Stages of Alzheimer's Disease and its Behavioural and Psychological Symptoms:

seniors' treatment and care preferences pre- and post-brief education

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Ontario Shores 5th Annual Mental Health Conference

Learning Objectives

- Understand clinical practice impetus for presenters' pilot study
- Learn about the study, its methodology, and its findings
- Discuss study's implications for seniors, their families, and their clinicians
- Discuss next steps for larger, multi-site study

Acknowledgements

- each research participant
- study funded by Physician Services Incorporated

- Tamara Arenovich, biostatistician CAMH
- Dielle Miranda, research coordinator CAMH
- Ontario Shores, UHN, CAMH and University of Toronto

The Research Team

- Robyn Waxman, MD FRCPSC principal investigator
- Barbara Russell, PhD MBA co-investigator
- Benoit Mulsant, MD FRSPSC co-investigator
- Oscar Iu, BSc co-investigator

How This Started…. the all-too-familiar case

- "Mr. Smith" is 80+ years old and married. He has always been a private man who valued independence and looking after his family
- When his major neurocognitive disorder of the Alzheimer's type reached moderate-severe stage, accompanied by intermittent aggression, his family moved him into LTC. They subsequently agreed to a "no CPR" order and his time there has been difficult, given the aggression
- When he develops pneumonia, his family agrees, despite some ambivalence, to transfer to an acute care hospital. Initial tx administered in Emergency department and physical restraints used, given escalating physical aggression

Would Mr. Smith want this?
Did his family anticipate having to make this kind of decision?

The General Public: minimal understanding about BPSD, esp. certain symptoms

Personal and Family Impact: significant moral distress
significant caregiver care burden
significant upheaval in the home/LTC facility

Medical Options: hospitalization and institutionalization
care options expensive and hard to access
pharmacological options have serious adverse effects

Tx/Care Planning: usually occurs too late; clinicians busy

Decision Making: Powers of Attorney uncommon
clinicians and family decisions ≠ patient preferences

3 Research Questions

- Will brief education about mild, moderate, and advanced Alzheimer's Disease (AD) significantly change subjects' treatment and care preferences in the moderate and advanced stages?

- Will brief education about BPSD significantly change subjects' preferences in all three stages of AD?
  - 5 symptoms to be studied: aggression
apathy
disinhibition
moodiness
psychosis

- Will a majority of subjects prefer BPSD management using pharmacological options, despite options' serious cardiac and neurological risks?

Mixed methods approach included:

- quantitative measures
  - AD knowledge questionnaire
  - adapted Health Belief questionnaire
  - 2 treatment/care decision grids

  These measures used three times: pre-brief education
post-brief education
one month follow-up

- qualitative measures
  - focus group discussions in small groups
  - Krueger’s methodology used to analyze subjects’ reasons for tx/care choices and any changes after brief education

Decision Grid 1. What would you want and not want?

Kinds of treatment / Your state of health…	Cardiopulmonary resuscitation & ventilation	Being hospitalized for tests and/or treatment	Relief of pain and symptoms at home
As it is today			
If you have mild dementia			
If you have moderate dementia			
If you have severe dementia			

Decision Grid 2. What would you want and not want?

Kinds of interventions / You have…	Cardio-pulmonary resuscitation & ventilation	Being hospitalized for tests and/or treatment	Relief of pain and symptoms at home		Rank order the following in terms of your preferences 1 = most preferable 2 = next most preferable 3 = least preferable
____________ (write in) the BPSD symptom you think is the most undesirable					___ medications ___ physical restraints ___ seclusion

Content:

- basic facts about AD
  - frequency
  - causes, risk factors
  - prognosis
  - available treatments and their effectiveness, risks
- 3 “Annie scenarios”…. living with:
  - mild dementia
  - moderate dementia
  - severe dementia

Time limit: 20 minutes

Inclusion criteria:

- healthy people >= 65 years of age
- no dementia diagnosis (self-report)
- fluent in English
- recruited at local community centers and CAMH

Study was reviewed and approved by:

- CAMH REB
- Ontario Shores REB
- UHN REB

Research services provided by CAMH

Study Results

- the quantitative findings -

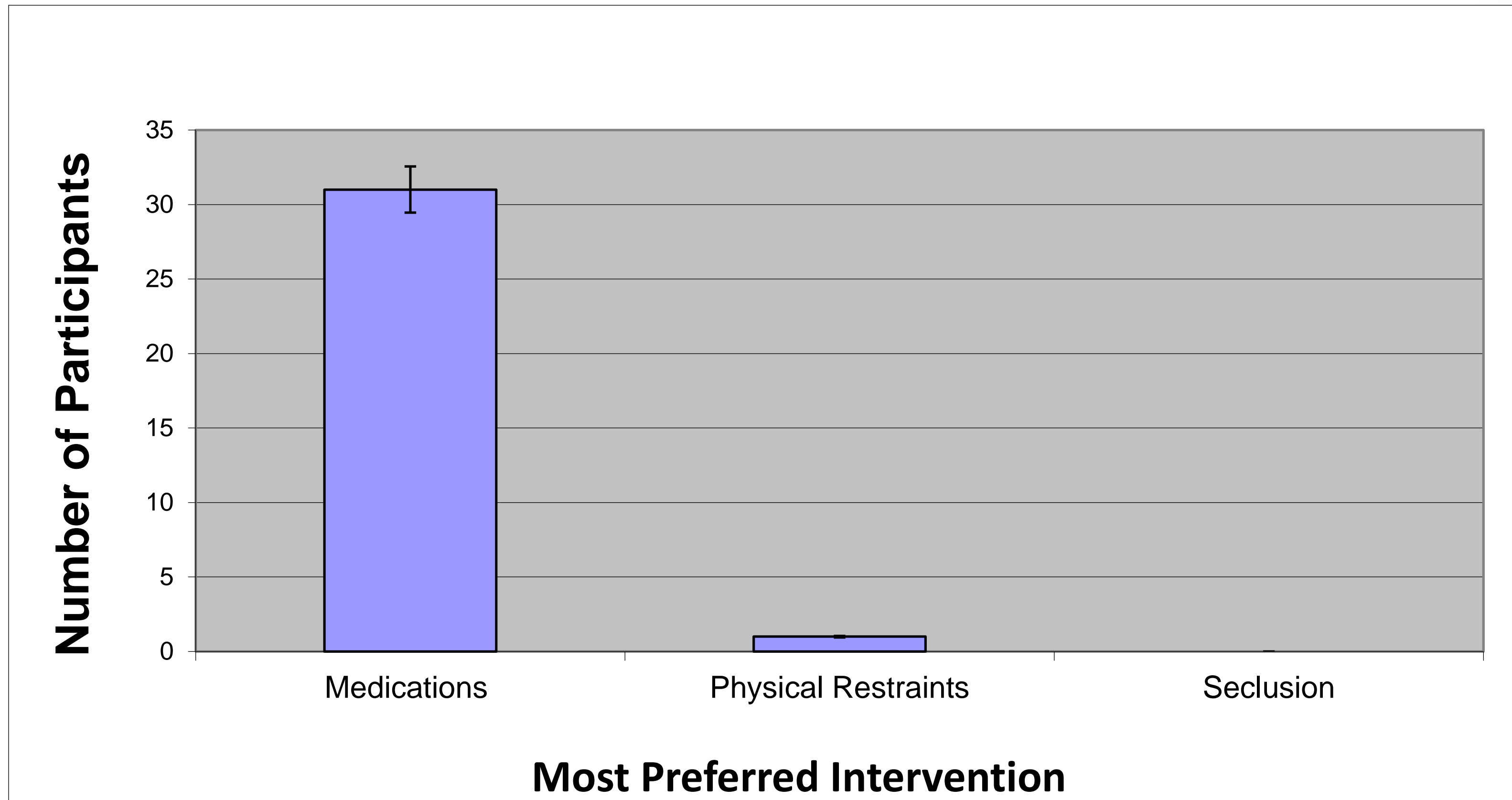
Subject Demographics

Baseline Characteristics		Count	%
Gender	female	24	75.0
	male	8	25.0
Has a Proxy for Health Care Decisions	no answer	2	6.3
