law—Bill 492—which protects low-income tenants aged 70 and older against eviction and repossession (under certain conditions), provided they have been living in the same apartment for more than 10 years.

This story shows that older tenants, who generally pay rents below market value in gentrifying neighbourhoods, can find themselves forced to leave their dwelling against their will. In the scientific literature, researchers^{1,2} point to three factors that make low-income older tenants vulnerable in the

private rental market: 1) they depend on a fixed income (retirement pensions), which are insufficient to keep pace with the rising cost of rents and services in the neighbourhood; 2) their rents are substantially lower than the market value because they have been living in the same dwelling for a long time; and 3) they are at a higher risk of social isolation and/or health problems, which affects their ability to respond to displacement threats and mobilize resources under stressful circumstances. In 2016, in Quebec, 63% of tenants who had received a notice of repossession or eviction had been living in their dwelling for at least 10 years, and 41% had been living there for more than 15 years.³

Displacement can be defined as a situation that occurs when external forces make it impossible for a person to continue inhabiting a dwelling.⁴ Rental insecurity refers to tenants' inability to determine how long they can continue to inhabit their dwelling.⁵ According to what I have observed in the field and learned through interviews, tenants often experience a continuum of situations aimed at making them leave their dwelling in the short or medium term. Rental insecurity is often exacerbated by landlords who try to get the person to leave of their own accord, but under tremendous pressure. Using

tactics that I will describe later on, they make it impossible or difficult for the person to remain in the dwelling. In addition to these threats, I have examined the record of actions taken by older persons, notably through their interactions with housing committees. These committees, mostly concentrated in Montreal's central neighbourhoods, help people exercise their rights and file complaints with the Régie du logement. Most also have a mission to educate people on their rights, and to hold social and political activities, mobilizing their members to fight for affordable and social housing. By contacting these committees and perhaps participating in their work, older tenants gain new perspectives on their home, the housing market and their city.

My study is based on more than two years of ethnographic field work conducted as part of a doctoral degree in urban studies at INRS-UCS, under the supervision of Anne-Marie Séguin and the co-supervision of Ignace Olazabal. The research, conducted between 2016 and 2018, focused on four housing committees in the neighbourhoods of Rosemont, Petite-Patrie, Villeray and the Plateau-Mont-Royal. A first phase of interviews (n=10) was completed with individuals active in these committees in order to obtain an overview >



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Pierino di Tonno in his apartment.

of the situation. A second series of interviews (n=25) was conducted with low-income older tenants who were involved to varying degrees in housing committee activities, and who had experienced a problem with their dwelling. In the sample of older tenants, the average age was 69 years. A total of 75% were women who mostly lived alone.

FROM PROBLEMS TO ACTION

VARIOUS HOUSING PROBLEMS

As mentioned above, displacement and rental insecurity often go hand in

hand. The two legal means to get tenants to move are repossession and eviction. For these to be valid, the notices must be sent within the time periods set by the Régie du logement. For example, in the case of a year-long lease, the notice must be sent six months before the end of the lease. The tenant has a relatively short time to refuse (one month). A hearing will then be held at the Régie du logement to determine the validity of the tenant's reasons for refusing to leave. The Régie is generally perceived by tenants as being "pro-landlords" and ineffectual. This distrust, coupled with sometimes long delays and complex procedures, generally

discourage tenants from taking legal action. Landlords may then offer monetary compensation to speed up the move. Tenants often end up accepting this compensation, as they do not have the resources to effectively defend their right to stay. Rental insecurity is more subtle. Landlords can contribute to this insecurity through various forms of harassment. The anecdotes related by interviewees suggest that a perception of rental insecurity is accompanied by a distrust of landlords' intentions. This distrust is triggered by insinuations, certain attitudes or unusual situations such as visits from professionals (representing a bank or insurance company), ➤

or the sale of the building. The suspicion is confirmed if the landlord uses certain levers such as a failure to respect tenants' privacy, extensive renovation and repair work, a wilful neglect of the building, abusive rent increases, illegal eviction, sexual harassment, verbal violence and intimidation. The aim is to undermine tenants' sense of security and attachment to their home.

*"The landlord sold, because he said he was paying too much in municipal taxes. He also said he couldn't keep up with the City's demands for renovations to his building. So he sold, just like that. He didn't tell anyone. Next thing I know, the new landlord—a promoter—arrives and hands me an eviction notice. That was in December. He wanted me out by January."
(PII-XI, W, 71 years old)*

CONTACT WITH A HOUSING COMMITTEE

The ageing tenants I spoke with who experienced this type of situation decided to contact a housing committee, for a number of reasons: to calculate and/or refuse a rent increase; to write a formal notice; to contest an eviction or repossession; to learn more about their

rights; and to obtain financial compensation for a move. Some also received "psychosocial" support and were accompanied by a committee member to the Régie du logement. In meeting with the committee staff and attending information sessions and other social activities, the tenants realized they were not alone in experiencing this type of situation. This was particularly true for older tenants living alone.

