



# DECISION AID FOR CAREGIVERS: CHOOSING A LIVING ENVIRONMENT FOR A RELATIVE WITH DEMENTIA

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# AIM OF THE PRESENTATION

- Provide up-to-date information regarding the decision-making process of caregivers
  - Perspective of caregivers
  - Role of health care professionals
- Introduce a new decision-aid to support caregivers
  - Development process of the DAC-CLERD
  - Validated version of the DAC-CLERD



# CONTEXT

- ◉ Deciding which living environment is best for a relative with dementia is one of the most stressful situation of their trajectory for family caregivers
- ◉ Health care professionals have few clinical tools at their disposal to support family caregivers
- ◉ New decision aid to promote caregiver-health care professional partnership



# DECISION-MAKING PROCESS

## DEFINITION

- Cognitive process resulting in the selection of a course of action among several alternative scenarios
- Taking into account:
  - Knowledge
  - Context
  - Needs, preferences, values
  - Emotions

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# DECISION-MAKING PROCESS

## ◎ CHOOSING A LIVING ENVIRONMENT FOR A PERSON WITH DEMENTIA

- Relative's role in the process is limited or inexistent because of dementia
- Caregiver's role is amplified
- Other stakeholders are involved:
  - Healthcare professionals
  - Family and friends
- Society

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# DECISION-MAKING PROCESS

## ACTIVATION OF DECISION-MAKING PROCESS

- Caregivers notice a deterioration

- Relative's condition
- Their own state of health

OR

- Idea of placement introduced by:

- Healthcare professional
- Private residence administrators

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(Ducharme, Couture and Lamontagne, 2012)



# DECISION-MAKING PROCESS

## DECISION-MAKING PROCESS FLUCTUATES ACROSS TIME

- Cessation of the process without re-activation
- Ongoing activation of decision-making process
- Switching between cessation and re-activation



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# DECISION-MAKING PROCESS

## CAREGIVERS EVALUATE:

- Current living environment
- Potential living environments

## CONTEXTUAL FACTORS THAT INHIBIT OR FACILITATE DECISION-MAKING PROCESS:

- Acceptability of a change of living environment for stakeholders

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# DECISION-MAKING PROCESS

## EVALUATING THE CURRENT LIVING ENVIRONMENT:

- Physical and cognitive states of their relative with dementia
- Security of their relative with dementia and of the entourage
- Their own physical and psychological abilities
- Formal help
- Informal help

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# DECISION-MAKING PROCESS

## EVALUATING POTENTIAL LIVING ENVIRONMENTS:

- Quality of care
  - establishment
  - personnel
- Geographical proximity
- Financial cost



# DECISION-MAKING PROCESS

## ACCEPTABILITY OF A CHANGE OF LIVING ENVIRONMENT

- The potential living environment is an decent alternative, personally and socially

- ◎ VALUE-LADEN DECISION
- ◎ HEART vs HEAD
- ◎ AUTONOMY vs SECURITY
- ◎ QUALITY OF LIFE



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# DECISION-MAKING PROCESS

## CONTEXTUAL FACTORS

- Acceptability of the change in living environment for all stakeholders
  - Caregivers
  - Relatives with dementia
  - Families/friends
  - Healthcare professionals



# DECISION-MAKING PROCESS

## WHY PLAN AHEAD

- ◉ To have the best alternative available (waiting lists)
- ◉ To reduce the chances of moving the relative more than once
  - Hospitalization
  - Transition unit
  - Different long term care facilities
- ◉ To have time to deal with emotions

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# DECISION-MAKING PROCESS

How health care professionals can support caregivers?

