Can we augment conversation for persons with dementia?

An international effort by clinical researchers
in Portland, Oregon USA and Dundee, Scotland

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Objectives for miniseminar

1. Describe dementia syndromes and review treatment options for persons with dementia and their caregivers. (NA & MFO)

2. Present data on use of electronic communication boards to support personal conversations by adults with moderate AD. (USA: MFO and CR)

3. Demonstrate CIRCA, and present data on reminiscence therapy with a hypermedia platform. (Scotland: NA)

4. General group discussion; thoughts from the expert participants. (NA)

Age profile trend in the UK – similar worldwide
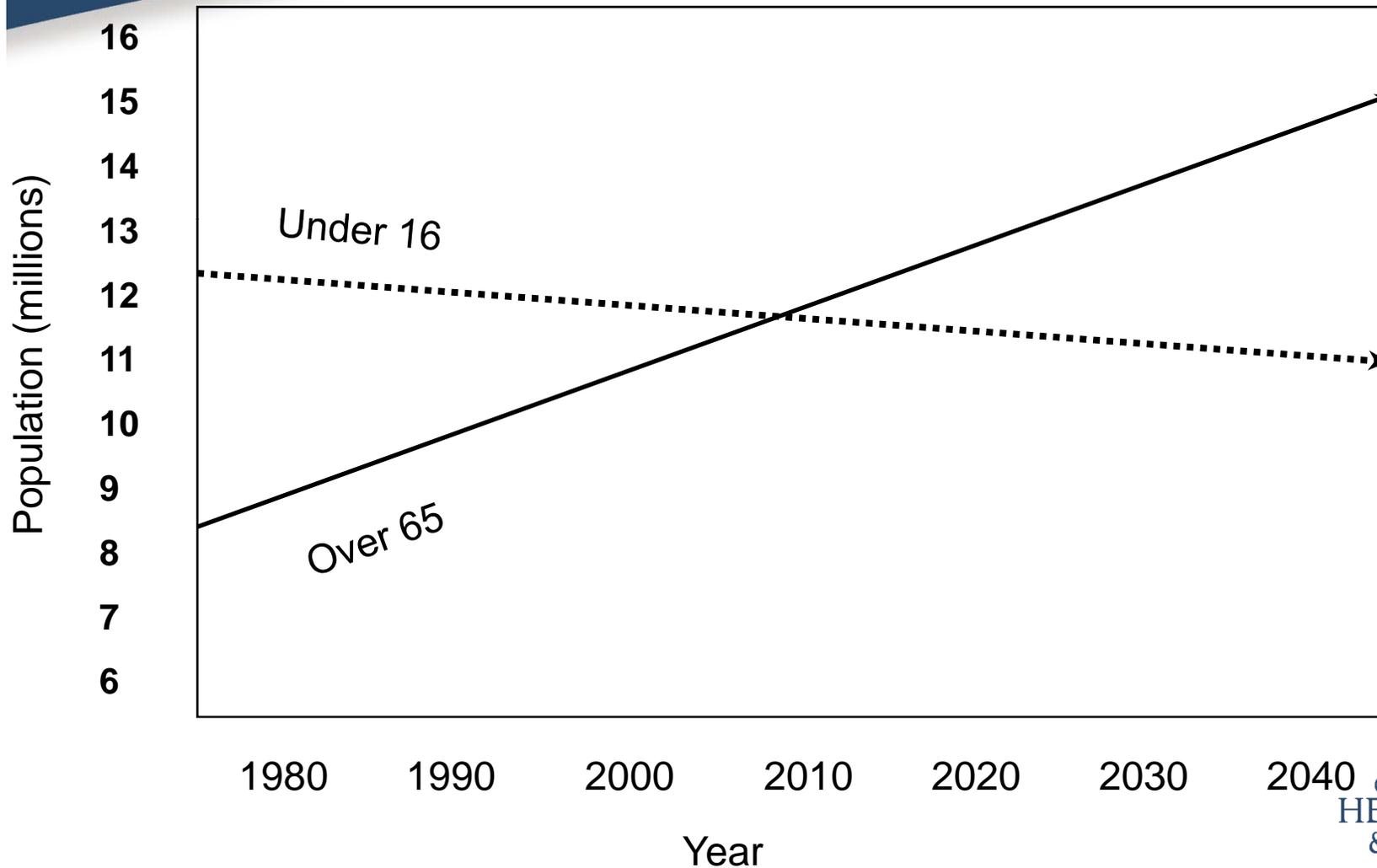
The inverting population pyramid

Old

Young

In the past

Now

In the near future
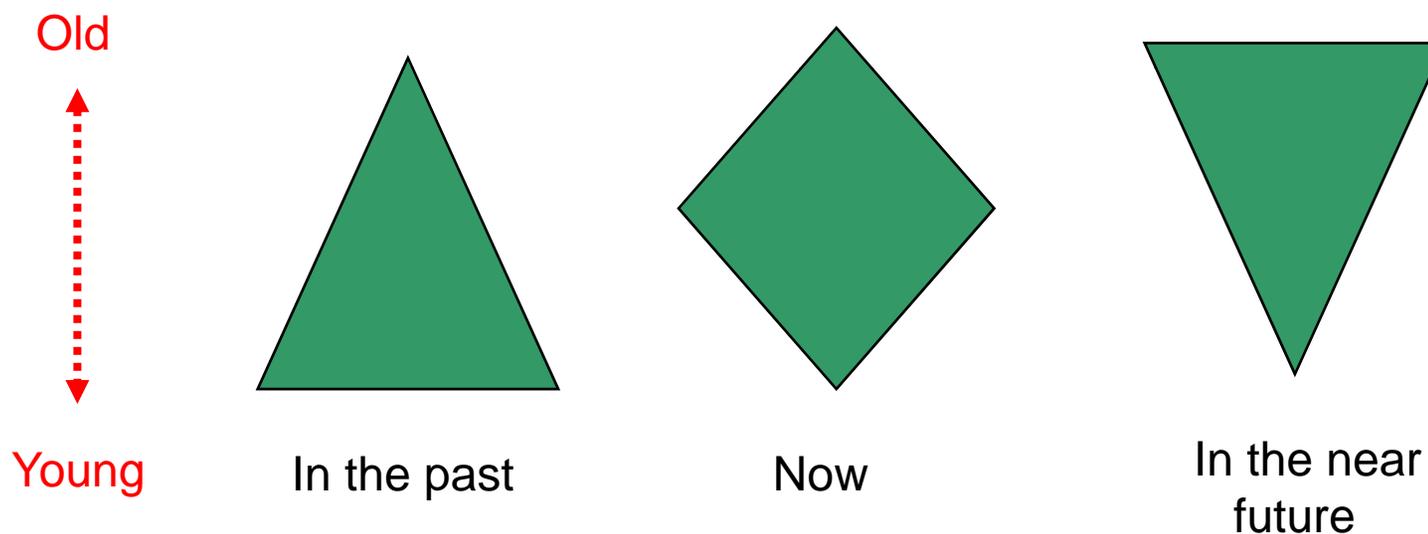
Prevalence of dementia

Age group	Approximate prevalence
65-69	2 %
70-74	3 %
75-79	6 %
80-84	11 %
Over 85	24 %

What is dementia ?

Decline in cognitive functioning produced by

– Alzheimer's disease (the mains cause)

– Stroke (second common cause)

– Some other diseases and conditions (minority of cases)

Dementia results

- Term 'dementia' describes the set of symptoms produced in the main by Alzheimer's disease and stroke

- Brain cells are killed off gradually

- Primary symptoms are
  Working (short-term) memory degradation
  General decline in cognitive abilities
  May be a loss of inhibition

Our knowledge very incomplete

- The brain is a 'distributed system' with lots of redundancy built in (helpful for coping with injuries)

- But new brain imaging techniques have taught us about areas of the brain specialising in surprising ways, for instance a locale for social inhibition

- Alzheimer's disease produces plaques and tangles that kill off brain cells – but plaques and tangles have been found in healthy people (see point one above)

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Dementia Syndromes

- Alzheimer's disease
- Vascular dementia
- Frontotemporal dementia
  - Primary progressive aphasia
    - Semantic dementia
    - Nonfluent progressive aphasia
    - Logopenic progressive aphasia

Treatment options for elders with dementia and their families

- The bad news : so far nothing found to reverse or arrest the condition

- Drugs – in about 50% of patients some drugs can slow the decline to a degree

- Cognitive exercise ('use it or lose it') – no evidence yet about this except an indication that people with lower educational levels seem to be more susceptible to develop dementia

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Support as treatment

- It seems likely that 'emotional memory' can persist longer than working (short-term) memory

- So quality of life an issue for people with dementia

- Better support can mean a happier state of mind
  Less wandering   Less aggression
  Less anxiety

Supporting the person with dementia

- 'Reality orientation' often not helpful

- Respect for the whole person (Kittwood)

- Validation (Feil)
    Assume that behaviour and
    communication carries meaning –
    be a detective – try to figure it out.
    Look for the underlying emotional message
        e.g. loss, confusion, enjoyable silliness

External memory aids:

- Notebooks,
- cards,
- communication boards,
- calendars,
- signs,
- timers,
- labels,
- color codes,
- tangible visual symbols)

