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Practical use of telemedicine in the chronically ventilated infant

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ABSTRACT

Telemedicine, or the use of electronic communication technology to improve patient health, is becoming more widely adopted as a means of bringing together patients, providers and family members to facilitate evaluation, monitoring, diagnosis and treatment. A particularly vulnerable group consists of children with dependence on technology, such as chronic mechanical ventilation. This chapter will provide an overview of how telehealth technology is currently being used, for supporting this patient population through 1) inpatient support 2) integration with the medical home 3) bridging care transitions 4) remote patient management and 5) multispecialty consultations. We will also discuss the impact on quality and cost, the current research environment and practical points for implementation into clinical practice.

1. Introduction

Telemedicine can be broadly defined as the use of electronic communications to exchange medical information in order to improve the health of the patient. The evolution of technology from simple voice (telephone) or text-based communications to our current state, in which audio, video, monitors, sensors, and peripheral devices are used to bring together various combinations of patients, provider and family members to facilitate evaluation, monitoring, diagnosis and treatment. Children today incorporate technology into their lives with a frequency and ease previous generations never could have imagined. This is true even of our neonatal population, who may begin using telemedicine care even in the prenatal stages for evaluation and monitoring, and then transition throughout their early lives as telemedicine supports resuscitation, transport, specialty consultations, family support and remote training. Technology is used not just in telemedicine support, but increasingly in medical care to support children with complex medical needs. The Maternal Child Health Bureau recognizes Children with Special Health Care Needs (CSHCN) as those who require more care and resources on a chronic basis. Children with medical complexity represent about 5% of the US pediatric population (www.childhealthdata.org), [1]. Of these, approximately 600,000 are estimated to be dependent on medical technology such as mechanical ventilation, feeding tubes, oxygen and/or monitors [2]. Approximately 1/3 of those children are graduates from the neonatal intensive care unit and have formidable management and safety challenges – 50% are seen in the emergency department within 3 months of discharge, and are the highest risk for readmission within the first 2 weeks after discharge [2,3]. As these children leave the neonatal intensive care units and transition to home, they continue to require the support of a coordinated care team including multiple specialists, primary care providers, nurses, case managers, therapists, nutritionists and others. Specialist availability, distance barriers and the cost and logistics of even short distance trips can be significant. The use of telehealth technology can help to achieve increased access and improved efficiency for this patient population through 1) inpatient support 2) integration with the medical home 3) bridging care transitions 4) remote patient management and 5) multispecialty consultations.

1.1. Inpatient telemedicine support

The American Academy of Pediatrics technical report on telemedicine offers insights into how telemedicine can be used to support neonates by increasing access to specialists and providing timely connections in urgent situations [4]. Support of both the neonate and the on-site team can be achieved with tele-resuscitation support. The use of telemedicine to remotely assist resuscitation of infants has been reported to improve adherence with Neonatal Resuscitation Protocol (NRP) standards and quality of the resuscitation [5,6]. A similar approach has helped identify and addressed gaps in resuscitation training [7–9]. The use of telemedicine throughout the neonatal course helps to lay the foundation for similar use in discharge planning and post discharge care for the chronically ventilated infant [10]. For infants, occupational and physical therapy can have positive neurodevelopmental impact that improves with repetitive exercise – therefore, using telemedicine tools to teach and coach caregivers to perform these exercises frequently with their baby could be beneficial.

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1.2. Integration into the medical home/bridging transitions

Planning a transition to home for a chronically ventilated infant begins with the patient centered medical home (PCMH). One of the core foundations for the PCMH is the use of health IT (https://pcmh.ahrq.gov/page/pcmh-foundations) which could include the use of telemedicine technology.

Applying this concept to children incorporates the core tenets of comprehensive care, expanded access, better communication, and coordinated care, along with partnership with the patient's family. The American Academy of Pediatrics recommends the patient centered medical home as an integral part of telemedicine implementation [11]. This begins with coordination between specialty care and primary care prior to discharge. A clear care plan should be developed and handed off to the primary care provider. This can be done though a telephone call, transmission of the electronic record and/or incorporate video handoff to allow assessment with both teams present in real time.

Studies looking at parental perceptions of home care for technology dependent children [12,13] have identified technical, social, emotional and financial concerns of parents as they navigate this transition. Parents report fear when they transition to home and lose the support of the hospital staff, as well as a need for a means to address gaps in knowledge or training. One way to address these needs is through post discharge follow up. A summary of 93 telemedicine “check in” visits shortly after discharge of complex surgical infants showed the feasibility of such check ins. The visits identified respiratory issues as amongst the top challenges faced by caregivers once they are home with their baby [14]. Parents often have questions about home monitors, oxygen and CPAP interfaces and usage. Using interactive telemedicine technology can help to facilitate real time troubleshooting of such equipment and education.

1.2.1. Transition to PCP

Transition of infants who are dependent on respiratory support from the NICU to the primary care provider can be challenging, especially those with 2 or more chronic conditions, and complex hospital courses. The use of telemedicine to perform patient handoffs from neonatal intensivists to primary care providers could have potential benefits, depending on the patient's conditions, medical complexity, and the provider's experience with caring for similar patients in the practice.