	no	9	28.1
	yes	21	65.6
Know or has known a person with dementia	no	3	9.4
	yes	29	90.6
Marital Status	married/common law	10	31.3
	divorced/separated	7	21.9
	single	8	25.0
	widowed	7	21.9
Is Canadian Born	no	17	53.1
	yes	15	46.9
Has a University Degree	no	15	46.9
	yes	17	53.1
Age	<= 71	9	28.1
	71 to 79	14	43.8
	>= 80	9	28.1
Age	mean (std deviation)	74.81 (5.57)	

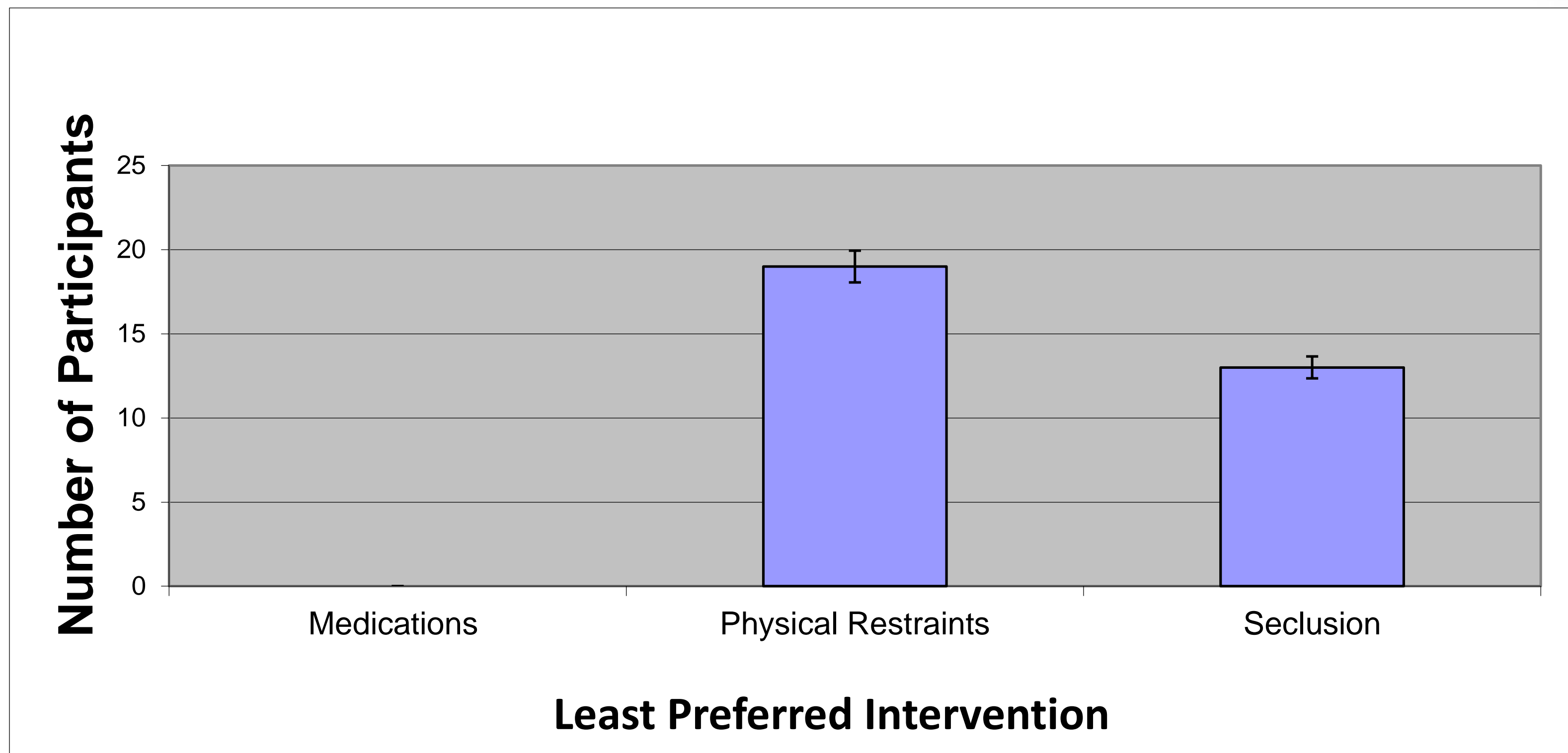
Brief Education's Impact on Treatment Preferences by AD Stage

