THE USE OF TELEMEDICINE TO ENHANCE CARE IN ALS AND OTHER NEUROMUSCULAR DISORDERS
DISCLOSURES

• Consulting Fees
  o Biohaven, Cytokinetics

• Research Support
  o Biogen, Biohaven, Cytokinetics

• Stipends
  o Wiley, Inc
TERMINOLOGY

• Telemedicine: Remote clinician/patient interaction.
  o This is the traditional way most of us think of telemedicine.

• Telehealth: Provision of a broader range of services remotely.
  o Collection of data on respiratory function, gait/falls, muscle strength, speech quality and speed, etc.

• For the purposes of this talk, telemedicine and telehealth will be considered equivalent.
SYNCHRONOUS AND ASYNCHRONOUS VOICE AND DATA TRANSMISSION

• Synchronous
  o Information transmitted in both directions during the same time period.
  o Binary transmissions between patient/caregiver and health care provider, or multi-person, with other providers or family members on the conference simultaneously.

• Asynchronous (store and forward)
  o Information is collected at one time period, then forwarded for review.
PATIENT LOCATIONS

• In their homes (the model used here)
• In other physicians’ offices
• In health care facilities such as an emergency department
EQUIPMENT NEEDED

- Smart phone and application
  OR
- Tablet and application
  OR
- Computer with a camera, internet connection, and web-based system
WHAT IS THE GAP TELEMEDICINE COULD FILL?

• Has the potential to improve the efficiency of health care while reducing the burden on patients

• Average 20 day delay to obtain a 20-minute physician appointment
  o Including travel and wait times, appointments take an average of 2 hours

• This has resulted in studies of telemedicine:
  o Feasibility
  o Acceptability
  o Outcomes relative to in-person care

Telemedicine in Neurology

• Telestroke was the earliest application of telemedicine to neurological care.
  - Acute assessment and coordination of care to a patient in an emergency room by a neurologist at another location.

• Has been used in chronic neurological disorders, including:
  - Multiple sclerosis
  - Migraine and other headaches
  - Parkinson’s disease
  - Epilepsy
ALS Standard of Care: The Multidisciplinary Clinic

- Patients are seen approximately every 3 months for evaluation by a multidisciplinary team
- Pulmonary function tests are performed at these visits
- Extends survival
- Likely improves quality of life
PATIENT PERCEPTIONS OF MULTIDISCIPLINARY ALS CLINIC

• Positives
  o Integrated care ("one-stop shopping")
  o Expertise of healthcare providers
  o Research and clinical trials

• Negatives
  o Travel distance
  o Long, exhausting day
  o Total time and wait time between providers

ADDITIONAL DATA REINFORCE THAT TRAVEL AND TIME POSE BARRIERS TO ALS CLinic ATTENDANCE

• Nearly half of patients with ALS in the US live more than 50 miles from an ALS center, and a quarter live more than 100 miles away
• Family caregivers spend an average of 11 hrs. per day caring for an individual with ALS. Physical and emotional burden worsens with disease progression

Sources:
IDEAL ALS CARE WOULD MAINTAIN BENEFITS AND REDUCE BURDENS

• Establish more multidisciplinary clinics? A challenge
  o Limited supply of health care providers with expertise in ALS
  o Smaller centers would see fewer patients, leading to less experience and expertise by providers
  o Some areas are too sparsely populated to support ALS clinics

• Telemedicine has the potential to fill this gap
  o Preserving multidisciplinary care and reducing time and travel
FEASIBILITY AND ACCEPTABILITY OF TELEMEDICINE FOR ALS

Supported by Several Studies of Synchronous Videoconferencing
Brisbane, Australia

• Two tertiary referral hospitals with multidisciplinary ALS clinics
• Telehealth visits reported for 38 patients, seen an average of 3 times each at intervals of 3-4 months
• Average driving distance per telehealth event: 612 km (386 miles), range 158-1824 km (98-1133 miles)
• Major problems addressed were symptom based; respiratory and palliative concerns were predominant.
• No assessment of health outcomes

MASS GENERAL, BOSTON, USA

- Retrospective chart review of video televisit encounters at MGH ALS clinic 09/2014 to 01/2016
- Encounters with a physician or nurse practitioner (not a multidisciplinary team)
- 97 patients in their homes
- Median distance 211 miles
- Average visit 32 minutes
Patient characteristics: many had advanced disease
- One-half ambulatory
- One-third using NIV or gastrostomy
- 23% had tracheostomy
- 12% receiving hospice services

Most commonly addressed: medication management, goals of care, research, equipment.

