HARNESSING THE POWER OF TELEMEDICINE FOR PEDIATRIC PALLIATIVE CARE

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Describe the rationale for incorporating telemedicine into the care of palliative care patients and its potential benefits.

Identify proven and expected challenges in implementing telemedicine for palliative care patients.

Describe key steps for integration of a successful and sustainable telemedicine program into palliative medicine programs.
Telemedicine: Where it has been and where it is going

- Telemedicine, Telehealth Mobile Health
- Enhance communication
- Rapid Growth
- Widely used
Pushing Beyond Imagination
Telemedicine: Inpatient Setting
### Challenges to Pediatric Telemedicine

**Table 2**

Challenges to telehealth adoption

<table>
<thead>
<tr>
<th>Type of Challenge</th>
<th>Specific Issues</th>
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</thead>
<tbody>
<tr>
<td>Technological barriers</td>
<td>• Lack of infrastructure, particularly in rural and underserved areas</td>
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<tr>
<td></td>
<td>• Lack of high-quality systems to adequately convey imaging, like echocardiography and other radiologic testing</td>
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<tr>
<td>Provider concerns</td>
<td>• Lack of integration into current workflow, adding time to providers’ already busy schedules</td>
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<td></td>
<td>• Resistance on the part of consulting providers “to step on the toes of others”</td>
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<td></td>
<td>• Resistance from community providers to being criticized or supervised</td>
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<td></td>
<td>• Discomfort with telehealth and associated technology because of lack of familiarity</td>
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<tr>
<td>Patient concerns</td>
<td>• Privacy concerns</td>
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<tr>
<td></td>
<td>• Concerns about ability to properly use technology</td>
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<tr>
<td></td>
<td>• Loss of face-to-face interactions with providers</td>
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<tr>
<td>Financial barriers</td>
<td>• Start-up and ongoing maintenance cost for technology, personnel, and training</td>
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<tr>
<td></td>
<td>• Lack of clear and consistent reimbursement policies</td>
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<tr>
<td></td>
<td>• Unclear return on investment</td>
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<tr>
<td></td>
<td>• Misaligned incentives (i.e., physicians would rather bring patients to their own institution, rather than spend extra time to keep a potential referral at a satellite site)</td>
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<tr>
<td>Credentialing and licensing barriers</td>
<td>• Many providers must get credentialed at all remote sites, which is a tremendous burden in terms of paperwork and time</td>
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<td></td>
<td>• State licensing requirements are highly variable and many states require providers to be licensed in any state in which they are providing telehealth consultation, not just their home state</td>
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<tr>
<td>Legal concerns</td>
<td>• Liability protections must be clear and protect providers at both sites</td>
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### Table 1

<table>
<thead>
<tr>
<th>Study design</th>
<th>Number of adult studies</th>
<th>Number of pediatric studies</th>
<th>Number of participants</th>
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<tr>
<td>Systematic/ literature review</td>
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<td>26-138 papers reviewed</td>
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<td><strong>Randomised Controlled Trials</strong></td>
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<tr>
<td>RCT</td>
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<td>27-44</td>
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<td>RCT (pilot)</td>
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<td>12-30</td>
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<tr>
<td>Abandoned RCT</td>
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<td><strong>Other quantitative designs</strong></td>
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<tr>
<td>Cohort</td>
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<td>1</td>
<td>12-63</td>
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<td>Retrospective chart review</td>
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<td>345-597 charts</td>
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<td>Cost comparison</td>
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<td>3 month period</td>
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<td>Analysis of survey</td>
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<td>6-160</td>
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<td>Mixed methods</td>
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<td><strong>Qualitative</strong></td>
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<td>Focus Group/Interviews</td>
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<td>1</td>
<td>6-190</td>
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<td>Case Study</td>
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<td>1-3</td>
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<tr>
<td><strong>Total</strong></td>
<td>27</td>
<td>6</td>
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Outcomes in Telemedicine Pediatric Palliative Care