Time	Treatment Wanted	AD Severity				Av. knowledge score (SD)
		As Is	Mild	Mod-erate	Severe	
pre- brief education	CPR & ventilation	**87.5 %**	**68.8 %**	**56.3 %**	**12.5 %**	72.7 % (14.1 %)
	Hospitalized for tests/tx	**93.8 %**	**81.3 %**	**62.5 %**	**31.3 %**	
	Relief of pain/symptoms at home	**93.8 %**	**90.6 %**	**83.9 %**	**59.4 %**	
post- brief education	CPR & ventilation	**87.5 %**	**68.8 %**	**50.0 %**	**9.4 %**	78.7 % (12.5 %)
	Hospitalized for tests/tx	**96.9 %**	**87.5%**	**59.4 %**	**21.9 %**	
	Relief of pain/symptoms at home	**96.9 %**	**93.8 %**	**78.1 %**	50.0 %	
1 month follow-up	CPR & ventilation	**81.5 %**	**69.2 %**	**32.0 %**	**3.7 %**	83.0 % (9.1 %)
	Hospitalized for tests/tx	**96.3 %**	**88.9 %**	**48.0 %**	**14.3 %**	
	Relief of pain/symptoms at home	**93.1 %**	**93.1 %**	**76.9 %**	**55.6 %**	

