OREGON HEALTH & SCIENCE UNIVERSITY

Augmentative and Alternative Communication for Adults with Total Locked-In Syndrome

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Today's Topics

- Intro to TLIS
- Intro to BCI (brain-computer interface)
- OHSU studies
  - BCI for yes/no communication
  - Interviews with spouses
  - User-centered design of AAC
- Partner training
- Ethical issues

Locked-in Syndrome

What is LIS?

- Severe or total paralysis with preserved consciousness
- Also known as "minimal movement"
  - See work by Susan Fager, David Beukelman, and colleagues

More on LIS

- Underlying diagnoses include:
  - Brainstem stroke
  - Advanced ALS
  - TBI
  - Tumor
- Average age range: 17 – 52 years
- Younger patients have better potential of survival
- More than 85% of individuals are still alive after 10 years

More on LIS

- Highly recommended:
  - *The Diving Bell and the Butterfly* by Jean-Dominique Bauby
  - Film adaptation from 2007

Classifications of LIS

- Incomplete LIS: Recovery of some voluntary movements in addition to eye movements
- Classic LIS: Preserved vertical eye movement and blinking
- Complete or Total LIS: Quadriplegia and anarthria; no voluntary movement (Bauer et al, 1979)

AAC for people with LIS

- Low-tech: blinking or eye movement, partner-assisted scanning
- High-tech: SGD with eye control, switch scanning, or other alternative access

AAC for people with LIS

- People with total LIS have no voluntary motor function
- Others with LIS may not have consistently reliable motor function (fatigue, illness)

AAC for people with LIS

AAC for people with LIS

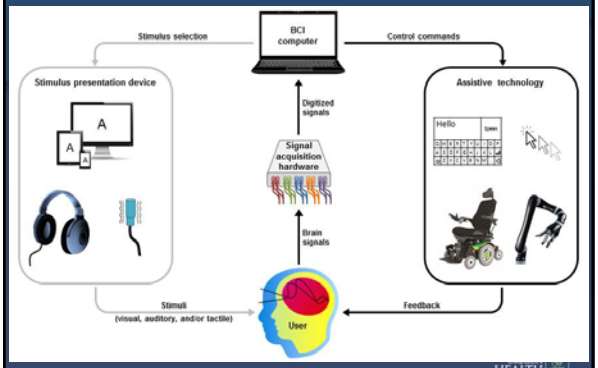
AAC for people with LIS

How can we break the ice?

Introduction to BCI

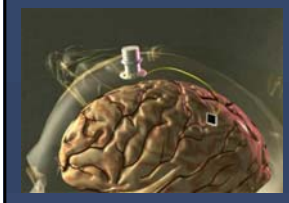
Brain-Computer Interface (BCI)

- Technology whereby a computer detects a 'selection' made by a person without using muscle activity
- Uses the person's changes in brain activity as the control signal
- Allows people can interact with their environments through brain signals rather than through muscle movement



Current human BCI research for communication & control

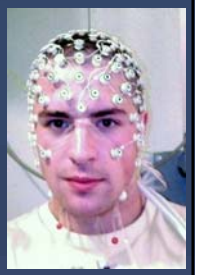
Invasive BCI: Braingate



Noninvasive BCI (EEG)

Electroencephalography (EEG)

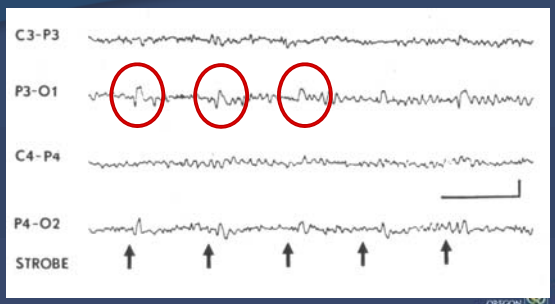
- Electrodes placed on scalp
- Records voltage fluctuations from ionic current flows in neurons
- Often used for diagnostic tests: epilepsy, disorders of consciousness, sleep studies
- Shows reactions to stimulation



