Preserving Legacy: A Guide to Message Banking a Patient's Voice

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Conflict of Interest Statement

John Costello has no financial relationship with any companies, manufacturers or tools discussed in this presentation. John is a full-time employee of Boston Children's Hospital.

Kaytie Dimery has no financial relationship with any companies or manufacturers or tools discussed today. Kaytie is a graduate student at Emerson College.

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Begin with THANK YOU to many extraordinary people with ALS
DO NOT Video record or Photograph my videos

YOU MAY TAKE NOTES

what I think

what I say
Opening statement at each eval:

“My goal is to waste your time”

Knowledge is power

• Message banking
• Non-electronic strategies
  – Independent
  – Partner assist
  – Context specific
• Voice supplementation
• Emergency call
• High tech SGD/integrated system

MESSAGE BANKING
A BRIEF HISTORY
1994: CHB founded a model of AAC service delivery in the ICU including preoperative ‘voice banking’.

Parent perspective on hearing daughter’s voice

Programmed devices awaiting patient admission
Sometimes I was tempted to ‘reject’ but I learned a valuable lesson from an 11 year old!

Categories of banked messages
(analysis of messages banked by 50 patients age 4 – 27 years)

- Personal needs
- Social
- Control
- Positioning
- Statements/ directives
- Questions
- Emotions/Feelings
- Leisure/ entertainment
- Sarcasm
- Clarifications
- Comfort
- Medical


2006
CHB Augmentative Communication Program asked by local ALS provider to see PALS.

2009
- Pilot program launched under grant for fast-forwarding SGD assessments
- Through fast-forward, initial PALS referrals for high-tech SGD candidates seen by J. Gosnell
- Referrals diversified to head/neck cancer patients post-op
- Suggested our pediatric pre-op model could be applied.
Sidebar:
Let’s examine terminology

The term ‘voice banking’ has continued to be used since we introduced it in the early 90’s BUT technology has changed!

With research and advanced technology, the term **Voice Banking** is now used to define a more sophisticated strategy.
• Model talker
• Cereproc (Edinburgh Scotland)
• OKI Electronic Industry Co Japan
• Edinburgh Voice Banking and Reconstruction project
Custom voice created by Scottish company ‘Cereproc’
http://www.cereproc.com/en/home

Voice Banking is a process of recording a large inventory of your speech that is then used to create a synthetic voice that approximates your natural voice.

Done successfully, this would allow one to spell and create unique messages and then speak them through a synthesizer that approximates one’s natural speech. The science behind this process continues to be in development with beta-versions of available software. The ModelTalker is one such project from the University of Delaware Speech Research Lab. The website is: www.asel.udel.edu/speech/ModelTalker.html
Message Banking with your own voice
digitally record and store words, phrases, sentences, personally meaningful sounds
and/or stories using your natural voice, inflection and intonation.

These messages are catalogued as.wav files and may then be linked to messages
in a variety of augmentative communication technologies or sound storage files.
This will allow you to ‘retrieve’ a message and speak it in your own voice but
does not allow you to create novel messages by spelling. If you have recorded
individual words, you may combine these words to create unique messages,
although the output will sound more staccato than your natural speaking.

Vocabulary

• Vocal play with children
• Many loving messages to children
• Many messages to wife
• Vacation/quality family time messages
• Anger
• Defending self dignity anticipating severe
disability
• Directives to anticipated staff
• Changes in physical state
• Refusal of medical treatment

- set at 16/44 baud rate
- Must use wind guard
- Hold close to mouth for
  best quality
- Practice timing of push -
  speak – push
Strategies/categories identified by patients

- Pillow list
- Drinks list
- Personal care list
- Messages related to special events over the next two years
- Not what I meant
- Defense again
disability discrimination
- Defense in
disability discrimination
- Defense again
disability discrimination

NON-ELECTRONIC STRATEGIES

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VOICE ASSIST/AMPLIFICATION

EMERGENCY CALL

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Early referral of PALS

- Determining goals and motivations
- Voice vs Message banking
- Bank now, select platform later
- Vocabulary and counseling

Tools and options to consider (based on patient's interest)
- Simple/low tech
- iDevice options
- Dedicated/integrated SGD

Charlie, age 42
Diagnosed with ALS at age 41

Messages that reflect 'you'

My voice
May 2011

July, 2011, having a little fun with message

Need to bank more, body is changing

Has been banking messages in many formats for children

Vocabulary

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Susan

Heard of voice banking on web

27 days later

Strategies that change with you

Considering vocabulary lists
Kim’s husband commenting on hearing his wife’s recordings

MP
Age 68
First (and only) Message Bank Session

July 2013
September 2013

Not losing self (Oct 2013)

*Rubber Ducky* Oct 2013
Intro tech early October 2013

November 2013

January 9, 2014
Our Experience Integrating Message Banking Model with Current Technologies

Practical OPERATIONAL Considerations

GOALS:

1. Configure programming so that recorded (digital) messages play in combination with synthesized speech from the message window
2. Organize messages in a personally intuitive structure that promotes easy use in spontaneous conversation
3. Load messages and programming onto users’ devices, integrating with their current page sets
4. Receive feedback from users on organization and function

1. Configure Programming

• We want the user to be able to play recorded (digital) messages both alone and combined with synthesized speech
• In essence, when the whole text is spoken from the message window, the programming should dictate:
  – which word(s) were intended to be produced via message banked sound file
  – which word(s) to generate with synthesized speech
Current Technologies We Have Successfully Used

• DynaVox Series 5 Software

Current Technologies We Have Successfully Used

• Tobii Communicator
  – Integration with Sono Key package

2. Organize Messages

• Best when user is intimately involved in organization and categorization process
• Many considerations regarding organization structure and function, e.g.,:
  – Multi-level categorization and ease of message access
  – Verbatim transcription vs. shorthand label on the button
  – Speaking messages on button selection vs. sending to the message window, then selecting ‘Speak’
  – Access to keyboard from each page for combination of message banked phrases with synthesized speech output
3. Load Messages and Programming

- Integrate custom message banking pages within user’s existing page set
  - Save message banking pages to device
  - Customize access for integration of banked messages into communication pages
- Save sound files to user’s hard drive and direct the software to seamlessly locate and play those files when message selected

4. Receive Feedback

- Deliver page sets to users as quickly as possible for them to explore, use, and provide feedback

Message Banking with Apps

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Predictable (Therapy Box):

**Import audio in Predictable**

**NOTE:** You will not be able to hear the recorded voice until the end of the process.

1. open app
2. click on the device
3. select the "add" tab
4. tap on the button where you can see the "add starting" section
5. tap on the button
6. tap on "add" tab
7. Tap on "add" the audio you wish to import into Predictable
8. you can select a group of recordings
9. repeat this step if necessary
10. each recording will be listed alphabetically
11. select the ones you wish to add
12. tap on the button
13. tap on the button
14. tap on the button to add the recording
15. tap on the button to add another recording
16. tap on the button to add another recording
Message Banking with Apps

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