The Dining Room

My Mother's Treasures
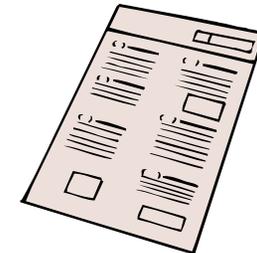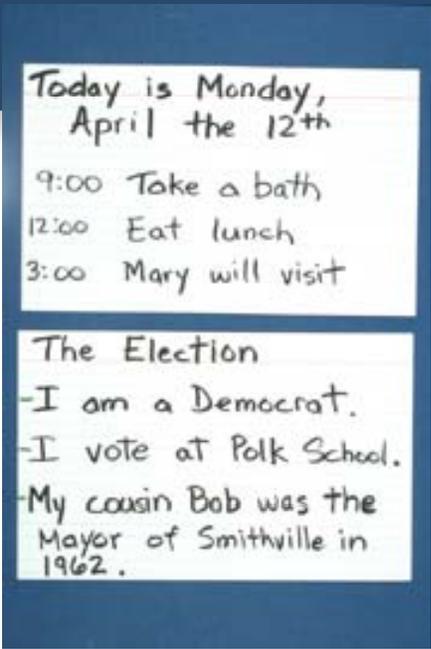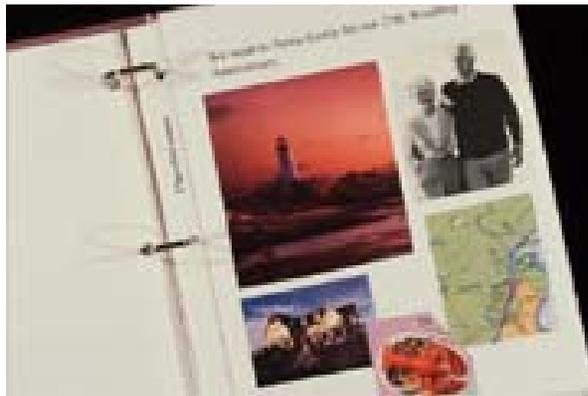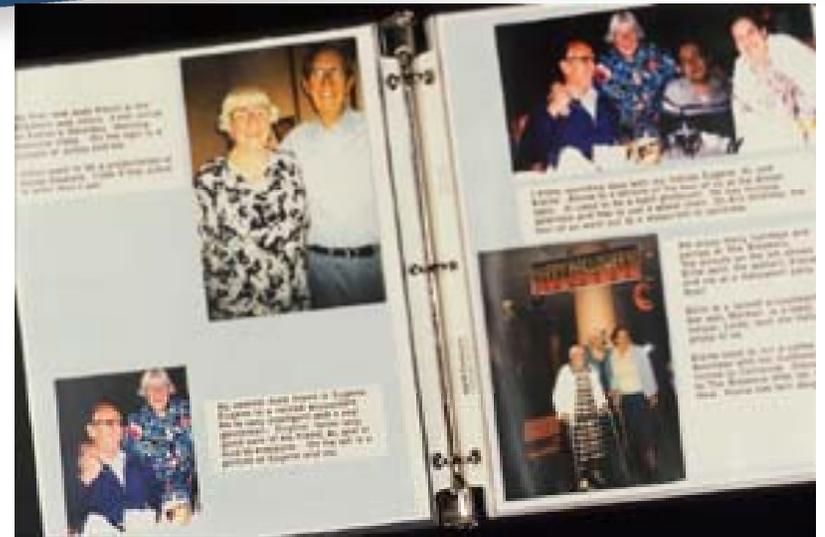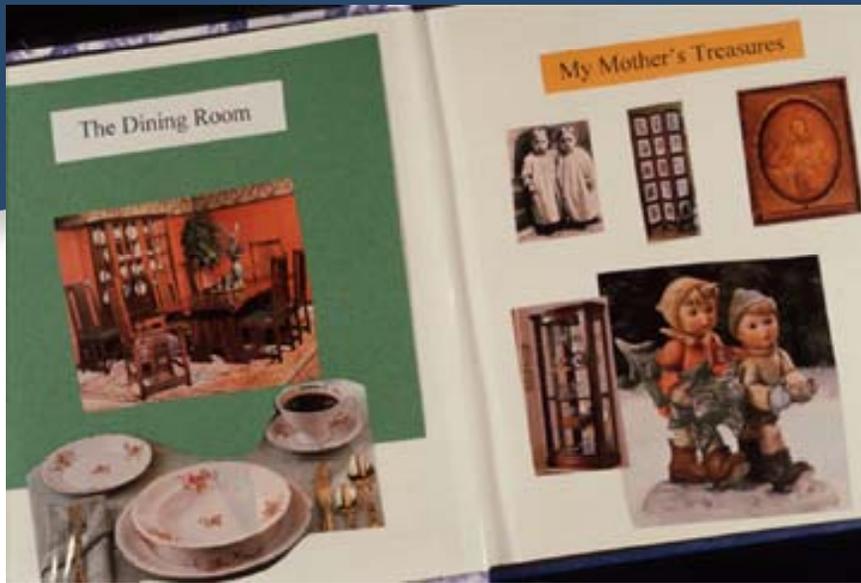
REKNEW-AD

- Reclaiming
- Expressive
- Knowledge
- In Elders
- With
- Alzheimer's
disease

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Premise for REKNEW-AD research

- Nonverbal symbolic representations may serve as semantic primes to stimulate information retrieval needed for functional conversation in DAT.

- Knowledge of the level of representation most accessible to an individual with dementia would be useful in selecting an appropriate AAC device.

Premise of pairing AAC and dementia

- Pairing the external aid with familiar and spared skills (such as page turning, reading aloud) should maximize a person's opportunity for success.

- These skills are based on intact procedural memory.

- The stimuli are relevant to a person's ADLs.

REKNEW-AD research question:

- Do AAC tools improve the quantity or quality of conversation by individuals with moderate Alzheimer's disease?

Bourgeois research (1991-1994)

- Made individualized memory wallets or cards
- Persons with mild AD
- Measured outcomes of conversations between trained caregivers (spouse, adult child, day staff)
- Wallets: Pictures and words for 3 topics:
  - Family names
  - Biographical information
  - Daily schedules.

Results

- Increased the frequency of factual information;
- Decreased the rate of ambiguous, perseverative, erroneous, or unintelligible utterances;
- Increased the conversational responsibility (turn taking) of person with dementia;
- Increased the number of on-topic statements during a conversation.

Now we know that non-electronic AAC options work. How can we examine these approaches further?

Specific Aims

1. To compare the effects of different input modes in an AAC device on conversational skills of persons with moderate AD.
   - Print alone
   - Print + photographs
   - Print + 3-dimensional miniature objects
   - Photographs alone
   - 3-dimensional miniature objects alone
   - Control condition (no board).

2. To compare the effects of output mode in an AAC device on the conversational skills of persons with moderate AD.

– Digitized speech output
– No speech output

Design for today's reported study:
conversations per participant

Input/ Output	No Board	Print only	2-D + Print symbols	3-D + Print symbols	2-D symbols only	3-D symbols only
Voice output	2	2	2	2	2	2
No Voice Output		2	2	2	2	2
Totals	2	4	4	4	4	4

- Conditions are varied within each of 5 participants.
- Each subject participates in 22 conversations.
- 2 conversations are conducted each day.

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Board example: Carol uses *print alone with voice output*

Questions you should be asking by now:

- What do these AAC devices look like?
- What do they sound like?
- What are the different input modes (symbols?)
- How does a participant use the device?

Subject: *"I loved to bowl."*

Subject criteria

- Diagnosis of probable or possible AD by a board certified neurologist;

- Clinical Dementia Rating (CDR) = 2;

- Mini Mental Status Examination (MMSE) = 8-18 within 6 months of enrollment in study (or we administer);

- Vision and hearing within functional limits;

- English as primary language.

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Exclusion criteria

History of other neurologic or psychiatric illness (no CVA, reported alcohol abuse, traumatic brain damage, reported recent significant psychological or speech/language disorder).

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5 Subjects analyzed as of July 2006

Gender	3 Females	2 Males
Age	Mean = 75 yr.	Range = 56-83
MMSE (0-30)	Mean =12	Range = 8-16
CDR (0-2)	Mean =2	Range = 1-2
FLCI (0-88)	Mean = 57	Range = 42-77

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Bill's story

- 74 year old man
- MMSE= 12/30 ;
- FLCI= 60/88;
- Lives with wife at home;
- Son lives above in duplex;
- Is a WWII veteran;
- Previous occupations:
  - Missionary; truck driver;
  - Contractor; college student
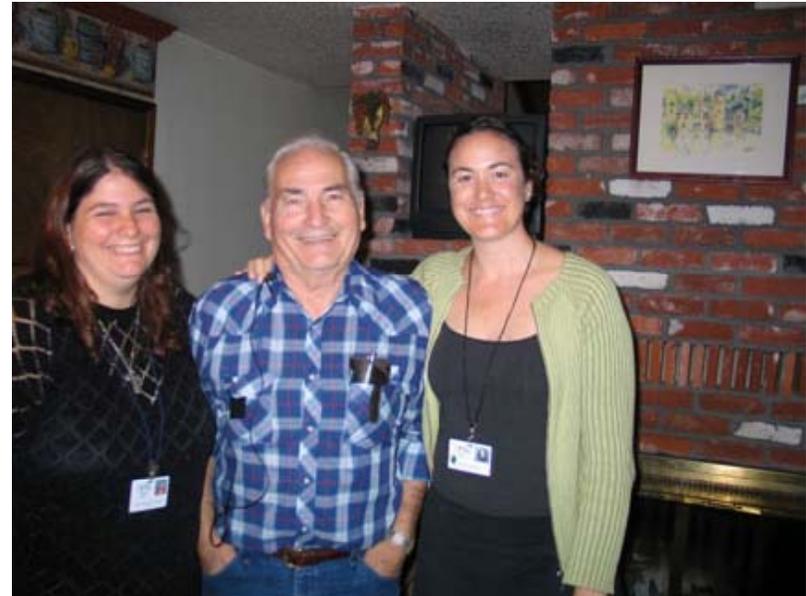
Method

1. Identify participant and randomly assign to condition;

2. Determine participant's preferred topic and vocabulary;

3. Develop communication device for each condition;

4. Conduct 2 videotaped conversations with participant for each condition.

What messages should be chosen?