1.3. Remote patient management

Once an infant has successfully transitioned to home, there is still need for ongoing training and support which can be augmented by use of telemedicine. Parents of technology dependent children report a need for support of babysitters and others who may try to provide respite care, fearing knowledge gaps in home care staff and a need for reassurance from a trusted provider who is familiar with their child [12]. As described earlier, telemedicine has been used to support neonatal resuscitation in the delivery room and other inpatient environments. Interestingly, the severity and complexity of unresolved medical conditions present on discharge that are left to be managed in the ambulatory setting has risen [15]. The potential risk for needing remote and acute assistance with sicker children at home has increased. Progress in this offers encouraging prospects for using telemedicine to assist healthcare professionals in the home management of ventilator Assisted individuals (VAI), such as children with skeletal dysplasia and thoracic insufficiency. Similar use in adults with chronic obstructive pulmonary disease have noted that while telemedicine can facilitate earlier intervention when needed, it can also lead to increased hospitalizations, face-to-face visits, or home care visits. A more comprehensive cost benefit analysis is needed, perhaps at the level of condition subgroups.

In addition to acute situations, the decision to recommend in-person visits and emergency department referrals for medically complex children is based often on incomplete information without visual aids. The logistics of transporting a chronically ventilated child has its safety risks as well as cost in human resources, time and money. Using telemedicine technology to assess these patients at home may help to provide both the parent and provider with enough information for earlier intervention and decide whether an in-person visit is justified. One such home program utilized audio and video connection to allow children on home ventilator support to connect to their care team. This intervention allowed the children to be cared for in the home. The use of telemedicine allowed improved clinical decision making and increased parent confidence in the assessment and treatment recommendations [16]. This program provided real time visual assessment of children in their homes. This care will be further augmented in the future as technology continues to advance with development of devices that will allow assessment of heart and breath sounds, temperature, otoscope examination, blood pressure, blood glucose and other parameters [17].

In a study of such a device with medically complex children, the ability to perform a parent facilitated exam was not only possible, but provided additional information and helped to both provide guidance for home care and detect critical needs that would not have been picked up by phone [18].

1.3.1. Pulmonary care

Infants with thoracic insufficiencies, airway secretion issues present a formidable pulmonary toilet problem. Published literature in adults and older children with similar issues have shown cautious promise where provider were able to prescribe chest physiotherapy promptly, associated with reduce hospitalization and emergency room admissions [10].

1.3.2. Pulmonary function testing

Monitoring spirometry and pulse oximetry in children with cystic fibrosis remotely and more frequently results in improved outcomes as well as significant cost savings [19]. Due to the flexibility of telemedicine technology and use, programs can be designed to suit the unique needs of different patient groups and individuals.

1.3.3. Ventilator management

While today's home ventilators have capability to transmit patient data, how best to utilize this technology that would lead to improved patient outcomes or healthcare quality remains to be determined. Organizations like American Thoracic Society and European Respiratory Society have recognized the potential positive impact of such tools but caution the need for scientific investigation of usefulness regarding patient outcomes and equipment reliability [20,21].

1.3.4. Medication management

Ref. [22] Implementation of antimicrobial stewardship program is a pivotal practice element for healthcare institution. We developed a remote infectious disease consultancy program via telemedicine in a high-specialized pediatric cardiac hospital. A consultation for antibiotic strategy for each patient was available via telemedicine in addition to biweekly discussion of all clinical cases. Aim of this study was to evaluate the impact of the remote stewardship program in terms of a) appropriateness of antibiotic prescription; b) incidence of multi-resistant infection; and c) cost. A ‘before - after’ study was performed comparing the period immediately before starting the program and one year after. There was a trend in the reduction of nosocomial infectious disease rate (9.5 vs 6.5 per 1000 person days), with a reduction in the overall antibiotic cost (25,000 vs 15,000 EUR) and in the average antibiotics packages used per admission (9 vs 6.7 packages). A significant reduction in the multi-drug resistant isolation rate was observed (104 vs 79 per 1000 person days, $p = 0.01$). In conclusion, the infectious disease meeting via telemedicine has been an effective tool for economic and professional development and multidisciplinary management of

complex patients. The appropriate use of antibiotics reduced the multi-drug resistant bacteria selection, thus improving patient safety.

1.4. Remote specialty consults

In addition to acute needs, routine assessments of the child in the home by both the primary provider and specialty consults may be of benefit. In some situations, remote visits to the home may be preferable to exams in an office setting. Having a child in a familiar environment provides invaluable insight, not only to physicians but also to therapists, counselors and other members of a medically complex child's healthcare team [23]. The ability to provide specialty services, such as pain management and palliative care have been shown to be feasible with associated cost savings and need for travel [24–26]. In school settings, these benefits were seen in addition to perceived reduction in stress for the child and increased likelihood of a successful exam [27,28].