Conclusion: video visits are feasible

Penn State, Hershey, PA

• Prospective Study: March 2016 to Feb 2017
• Inclusion Criteria:
  o Had attended at least one in-person ALS multidisciplinary clinic visit
  o Clinically definite, probable, probable laboratory-supported, or possible ALS.
  o Had necessary software and hardware
• Encounters with multidisciplinary team
• 30 patients in their homes, 33 telemedicine visits
• Travel time to clinic: About equally divided into 3 groups:
  o Less than 60 min, 60-120 min, more than 120 min
• Visit length: 15-30 minutes per provider (multiple providers/visit)
What patients and caregivers liked:
  - Absence of travel, being in their home, time savings, reduction in fatigue, increased comfort.

What patients and caregivers disliked:
  - Impersonal, problems with video/audio, lack of privacy, not getting out of home
  - Four caregivers expressed concerns about lack of a physical examination, although no patient did so.

**Penn State (3)**

- **What healthcare providers liked:**
  - Patients more comfortable and less stressed, ability to see patients who would otherwise not be able to be seen, patients were more open and talkative, patients could be observed in their homes.

- **What healthcare providers disliked:**
  - Problems with video/audio, no physical examination, no cues from body language, less of an emotional connection.

- **Overall, feasibility high and satisfaction high as rated by patients, caregivers, and healthcare providers**

OUTCOME DATA

Very Limited For ALS Synchronous Videoconferencing
Cleveland VA ALS Center

- Patients with ALS were given choice of in-person or telemedicine care
- Patients were in their homes
- Evaluations always included physician and nurse. Other providers were based on assessment of patient’s needs
- PFTs or modified barium swallow performed locally prior to telemedicine visit if deemed necessary.
- Quality of care was based on AAN quality measures
- Outcomes were survival, disease progression, malnutrition
- Findings: Same quality of care. Similar outcomes.

NOW THAT TELEHEALTH IS AVAILABLE, IS LIKELY FEASIBLE AND ACCEPTABLE, AND MAY RESULT IN HIGH QUALITY CARE WITH GOOD OUTCOMES, HOW DO WE INCORPORATE IT INTO ROUTINE ALS PATIENT CARE?
ROLES OF TELEMEDICINE IN ALS CARE

• As a substitute for regularly scheduled visits with the multidisciplinary team
  o For those who can no longer travel to clinic

• To decrease the length of an in-clinic visit
  o 1-on-1 videoconferencing with selected team members prior to the in-clinic visit
  o Particularly relevant for encounters not requiring physical contact.

• As needed for urgent matters
  o 1-on-1 videoconferencing with selected team members
  o Triggered by communications from patients or caregivers
  o Examples: 1) psychological crisis: mental health professional; 2) visualize and discuss transfer or personal care techniques: PT or OT; 3) visualize and discuss bedsore or problem with feeding tube: nurse; 4) discuss goals of care or genetic test results: physician
Based on these considerations, we have now incorporated ALS telemedicine fully into our ALS clinic in these roles.
Telemedicine Utilization in an ALS Clinic
METHODS

- Based on input from the ALS nursing staff regarding the burden of travel to patients and caregivers for in-person visits, selected ALS patients were offered two types of telehealth visits into their homes using Penn State Health OnDemand:
  1. Multidisciplinary visits with members of the ALS team on ALS clinic days
  2. 1-to-1 visits with individual ALS healthcare providers on other days.
- Metrics were recorded by the telehealth platform from October 2018 through August 2019
RESULTS
Fifty-three patients and caregivers, 1 to 6 visits each = 98 total telehealth visits
Average visit length: 1 hour, 46 minutes. Range 5 minutes to nearly 4 hours.