- Reduction in anxiety
- Enhanced communication
- Decreased unplanned admission rates
- Decreased healthcare utilization
AAP Issues Recommendations on Telemedicine in Pediatric Health Care

6/29/2015

Telemedicine can improve patients' access to care, help fill shortages of physicians and increase communication among clinicians. But it can also lead to fragmented health care. In a new policy statement, the American Academy of Pediatrics (AAP) makes recommendations on the use of telemedicine in children's health care and how it will impact the pediatric workforce. The policy statement, “The Use of Telemedicine to Address Access and Physician Workforce Shortages,” is published in the July 2015 Pediatrics (published online June 29). In the statement, the AAP recommends reducing barriers to telemedicine to improve patients' access to pediatricians and pediatric specialists. Physicians who deliver health care via telemedicine should receive equitable payment, according to the AAP. Regulatory authorities should also examine ways to overcome administrative, financial and legislative barriers to implement telemedicine, including efforts to facilitate interstate licensure so that care can be delivered across state lines to children living in underserved communities. The AAP recommends that telemedicine services should be delivered in the context of a medical home, because this model of health care provides continuity and efficiency. Virtual health care services that are provided outside of the medical home lead to a loss of continuity in care, quality of care and patient safety, according to the AAP.

###
Telemedicine & Pediatric Palliative Care: A Good Match

- Key Aspects of Palliative Care:
  - Expert communication
  - Symptom assessment and management
  - Education
  - Addressing goals of care

- Telemedicine is primarily visual
  - Much of communication is nonverbal

- Exam
  - Limited, but much can be assessed
Telemedicine At Rady Children’s Hospital

2012
- NICU 1st VGo Deployment

2013
- NICU VGO Deployments
- OT/PT/RT NICU VGOs
- Palliative Home Health
- CHOC VPN for Oncology

2014
- ED Peds Surg Pilot
- Murrieta Peds Surg Pilot
- La Maestra ENT Pilot
- Endo retinal camera store and forward pilot

2015
- ED/Derm Store and Forward
- Anesthesia Post Op

2016
- Murrieta Speech Therapy pilot
- Home Speech Therapy pilot
- La Maestra Asthma pilot
- CPCMG eVisits

2017 and Beyond
5 mos old former premie, initially in NICU for 2 weeks

Developed meningitis and sepsis at 4 weeks old

Hospitalized at another hospital until 4 months of age, when he was transferred to us

Hospitalized for all but 2 weeks of his first 5 months of life
Jaden’s Story: Medical

- Hypoxic Ischemic Encephalopathy from meningitis
- Spastic quadriplegic cerebral palsy and global developmental delay
- Chronic respiratory failure with tracheostomy-ventilator dependence
- G-Tube/fundoplication
Jaden’s Story: Personal & Social

- Lives in paternal grandparents’ home in Riverside county
- Mother and father are both young
- Has one older brother
- “Strong, expressive and a blessing”.
- “He has a special light"
- Alive against the odds “for a purpose”
Jaden’s Story: Goals of Care

- Prolong life
- Give him the opportunity to show them how he will progress.
- Avoid suffering (recurrent illness/hospitalizations, being unhappy, or being in pain)
- Spend time at home
- Experience outings such as the park
- Referred to Supportive Homecare
Rady Children’s Palliative Care Program

- Active patients: 350
  - Inpatient Consultation
    - Average daily census: 15.5 patients
    - New consults/month: 15.5
  - Outpatient Clinic: 1.5 days a week
    - Total visits/week: 7
    - Telemedicine visits/week: 2
- Homebased Supportive Care
  - Daily census: 100 patients
- Hospice
  - Daily census: 5 – 10 patients
Home Based supportive care

- **Staffing**
  - Nurse care coordinator – 1.0 FTE
  - Home care nurses – 3.0 FTE
  - Home care social worker – 1.5 FTE