- Autobiographical memories might be accessible.

- Messages that affect the environment might be more meaningful.

- Message topics have been documented within the language of elders.

Some elder speak topics

Emotional

- Losing something important
- Being embarrassed
- An argument
- Pet dying
- Being discipline at school
- Being lost
- Meeting a special friend
- Being chosen
- Wearing a special piece of clothing
- Holiday

Family Events

- Birth of sibling
- Someone's death
- Child's first day of school
- First house
- Moving to new home
- Moving to new school
- First love
- Wedding
- Engage
- First dance
- First child

Lena's cooking board (2-D only)

Lena's cooking board (3-D only)

Lena using the 2-D+print board

"*Well, I could use this board to talk from breakfast to hell and back!*"

Coding System:
Social Communication Framework

- A social communication framework relies on the notion of grounding, or the joint establishment of meaning (Clark, 1999).

- A communicative act occurs when partners establish what information is to be entered into common ground.

Conversational Dynamics Coding Scheme

- The Conversational Dynamics coding scheme is based on a social communication framework. It draws heavily on the work of Clark and Brennan (1991), Clark (1996,1999) and Clark & Fox Tree (2002).

Structure of Proposed Coding System-final as of 04-12-06!

(1) TRACK (labeled "Subjects" in Observer)	(2a) MODE	(3) COMPLETENESS+ TOPIC MANAGEMENT STRATEGY	(4) CONTENT
Main only	Speech only	Completed-Initiate	
	Minimal Speech only		
	Speech+Gesture	Completed-Maintain	Board Topic
	Minimal Speech+Gesture		
Main+Expl Collateral	Speech + Ref to Board	Completed-Elaborate	
	Minimal Speech + Ref to Board		
	Speech+Gesture+Ref Board	Completed-Revive	Other Topic
Main +Flag Collateral	**Minimal** Speech +Gesture+Ref. Board		
	Gesture only	Abandoned	
	Ref. Board only		
Main +Expl Coll + Flag Coll	Gesture+Ref. Board	Interrupted	

>>>>>>>>>>>>>>>>>>>>

(2b) NOT MAIN

*Expl. Collateral only
*Flag Collateral Only
*Expl. + Flag Collateral Only
*Vacuous Language
*Unintelligible
*Perseverate
*No Response

*NOT MAIN!

(I know this is silly, but we have to add this code because Observer is weird)

Non-utterances

- Vacuous Language: nonsensical, rambling utterances

- Unintelligible

- Perseveration: involuntary return to a phrase that occurs at least 3 times in conversation

- No Response: participant does not respond to partner's bid.

Utterance (the unit of analysis)

- An utterance involves a proposition that is completed, abandoned or interrupted within the bounds of a **conversational turn**.

- An utterance is bounded by either a pause, a change in topic management strategy (for completed propositions), abandonment or interruption.

Utterances are coded first for

Signal Track

Signal Track:
Main versus Collateral

- Main Track utterances relay propositional content

- Collateral Track utterances comment on the propositional grounding that may or may not be occurring in the conversation.

Explanatory Collaterals
advance the conversation by managing it for both the speaker and the listener.

- Feedback "I didn't hear that" "I don't' know what you mean" "That's what I just said"
- Interest signals: "um-hmm", "yeah" (to keep the conversation going and show you're still engaged)
- Navigation signals: "I'm trying to think who this is" "I can't remember what I was trying to say"
- Checking: "Know what I mean" "Did you hear me?"
- Repair/self-editing: "I mean…"
- Taking the floor: "I have something to say about that"
- Wrapping up: "that's all I have to say"

Flag Collaterals

serve as flags or signals that the speaker is having difficulty with the conversation, but. don't reveal any insight into *what's* wrong

- Pause fillers: "um", "ah", "whatever", "blah, blah, blah", "anyway")
- False starts, hesitations: "I,I,I…", "I said, he said, I say, I…" It's okay, he's okay, I hope, he's okay"

Main Track Utterances
convey propositional content

- I used to scuba dive all the time.
- My wife is a good woman.
- I wish I could see Richard..
- Do you know about that trip?
- Yes. (in answer to a question)

Mode (for Main Track only)

- Speech
- Minimal Speech (1-word utterance)
- Gesture
- Reference to Board

Completeness (for Main Track only)

- Completed

- Abandoned

- Interrupted

Topic Management Strategy
(for Completed utterances)

The Topic Management Strategy is dependent upon the history of the conversation: it shows us how the current utterance relates to previous utterances.

- Initiate
- Maintain
- Elaborate
- Revive

Content (for Completed utterances)

- Board Topic

- Other Topic

Reliability

Mean Index of Concordance across participants:

- Signal Track--.82
- Mode--.82
- Completeness--.87
- Topic Management Strategy--.82
- Content--.86
- Overall--.84

NOLDUS Observer 5.0 Software

- Coding
- Reliability
- Summary Statistics
- Lag sequential analyses

Data analyzed for each subject thus far for pilot study

Input/Output	No Board	Print only	2-D + Print symbols	3-D + Print symbols	2-D symbols only	3-D symbols only
Voice output	2	2	2	2	2	2
No Voice Output		2	2	2	2	2
Totals	2	4	4	4	4	4

"What do you mean you don't have all the subject data analyzed yet? "

Results (thus far)

Characteristics of conversations in general

- Wide variation in number of utterances per subject (range =16-55 utterances per 5 min.).

- Little variation in characteristics of utterances between subjects.

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Independent Variables

- Time (no effect)

- +/- Voice Output (no effect)

- Control versus Experimental conversations

- Print versus 2-D+Print versus 3-DPrint

Composite Variables

SIGNAL TRACK
- %Utterances including Main Track
- %Utterances including Explanatory Collateral
- %Utterances including Flag Collateral

MODE
- % Main track utterances including Gesture
- % Main track utterances including Reference to Board

COMPLETION
- % Main track utterances completed

TOPIC MANAGEMNT STRATEGY
- %Completed utterances including Initiation or Elaboration of topic