<table>
<thead>
<tr>
<th>Description</th>
<th>Duration</th>
</tr>
</thead>
<tbody>
<tr>
<td>Average Visit Length</td>
<td>1 hour 46 mins.</td>
</tr>
<tr>
<td>Min. Visit Length</td>
<td>5 mins.</td>
</tr>
<tr>
<td>Max. Visit Length</td>
<td>3 hours 51 mins.</td>
</tr>
<tr>
<td>Range of Visit Lengths</td>
<td>3 hours 46 mins.</td>
</tr>
<tr>
<td>Median Visit Length</td>
<td>1 hour 49 min.</td>
</tr>
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</table>
Number of monthly telemedicine visits ranged from 2 to 13.
Eighty-one (83%) of these visits replaced in-person multidisciplinary clinic visits.

### TEAM VISITS

- **1-60 mins.** 8, 10%
- **61-120 mins.** 12, 15%
- **121-180 mins.** 29, 36%
- **181-240 mins.** 32, 39%

<table>
<thead>
<tr>
<th>Average Visit Length</th>
<th>2 hrs. 2 mins.</th>
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<tbody>
<tr>
<td>Min. Visit Length</td>
<td>7 mins.</td>
</tr>
<tr>
<td>Max. Visit Length</td>
<td>3 hrs. 51 mins.</td>
</tr>
<tr>
<td>Range of Visit Lengths</td>
<td>3 hrs. 44 mins.</td>
</tr>
<tr>
<td>Median Visit Length</td>
<td>2 hrs. 1 mins.</td>
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</table>
SEVENTEEN (17%) WERE INDIVIDUAL HEALTHCARE PROVIDER VISITS

<table>
<thead>
<tr>
<th>Description</th>
<th>Duration</th>
</tr>
</thead>
<tbody>
<tr>
<td>Average Visit Length</td>
<td>27 mins.</td>
</tr>
<tr>
<td>Min. Visit Length</td>
<td>5 mins.</td>
</tr>
<tr>
<td>Max Visit Length</td>
<td>1 hr. 50 mins.</td>
</tr>
<tr>
<td>Range of Visit Length</td>
<td>1 hr. 45 mins.</td>
</tr>
<tr>
<td>Median Visit Length</td>
<td>22 mins.</td>
</tr>
</tbody>
</table>

Average Visit Length: 27 mins.
Min. Visit Length: 5 mins.
Max Visit Length: 1 hr. 50 mins.
Range of Visit Length: 1 hr. 45 mins.
Median Visit Length: 22 mins.
DISTANCE TO CLINIC: TELEMEDICINE VS. IN-CLINIC PATIENTS

- Participating patients lived, on average, 52 miles from the ALS clinic (range: 7-188 miles).
- Approximately 13% had a travel distance to clinic of more than 100 miles.
- Over 8,300 miles were saved.

- Patients who had in-clinic visits over the same period lived an average of 35 miles from the clinic. Only 1.4% had a travel distance to clinic of more than 100 miles.
Patients who lived farthest away, and those from more rural areas, appeared to be over-represented in the telemedicine vs. in-clinic group.
DISCUSSION

• Telemedicine provided a viable alternative for ALS care for those patients unable or unwilling to travel to ALS clinic.

• It was used in place of both multidisciplinary and 1-to-1 visits.

• Telemedicine patients generally lived at a greater distance from ALS clinic than those making in-person visits, supporting the use of this platform for those for whom travel would be the greatest burden.
PREDICTORS OF TELEHEALTH UTILIZATION FOR ALS CLINIC PATIENTS
METHODS

• Beginning in November 2017, all patients seen at the Penn State Hershey ALS clinic were offered participation in a study of telemedicine, but were not required to use it.
• Comparisons were made between enrolled patients who had at least one telemedicine visit and those who did not
RESULTS
114 patients were enrolled

One-third (38) of patients participated in a telemedicine visit
Patients with at least 1 telemedicine visit had lower physical and respiratory function and were more likely to use NIV than patients who never had a telemedicine visit.