"I went there and got my membership card. I explained my problem. I was really stressed because I live alone. So I explained my problem and they told me not to worry." (PII-IV, W, 70 years old)

Landlords and tenants usually conduct their business in a private space (the building or apartment doorway). Housing committee staff can move this relationship into the public, legal and institutional spheres. As mentioned earlier, tenants need to exercise their right to housing. They also need to know the necessary steps and deadlines—for refusing an eviction notice, for example. By helping them navigate these legal procedures, housing committees can help change the rules of the negotiation or conflict. If landlords know their

tenants are receiving support from a housing committee, they may be dissuaded from applying certain tactics.

PARTICIPATING

After an initial contact, some individuals become active committee members and start participating in the organization's activities. The main motivating factors and rewards are social contact and political action. All of the committees hold a variety of social and awareness activities, including discussion groups, barbecues, walks, info sessions and community meals. Several interviewees were glad to be able to share their story and form bonds with the committee staff. Others were more attracted to the political side—fighting for housing rights and for future generations, as one 68-year-old woman noted. By becoming more aware of urban issues, these individuals are better able to understand the dynamics at play in their neighbourhoods. The committees can also serve as intermediaries, registering tenants on lists for social housing.

"Yeah, I understand what's going on. I knew how things worked on the Plateau, but I didn't know some of the horror stories. When I became aware, I decided to get involved. I want >

to defend people who can't speak for themselves. They really need this help!" (PII-IX, M, 71 years old).

AGEING-IN-PLACE?

Older low-income renters facing rental insecurity and/or displacement can greatly benefit from establishing ties with a housing committee. The committee can help them understand the rules of the game and provide tools to navigate the rental market, the legal system and the city in general. Most of the tenants interviewed for this study wanted to leave their dwelling because of a conflictual relationship with their landlord and problems related to their living space. However, they wanted to choose the conditions and timing of their departure. They especially wanted to move into social housing (coop, low-cost housing, non-profit housing) in order to pay a rent below the market rate. In addition, these spaces are often designed for people with physical impairments. The tenants, who now play an active role in housing committees, know better than anyone that rents are increasing beyond their capacity to pay in central neighborhood. Although they would like to move, they do not want to leave their neighbourhood. They would like to age-in-place, not necessarily in a particular (often inadequate) dwelling,

but in a familiar neighbourhood. With very long waiting lists and insufficient public housing, tenants sometimes have to wait several years before they are offered a spot. So they are stuck between waiting for a better apartment and trying to negotiate better conditions where they are. For Leibing and al. (2016),⁶ a home becomes "liminal" when it is under constant threat of being lost, for a variety of reasons (health, urban dynamics). Therefore, many tenants opt for a strategy of delaying an inevitable move and adapting as best they can to the uncertainty.

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1. Morris, A. (2007). On the edge: The financial situation of older renters in the private rental market in Sydney. *Australian Journal of Social Issues*, 42(3), 337-350. doi:10.1002/j.1839-4655.2007.tb00062.x
 2. Portacolone, H. & Halpern, J. (2016). "Move or suffer": Is age-segregation the new norm for older Americans living alone? *Journal of Applied Gerontology*, 35(8), 836-856. doi:10.1177/0733464814538118
 3. Regroupement des comités logement et associations de locataires du Québec. (2016). *Les évictions de locataires pour le profit, ça suffit!* Retrieved from <https://www.rclalq.qc.ca/les-evictions-offit-ca-suffit>
 4. Baeten, G., Westin, S., & Pull, E. Molina, I. (2016). Pressure and violence: Housing renovation and displacement in Sweden. *Environment and Planning A*, 49(3), 631-651. doi:10.1177/0308518X16676271
 5. Morris, A., Hulse, K. & Pawson, H. (2017). Long-term private renters: Perceptions of security and insecurity. *Journal of Sociology*, 53(3), 653-669. doi:10.1177/1440783317707833
 6. Leibing, A., Guberman, N. & Wiles, J. (2016). Liminal homes: Older people, loss of capacities, and the present future of living spaces. *Journal of Aging Studies*, 37, 10-19. doi:10.1016/j.jaging.2015.12.002



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