Telemedicine can also be used to support multispecialty clinics. Chronically ventilated children may require multiple specialists and care team providers, and coordinated clinics have been shown to have many benefits, however barriers of time, space and logistics can make them cost prohibitive [29]. Allowing a child with multispecialty needs to attend a virtual clinic from home, school or a primary care office would break down many of these barriers and allow more availability and flexibility [30–32]. Providers can also communicate directly with primary providers or school staff to provide information and education as to the child's condition and needs.

1.5. Clinical limitations: physical examination

While in person examination remains the gold standard for obtaining the highest quality and most comprehensive physical examination, much can still be done remotely through visual inspection and/or the presence of a nurse or family member with the patient. Current telemedicine peripherals allow high quality remote auscultation, fundoscopy, otoscopy, and high definition camera system that can zoom and pan to see pupillary reactions. Diagnostic peripherals allow for video EEG, EKG, spirometry, and ultrasound.

1.6. Logistic technological requirements, security, documentation and interoperability

Implementation of telemedicine requires certain system infrastructures to be in place [33] such as clinical champions, technical support, and reliable simple to use equipment.

Connectivity challenges which must be addressed include adequate bandwidth, interoperability of technology and firewall traversal. Using devices outside of the health system control must be evaluated from a security standpoint to ensure adequate protection of patient information. Technology support of both hardware and software in various settings is also a concern [26]. Testing, collaboration with information technology support and backup plans are an integral part of program development.

1.7. Impact on quality and cost

Quality. While the value proposition of telemedicine remains unclear as a complex equation of quality over cost. However, a practical approach for evaluating and monitoring program has been proposed by the National Quality Forum (NQF Quality Framework). Their domains like those offered by the Institute of Medicine quality address effectiveness, efficiency, timeliness, safety, patient centeredness, equitability. The cost side of the equation includes financial, human resources, process, unused inventory, and "non-value added" effort and processes. Such differences can result in support challenges. Since medically complex patients incur > 60% of all children health care expenditures [15], the potential cost savings are tremendous as long as safety is preserved. However, because the value equation is different for the various stakeholder groups (patient, provider, health system, practice, hospital, payers), unanimous support can be a challenge.

1.7.1. Cost and reimbursement

Cost effective in the ICU in certain populations [34]. Cost effective of "hospital at home" programs [35]. While many ventilated infants are insured by Medicaid, regulation details differ amongst states. Coverage depends on service offered and specialty services involved. Some states exclude coverage for store and forward technology or remote patient monitoring. Many states require a specific patient setting for care to be provided, and may exclude home or schools, while others do not recognize non-physician providers and or/may require the provider to be in a specific setting. Updates and details of state policies and telemedicine practices can be found at the Consortium of Telehealth Research Centers, funded by a HRSA Initiative (https://www.telehealthresourcecenter.org/).

Research

There is a "booming use" of telehealth without a corresponding "booming understanding" of its impact, advantages, and limitations. Formal research to answer such questions fall into one of three broad domains: clinical trials, implementation/quality science, and descriptive. The majority of Pediatric telehealth studies have described telehealth use in small cohorts and the very few that focus on ventilated infants involved newborn resuscitation [5]. In a small cohort of ventilated children described, telemedicine appeared to enable earlier diagnosis and treatment of life threatening events [36]. The American Academy of Pediatric Section on Telehealth Care have established research interest groups, one of which focuses on medically complex children, with hopes of identifying evidence based best telehealth practices through multicenter research (https://www.aap.org/en-us/about-the-aap/Sections/Section-on-Telehealth-Care/Pages/SPROUT.aspx).

Practice points

While research measuring impact of telehealth on ventilated assisted infants gains momentum, those wishing to use telehealth for ventilated infants could benefit from the Operating Procedures for Pediatric Telehealth [37].

Definitions. The geographical location of the patient and provider are termed, respectively, as the originating and distant (remote) site.

Security. The ATA Core Guidelines (https://southwesttrc.org/sites/southwesttrc.org/files/ATA%20Core%20Guidelines.pdf) describe standards for video and audio equipment used on mobile devices that includes installation of up-to-date antivirus software and security patches. "Medical grade" applications should be used and secured in accordance with existing privacy guidelines. Patient related information, including images, should not be sent via standard texting applications or stored on personal mobile devices.

Consent. Generally, states differ in terms of their opinion on consent, which is typically dependent on the situation (timing, condition, episode). In emergency situations, consent can often be waived. Legal representative should have knowledge of the telemedicine service compared with in-person care, billing arrangement, applicable credentials of the distant site provider. Patient verification should be done at each encounter. If encounters are to be recorded, providers should refer to state-specific laws, disclose that encounter will be recorded to parents/legal representatives and obtain written consent.

Encounter. Originating and remote sites must meet standards for privacy with minimal distraction and background noise. All

parties present should be introduced at the beginning of the encounter. No personal health information not belonging to the patient should be visible. Providers should routinely communicate with the patient's primary care provider about a telehealth encounter, especially on recommendations on care plan changes.

Licensure. Provider must have a valid professional practice license in the state where the patient is located at the time of the encounter. However, exception rules exist for certain circumstances according to state specific laws. Providers and their legal representatives should review credentials and privileges in accordance with local, state, and federal regulations at the remote and originating site.

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