<table>
<thead>
<tr>
<th></th>
<th>At least one telehealth visit (n=38)</th>
<th>No telehealth visits (n=76)</th>
<th>p-value</th>
</tr>
</thead>
<tbody>
<tr>
<td>ALSFRS-R score (mean)</td>
<td>21.4</td>
<td>28.1</td>
<td>&lt; 0.001</td>
</tr>
<tr>
<td>FVC % predicted (mean)</td>
<td>52.9</td>
<td>64.5</td>
<td>0.012</td>
</tr>
<tr>
<td>Age (mean)</td>
<td>62.0</td>
<td>61.9</td>
<td>0.672</td>
</tr>
<tr>
<td>Disease duration in years (mean)</td>
<td>1.6</td>
<td>1.9</td>
<td>0.255</td>
</tr>
<tr>
<td>NIV use</td>
<td>21/35 (60.0%)</td>
<td>15/60 (25.0%)</td>
<td>0.001</td>
</tr>
<tr>
<td>Gender</td>
<td>68.4% male 31.6% female</td>
<td>42.1% male 57.9% female</td>
<td>0.008</td>
</tr>
<tr>
<td>Hospice</td>
<td>7/38 (18.4%)</td>
<td>12/63 (19%)</td>
<td>0.938</td>
</tr>
<tr>
<td>Gastrostomy/PEG</td>
<td>10/38 (26.3%)</td>
<td>16/63 (25.4%)</td>
<td>0.918</td>
</tr>
<tr>
<td>Tracheostomy</td>
<td>3/38 (7.9%)</td>
<td>3/63 (4.8%)</td>
<td>0.405</td>
</tr>
<tr>
<td>Needing assistance to travel</td>
<td>29/36 (80.6%)</td>
<td>48/75 (64.0%)</td>
<td>0.077</td>
</tr>
<tr>
<td>Comfortable or very comfortable with technology</td>
<td>30/38 (78.9%)</td>
<td>49/75 (65.4%)</td>
<td>0.136</td>
</tr>
</tbody>
</table>
Those Living Farthest Away Were More Likely to Use Telemedicine

<table>
<thead>
<tr>
<th>Travel time to ALS clinic</th>
<th>At least one telehealth visit (n=38)</th>
<th>No telehealth visits (n=75)</th>
<th>p-value</th>
</tr>
</thead>
<tbody>
<tr>
<td>&lt; 30 minutes</td>
<td>3 (7.9%)</td>
<td>9 (12.0%)</td>
<td>0.748</td>
</tr>
<tr>
<td>30-59 minutes</td>
<td>8 (21.1%)</td>
<td>19 (25.3%)</td>
<td>0.640</td>
</tr>
<tr>
<td>60-89 minutes</td>
<td>11 (28.9%)</td>
<td>25 (33.3%)</td>
<td>0.669</td>
</tr>
<tr>
<td>90-119 minutes</td>
<td>3 (7.9%)</td>
<td>10 (13.3%)</td>
<td>0.539</td>
</tr>
<tr>
<td>≥ 120 minutes</td>
<td>13 (34.2%)</td>
<td>12 (16.0%)</td>
<td>0.028</td>
</tr>
</tbody>
</table>

- A larger percentage of patients with at least 1 remote visit lived 2 or more hours from clinic.
- Remote visits were common for patients living farthest away
  - 52% living ≥ 2 hours from clinic had a telemedicine visit, compared to 25% living < 30 minutes away.
  - All patients with 4 or 5 video visits lived at least 60 minutes from clinic.
DISCUSSION

• Patients with lower physical and respiratory function are more likely to utilize telemedicine
• Patients who live farther from clinic may use telemedicine more frequently than patients who live closer
Telemedicine Appears to Be Cost Effective
**Telemedicine Appears to Be Cost Effective**

- Comparison of cost of telemedicine visits for patients in their homes vs. cost of multidisciplinary clinic visits.

- “Assuming all visits in a year were televisits, after medical usefulness adjustment, patients would save 89% for a total annual savings of $3,988 compared with the annual cost of all in-clinic visits. Institutions would save 41% for a total annual savings of $1,310 compared with the annual cost of all in-clinic visits.”

