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Loss of Autonomy

Hearing the Voices of the Elderly and their Family Caregivers

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Introduction

- The origin of the project
- A few words about assessment
- The literature review
- The perception of loss of autonomy
 - The elderly persons point of view
 - The family caregivers point of view
- Conclusion

The origin of the project – from practice to research

- 2013 - Health promotion in home care services
- 2014 - Home care assessments for loss of autonomy: the OEMC
- 2015 – Loss of autonomy assessment project (research)
 - Evaluation in home care, long term care, community (homelessness), ethnic diversity, living environments
- 2016 – Funding application to Canadian Institute of health research

A few words about assessment



Standardized evaluations

- OEMC-type questionnaires to assess autonomy loss are used around the world
- 'Aging-in-place' – seniors remaining in their homes as long as possible is the goal of many governments
- Functional autonomy is prioritized – more than social
- Resources and support services are scarce or lacking everywhere



The literature review

- Two perspectives:
 - The perception of the aging person, and
 - The perception of the family caregiver in interrelation with their care receiver
- Parameters for inclusion:
 - Articles about Québec and Canada health care system, then other western world countries
 - Published since 2000 and as a result of a research study
- Results:
 - 64 articles found – 29 retained for in-depth analysis



The elderly person's point of view



Elders perception of their autonomy – Five themes emerged ...

1. Self-determination/doing for oneself
2. Belongingness/sense of identity
3. Having access to resources/public, private or family
4. Avoiding institutionalization
5. Loneliness/solitude/isolation

Self-determination/doing for oneself

- Taking care of oneself whether in their own home or in an assisted living facility
 - “I’ve never asked anyone for anything”; “I can make my own decisions for myself”
- Accepting help compromises their feelings of independence
- But, help with shopping and transportation OK for some if it increased their feeling of autonomy
- Many felt their independence was so important they were willing to deprive themselves
 - “If I can I’ll do it, if I can’t I do without it”
- Unwilling to ‘burden’ their children

Sense of belongingness and identity with the home



- “Aging-in-place”
 - Over 80% of elderly 65+ in Québec autonomous and still living in their own home
- Perception of security and safety
- Try to make assisted living feel like ‘home’
- Memories of their lives and families are in the home
- Ability to decide when and what to eat, when to go to bed and what to watch on TV
 - “I have so many memories of my husband, my garden in back, flowers, I used to get up early to wake him up”

Having access to resources/public, private or family



- Public resources – through health and social services or the community
- Help from family and friends
- Resources they can pay for
 - Some indicated they were most comfortable using resources for which they pay
- Seniors want what services to be offered in a way that respects their autonomy
- Public help was interpreted as a way to not have to rely on their families

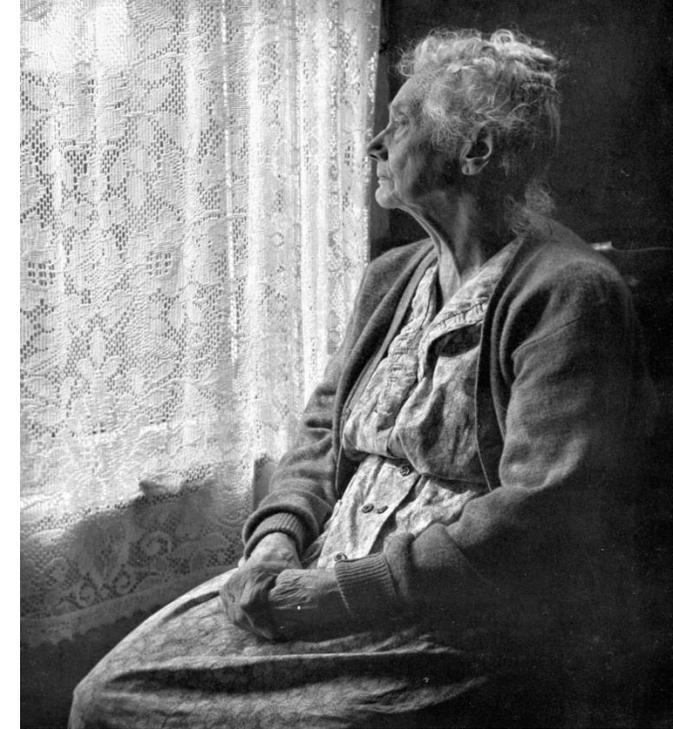
Avoiding institutionalization

- Long-term care institutions still have a very negative connotation for seniors
- Fear of institutionalization linked to a misunderstanding of the assessment process – perceived as a threat
- Sometimes they may minimize their needs to avoid placement



Loneliness/solitude/isolation

- Many accept there is a price to pay for staying in their homes
- Would rather stay at home if it means staying independent
 - “Here you’ve got your own bedroom, a little more privacy, you’ve got your bathroom”
- Some people go without help and endure inadequate situations in preference to asking for help



The family caregiver's point of view



Caregivers perception of their care receivers autonomy - Three themes emerged ...

1. Quality of their relationship
2. Their acceptance or denial of the situation
3. How they adjusted to the role / or overcompensated

Quality of their relationship



- Caregivers who had a poor relationship with their care receiver reported higher feelings of stress and burden
- Many developed strategies to maintain the fiction of autonomy
 - Using subterfuge to provide care
- Care receivers consistently overestimated their capacities and the caregivers underestimated them

Their acceptance or denial of the situation

- Denial of the reality of the situation was common
- Hope that things will get better
 - “She leaves notes for herself and makes the bed, she must be getting better” (husband of a wife with advanced dementia)
- Feelings that they were becoming the parent
 - “It’s difficult to become your parent, you see so much of yourself. It’s terrifying”
 - “I’ve taken to not letting her know when her next appointment is because she’ll drive me nuts”



How they adjusted to the role / or overcompensated

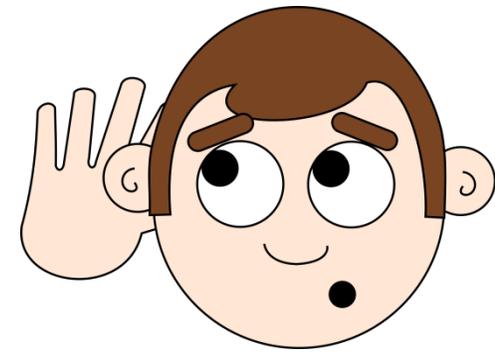


- Sometimes had to stop themselves from doing too much because it was increasing their loved ones dependence
- Many go out of their way to respect care receivers decisional autonomy
- Abandon their own projects, cut down on sleep, and don't take care of their own health
 - "Conciliation of these different spheres of life is sometimes impossible and can have an impact that causes them to quit their job and sacrifice their social life."

Conclusion



Hearing the voices of the elderly and their family caregivers ...



- Elderly people, in general will go to great lengths to preserve their independence
- Sometimes the elderly person has a different perception of their state of autonomy than their family caregivers
- Family members feel conflicted between helping their loved one stay independent and ensuring their safety
- How does the SAPA professional reconcile these differing opinions with their own OEMC assessment?