- **Services**
  - Care coordination
  - Home nursing and social work visits
  - 24 / 7 nurse phone call availability
  - PRN home nursing visits for symptom management
  - Proactive symptom management plans
  - Medical decision making support
Geographic area served
- San Diego County and South Riverside County

Common underlying diagnoses
- Genetic/chromosomal disorders
- Brain injury or anomaly
- Neuromuscular and neurodegenerative disorders

Common symptoms, recurring issues
- Status epilepticus
- Feeding intolerance
- Pulmonary symptoms

Highly dependent on medical technology
- Of 122 patients: 102 GT, 17 tracheostomy, 9 ventilator dependent
Jaden’s Story Continues

- Four hospitalizations in the next year
- Two episodes of cardiac arrest requiring CPR
- Shift care nursing
- Frequent Supportive Homecare visits and phone calls
- Mom starts nursing school
- Parents note progress:
  - Smiles and connects more
  - Moving more
  - Rarely requires supplemental O2
  - Less agitated
Jaden’s Story: Barriers

- Live >90 min away from hospital
- Oxygen desaturations and bradycardia on the travel ventilator, requiring bagging
- Requires Critical Care Transport for appointments
- Subspecialists include Pulmonary, Endocrine, GI, Nutrition
- Managing his brother’s and mom’s school schedule
- Dad: “Is there a way for him to have assessments and possibly treatments done at home so we can minimize his transport?”
Barriers Faced By Pediatric Palliative Care Patients

- Transporting medically fragile children who are highly dependent on technology
- Time away from work
- Language-based disparities
- Large catchment area of Rady Children’s Hospital
- Burden of multiple specialty appointments
Telemedicine Visits

- Visit Mechanics
  - Pre-authorization obtained for RN and physician visit
  - Nurse in home & Physician/care coordinator in office
  - RN internet access through 4G wireless network

- Technology
  - Application: Zoom
  - Hardware: 2 computers & cameras
  - All information stays on RCHSD servers
Implementation

- **Pilot:** 15 visits
  - Regular phone calls with billing & authorizations staff
  - Learning curve on use of zoom
  - Computers better than ipads
  - Some connectivity issues

- **Current program:**
  - 20 visits
  - Capacity of 2 visits a week
Billing

- Medi-Cal/Capitated to RCHSD/HealthNet
- Office based code with a GC modifier
- All charges have been reimbursed
- Can not bill most private insurers
Jaden’s Story Continues

- At home without hospitalizations for 1 year
- At age 2, accidentally decannulated at home with delay in replacement
- Over next 5 months, parents note decline
  - Rarely smiles
  - His “aura” is lost
  - “Stagnant”
  - “Alive but not living”
- Parents request compassionate withdrawal of the ventilator
Before telemedicine implemented, required batching of all specialty visits on one day

Used telemedicine to discuss goals of care and end-of-life preferences with parents

- What worked
- Challenges

Care coordination

Admitted to hospital from home for ventilator withdrawal.
Outcomes

- **Physician satisfaction: 3 physicians**
  - Very satisfied with ability to manage symptoms & discuss goals of care
  - Limitation in physical exam
  - Difficult to see rashes

- **Nurse satisfaction: 8 nurses**
  - Opportunity for learning
  - Cannot chart during visit
Outcomes

- Patient family satisfaction
  - Appreciate not having to travel to appointment
  - Appreciate not exposing patient to sick patients
  - All surveyed prefer telemedicine visits over office visits
  - “Thank you for making caring for my special needs son easier”
  - “Quality of the image and lag time of image and audio needs improvement”
Challenges

- Scheduling
- Limited capacity
- Limited physical exam
- Nurse needs to be in the home
Nurse/physician team assigned to full day of visits

Dedicated computer for visits so nurse is able to chart

Nurse care coordinator consultation without nurse in the home

Ability to serve outlying areas where supportive home care is not available

Partner with PCPs to provide consultation in the medical home
Thank You!

gratitude
"I can do things that you cannot. You can do things I cannot. Together, we can do great things."

Mother Teresa