Northern New England Palliative Care Teleconsult Research Laboratory

Ava Daruvala  
Maine Medical Center

Rebecca N. Hutchinson  
Maine Medical Center

Eric Anderson  
Maine Medical Center

Paul Han  
Maine Medical Center

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Palliative care (PC) is an approach that improves the quality of life of patients and their families. Delivery of PC via telehealth technology (tele-PC) has been proposed as a solution to increase access to PC in rural areas. The feasibility, acceptability, and effectiveness of applying telehealth technology to PC remains unknown. The overarching purpose of the proposed study is to 1) evaluate the feasibility and acceptability of a tele-PC intervention for seriously ill patients, and 2) generate pilot data to better understand provider-patient communication during tele-PC consultations.

### Methods

**Subject cohorts:**
- Advanced heart failure patients (n=10)
- Primary caregivers of advanced heart failure patients
- Visiting nurses who regularly work with advanced heart failure patients
- Clinicians who deliver the tele-PC consultation

**Pre-Consult Surveys:**
- Patient Baseline
- Kansas City Cardiomyopathy Questionnaire-12 (KCCQ-12)

**Day of Teleconsultation:**
- PANAS survey (Based on serious illness conversation guide. PC clinician to discuss patient’s understanding of illness, information preferences, prognostic awareness, functional priorities, goals, fears, hopes, worries, and strengths.)

**Post-Consult:**
- Surveys
  - Patient Follow Up (48 hours post consult): feasibility and acceptability questions
  - KCCQ-12 (2 weeks post consult)
  - Qualitative Guided Interview (2 weeks post consult)

### Qualitative Survey Questions

#### Quality of life

Considering all parts of your life – physical, emotional, social, spiritual, and financial – over the past week, how would you rate your quality of life?

<table>
<thead>
<tr>
<th>0</th>
<th>1</th>
<th>2</th>
<th>3</th>
<th>4</th>
<th>5</th>
<th>6</th>
<th>7</th>
<th>8</th>
<th>9</th>
<th>10</th>
</tr>
</thead>
<tbody>
<tr>
<td>Excellent</td>
<td>Good</td>
<td>Very Good</td>
<td>Slight Good</td>
<td>Slight Bad</td>
<td>Bad</td>
<td>Very Bad</td>
<td></td>
<td></td>
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</table>

#### Distress from uncertainty

Over the past week, how much have you been bothered by uncertainty about what to expect from the course of your illness?

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<th>7</th>
<th>8</th>
<th>9</th>
<th>10</th>
</tr>
</thead>
<tbody>
<tr>
<td>Not at all</td>
<td>Slightly</td>
<td>Moderately</td>
<td>Quite a bit</td>
<td>Completely</td>
<td></td>
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</table>

#### Prognostic awareness

If you had to take a guess, how long do you think you might live?

<table>
<thead>
<tr>
<th>1 year</th>
<th>2 years</th>
<th>5 years</th>
<th>10 years or more</th>
<th>Other</th>
</tr>
</thead>
</table>

#### Perceptions of patient centered communication

Thinking about the teleconsultation conversation yesterday, how much did you feel heard and understood by the palliative care clinician?

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</table>

#### Affect and emotion

Please indicate the extent to which you feel this way currently:

<table>
<thead>
<tr>
<th>Not at all</th>
<th>Very Slightly</th>
<th>A Moderate Amount</th>
<th>A Great Deal</th>
<th>Extremely</th>
</tr>
</thead>
<tbody>
<tr>
<td>A</td>
<td>B</td>
<td>C</td>
<td>D</td>
<td>E</td>
</tr>
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</table>

#### Responses to teleconsultation

How would you compare having a conversation with the palliative care clinician using teleconsult compared to an in-person conversation?

<table>
<thead>
<tr>
<th>Teleconsult</th>
<th>Much Better</th>
<th>Teleconsult a Little Better</th>
<th>About the Same</th>
<th>Office Visit a Little Better</th>
<th>Office Visit Much Better</th>
</tr>
</thead>
</table>

### Qualitative Data

- Qualitative data will include individual in-depth semi-structured interviews with patients, caregivers, home nurses, and physicians.

### Psychophysiological Data

- Autonomic physiology is thought to relate to affective experience and can be unobtrusively measured without impeding the patient-clinician interaction using Empatica E4 sensors.
- We will explore 1) whether observed physiological changes are consistent with an affectively evocative conversation and 2) the variance of physiological responses, and the extent to which physiological states change during the tele-PC conversation.

### Challenges

- Technology
  - Reliable connection from clinician computer to patient tablet
  - Reliable sensor data capture
  - Quality of audio and video recording
- Mode and timing of survey administration in this elderly patient population

### Our partners

- Maine Healthcare at Home
  - MHCAH delivers high quality, home-based health services by professionally trained nurses, therapists, and social workers, particularly for chronic disease management.
  - In partner with Health Recovery Solutions (HRS), MHCAH provides their patients with technology for quick access to healthcare providers.
- University of Vermont (Vermont Conversation Lab)
  - We are working in parallel with Dr. Robert Gramling and his team of researchers at UVM, who are conducting this study in cancer patients.

### Acknowledgements/Contact Information

- Teleconsultations will be conducted and recorded via tablets provided by Maine Healthcare at Home and Health Recovery Solutions (HRS).
- Audio and video recordings will be analyzed in conjunction with psychophysiological data via machine learning.
- Technology
  - Reliable connection from clinician computer to patient tablet
  - Reliable sensor data capture
  - Quality of audio and video recording
- Mode and timing of survey administration in this elderly patient population

### Video/Audio Data

- Teleconsultations will be conducted and recorded via tablets provided by Maine Healthcare at Home and Health Recovery Solutions (HRS).
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### Acknowledgements/Contact Information

- This research was made possible by the Northern New England Clinical and Translational Research Network (UL1TR001123)
- Ava Daruvala: adaruvala@mnhc.org