EEG for control

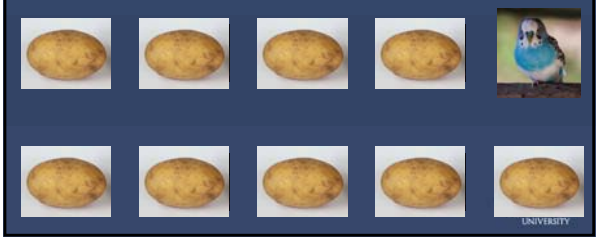
- Signal types
  - Steady state visually evoked potential (SSVEP)
  - Event-related potential (ERP)
    - P300
  - Motor imagery
- ERP = Brain response to a specific stimulus
  - Visual
  - Auditory
  - Tactile

ERPs: effect of single strobe flashes presented at 1 Hz during routine EEG

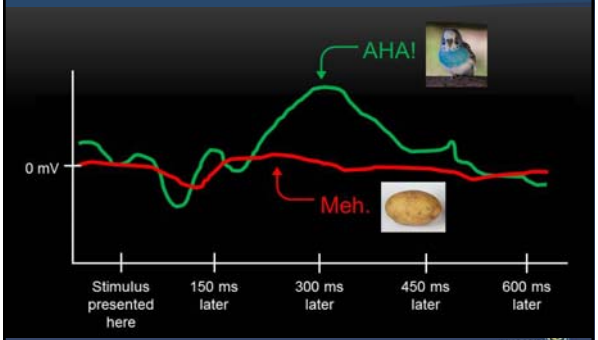


ERPs: P300

- Positive deflection in voltage occurring ~300ms (actually 250-500ms) after stimulus presentation
- Elicited by low-probability stimuli



ERPs: P300



ERPs in BCI

- ERP responses to known stimuli allow us to infer the user's intent
- Examples:
  - Binary-choice tactile BCI: Attend to vibrations on left hand for 'yes' or right hand for 'no'
  - Spelling systems: Appearance or highlighting of desired letter elicits P300

RSVP Keyboard™

- P300-based spelling system
- Letters appear rapidly on screen
- User looks for target letter in a stream of other letters

Are you ready?

GO_TO_THE_MOVIES
GO_TO_

+

GO_TO_THE_MOVIES
GO_TO_

S

GO_TO_THE_MOVIES
GO_TO_

N

GO_TO_THE_MOVIES
GO_TO_

_

GO_TO_THE_MOVIES
GO_TO_

A

GO_TO_THE_MOVIES
GO_TO_

B

GO_TO_THE_MOVIES
GO_TO_

T

GO_TO_THE_MOVIES
GO_TO_

Y

GO_TO_THE_MOVIES
GO_TO_

R

GO_TO_THE_MOVIES
GO_TO_

←

GO_TO_THE_MOVIES
GO_TO_

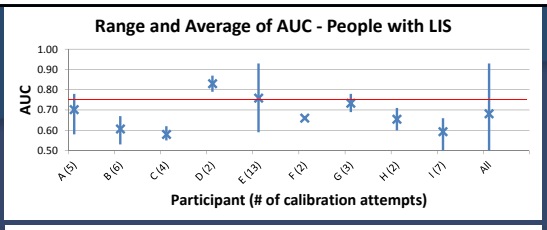
H

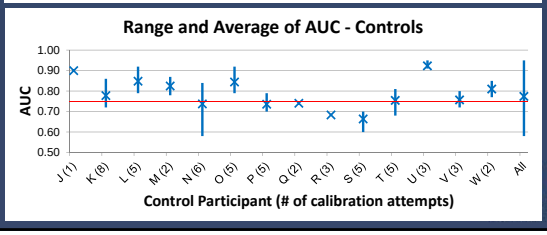
GO_TO_THE_MOVIES
GO_TO_T

DECISION: T

Here's the catch…

Current BCIs don't work for everyone, especially people with disabilities!