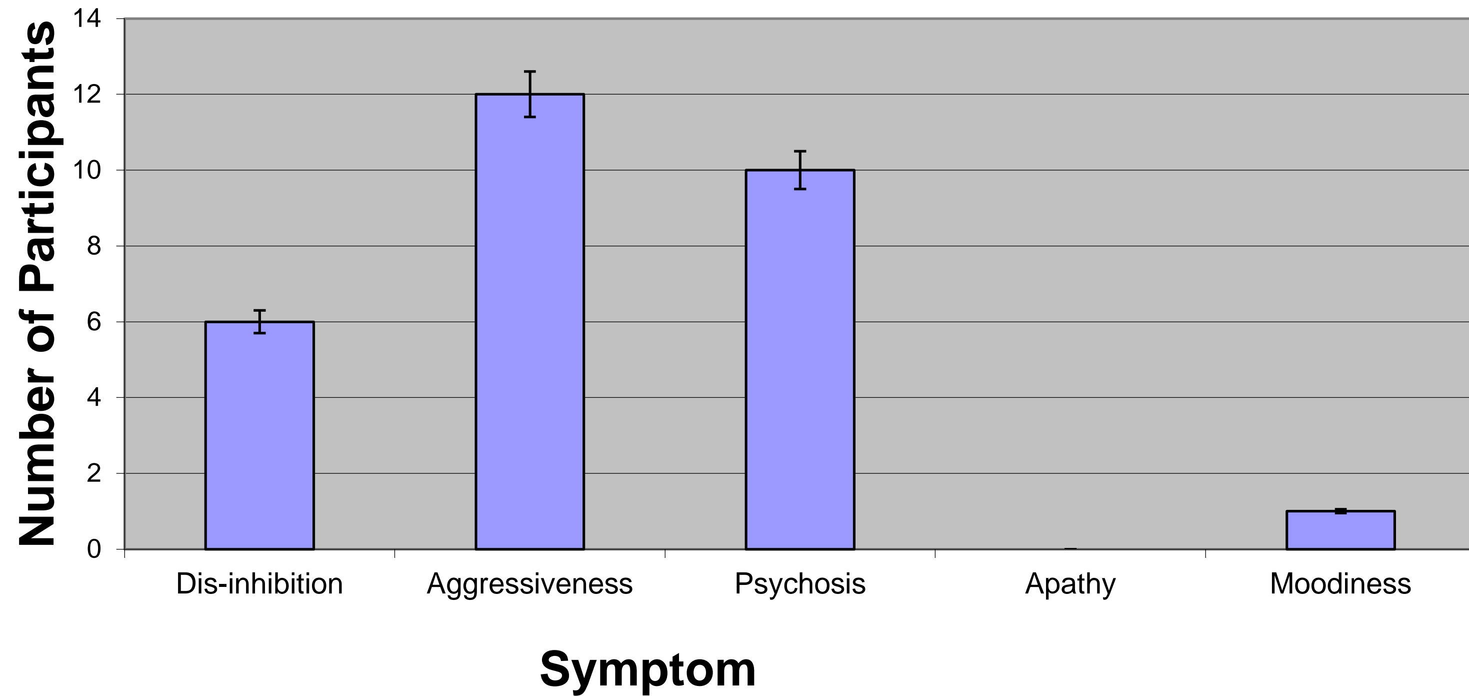
Frequency of Most Preferred Intervention to Manage BPSD



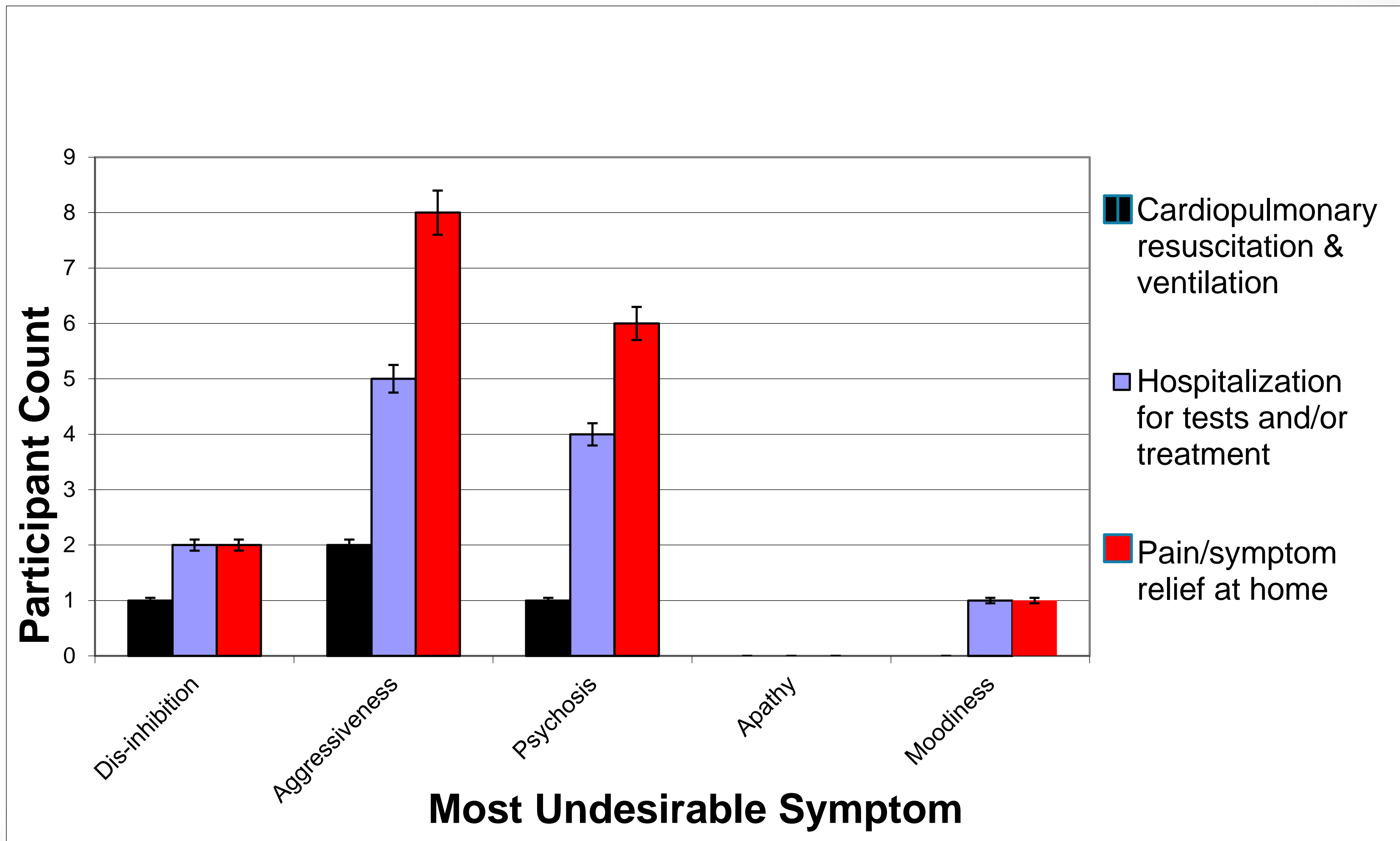
Frequency of Least Preferred Intervention to Manage BPSD



