Assistive Technology for Progressive Deficits in Communication and Access People with Advanced Multiple Sclerosis: Case Studies in Iterative Design (REH01)

Alexander Burnham, MS, CCC-SLP, MSCS

Director of TBH Institute and Rehabilitation Services, The Boston Home, Dorchester, MA

INTRODUCTION & OBJECTIVES

People with advanced multiple sclerosis (PwAMS; EDSS ≥6.5) often experience complicated and progressive deficits in motor speech intelligibility, vocal projection, and upper extremity control and coordination which can interfere with access to typical expressive communication modalities (e.g., speech, telephone & computer access, speech-recognition technology). Assistive technology (AT) can be useful in supplementing or replacing these functions to promote effective communication with partners and caregivers to maximize functional communication independence with minimal need for caregiver assistance. The sudden ubiquity of functional AT in mainstream commercial technology over the past 10-15 years has rendered the acquisition and customization of appropriate interfaces more achievable for more PwAMS (see Andrich et al, 2013).

The Boston Home (TBH) is a specialized residential care facility for 96 adults with advanced neurological disorders, including 81 PwAMS. Established in 1881, TBH has supported underserved populations throughout its history with innovative and creative approaches. The median age of the population is ~58, which represents a more tech-proficient population than in most LTC facilities who also have communication partners who prefer to communicate electronically despite the residents' significant motor access limitations d/t MS-related motor weakness and spasticity. Through partnerships with several AT-oriented organizations and exploration of resident's capabilities and communication needs and goals, the rehab staff (PT/OT/SLP), Nursing, Activities, and ATP's implement and modify the most functional AT options and adapt PRN as deficits and goals change over time with progressive accumulation of disease burden – an approach of continuous reassessment, revision, and redeployment known as ***iterative design*** (see also Lenker & Paquet, 2004; Cook & Polgar, 2015).

OBJECTIVES: Readers of this poster will:

- have the opportunity to understand how PwAMS can maximize functional independence with appropriate and supported access to AT
- recognize how mainstream and ubiquitous technology can be modified and interfaced with more customized AT to meet unique access challenges in the MS population through the evaluative process of iterative design
- have a better understanding of how nursing and allied health/rehab disciplines can collaboratively support PwAMS to meet communication needs and complete electronic ADL's even in the presence of severe motor disability

CASE STUDY 1

50+ y.o. RHM Dx with MS ca. 1985, resident of TBH since 1993. Steady progression of motor deficits culminating in spastic quadriplegia and severe hypophonia. No current DMT's. All close family members live out of state and communicate daily with him via hands-free speakerphone with single-button remote provided for free by Mass Equipment Distribution Program (MassEDP) from bedside or when seated upright in TIS w/c (dependent for mobility).

INITIAL DESIGN: Single-button manual remote for phone

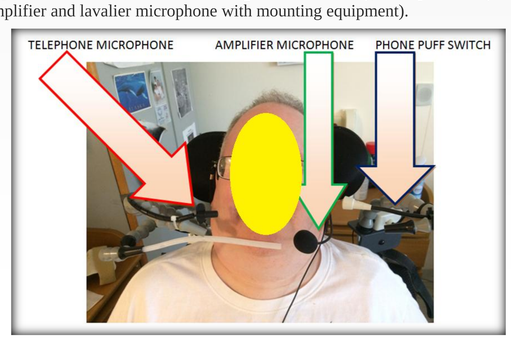
ITERATIVE DESIGN #1: Add vocal amplification using headset microphone and w/c-tray mounted speaker holster.

ITERATIVE DESIGN #2: Transition to puff-switch operation of single-switch remote via breath control for activating calls with preprogrammed contacts or answering inbound calls when manual remote no longer accessible.

ITERATIVE DESIGN #3: Add lavalier microphone with battery pack on w/c to pickup and directly input vocal responses into speakerphone when pt positioned remotely from phone. Requires weekly recharge for transmitter.