What we know so far…

- EEG-based systems: generally poor results for people with TLIS
- Invasive systems: limited human trials
- fMRI-based systems: some promising trials with people with DOC and TLIS (but expensive and difficult to access)
- Commercial EEG-based system (mindBEAGLE): mixed results for people with DOC or TLIS

mindBEAGLE: A COMMERCIAL BCI SYSTEM

mindBEAGLE

- Made by g.tec (Linz, Austria)
- Designed for consciousness assessment and communication for people with DOC

mindBEAGLE

- mindBEAGLE paradigms:
  - Auditory P300 (response detection only)
  - 2-tactor P300 (response detection only)
  - 3-tactor P300 (response detection and yes/no communication)
  - Motor imagery (response detection and yes/no communication)

mindBEAGLE FOR YES/NO COMMUNICATION

mindBEAGLE MI

- Goal: trial mindBEAGLE motor imagery paradigm with people with LIS
- Questions:
  - Can people with LIS learn to control an MI BCI with repeated practice?
  - Does a custom MI prompt improve performance compared to a generic prompt?
- Outcome variables:
  - Assessment score
  - Yes/no questions (#/10)

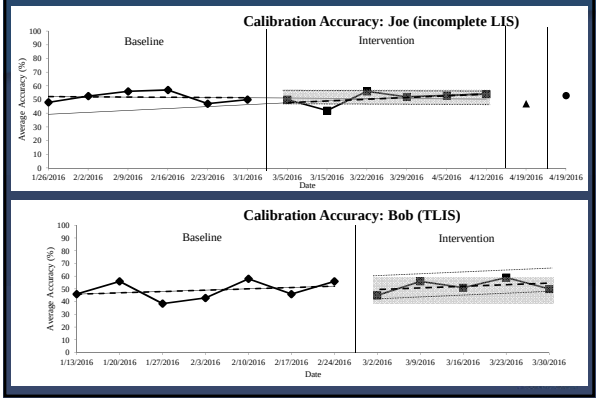
mindBEAGLE MI

- 2 participants
  - Joe: incomplete LIS after brainstem stroke
    - Previously successful with P300-based RSVP Keyboard™
  - Bob: total LIS or DOC due to advanced ALS
    - Spouse reports inconsistent yes/no response
      - "Good days and bad days"
      - Not observed during study visits
    - Previous experience with mindBEAGLE P300 paradigms: inconsistent performance

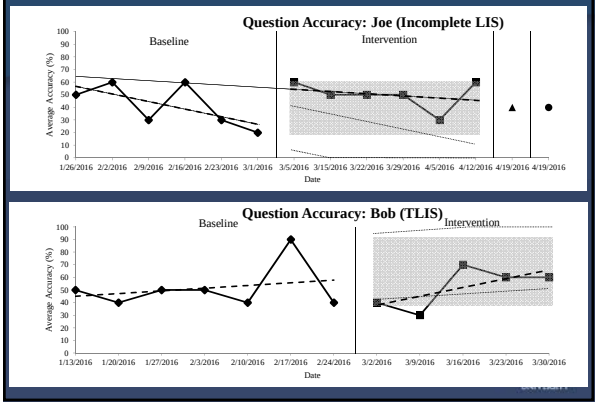
mindBEAGLE MI

- AB design
  - A: 6-7 sessions with generic MI prompt
  - B: 5-6 sessions with custom prompt
- Generic prompt: imagine touching thumb to fingers
- Custom prompts: imagine wrestling moves or guitar playing

mindBEAGLE MI: Results



mindBEAGLE MI: Results



mindBEAGLE MI: Discussion

- mindBEAGLE MI was not effective for these participants
  - (Very small sample!)
- Custom MI prompt had no effect

mindBEAGLE MI: Discussion

- Bob's status unknown: LIS vs. DOC?
- Joe had poor performance despite preserved consciousness & cognition
  - Poor BCI assessment performance = inconclusive result
- Further exploration needed

What do spouses of people with LIS think about BCI?

Purpose of this study

To gain insight into the current communication needs of families living with TLIS, as well as how future BCI research and design might work toward meeting those needs

Methods

Study design: Qualitative interview, case studies

Participants:

	Francine	Sandra
Age	69	45
Education	Graduate degree	Some graduate school
Spouse's condition	Diagnosed with ALS 1996; mechanically ventilated since 1999	Brainstem stroke secondary to AVM 2009
Other	Francine and Bob have been married for 36 years and live together in a private residence.	Sandra and her spouse have been married for 18 years. She lives at home with their 2 children; spouse lives at an AFH.