# Signal Track
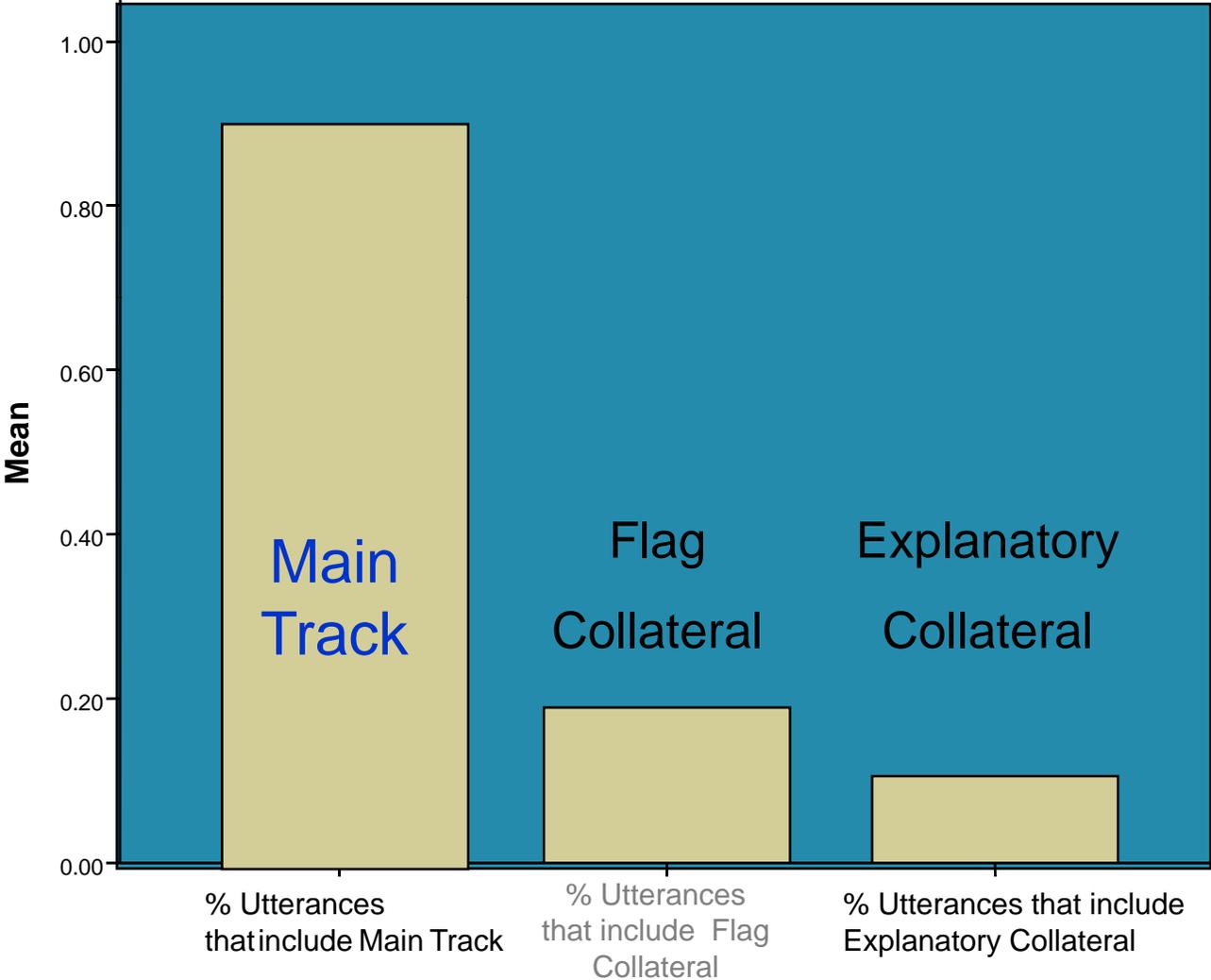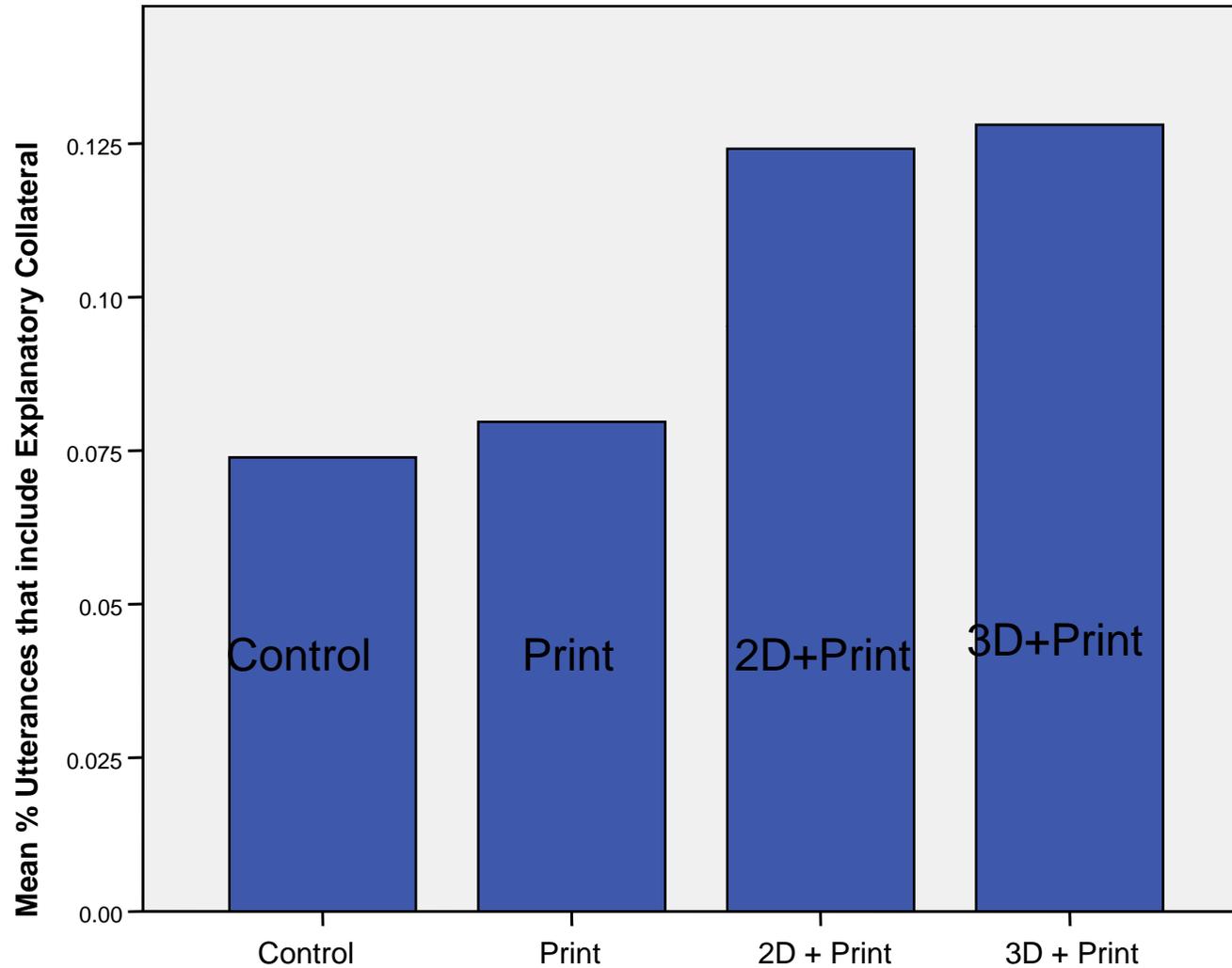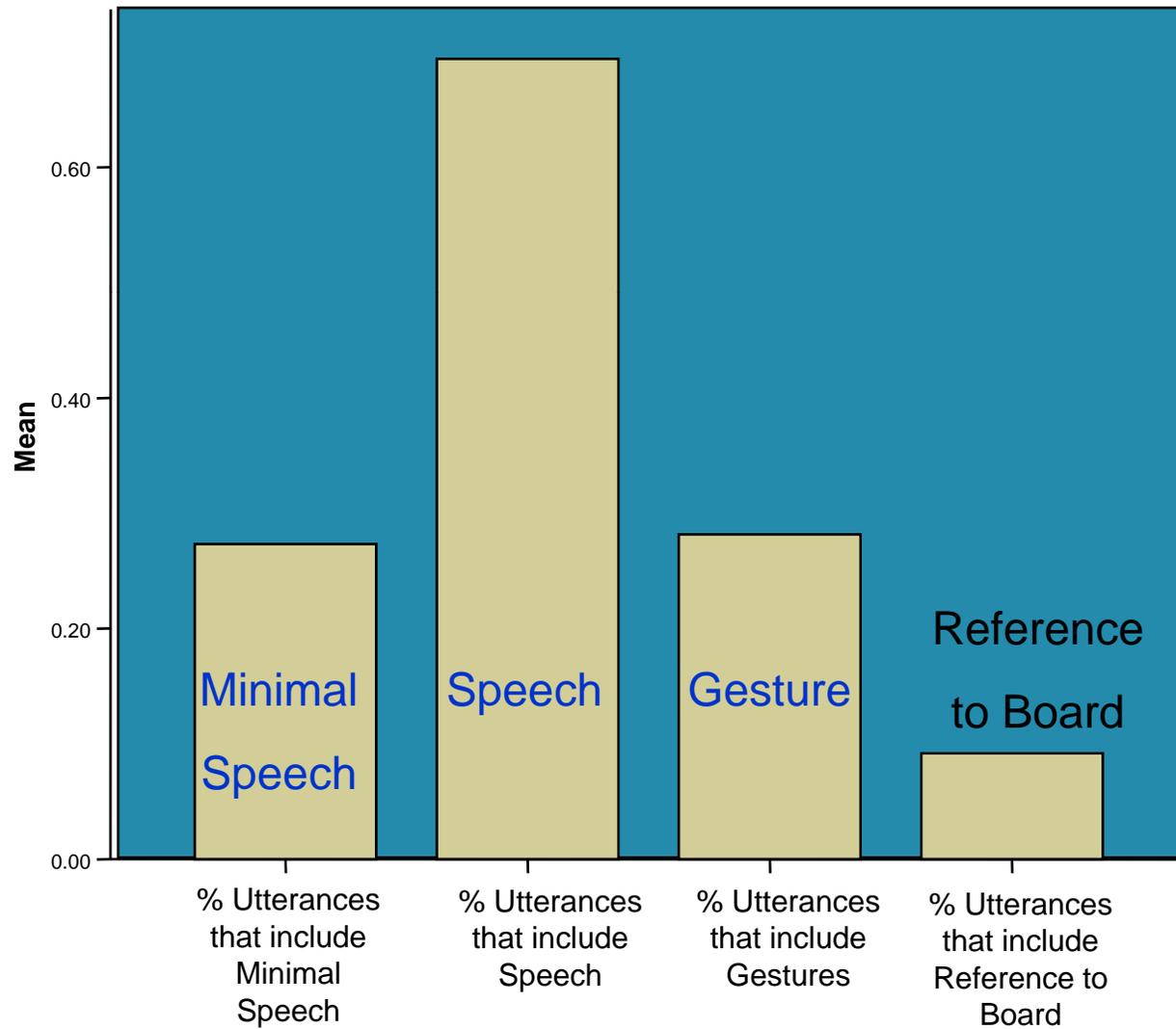
Mode

