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This newsletter is intended for people who participated in the Research Centre on Aging's projects. It is also distributed to anyone who wants to receive it.

Please contact us for more information.

Participating in Decision-Making in an End-of-Life Context

By Chantal Caron, Ph. D.



Chantal Caron is a Researcher at the Research Centre on Aging and an Assistant Professor at the Nursing School of the Université de Sherbrooke's Faculty of Medicine and Health Sciences.

Individuals suffering from cognitive impairment (memory disorders) become incapable of making decisions regarding their health care as they enter the advanced stages of illness. It is therefore often incumbent upon family caregivers (spouses, children, nephews, nieces and other relatives) to make these health decisions for them. The medical paternalism that once existed is now being replaced by

negotiations among relatives and medical staff, a process encouraged in the current legal and ethical framework. However, deciding on the most appropriate end-of-life treatment for a loved one is a difficult process. It can be stressful for families and open up a full range of emotions.

Death remains a taboo in our society. Research involving families who have had to make critical decisions in the end-of-life stages of a loved one is scant, especially when the patient suffers from cognitive impairment. For this reason, our research team decided to investigate the concerns of family caregivers when dealing with the end-of-life stages of a loved one who is no longer able to participate in the decision. Moreover, we have described how family caregivers make decisions regarding medical treatments during the end-of-life stages of an elderly relative.

This is one of the first studies on the subject. Twenty-four caregivers participated in our investigation. The majority was children (58%) who

had to make decisions for their elderly parents. Other participants included spouses (16%) or other relatives (niece, daughter-in-law and so on).



The decision-maker's role: How to decide for a relative who is ill?

The people who participated in our study stated that the role of the decision-maker was nebulous. Caregivers didn't understand what was expected of them. This was primarily due to the fact that medical teams (doctors, nurses, nutritionists and so on) didn't systematically discuss the aforementioned role with families when their loved ones were admitted to long-term care centres, nor at other moments during the residency period. There exists an underlying expectation in long-term care that families will participate in decisions about treatment when required to do so. However, our research found that this expectation is not realistic. Families are often

DID YOU KNOW

According to the Quebec Department of Health and Social Services, between 60 to 80 per cent of older adults living in long-term care facilities have been diagnosed with one form or another of cognitive impairment (Alzheimer's disease, vascular dementia, etc.)

See *DECISION-MAKING* on page 4...

Accompanying Persons Suffering from Alzheimer's Disease: Promising Approaches

By Ghyslaine Lalande, M.A.



Ghyslaine Lalande is a research officer at the Research Centre on Aging. She conducted this study with Gilbert Leclerc, Ph.D., a researcher at the Research Centre on Aging and an associate professor at the Université de Sherbrooke's Faculty of literature and human sciences.

The responsibility for caring for people suffering from Alzheimer's or other analogous diseases often falls upon families. They do so according to their abilities and the evolution of the disease. However, when monitoring and administering the required care become too demanding, and there is no relief for families, they risk exhaustion. Entrusting their relative to a caregiving facility, usually a residential and long-term care centre (CHSLD), must then be considered.

New approaches are being developed to offer a better quality of life to people in housing. We have conducted a study to compare two approaches that were developed in Quebec and to evaluate their effects on residents and their families and professional caregivers. The approaches are known as *Carpe Diem* and the extended prosthetic approach.

These approaches have the common characteristic of providing affected persons with housing that resembles a family residence as closely as possible. The number of affected persons rarely exceeds 12 in such an environment. Moreover, they can continue conducting certain activities that have been adapted to their capabilities. These approaches have led to the development and implementation of a culture and methods that help maintain the capacities of affected persons. They also foster quality relations among caregivers, residents and their families.

The *Carpe Diem* approach

The *Carpe Diem* approach was implemented in 1996 by the Alzheimer's Society in Mauricie at *Maison Carpe Diem* in Trois-Rivières. Under this approach, the caregivers' perceptions of people suffering from Alzheimer's determine their attitudes, which leads to adopt a non-judgmental attitude toward certain behaviours. Instead they try to understand their meaning and to determine the appropriate course of action that is to be taken and continuously adapted. Respecting those who are affected, upholding a confidence-based relationship, reinforcing self-esteem and diligent attendance qualify the support as well as providing attention.

The extended prosthetic approach

Many CHSLDs have adopted this approach. The St-Brigid's Home CHSLD in Quebec implemented it in 2001 by setting up a special care unit for people afflicted by or who show signs of "disruptive" behaviour.