Protocol Design:

- 3 Interviews: 2 prior to BCI trials, 1 exit interview
- 3 mindBEAGLE trial sessions with spouses

Interview Questions

- 16 questions regarding:
  - Strategies for communication
    - How strategies have changed over time
  - Spouse's role in communication and decision making
  - Concerns regarding communication
  - Quality of life
  - BCI trial sessions
  - Hopes and concerns about BCI

Results

Major Themes:

Francine

- Different communication methods for different contexts
- Increasing role in facilitating participation
- Increasingly idiosyncratic and subtle communication methods
- Increasing unreliability of communication

Results

Major Themes:

Sandra

- Difficulty knowing he's "there", but unable to communicate
- Strong desire to connect her spouse with others through communication
- Uncertainty and doubt surrounding cognitive-communicative status

Results

Major Themes:

Sandra

- Experience of internal and external pressure to "do more"
- Variability in terms of both communication status and reliability of communication method

Results

Major Themes:

Francine & Sandra

- Emotional response to communication limitations
- Trial-and-error nature of finding methods of communication
- Changes to communication network and participation
- Resourcefulness and determination to find means of communication

Results

Ideal BCI System:

- Alternative stimuli that do not require vision
- Reliable binary, ternary, or spelling system
- Quick, easy set-up
- Simple and easy for BCI user
- Comfortable and not messy
- Voice output
- Emotional expression
- Environmental control
- Control of bionic arm or other prostheses

Discussion

- Communicating and making decisions on behalf of a loved one with TLIS can be very stressful
  - Uncertainty and inconsistency in communication methods
  - Making life-and-death decisions without direct input from person with TLIS
  - Internal and external pressures
- Reliable and clear communication would bring peace of mind and help spouses honor their loved ones' wishes
- Both spouses want to help loved ones with TLIS connect with valued people, interests, and activities

Discussion, cont.

- Family members of people with TLIS (and other disabilities that may create need for BCI) must have a voice in BCI R&D
- Caregivers' determination, ingenuity, and experience can be highly instructive for BCI-AAC researchers, developers, and clinicians
- As BCI R&D advances, the needs, desires, and experience of those caring for people with LIS and TLIS offer invaluable insight and must be considered if BCIs are to become functional communication systems

User-centered design of a communication system for TLIS

UCD Project Goal

- Create a customized device that will allow a person with TLIS to communicate

UCD Project Participant

- Vincent, husband of Sandra
- 46 years old
- Former engineer
- Brainstem stroke secondary to AVM in 2009
- TLIS
  - Inconsistent, often ambiguous communication using eye movements and blinks
  - No reliable, consistent method of communication

UCD Project Team

- Core team:
  - Sandra (an engineer)
  - 2 engineering PhD students
  - SLP
- Collaborators and advisors:
  - PI/SLP
  - Neurologist
  - OT/vision specialist
  - PT
  - Research assistants

User-Centered Design Process

- Sandra serves as proxy for Vincent and as an expert on his abilities and needs
- Regular core team meetings
- Home visits with Vincent (and Sandra) to trial system
- Iterative design: changes based on results from home visits and team discussion

UCD System Concept

- Take advantage of voluntary eye movement
  - Inconsistent, poorly controlled, and difficult to distinguish due to nystagmus
- Evidence is weak, so collect more of it
- Start with binary choice, then introduce spelling

UCD System Design

- EyeX eye tracker (Tobii, Danderyd, Sweden)
- Custom software
- Monitor on rolling floor stand

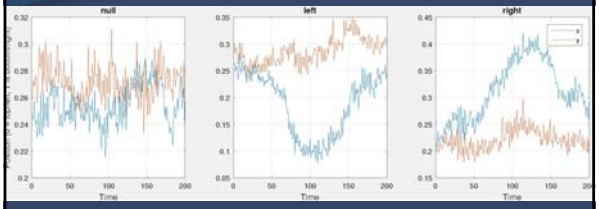
UCD Project Progress to Date

- Inconsistent eye tracking
- Lots of trial and error with hardware, software, positioning, room lighting, etc.
- Inconsistent performance with yes/no questions…

BUT…

UCD Project Progress to Date

- System can classify his eye movements!