CAREGIVERS INVOLVED: PT, SLP, ATP, Nursing, resident and family

EQUIPMENT: Free from MassEDP (phone + switches); TBH purchase (vocal amplifier and lavalier microphone with mounting equipment).



CASE STUDY #2

50+ y.o. RHF Dx with MS ca. 1986, resident of TBH since 2013. Rapid progression of motor deficits culminating in spastic quadriplegia and severe hypophonia. Takes 20 mg SQ glatiramer acetate QD. Had private PCA for daily companionship x 2 years until funding ended, but resident wanted to maintain communication with PCA and family members living out of state or at other SNF. Resident also desiring to operate TV remote independently. Best access site = facial but limited d/t impaired cervical ROM and placement of sip-and-puff pneumatic PWC drive control (on blue tubing in photo below) and straw for chair-mounted water bottle.

INITIAL DESIGN: Vocal amplification with headset microphone w/ 3D-printed mount for PWC tray (see white box in photo below).

ITERATIVE DESIGN #1: Use iPhone 5c with native speech-recognition access, but requires plug-in power for model. Car charger connected to PWC battery to mimic direct AC power to utilize speech recognition. Device mount fabricated to position phone in elevated visible location for resident to visualize screen in the effective absence of cervical flexion capacity.

ITERATIVE DESIGN #2: Add use of headphone/microphone combination as pt unable to activate phone speech-recognition threshold at 2-ft distance d/t progressive deterioration of hypophonia (see below). Placement of vocal amplifier speaker also too low to be transmitted by phone, so headset also serves to improve intelligibility and to provide modicum of privacy for personal phone calls. Resident also encouraged to use FaceTime for video conferencing (which can be activated via speech-recognition) to enhance intelligibility with facial and visual cues not present in voice-only calls.

ITERATIVE DESIGN #3: Add Amazon Echo Dot for speech-recognition input paired with Logitech Harmony Hub for IR signal blast to TV. Field microphone on Echo Dot more sensitive than that on iPhone, with the result that no external microphone required for access.

ITERATIVE DESIGN #4: Fine-tune speech-recognition accuracy on phone to promote use of dictated text messages again for improved intelligibility of remote communication in written vs vocal interactions.

CAREGIVERS INVOLVED: PT, OT, SLP, ATP, Nursing, resident and family

EQUIPMENT: Resident/family purchase (phone, Harmony Hub, Echo Dot); TBH purchase (vocal amplifier, car charger components, phone and amplifier mounting equipment).

N.B: Use of brand names in this poster does not represent an endorsement of these specific devices or manufacturers but are included for illustrative design and replication purposes. The beauty of iterative design is that often multiple devices or modifications can meet the same communication goal or accessibility need for the same PwAMS.

CASE STUDY #3

40+ y.o. RHF Dx with MS ca. 1993, resident of TBH since 2010. Rapid progression of motor deficits culminating in BLE paraplegia, BUE ataxia, and severe spastic dysarthria. No current DMT's. Desires to access augmentative communication device as supplement for verbal expression but also wishes for device to have higher-resolution accessible digital camera to continue some of her premorbid work as photographer.

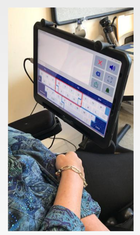
INITIAL DESIGN: iPad 2 with PWC mount oriented off L armrest (fabricated from old chair/headrest parts) to promote ease of R hand direct selection using capacitive stylus and not obstruct access to joystick control. Stylus tied to mount with flexible cord to reduce loss risk if dropped.

ITERATIVE DESIGN #1: Use of touch accommodations to compensate for progressive motor access limitations even with stylus to allow for longer dwell times and minimize inadvertent selections during typing Speech-recognition access not feasible d/t dysarthria severity.

ITERATIVE DESIGN #2: Exploration of dedicated AAC system (Tobii C12) with possible switch input and eyegaze tracking as BUE weakness and spasticity worsened,but resident not satisfied with rear camera resolution.