It provides a safe and adapted social, family-style environment whose purpose is to compensate the residents' cognitive impairments. It attempts to limit the sources of stress that would require a level of concentration that is too difficult to maintain for residents. Respect, kindness, awareness and patience characterize interventions. The preferred strategies include observation, anticipating the residents' needs and behaviours, and creating a diversion. The needs of each resident are reassessed on a regular basis in order to adapt the required interventions.

Positive results

In both environments, we noted that families are welcomed by staff. Their co-operation is called upon to better understand the residents' backgrounds and preferences. Those affected maintain their functional independence for a longer period than people in a conventional long-term care unit. There is no restraint and psychotropic drugs are not used as much. Residents are less anxious, smile more and show more interest in their surroundings when using both approaches. Their unusual behaviour is downplayed and less frequent. Their social interactions are more common and more positive, and their psychological well-being is much greater. Families frequently refer to the respect, generosity and affection shown by caregivers. They consider that their loved one is receiving quality care that is better adapted to their needs. That reassures families and they feel less guilty about having left their loved ones under the responsibility of other caregivers.

Eight factors seem to be at the source of these results: 1) there are few residents; 2) a family-type environment; 3) a detailed selection of staff (capacity to establish a respectful and warm relationship with people, adaptable personalities, team-oriented); 4) decompartmentalised tasks in which the priority is to respond to the residents' needs; 5) continuously updated training; 6) teamwork in which the focus is mutual assistance; 7) effective communication; 8) a management style that supports the caregivers' in their tasks.

However, both approaches have differences. The institutional nature of CHSLDs raises significant challenges. The numerous rules and collective agreements constitute significant bottlenecks. However, the experience at St-Brigid's Home shows that they can be overcome. Organisations can adapt when managers have a vision and leadership.

DID YOU KNOW

"Dementia" is a medical term that describes a number of neurological diseases that are characterized by a gradual and irreversible change in cognitive functions. To avoid the social stigma associated with the French term "démence" because of its negative undertones, many francophones suffering from it prefer to specify Alzheimer's disease, or other similar diseases they might be afflicted with.

See *ALZHEIMER'S DISEASE* on page 4...

The Immune System and Aging... Watch For the Signs!

By Anis Larbi, doctoral student in immunology



Anis Larbi is a student at the Research Centre on Aging and at the Faculty of Medicine and Health Sciences at the Université de Sherbrooke. He is conducting research under the guidance of Dr. Tamàs Fülöp, M.D., Ph.D., and Abdel Khalil, Ph.D., both researchers at the Centre, as well as Gilles Dupuis, Ph.D., of the Université de Sherbrooke's immunology programme.

Many changes and adaptations occur in our organism as we age. Among them is a reduction in our capacity to fight off infections. That is why elderly people suffer from chronic diseases and require more time to recover from infections such as the flu or tuberculosis. The immune system is the cause.

The immune system consists of cells that circulate in the bloodstream. During an infection, cells interact to allow the immune response. "T lymphocytes" are important cells in the global immune response. It is also these cells which become defective with aging.

In our immunology laboratory, managed by Dr. Tamàs Fülöp, we are interested in the study of defective mechanisms in T lymphocyte response among the elderly. Under certain conditions, T lymphocytes are activated during a bacterial or viral infection. We showed that it is the transmission of the signal through the membrane that is defective.

By analysing T lymphocyte membrane through the telescope, we were able to determine that changes in the membrane partially explain that the receptor's signal is not properly transmitted. That would explain why the response is diminished or not suitably adapted (Table 1).

The induction of the signal is therefore carried out at the membrane of T lymphocytes and therefore so is the induction of the immune response. We are pursuing studies on specific areas of the membrane called lipid rafts. Those areas are rich in cholesterol and are mobile.



We have shown the capacity of lipid rafts to move in the membrane diminishes, partially as a result of an increase in cholesterol in the cell membrane. This altered mobility explains that the signaling and activation of T lymphocytes are affected by aging.

We are pursuing studies to understand the mechanisms of cholesterol regulation by T lymphocytes. Moreover, we are studying the generation and the cycle of lipid rafts in order to understand changes that occur with aging.

These studies allow us to understand why T lymphocytes do not respond adequately when a person ages, because we know the direct impact on health. The scientific community is now increasingly focusing on diseases related to dysfunctions in lipid rafts. It's a new field in research on aging that needs further exploration. 🧪

DID YOU KNOW

that frequent benign illnesses, difficulties in recovering from infections, the appearance of a few pathologies and frailty are signs of a weakened immune system?

Did you know that physical activity, diet and personal health practices (sleep, stress and so on) affect the immune system?

Consult your physician. He's there to help you!