- “A mix of 2 in-clinic and 2 televisits leads to an annual MU-adjusted cost-savings to the patients of $1,994 (45%) and to institutions of $655 (20%).”

- Conclusion: Video televisits provide marked adjusted cost savings for patients and institutions under a variety of different assumptions.

ASYNCHRONOUS TELEMEDICINE

Store and Forward Model
High Patient Satisfaction and Generally High But More Variable Provider Satisfaction

- A nurse was trained by members of the ALS team to perform a home multidisciplinary assessment.
- Nurse traveled to patient’s home and performed assessment.
- A video and audio recording was made of the assessment.
- Healthcare providers on the team reviewed the assessment later.
- Providers made care recommendations to the clinic director.
- Clinic director formulated a plan.
- Plan conveyed to patient by nurse via video conference or telephone call.

HOME MONITORING OF RESPIRATORY FUNCTION: Remote PFTs

THE ROLE OF NONINVASIVE VENTILATION (NIV) IN ALS

• AAN guidelines recommend considering the initiation of NIV for MIP that is weaker than -60 cm water or for FVC less than 50% of predicted.
• NIV in ALS prolongs survival, slows rate of respiratory decline, and positively impacts HRQoL for sleep, physical fatigue, and depression.
• Regular pulmonary function tests (PFTs) are a routine part of the ALS clinic evaluation and part of the ALS quality measures of the AAN.
• When ALS clinic visits are performed remotely via telemedicine, patients must be transported to a facility for PFTs. This increases the burden of telemedicine visits and undercuts the goal of providing care in the home.
METHODS

• Inclusion criteria:
  o Patients with ALS, PLS, or PMA from our institutional ALS clinic.
  o No cognitive impairment.
  o ALSFRS-R score of 2 or more on all items for speech, swallowing, saliva.

• Patients performed PFTs (forced vital capacity [FVC] and maximum inspiratory pressure [MIP]) with a respiratory therapist on clinic day.

• Same day, in another clinic room, they performed simulated remote PFTs.
  o In room were computer with monitor, and equipment identical to that we anticipated eventually using for performing FVC and MIP at home.
  o At the other end of the live video connection was a respiratory therapist coaching them

• Analysis was performed on the best of 3 responses
RESULTS: High correlation of RPFT and standard assessments

Forced vital capacity (FVC)

\[ y = 1.02x + 5.48 \]

\[ r^2 = 0.82 \]

\[ p = 0.0000 \]

Sensitivity to detect FVC <50% = 1; Specificity = 1

Maximal inspiratory pressure (MIP)

\[ y = 1.02x + 3.73 \]

\[ r^2 = 0.85 \]

\[ p = 0.0000 \]

Sensitivity to detect MIP <60 = 0.89; Specificity = 0.82
POSITIVE BIAS TO rFVC

- Different reference systems used internally by devices
- Use of volume, rather than % predicted, resulted in higher correlation for FVC.
Acceptability was high...

- Figure shows pairwise differences for survey responses.
- Mean response patient/caregiver dyad = 4.49
- Mean response therapists = 4.03
Next Step: More Frequent Assessment of Respiratory Function Using rPFTs
**The Rate of Change in FVC in ALS is Markedly Heterogeneous**

PRO-ACT data permits stratification of patients, based on FVC decline, into slow, moderate, and fast progressors. "Fast progressors" experience respiratory decline to $73.4 \pm 18.5\%$ of initial value in 100 days (PRO-ACT).
BUT...THE CLINIC MODEL IS HOMOGENEOUS

• The 3-month model of PFTs is based not on data, but on the accepted model of ALS multidisciplinary care
• More frequent PFTs might permit earlier initiation of NIV
• rPFTs could be performed more frequently than clinic or facility PFTs
WHAT IF WE COMPLETED rPFTs EACH MONTH?

• Of 217 patients on whom we reviewed FVC records, 144 experienced decline of FVC below 50%

• From clinic visits with PFTs every 3 months, we can calculate the time difference between estimated FVC threshold crossing (50%) and the next clinical measurement, for any single individual.

