

# THE COMPLEXITY OF CHOOSING A LIVING ENVIRONMENT FOR A LOVED ONE WITH DEMENTIA

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Current and future challenges in caregiving  
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# INTRODUCTION

- Caregivers start thinking about a change of living environment when :
  - Notice a deterioration in their relative's condition or in their own health
  - Idea of placement introduced by social and healthcare professionals or private residence directors
- This decision-making process is described by caregivers as “difficult”, “heartbreaking”, and “painful”
- Why is it so complicated?

# AIM OF THE PRESENTATION

- To better understand the complexity of choosing a living environment for a relative with dementia by exploring:
  - The complexity of the process itself
  - The contextual factors that facilitate or inhibit the process

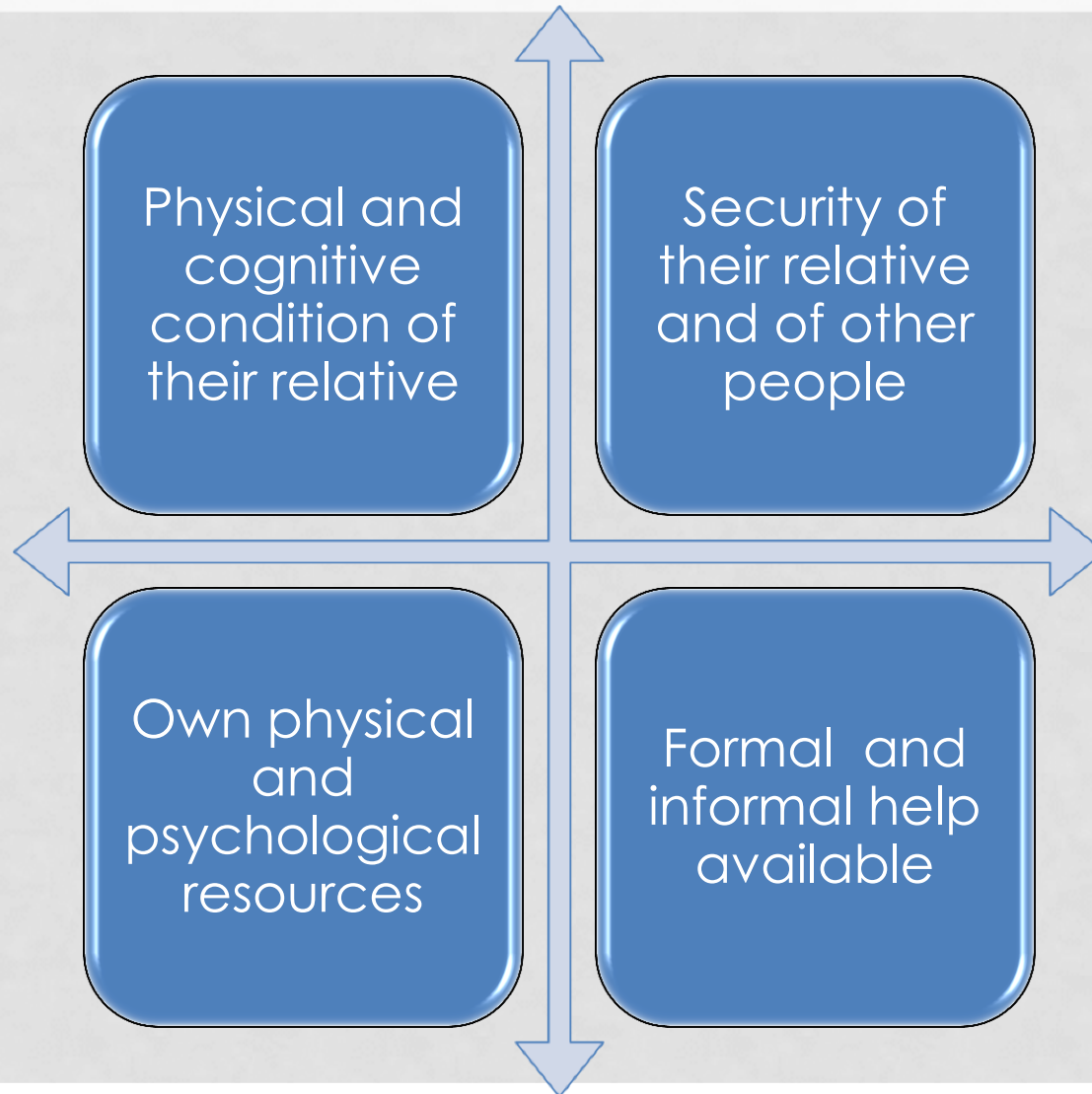
# THE COMPLEXITY OF THE PROCESS ITSELF

WHAT CAREGIVERS ARE THINKING ABOUT?

# WHAT IS A DECISION-MAKING PROCESS?

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

# EVALUATING THE CURRENT LIVING ENVIRONMENT



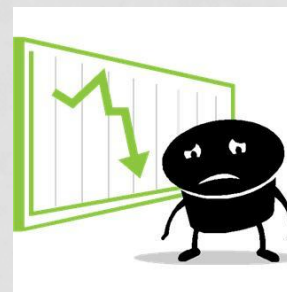
# EVALUATING POTENTIAL LIVING ENVIRONMENTS

- Quality of care
  - Establishment
  - Personnel
- Geographical proximity
- Financial cost