ITERATIVE DESIGN #3: Transition to iPad Air with Bluetooth-paired Tecla Dos dual switch adapter, although only single-switch scanning possible as pt's cervical ROM deteriorated and she was transitioning to switch-modulated PWC driving. Customized single switch (3D-printed in red in photo below) with ability toggle between inputs for iPad access & PWC control. Pt using basic word-prediction text-to-speech apps to facilitate message input, although her preference consistently to type out all intended statements without prediction substantially slowed composition of statements. Car chargers x 2 mounted to PWC to provide continuous power to switch adapter and PRN recharge capacity for tablet.

ITERATIVE DESIGN #4: Briefly attempted to place single-button Bluetooth manual control for activation of camera shutter for taking still photos, as pt appreciated increased camera resolution on device. This switch and pt's ability to activate with R thumb pressure both did not function as intended consistently.



ITERATIVE DESIGN #5: Transition to Speech Assistant app with more functional 3rd party QWERTY keyboard for ease of switch-scanning groupings and character selection more c/w efficiency needs of switch-input users (see photo to R above). App also promotes ease of exporting text to email and text messages app, and therefore serves as method for promoting functional written expression between resident and remote family, as both voice and video calls are severely unintelligible.

CAREGIVERS INVOLVED: PT, OT, SLP, ATP, Activities, Nursing, resident and family

EQUIPMENT: Resident/family purchase (iPad x 2); TBH purchase (Tecla Dos, most mounting equipment & 3-D printed materials, stylus); donation (used headrest hardware for w/c mount).

OUTCOMES AND FUTURE DIRECTIONS

CS #1: Rarely OOB d/t complex renal/respiratory complications, so now also has Amazon Echo Dot smart speaker to accept Drop-in calls from family (not yet able to activate even with vocal amplification d/t profound dysphonia and recent onset of spastic dysarthria). Device purchased by facility; SLP and ATP involved in setup and modifications.

CS #2: Transitioned to iPhone 8 in 2019, which permits speech-recognition activation without need for direct power supply, thereby reducing need for cable except for battery recharge PRN when pt OOB. Device purchased by resident's family; SLP and ATP involved in setup.

CS #3: Transitioned to iPad Pro in early 2020 with limited navigation and typing access possible using head tracking via front-facing "TrueDepth" camera and ability to unlock device using Face ID without password input. Device purchased by resident's family; PT, SLP, ATP, Activities, and Nursing involved in trials, setup, and modifications.

Outcomes in terms of satisfaction with AT access, services, and devices from PwAMS and caregivers are often measured by post-hoc surveys and questionnaires (e.g., QUEST (Demers et al, 2002)) and successfully meeting originally defined goals (Ranada & Lidström, 2019). The concept of iterative design is most feasible in a residential setting where consistent caregivers can perceive progressive accumulation of disease burden or cognitive/communication deterioration requiring additional AT modifications or receive resident concerns re: awareness of declining access. This can also be achieved in outpatient settings with good follow-up communication between providers and clients to ensure that access needs can be addressed in a timely and cost-efficient manner. Future assistive technology directions for PwAMS with communication deficits include implantable devices that indirectly improve voice and speech or directly allow for access, more targeted consideration of client preferences and premorbid characteristics in communication output prior to onset of communication deficit, and continued increase in seamless integration into readily available mainstream technology.

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- State AT Centers funded by AT Act: https://www.ataporg.org/programs
- The International Society for Augmentative and Alternative Communication: https://www.isaac-online.org/
- The Rehabilitation Engineering and Assistive Technology Society of North America: http://www.resna.org/
- The Assistive Technology Industry Association: https://www.atia.org/
- National Library Service: Talking Books: http://www.loc.gov/nls/

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Email: aburnham@thebostonhome.org

Phone: 617-326-4303

Website: http://www.thebostonhome.org/

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