# Bill uses all modes

Reference to Board by Condition
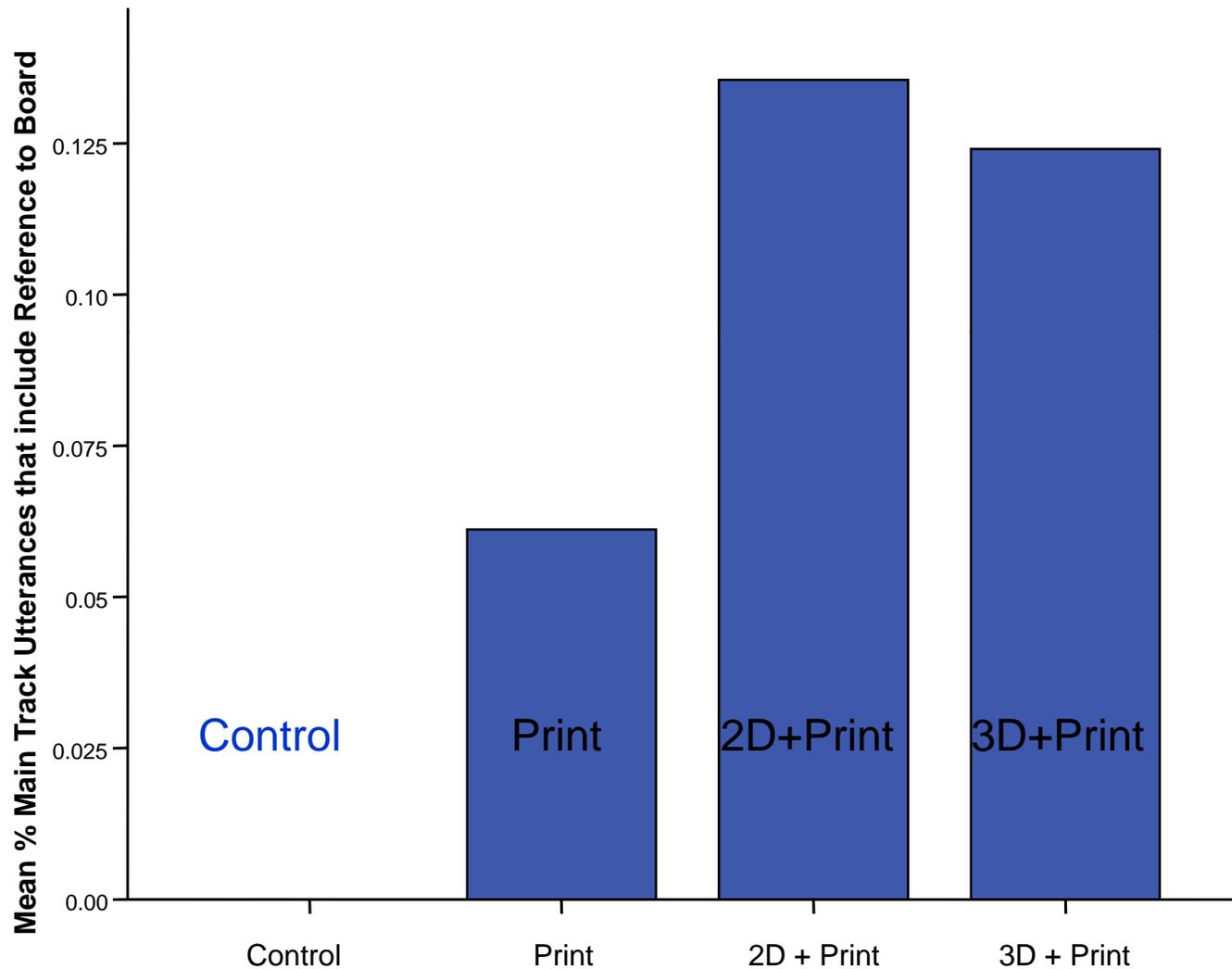
# Henry "refers to board" often
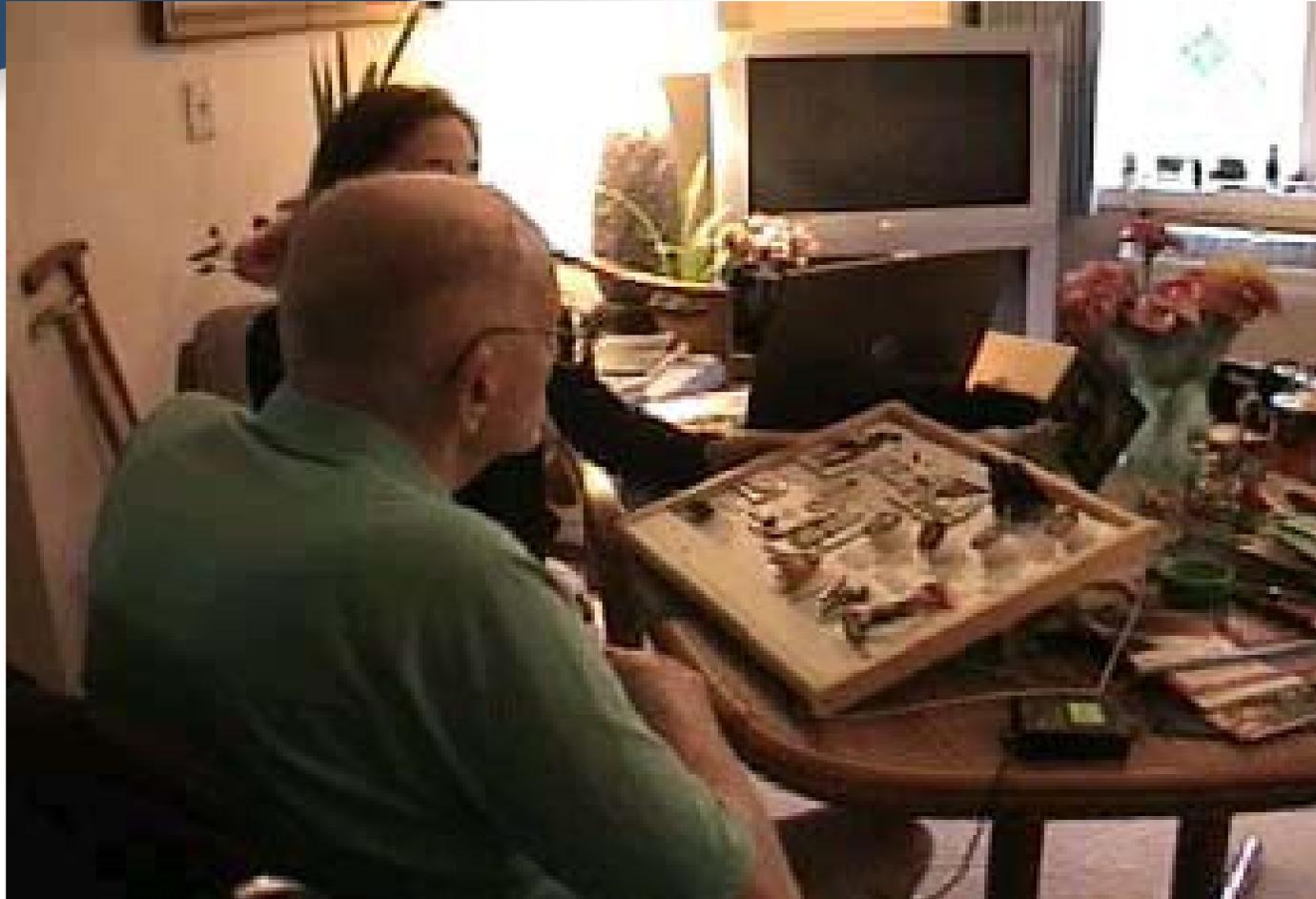
# Completeness
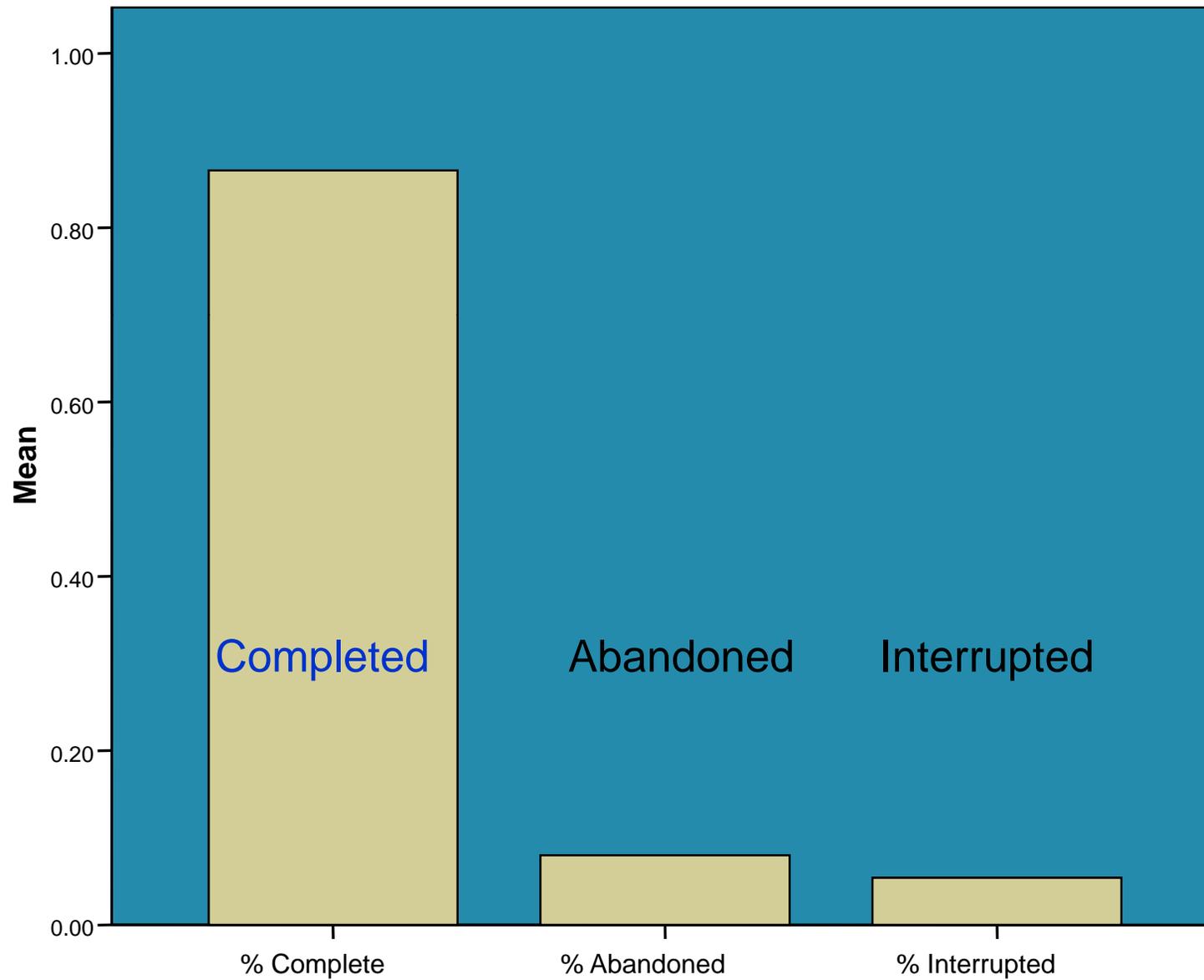