# 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

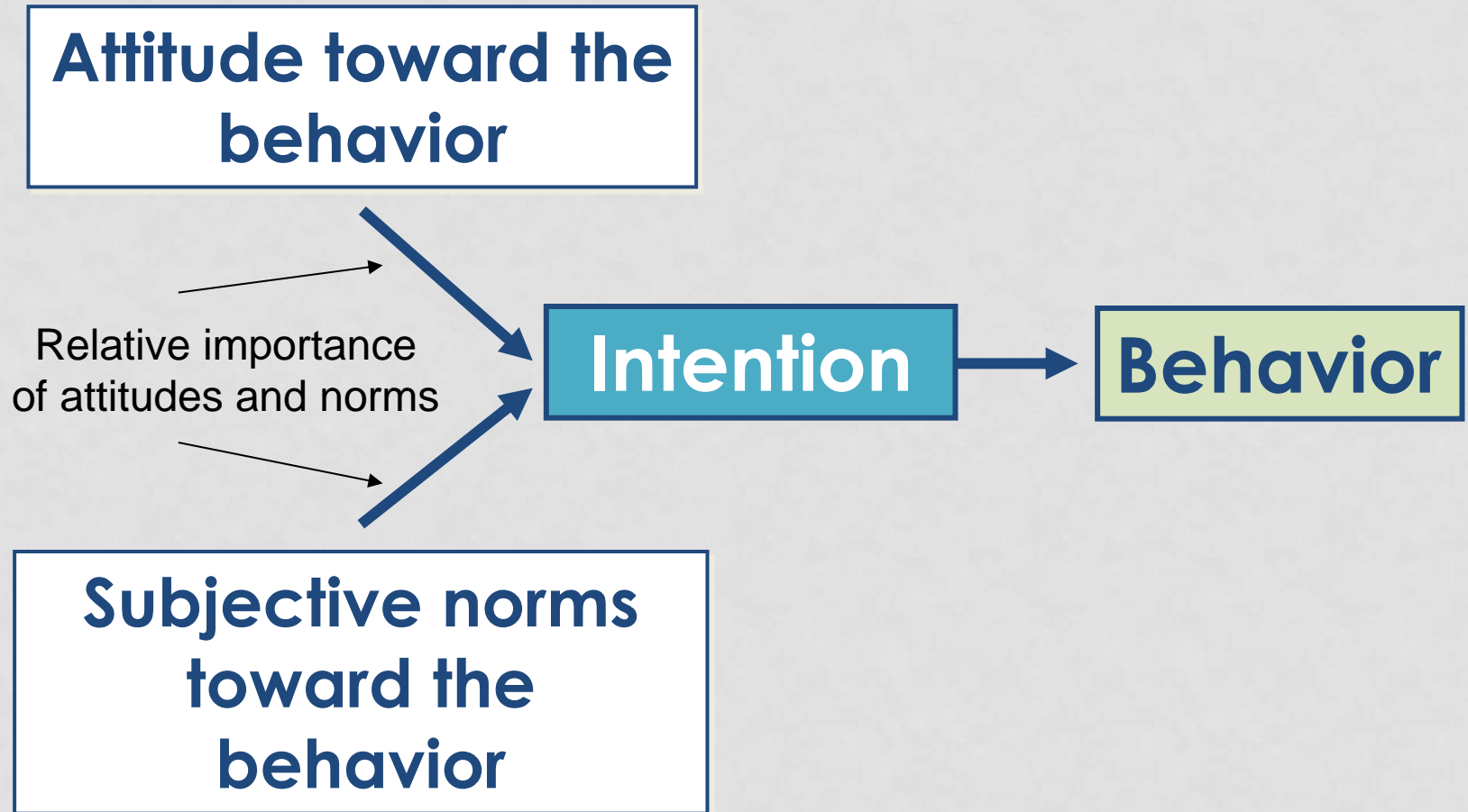


(Ducharme, Couture and Lamontagne, 2012)

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

WHO INFLUENCES CAREGIVERS?

# THEORY OF PLANNED ACTION



# ACCEPTABILITY OF THE CHANGE IN LIVING ENVIRONMENT

## DEFINITION

- The notion that a change of living environment, in the case of a particular person with dementia, is personally and socially perceived as acceptable, suitable as well as decent.
- VALUE-LADEN DECISION
- HEART vs HEAD



THE HIGHER THE LEVEL OF ACCEPTABILITY, THE EASIER THE DECISION-MAKING PROCESS FOR CAREGIVERS

# ACCEPTABILITY FOR THE CAREGIVER

## HIGH

- Acknowledges being incapable of keeping the relative at home
- Feels more anxiety keeping the relative at home than making the decision to choose a new living environment
- Needs independence

## LOW

- Has a negative attitude toward other living environments
- Expresses guilt and anxiety
  - Has the impression of “getting rid” of their relative
  - Considers their role is based in reciprocity and gratitude toward relative
  - Is afraid of other people's opinion

# ACCEPTABILITY FOR OTHER STAKEHOLDERS

**Caregivers' take into account the acceptability of a  
change of living environment for other stakeholders  
(implicit or explicit)**

Relative with dementia

Families/friends

Social and healthcare professionals