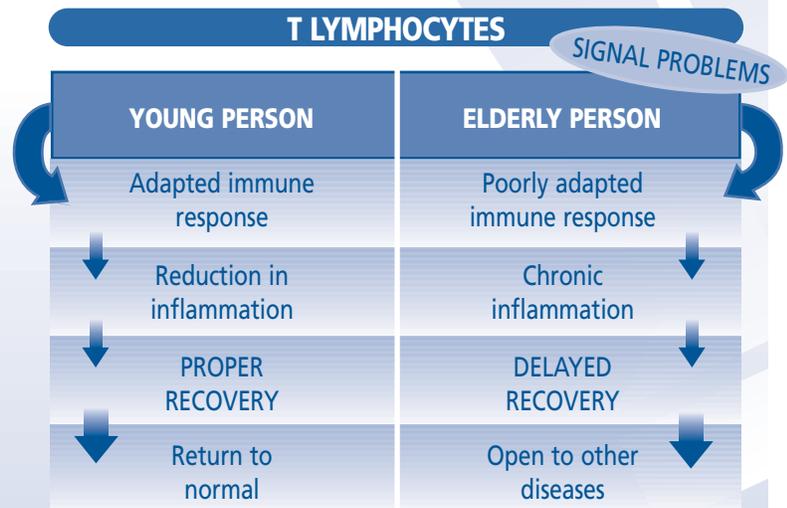


Table 1. **T lymphocyte response during aging.** Among the elderly, problems in transmitting the intracellular signal do not allow for an adequate and controlled immune response. This deregulation leads to a vicious circle that is provoked by chronic inflammation.

...DECISION-MAKING

not prepared to assume this role. Exchanges between the medical team and caregivers should be planned in order to clarify the family's expectations for their loved one's final days.

This being said, we can state that **families want to be involved** when a situation requires medical treatment. With the rare exception of family caregivers who had practically blind faith in professional caregivers, most of those who participated in our study felt a need to get involved in the decisions or, at the very least, to understand the treatments that were being proposed by the medical team. Participation gave family caregivers the impression that they were contributing to the well-being of their relative, as well as gaining a better understanding of how the illness was evolving, better preparing them for the inevitable death of their loved one.

Quality of life at the centre of decision-making

Quality of life is unquestionably the main concern for family caregivers when they participate in the decision-making process. Quality of life during the end-of-life stages is often evaluated by family caregivers by taking into account the following elements: their loved-one's preferences, their personal experiences, their ability to move and/or to communicate, other illnesses and symptoms affecting their health, and social involvement in the nursing home setting (enjoying interactions with others and attending organised events, for instance).

Families are less likely to want the medical team to administer intensive medical treatments when they perceive that the elderly person's quality of life is diminished.

"The doctor asked: 'What do you want us to do if your mother gets something?' I said: 'Give her all that she needs so that she doesn't suffer. That's all.' My concern was to alleviate any pain, but not to do anything to extend her life. She no longer had any quality of life, so what would have been the point?"

In conclusion, the results of our study show that families are very concerned by the end-of-life stages of their loved one, especially when the relative, as a result of a cognitive disorder, can no longer express what kind of care he/she wants.

We believe that implementing a palliative care approach in long-term care facilities would open a dialogue between the professional and family caregivers about the death of a loved one and would alleviate the difficulties connected with end-of-life decisions. As such, the dying person's final moments would be lived according to his/her wishes, making it easier for relatives to mourn their loss. 

...ALZHEIMER'S DISEASE

While the extended prosthetic approach improves the quality of life of residents, we noted that those suffering from Alzheimer's or other analogous diseases can live for a long time in a smaller and less constraining environment such as *Maison Carpe Diem*. People living there take fewer psychotropic drugs and families are satisfied because they can participate in decisions regarding the care being provided to a loved one. 

Don't miss the upcoming Board of Governors' conference:

Physical activity, obesity and health among the elderly

By **Martin Brochu, Ph. D.**,

Researcher at the Research Centre on Aging, Assistant Professor at the Faculty of Physical and Sports Education of the Université de Sherbrooke

Tuesday, November 8, 2005 at 2 p.m.

At the Amédée-Beaudoin Community Centre
10 Depot St., Lennoxville

Admission is free for all attendants.



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Greetings to the researchers **Chantal Caron**
and **Martin Brochu**, who are joining the team.

**Committee: Martin Brochu, Chantal Caron,
Nadine Fortin, Nancy Leclerc**

If you are moving or no longer wish to receive *Encrâge*, you can contact Lucie Duquette at (819) 829-7131.