# Completed Main Track by Condition
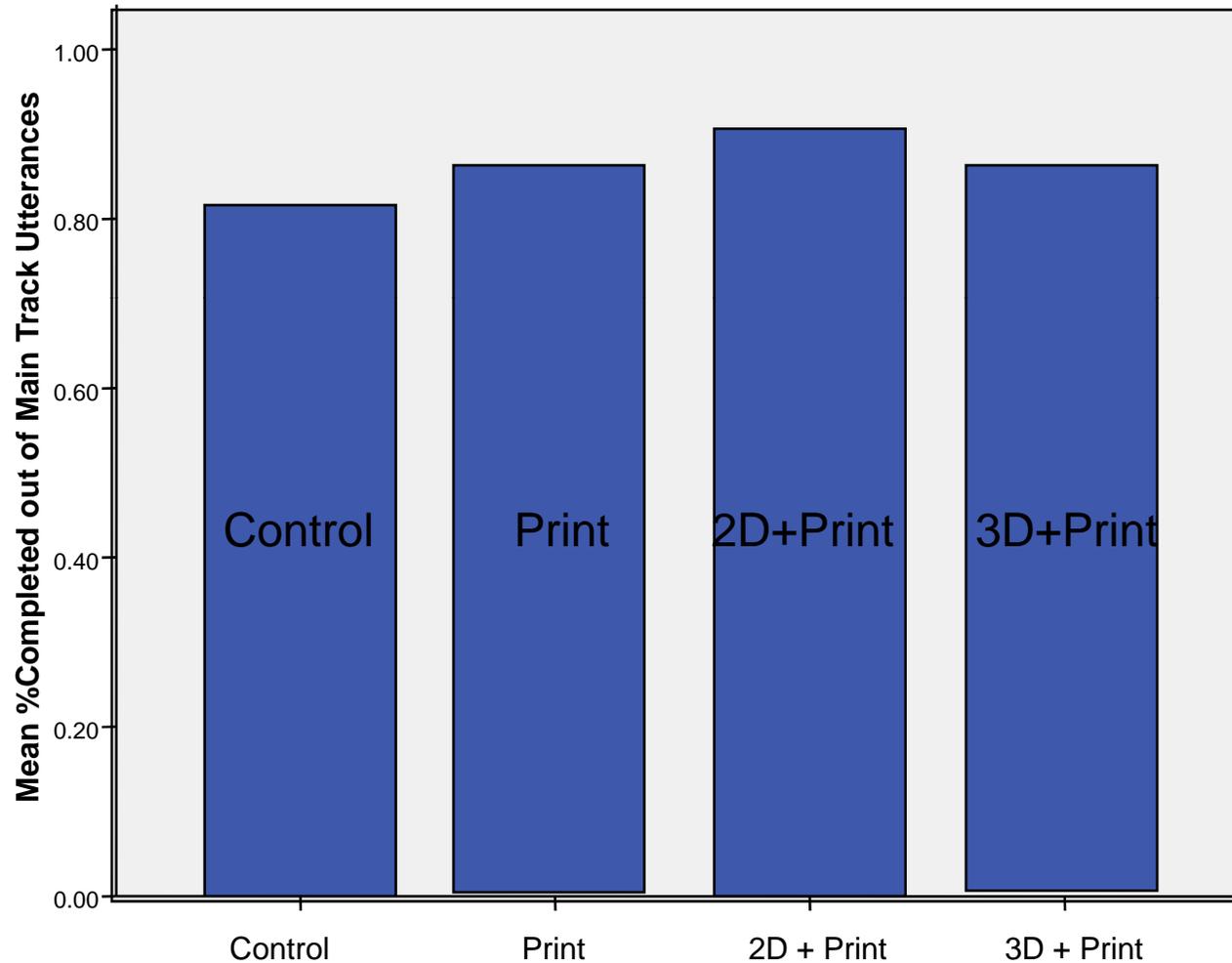
Topic Management Strategy
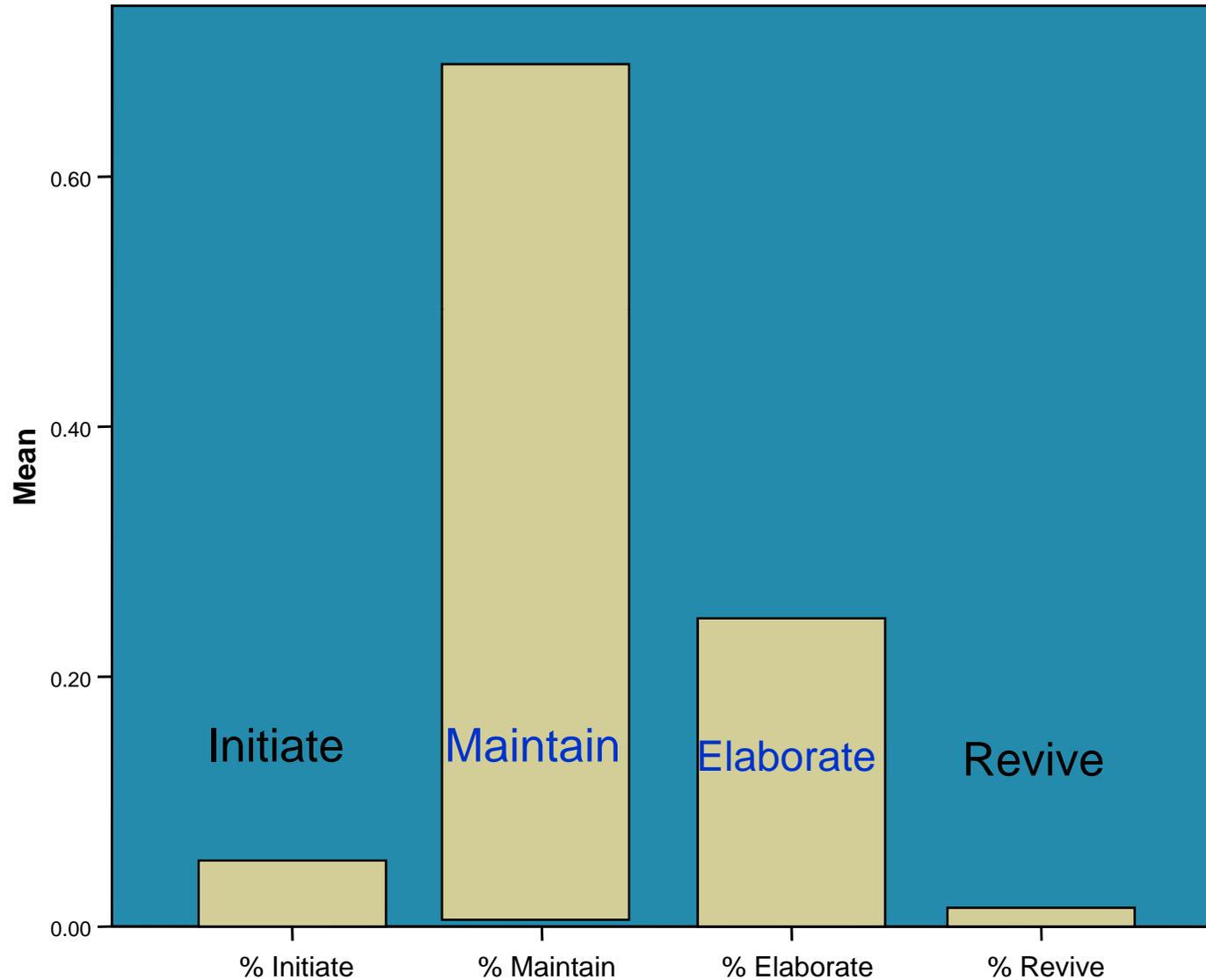
Initiation+Elaboration by Condition