# ACCEPTABILITY FOR THE RELATIVE WITH DEMENTIA

- Difficulties related to :
  - Involving the relative in the decision-making process
  - Deciding for elderly relative
- Relative open to a change of living environment makes the process easier
- For reluctant relative, caregivers :
  - Wait for relative to be unaware of events because of cognitive impairment
  - Lie (vacation/temporary)
  - Try to convince by visiting

# ACCEPTABILITY FOR FAMILY AND FRIENDS

## HIGHER ACCEPTABILITY WHEN:

- More than one family member has the responsibility to make the decision
- There is a consensus regarding the need for a change of living environment
- Other family members acknowledge the impact of the situation on the health of the caregiver

# ACCEPTABILITY FOR SOCIAL AND HEALTH CARE PROFESSIONALS

## HIGH

- Has the same perception as the caregiver regarding the situation
- Provides emotional support

## LOW

- Pressures against placement
- Excludes caregiver's point of view
- Does not provide help to navigate the health care system

# CONCLUSION

- What makes choosing a living environment for a relative with dementia so complicated?
  - Two step process : Evaluating the current and potential living environments
  - Cessation and reactivation of the process
  - Level of acceptability (value-laden)
  - Involves many stakeholders
- Acceptability of a change of living environment for other stakeholders is crucial to make the process easier for caregivers