- ◉ Assessing the need for change of living environment
- ◉ Navigating through the health care system
- ◉ Taking care of family dynamics

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(Couture, Ducharme and Lamontagne, 2012)



# DECISION-MAKING PROCESS

## IMPACT OF SUPPORT FROM HEALTH CARE PROFESSIONALS:

- ⦿ Increased knowledge
- ⦿ Caregivers feel more confident about their decision
- ⦿ Easier when caregivers and health care professionals evaluate the situation in a similar manner

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# DECISION-MAKING PROCESS

## PARTNERSHIP APPROACH

- Sharing opinions
- Identifying and acknowledging needs
- Empowerment
- Clinical as well as social interventions

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# DAC-CLERD

## ◎ DECISION-AIDS

- Clinical tools that support users by structuring the decision-making process with the collaboration of health care professionals
- Useful when the decision depends on the person's values and preferences

Decision-Aid for Caregivers: Choosing a Living Environment for a Relative with Dementia (DAC-CLERD)



# DAC-CLERD

## DEVELOPMENT PROCESS

- Systematic review of qualitative studies
  - To explore the main concerns of caregivers during this decision-making process;
  - To explore contextual factors that inhibit or facilitate the decision-making process.



# DAC-CLERD

## DEVELOPMENT PROCESS

### ◎ Content validation

- Items are comprehensive and adequately reflect the perspective for the population of interest;
- Format, instructions and response options are relevant;
- Instrument is understandable and acceptable.



# DAC-CLERD

## DEVELOPMENT PROCESS

### ◉ Field testing

- Evaluate how relevant is the decision-aid to help caregivers with their decision-making process
- Evaluate how the decision-aid helps health care professionals support caregivers



# DAC-CLERD

- ◉ 12 open-ended questions (4 sections) to explore main concerns and contextual factors
- ◉ Designed for caregivers that have expressed a desire to discuss a change in living environment for their relative with dementia;
- ◉ To be used by a healthcare professional in a one hour session with the caregiver to promote partnership:
  - To identify the needs of the caregiver and of the relative with dementia
  - To guide future interventions for assisting the dyad to make a well-informed decision



# DAC-CLERD SECTION 1 : EVALUATION OF THE CURRENT LIVING ENVIRONMENT

1.1 "What is it about your situation that makes you think that keeping your relative at home is still a viable option?"

- Aim : Identify the positive aspects of keeping their relative at home
- Examples of answers :
  - Elderly relative's level of autonomy adequate for environment
  - Uprooting of elderly relative avoided
  - Greater liberty at home for the relative



# DAC-CLERD SECTION 1 : EVALUATION OF THE CURRENT LIVING ENVIRONMENT

1.2 "What is it about your situation that is prompting you to consider a change in living environment for your relative?"

- Aim : Identify the negative aspects of keeping their relative at home
- Examples of answers :
  - Specialized care not available
  - Physical environment not safe for elderly relative
  - Reduction in caregiver's social contacts



# DAC-CLERD SECTION 1 : EVALUATION OF THE CURRENT LIVING ENVIRONMENT

## 1.3 “How would you describe your ability to take care of your relative lately?”

- Aim : Evaluate the caregivers physical and psychological state and needs to pursue caregiving
- Examples of answers :
  - Ability of family caregiver to pursue and persevere with caregiving
  - Difficult because of lack of sleep
  - Potential for abuse (violence or negligence)





# DAC-CLERD SECTION 2 : EVALUATION OF POTENTIAL LIVING ENVIRONMENTS

2.1 "In your opinion, what are the essential elements needed to ensure the quality of life of your relative?"

- Aim : Identify the most important needs of the relative according to the caregiver
- Examples of answers :
  - Social contact
  - Able to go outside
  - Quiet environment



# DAC-CLERD SECTION 2 : EVALUATION OF POTENTIAL LIVING ENVIRONMENTS

## 2.2 "What is your perception of other potential living environments for your relative?"

- Aim : Identify other potential living environments considered and informational needs
- Examples of answers :
  - Long term care is a last resort
  - No other members of my family wants to take care of my relative
  - Already visited two residence for the elderly



## DAC-CLERD SECTION 2 : EVALUATION OF POTENTIAL LIVING ENVIRONMENTS

2.3 "How would you imagine your role as a caregiver if your relative moved to another living environment?"