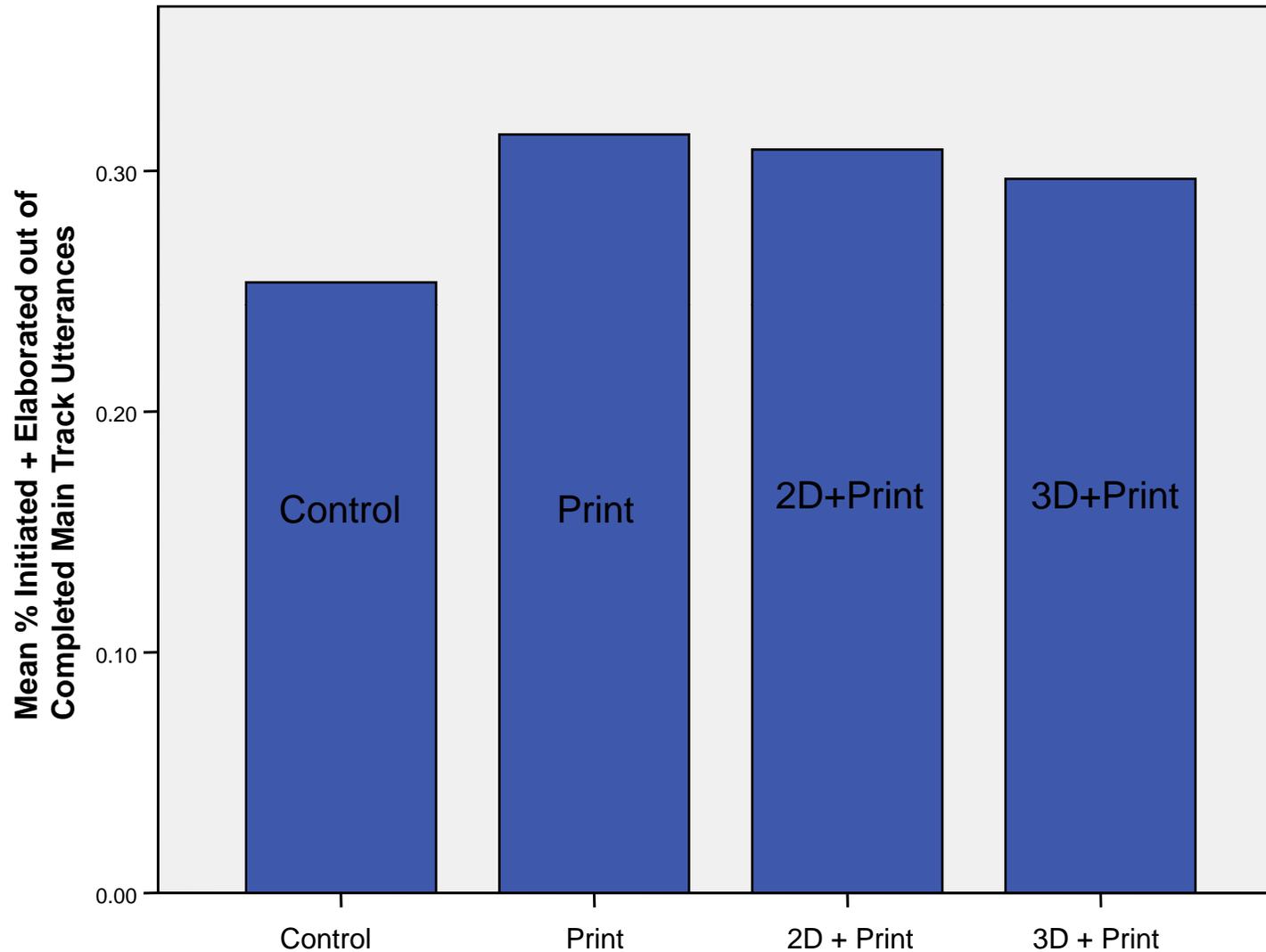
Content
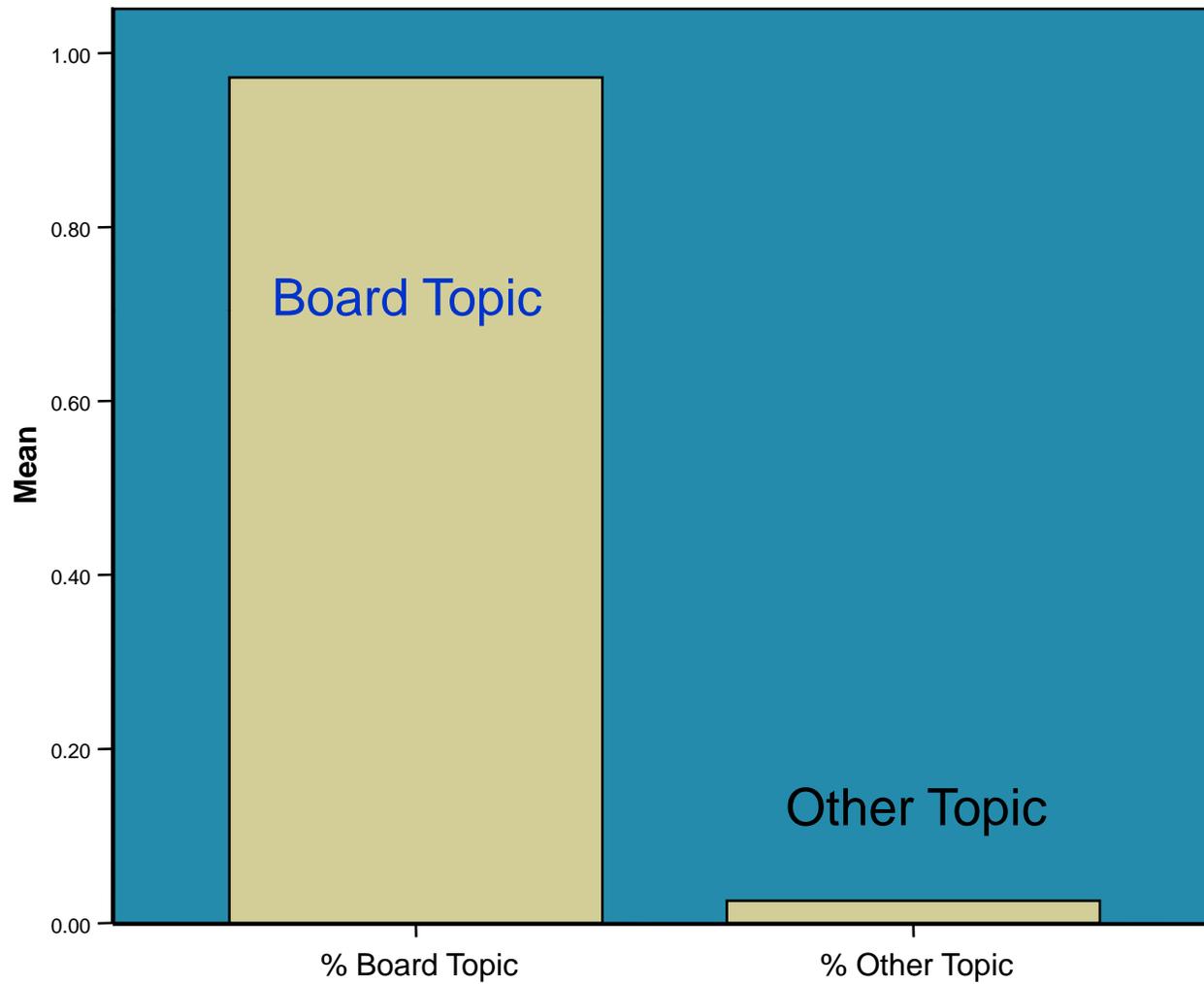
Board Topic by Condition
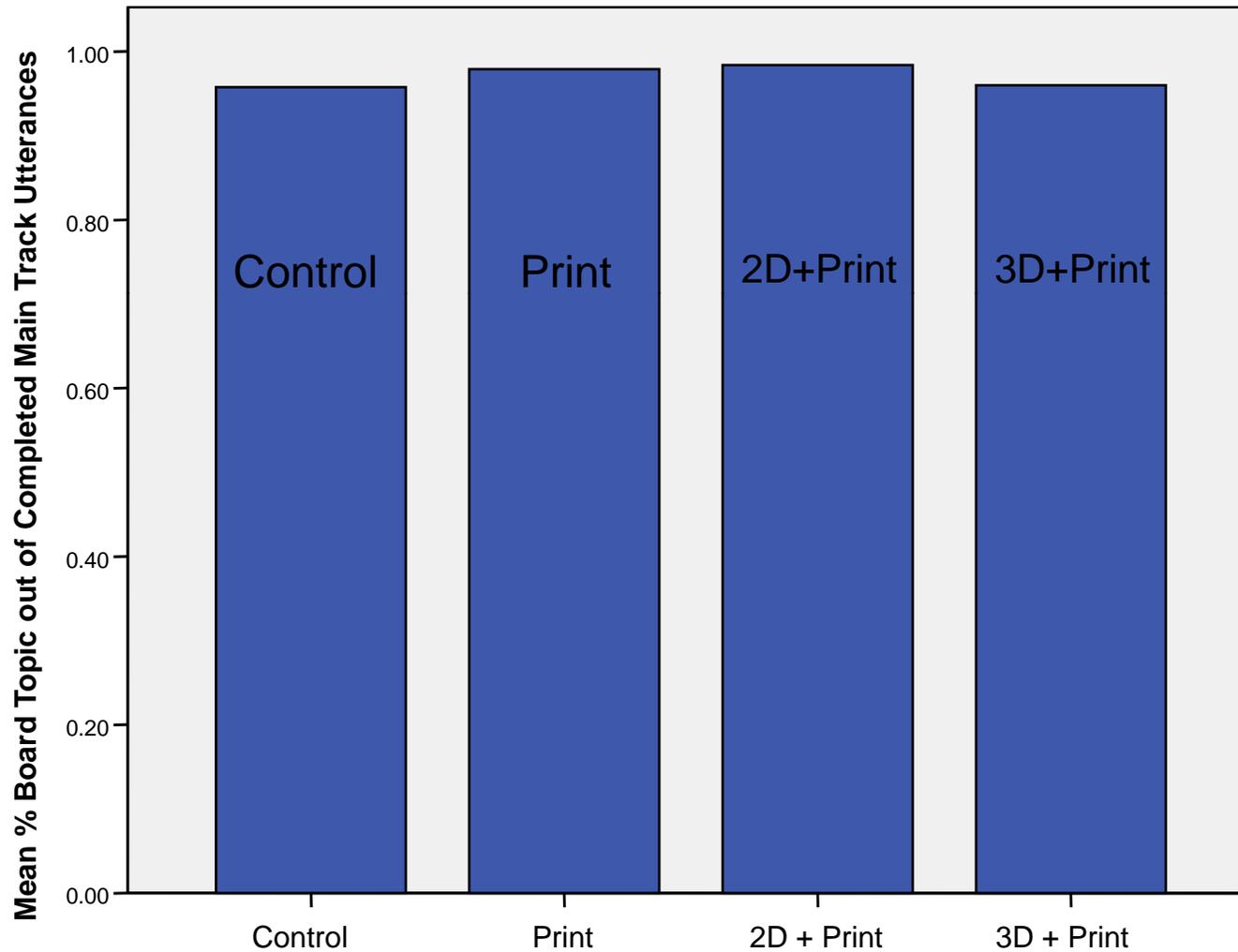
Design for Full Study:
participants per condition (48 total)