• 100/144 had an interval of more than 30 days, indicating they would have had earlier initiation of NIV with rPFTs monthly.
NEXT STEPS

• Patient care: We have initiated more frequent rPFTs in selected patients.
• Research: We are planning to more carefully explore outcomes in patients undergoing more frequent rPFTs.
GAIT AND FALLS
Another Area Where Telemedicine May Improve Patient Care
BACKGROUND

• Patients with ALS fall, and the consequences may be profound
• Assessment of fall risk, with the goal of preventing or at least reducing the frequency of falls, is an important part of ALS care.
• One of the ALS quality measures published by the AAN is querying patients for falls occurring in the past 12 months.
Epidemiology

• The rate of falls in ALS has not been clearly established.
  o Rates range from 0.05 to 0.2 to 1.8 falls per patient-month.
• Self-reporting of falls is compromised by recall bias, resulting in low sensitivity and underreporting of fall events.
GAIT ASSESSMENTS OF PATIENTS WITH ALS

• Individuals with ALS have gait measures that differ from healthy controls
• Increased and highly variable gait cycle time (time to complete a full walking cycle)
• Reduced stride length with increased variability in stride length
• Gait assessment of individuals with ALS under the traditional model of care occurs once every 3 months by the physical therapist in multidisciplinary clinic.
  o Can we obtain more precise assessments?
METHODS

• We piloted the use of a wearable sensor as a way to provide regular estimates of step length, duration, and walking speed
• 30 patients, most with ALS, but a few with PLS or PMA
• All evaluations were performed during ALS clinic visits
• Patients wore sensors to detect accelerations and rotations of the body during therapist-guided walking
• ALSFRS-R walking subscore (FRSw) (a single question on the ALSFRS-R) was recorded.
Walking speed distinguished those walking with assistance and without, as well as those with FRSw scores of 2 vs. 3 and 2 vs. 4.
CONCLUSIONS

• Step length and duration measured from a short period of normal walking correlated with functional measures of ambulatory health (FRSw).

• Implemented in the home, gait tracking could support physical therapy to reduce fall risk by allowing for evidence-based and timely decision support regarding safe mobility.
NEXT STEP: HOME ASSESSMENTS OF GAIT OF PATIENTS WITH ALS USING WEARABLE DEVICES

Beginning Enrollment: Single-Center Study
AIM 1: ASSESSMENT OF PATIENT MOVEMENT IN RELATIONSHIP TO FALLS

- Activity via a pendant monitor
- Arm activity monitoring via sensors worn on the wrists
- Gait monitoring via gait sensors worn by patients
AIM 2: ACCURATE ASSESSMENT OF FALL REPORTING

• Patients have a tablet computer with an application for reporting falls.
• Patients enter all falls into the app.
• In addition, the patient will be prompted to complete a fall report if a fall is detected by the Activity Sensor.
Frequent Electronic Collection of Clinical or Research Data

Without In-Clinic Visits
THE TIM SYSTEM

• Development of an app for a tablet computer
• Patients and caregivers receive weekly questions related to limb function, bulbar function, nutrition, respiratory function, and ‘wellbeing’.
• Caregivers communicate about strain, depression, anxiety.
• Wi-fi enabled scales communicate information about weight.
• Information is displayed for the clinician in a clinically useful way, tracking trends in weight, caregiver strain, and other measures.

ALS AT HOME: APP FOR SMARTPHONES

- Data collection for clinical trials
- Goal is to decrease the burden on patients and caregivers.
- Measures performed at home and transmitted electronically:
  - Handgrip dynamometry
  - Spirometry
  - Electrical Impedance myography
  - ALSFRS-R
  - Separate speech app. Patients speak specific phrases into the phone. These are automatically uploaded to a separate cloud-based repository for analysis.

THE ALL-ELECTRONIC PROCESS FACILITATES STUDY ENROLLMENT

- Participants were recruited via on-line resources:
  - CDC ALS patient registry (https://www.cdc.gov/als/)
  - ALS Association and the Muscular Dystrophy Association websites
  - Advertisements in Facebook and Google
  - Social media: Facebook®, Twitter®, and Reddit®
- Diagnosis confirmed by review of records
- Patients consented, enrolled, and trained on-line
- Potential to reduce patient burden, increase enrollment
THE USE OF SOCIAL MEDIA TO CREATE A VIRTUAL SUPPORT GROUP
TRADITIONAL SUPPORT GROUPS

• Support Groups are a traditional way for patients with rare or life-threatening diseases and their caregivers to meet and provide friendship and support to one another.