- Aim : Identify post-caregiving issues
- Examples of answers :
  - Never thought about that
  - Want to be able to visit my relative everyday
  - I will be responsible for medical appointments



# DAC-CLERD SECTION 3 : ACCEPTABILITY OF A CHANGE OF LIVING ENVIRONMENT

## 3.1 "When you consider the idea of a change in living environment for your relative, how do you feel?"

- Aim : Identify emotions related to a change of living environment for the relative
- Examples of answers :
  - Guilt/sense of abandoning their relative
  - Solitude without the elderly relative
  - Relief



# DAC-CLERD SECTION 3 : ACCEPTABILITY OF A CHANGE OF LIVING ENVIRONMENT

3.2 "If I were to ask you to tell me, on a scale of 0 to 10, how ready you are to move your relative to a new living environment (0 not at all ready and 10 totally ready), what would you say? Can you explain your response? "

- Aim : Evaluate level of readiness
- Examples of answers :
  - 0 - Not ready at all, it will never happen
  - 7 - Almost ready, need more information
  - 10 - Totally ready, can't keep the relative at home



# DAC-CLERD SECTION 3 : ACCEPTABILITY OF A CHANGE OF LIVING ENVIRONMENT

3.3 "How do the people around you react to the possibility of moving your relative to a new living environment?"

- Aim : Explore acceptability for other stakeholders (relative with dementia, friends and family, other health care professionals)
- Examples of answers :
  - Reluctance of elderly relative to be placed
  - Other family member disagree
  - Health care professionals say it's time



# DAC-CLERD SECTION 4 : IDENTIFYING INFORMATIONAL AND SUPPORT NEEDS

4.1 "What is it about your situation that makes it harder for you to make such a decision?"

- Aim : Identify the main concerns of the caregiver
- Examples of answers :
  - Family members disagree
  - Guilt
  - Not enough information



# DAC-CLERD SECTION 4 : IDENTIFYING INFORMATIONAL AND SUPPORT NEEDS

4.2 “Are you missing any information right now that would make it easier for you to make such a decision?”

- Aim : Assess informational needs
- Examples of answers:
  - Procedures for long term care
  - Cost of residences
  - Waiting lists





## DAC-CLERD SECTION 4 : IDENTIFYING INFORMATIONAL AND SUPPORT NEEDS

4.3 “Given the discussion we just had, what is the most pressing need you have that we could work on together in order to make it easier for you to make such a decision?”

- Aim : Plan the next step
- Examples of answers :
  - Convince relative with dementia to move
  - Talk to other family members
  - Visit long term care establishments



# DAC-CLERD

## CONSIDERED HELPFUL TO:

- ◉ Open dialogue between caregivers and health care professionals
- ◉ Discuss issues that caregivers have not yet reflected upon and that they would not have considered by themselves
- ◉ Help case managers to cover all the important issues



# DAC-CLERD

## CONSIDERED LESS RELEVANT WHEN:

- ◉ Decision-making process is easier because caregiver:
  - Has gone through this process before
  - Does not need psychological support
  - Sees no other option than placement
  - Has contacts within the health care system



# ADVICE FOR USING DAC-CLERD

1. Providing a copy of the DAC-CLERD prior to the one-hour meeting
2. Presenting a personalized introduction
3. Having an open attitude and a trusting relationship



# CONCLUSION

- DAC-CLERD :
  - Covers the preoccupations of caregivers when choosing a living environment for a relative with dementia
  - Is designed to promote a partnership approach
  - Should be used with caregivers that have expressed a desire to discuss a change in living environment for their relative with dementia
- A promising field-testing phase is undergoing and results will be available in 2015.





# Thank you for your attention!

## ANY QUESTIONS?

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