Output	FLCI (language screening score)	Input Mode		
		Print only	2-D +Print symbols	3-D + Print symbols
Voice output	Hi	4	4	4
	Lo	4	4	4
No Voice Output	Hi	4	4	4
	Lo	4	4	4
Total		16	16	16

• Conditions are varied between subjects.

• Each subject participates in 4 conversations without board and 4 with board with randomly assigned symbol type.

• 1 control and 1 experimental conversation conducted at each visit.

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37 Subjects as of July, 2006

Gender	12 Males	25 Females
Age	Mean = 74 yrs	Range = 50 – 94 yrs.
MMSE (0-30)	Mean =12	Range = 5-18
CDR (0-2)	Mean = 1.5	Range = 1-2
FLCI (0-88)	Mean = 64	Range = 27-85

Stay tuned in for results….

- We'll see you again in Montreal!

Acknowledgements

- Layton Center for Aging and Alzheimer's Disease Research, Portland, Oregon, USA

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- DOE/NIDRR award #H133G040176

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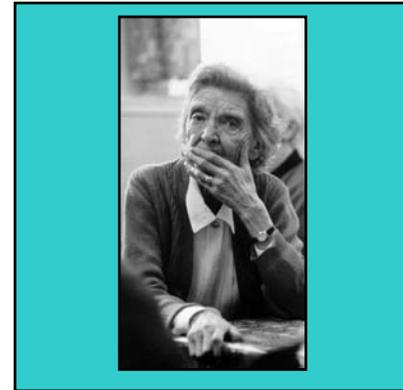
The development of CIRCA, a communication support system for people with dementia

Reminiscence as a communication aid for people with dementia

- Reminiscence an empowering activity for older people.

- For people with dementia it can tap into their relatively intact long-term memory

- But -- a large variety of materials to collect and organise : scrapbooks, cassette tapes, videotapes

- And -- the activity tends to be totally directed by the carer

Aim of CIRCA

To create an easy to navigate hypermedia system based on reminiscence to enable people with dementia to recapture their ability to communicate and interact on a more equal footing

Multidisciplinary team essential

Interactive media design
Gary Gowans
Jim Campbell

Software engineering
Norman Alm
Richard Dye

Dementia psychology
Arlene Astell
Maggie Ellis

from

Dundee
University

and

St Andrews
University

Design issues

Usability by people with dementia and carers

- Touch screen
- Ways to focus attention
- Enjoyment

Modelling conversation flow

Stepwise movement through topics

Prompting communication, not just entertaining

Consulting with potential users

Two service agencies as partners :
Alzheimer Scotland

Dundee Social Work Department

Active involvement of
85 people with dementia
50 carers and relatives

Requirements gathering from users

Development of CIRCA informed by users at every stage

People with dementia, family caregivers, professional caregivers and care facility managers involved throughout

Measured benefits to all parties

Deciding on the media

What stimuli evoke reminiscence?

Photographs commonly used - which kinds of photographs should we use in CIRCA?

Can images of generic events elicit personal memories?

Yes – contents of images less important than the memories they elicit

Initial piloting of the interface

3 people with dementia and 3 carers in own home and 3 people with dementia and 3 carers in daycare

All participants enjoyed using CIRCA and gave feedback

Both caregivers and people with dementia found CIRCA easy to use

People with dementia used the touchscreen with encouragement

Professional caregivers thought that the system "got clients talking more than usual"

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Comparison with traditional reminiscence sessions

9 people with dementia used CIRCA and 9 used TRAD with a caregiver for 20 minutes

Measures :

- Person with dementia
  - Engagement, enjoyment
  - Topic initiation
  - Topic maintenance

- Interaction partner
  - Enjoyment
  - Control of interaction
  - Maintenance moves

Some of the results

Person with dementia		
Mean (SD) range	CIRCA (N=9)	TRAD (N=9)
Choosing	6.1 (4.2) 1-12**	0.33 (0.7) 0-2
Memories	12.44 (8) 6-31*	58.2 (21.2) 13-84
Interaction partner		
Offering choice	10 (4.9) 3-18**	0.77 (1.6) 0-5
Asking questions	12.1 (8) 4-29*	48.1 (28.1) 14-98

* = p<.01; ** = p<.001

Important finding

- Overall more memories produced in TRAD *but*

- Proportionately more new information in CIRCA sessions (p<0.01)

- CIRCA presented people with dementia the opportunity to choose and initiate

- In TRAD sessions interaction partner was in control and maintained conversation

Evaluating CIRCA – Study1

Caregivers offered PWD choice of reminiscence subjects/materials more often when using CIRCA

PWD thus enabled to take the lead

Equalised social roles of PWD and caregivers

Provided a shared activity to enjoy together

Evaluating CIRCA - Study 2

Comparison of traditional reminiscence and CIRCA with same 11 people carrying out both activities

Replicated findings from Study 1

Family photographs study

Personal photograph study - 5 PWD and 5 family carers

Caregivers tell stories about the photographs

PWD make mistakes - feel they 'should know' information

Both parties upset because believe emotional/personal significance should assist memory

Actually creates expectations which PWD are unable to meet

Conclusion : we need 'failure-free' activity

CIRCA care home evaluation

CIRCA used by individuals and groups.

Generated interest and attracted residents to join in

Music provided an easily accessible group activity in this setting

  e.g. a visually-impaired resident who was often isolated was able to join in and make choices along with everyone else

Residents spontaneously commented on how much they enjoyed CIRCA

CIRCA daycare evaluation

CIRCA provided a group activity for PWD with wide range of dementia severity

People with more advanced dementia particularly responded to singing and moving to music

Music provided alternative means of interaction and communication

Caregiver found CIRCA enjoyable for a group

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Comparing CIRCA with non-reminiscence activities

6 staff members and 12 people with dementia over four weeks

PWD and caregiver interactions using CIRCA compared to four other commonly used activities (taking rubbings, cookery, flower arranging, working with fabric)

CIRCA better at supporting positive social interactions between PWD and caregivers – more equal control over the activity

Commercialising CIRCA

Company being set up to market CIRCA, initially in Scotland, then the UK

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