• Barriers to attendance are the same that create a barrier for ALS clinic attendance: travel, time, exhaustion.

• Paradoxically, it is those individuals whose disease is advancing most rapidly, or has created the greatest physical and psychological burdens, who may benefit most from a support group.
BACKGROUND

• The ALS Association Greater Philadelphia Chapter supports our ALS center among others, and hosts resource/support groups throughout eastern PA, southern NJ, and Delaware.
• The Penn State Hershey support group is facilitated by our ALS clinic psychologist.
METHODS

- Patients and caregivers from our ALS support group began tending a community garden.
- In June 2018, a Facebook group was founded to help manage the garden.
- The psychologist regularly reviews group content and consults with the page administrator (an elected member of the group) to answer questions and address concerns.
RESULTS: ACTIVE USE OF SOCIAL MEDIA

• The Facebook group remained active through winter when the garden was closed.

• There are 70 members of the Facebook group, comprised of patients, family members of living and deceased patients, and Chapter staff.

• There have been 582 posts, 747 comments, and 1,863 reactions.
  o Pictures, videos, and updates of themselves, tips for one another, inspirational quotes, and pictures from get-togethers.
RESULTS: IMPACT ON IN-PERSON ATTENDANCE

- Despite a decrease in the number of attendees at in-person support groups across the Chapter, our group has experienced an increase in attendance since the creation of the Facebook group.
DISCUSSION

• The use of social media has increased socialization and connection among our patients and their caregivers, and has allowed caregivers of deceased patients to preserve their relationship with the ALS community.

• Next steps include implementing similar groups at other sites.
BARRIER TO TELEMEDICINE: LICENSURE

• Practitioners providing services via telehealth must be licensed in the state where the patient is located.

• To expedite the practice of telemedicine in other states, many states have now joined the Interstate Medical Licensure Compact (IMLC).
**INTERSTATE MEDICAL LICENSURE COMPACT (IMLC)**

- An expedited pathway to licensure for qualified physicians who wish to practice in multiple states.
- IMLC mission: to increase access to health care for patients in underserved or rural areas and allowing them to more easily connect with medical experts through the use of telemedicine technologies.
- An agreement between 29 states, D.C, and the Territory of Guam.
**Barrier to Telemedicine: Billing**

- Medicare and most insurers reimburse for some telemedicine visits, but not commonly for synchronous videoconferencing of encounters with established patients in their homes.
- This likely will change in 2020.
CONCLUSIONS

1. Traditional in-clinic ALS multidisciplinary care is valuable, but poses a substantial burden for many patients and caregivers due to time and travel requirements.

2. Synchronous videoconferencing appears to be a viable adjunct to in-clinic care for individuals with ALS
   - It is feasible, acceptable, and may be associated with outcomes at least equivalent to traditional multidisciplinary care.

3. Telemedicine can be incorporated into a busy ALS clinic.
   - Most likely to be used by those with lower physical and respiratory function, and those who live farther from clinic.
CONCLUSIONS 2

4. Telemedicine is cost effective.

5. Telehealth be used for the remote collection of clinical and research data, including respiratory function, gait, falls, handgrip strength, weight, and speech.

6. Licensure and billing remain barriers, but are being addressed.

7. Further development of in-home data collection should enhance the ability of ALS healthcare providers to care for individuals with ALS.
THANK YOU TO OUR PATIENTS AND CAREGIVERS
OTHER ACKNOWLEDGMENTS

• Financial Support
  o Charitable donations to the Penn State Hershey ALS Program
  o Penn State Clinical and Translational Science Institute
  o ALS Association Greater Philadelphia

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  o Andrew Geronimo, PhD
  o Anne Haulman, MPH, CCRC, ACRP-PM
  o Susan Walsh, RN, MSN, ACNS-BC

Assistance with preparation of PowerPoint: Amit Chahwala, Data Analyst
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