Frequency of Most Undesirable BPSD



Frequency of Preferred Interventions for Most Undesirable BPSD



- the qualitative findings -

- Obtained new information about AD
- Obtained new information about a particular symptom
- Family burdens become too great
- Medical interventions become futile
- Life becomes purpose-less, wasted
- There’s always hope
- Life matters

Symptom	Reason
psychosis	- being disconnected from surroundings - more likely to be a risk to others - more likely to have the other symptoms
disinhibition	- embarrassment
aggression	- antithetical to my nature/self-image - never want to hurt others

AD Stage	Reasons
mild	AD isn’t so bad at this stage
moderate	AD isn’t so bad at this stage
severe	I don’t want to die There is hope

Intervention	Reason
"black box" medication	- very low risk of stroke/early death - reasonable likelihood that it will work
physical restraints	- people will still be nearby - seclusion is too lonely
seclusion	- being alone is not frightening/awful - less restricting compared to restraints - being restrained is unimaginable or would be completely intolerable

Trends Noted

- 10 % increase in knowledge from pre-brief education to 1 month follow up
- increased preferences for less intensive intervention if subject knew someone with AD or had a university degree
- not knowing someone with AD linked to 6x more likely to prefer intensive intervention for AD
- increased AD knowledge linked to increased preferences for less intensive interventions
- despite cardio-neurological risks, "black box" medications preferred to manage BPSD

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Pilot Study Limitations

- Possible subject recruitment bias
- Only healthy seniors recruited

What's Next?

- A larger, multi-site study
  - explore beliefs, attitudes, preferences of seniors diagnosed with mild neurocognitive disorder or early dementia
  - explore beliefs, attitudes, preferences of familial caregivers
  - compare brief education with video cases versus written cases
- Develop a resource for physicians to direct their patients to
  - resource is to encourage/help patients have advance care planning discussion with their family/caregivers about dealing with foreseeable BPSD symptoms

Questions?

Thank you.

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