- In one visit, 3/3 yes/no questions correct

UCD Project Challenges

- Unknown, possibly fluctuating, consciousness and cognitive status
- Positioning and room lighting for eye tracking

UCD Project Next Steps

- Hardware optimization (purchasing new eye tracker)
  - Camera mounted on glasses instead of monitor
- "Virtual Vincent" for initial testing of software modifications
- More testing!

Communication partner training

Why train communication partners?

- Communication is a basic human right!
- Each person has the right to:*
  - request desired objects, actions, events and people
  - refuse undesired objects, actions, or events
  - express personal preferences and feelings
  - be offered choices and alternatives
  - reject offered choices
  - request and receive another person's attention and interaction
  - ask for and receive information about changes in routine and environment
  - receive intervention to improve communication skills
  - receive a response to any communication, whether or not the responder can fulfill the request
  - have access to AAC (augmentative and alternative communication) and other AT (assistive technology) services and devices at all times
  - have AAC and other AT devices that function properly at all times
  - be in environments that promote one's communication as a full partner with other people, including peers
  - be spoken to with respect and courtesy
  - be spoken to directly and not be spoken for or talked about in the third person while present
  - have clear, meaningful and culturally and linguistically appropriate communications

National Joint Committee for the Communicative Needs of Persons with Severe Disabilities. (1992). Guidelines for meeting the communication needs of persons with severe disabilities. Asha, 34(Suppl. 7), 2–3.

Why train communication partners?

- Opportunities to recognize misdiagnosis or recovery
  - LIS may be confused with disorders of consciousness (minimally conscious state, unresponsive wakefulness)
  - PLIS may be misdiagnosed for months or years
  - People with TLIS may regain some function
  - Family members are often the first to recognize communication attempts (54% of cases, in one study!*)

* Leon-Carrion, J., van Eeckhout, P., Dominguez-Morales Mdel, R. and Perez-Santamaria, F.J. (2002b) The locked-in syndrome: a syndrome looking for a therapy. Brain Inj., 16: 571–582.

Communication Partner Strategies

- Inspiration from the Communication Bill of Rights
  - Provide attention and interaction
  - Provide information about changes in routine or environment
  - Speak with respect and courtesy, directly to the individual
  - Use clear and appropriate communication

Communication Partner Strategies

- Minimize noise and distractions
- Make eye contact and stay in individual's line of sight
- Assume individual can hear and understand
- Use multimodal input
- Provide interest and stimulation
- Provide information
- Share news and experiences

Communication Partner Strategies

- Watch for attempts at communication
  - Making eye contact
  - Blinking
  - Eye pointing
  - Vocalizations
  - Movements

Communication Partner Strategies

- Provide opportunities for communication
  - Give simple commands
  - Ask yes/no questions
  - Offer choices – movie or audiobook?
  - Request different response modalities
    - Eye blink
    - Eye movement (especially vertical)
    - Any other observed movement – could it be a volitional movement?
  - Provide adequate time for response
  - Try at different times of day

Ethical considerations

Ethical considerations

- Informed consent and care decisions
  - Typically given by a family member
  - Whenever possible, seek assent from the person with TLIS
  - Misdiagnosis is common, and decisions may be made based on incorrect information
  - Healthcare workers' assumptions or prejudices may affect their recommendations

Ethical considerations

- Reliability of communication
  - Technology factors
    - Difficulty recognizing weak/inconsistent signals
    - Buggy software
    - Unreliable hardware
  - Environmental factors
    - Other medical equipment may affect BCI
  - Human factors
    - Fatigue
    - Medications
    - Consciousness
    - Emotional state

Ethical considerations

- Benefits vs. risks
  - Physical harm
    - Invasive BCI requires major surgery
    - Risk of infection, hemorrhage, or tissue changes
  - Mental/emotional harm

Ethical considerations

- Managing expectations
  - Potential of new technologies
  - Learning curves and potential cognitive deficits
    - Attention, working memory, effects of medications
  - Prognosis for recovery and reliable communication

More on BCI at ISAAC…

- "Challenges and opportunities in creating synergy between AAC and brain-computer interfaces"
  - Fried-Oken, Hochberg, Huggins, Romski, & Vaughan
  - Thursday, 14:00-15:30
  - Metro East

Thank you!

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Melanie Fried-Oken, PhD, P.I.

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