Pediatric Diabetes Telehealth Improves Access to Care for Rural Families: Role of APRNs

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Abstract

This paper presents an overview of the leadership role of advanced practice registered nurses (APRNs) with the implementation and evaluation of a newly implemented pediatric diabetes telehealth program. Type 1 diabetes has increased in children by 23% from 2001-2009. Rural communities additionally have increased disparities related to access barriers and a large minority population with poorer overall health. Research evidence supports telehealth as an effective alternative to bring preventive diabetes care to remote areas. The project took place at a rural pediatric outpatient specialty clinic in partnership with a tertiary center telehealth network. The telehealth program quality improvement (QI) project explored caregiver satisfaction for this newly implemented program. Following teleconferencing, a convenience sample of caregivers (N=14) completed a 9 item Telehealth Diabetes Caregiver Satisfaction Survey (TDCSS), adapted from a validated, reliable Telepsychiatry Survey. TDCSS responses (1=strongly disagree to 5=strongly agree) indicated caregivers were highly satisfied with the communication/privacy (M=4.8), access to care (M=4.1), and quality of services (M=5.0). Integral to the quality of the telemedicine clinic initiative was the multidisciplinary collaborative teamwork, continuous QI, and dependable technology. APRNs provided technology expertise, interdisciplinary collaboration leadership, care coordination, and advocacy for policy changes. Future nursing implications are to recognize the impact of telehealth and APRNs leadership role to help implement these innovative programs into rural communities to improve access to care, health care cost and outcomes. APRNs can conduct future translational research to establish best practice guidelines for telehealth. Future QI could include longer studies with clinical metrics such as HbAIC, hospitalizations, emergency room use, and caregiver burden and quality of life measures.

Key Words: telehealth, pediatric, diabetes, access to care, advanced practice nurses role

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Diabetes is a public health challenge worldwide and one of the most common chronic diseases among children (Centers for Disease Control and Prevention, 2012). Rural communities additionally have a large minority population with limited access to specialist for prevention education, surveillance, and poorer overall health. A multicenter SEARCH for Diabetes in Youth study revealed the prevalence of type 1 diabetes has increased in children by 23% from 2001-2009 (Pettitt et al., 2014). The study also indicated increased disparities in racial/ethnic minority children with the presence of substantial access barriers (Valenzuela et al., 2014). The Increased incidences are resulting in a lifelong chronic disease and severe complications beginning at a much younger age. All children and their families should be provided with the opportunity for self-management education and monitoring at least every three months (American Diabetes Association, 2014). A top priority for Rural Healthy People 2020 is to decrease health disparities and improve access to care, particularly among minority low income children (Bolin & Bellamy, 2012).

Research evidence supports telehealth as an effective alternative to bring preventive diabetes care to remote areas. Institute of Medicine (2010) *Future of Nursing Report* suggest that advanced practice registered nurses (APRNs) are well positioned to lead change as health care moves beyond the hospital to more preventive services throughout the community and respond to issues in this evolving complex healthcare system (Orsolini, 2014). To accomplish this, Doctor of Nursing Practice (DNP) curricula are emphasizing leadership, evidence-based practice, interdisciplinary collaboration, and healthcare technologies to advance health, specifically electronic health records and telehealth (American Association of Colleges of Nursing, 2006). This paper presents an overview of the leadership role of APRNs with the implementation and evaluation of a newly implemented pediatric diabetes telehealth program for a rural community with limited access to pediatric diabetes specialists.

Rural Pediatric Diabetes Telehealth

Telehealth is providing a tool to enhance the quality of pediatric health care with collaboration with primary care medical home for the development of self-management skills, and empowering these families to participate in prevention strategies (Kent et al., 2013). Telemedicine or telehealth is defined as "the use of medical information exchanged from one site to another via electronic communications to improve a patient's health status" (American Telemedicine Association Standards and Guidelines Committee, 2014, p.4). Implementation of the Affordable Care Act has the potential to address provider shortages through patient-centered medical home innovations, such as telemedicine, with an emphasis on achieving better outcomes and patient care experiences (National Conference of State Legislatures, 2011). Diabetes complications can be prevented or delayed with tight glycemic control through family-centered prevention education and surveillance (The U.S. Department of Health and Human Services' National Diabetes Education Program, 2013).

The results of Guljas, Ahmed, Chang, & Whitlock (2014) integrative review suggest that telemedicine can play an integral role in managing type 1 diabetes, as measured by compliance with blood glucose monitoring, glycemic control, satisfaction, and self-management in rural communities. A school-based telemedicine RCT in this review revealed lower HbA1c, improved quality of life, reduced urgent diabetes related calls by the school nurse, and there were fewer hospitalizations and emergency department visits (Izquierdo et al., 2009).

Telehealth Program Implementation Theory

The Chronic Care Model (CCM), developed by Edward Wagner, uses concepts involving individual, provider and community resources to direct care and education toward a more self-managed, preventative care approach (Wagner & Austin, 1996). Stellefson, Dipnarine & Stopka (2013) systematic review provides evidence that CCM is effective in

improving the health of people who have diabetes with positive clinical and process outcomes. Using two main concepts of the CCM, efforts will be focused for this project on the linkage of tertiary center specialist in collaboration with families and local community diabetes team networked through telehealth. The essential goal was to improve quality of care, reduce disparities through increased access to diabetes experts which in turn may lead to future improved patient outcomes. See figure 1.

Telehealth Program Quality Improvement Methods

In order to implement this innovative model of care, a community coalition consisting of a diabetes physician specialist, pediatric hospitalists, APRNs, a certified diabetes educator, and a dietician was formed. The telehealth program was implemented on the Lower Eastern Shore of Maryland in a pediatric outpatient specialty clinic at Peninsula Regional Medical Center (PRMC) in partnership with Washington Nationals Diabetes Care Complex telemedicine network at Children's National Medical Center (CNMC). The Lower Eastern Shore of Maryland is a federal-designated medically underserved, rural area with a lack of access to specialized pediatric diabetes care related to geographical location (Maryland Department of Health and Mental Hygiene, 2007).

Quality Improvement Caregiver Satisfaction Survey

Protection of human rights. The telehealth program Quality Improvement (QI) project explored caregiver satisfaction for this newly implemented program and was developed, implemented, and evaluated as part of a Post-Master's Doctor of Nursing Practice (DNP) project. Following exempt approval from University of Maryland Baltimore (UMB), PRMC and CNMC, the QI project was conducted over two months, averaging 7 encounters per month. All caregiver responses were kept confidential, and all numerical data were provided in aggregate.

Caregiver satisfaction survey description. Caregiver satisfaction was defined in the context of this QI project as caregiver's (parents/grandparents) perception of the quality of the telemedicine consultations to meet their family's needs. The Telehealth Diabetes Caregiver Satisfaction Survey (TDCSS) was adapted from Myers, Valentine and Melzer's (2008) Parent-Reported Satisfaction Telepsychiatry Survey with the authors' permission. The TDCSS consists of nine items, focusing on three major domains: communication quality and privacy (items 1, 2, 3), increased access to care (items 4, 5, 6), and quality of telemedicine services received (items 7, 8, 9).

Caregiver satisfaction survey results. TDCSS survey responses (1=strongly disagree to 5=strongly agree) indicated caregivers (N=14) were highly satisfied with the communication and privacy (M=4.8), access to care (M=4.1), and quality of services (M=5.0). Caregivers reported they could talk comfortably with the physician and understood the recommendations for their child. Over half of the caregivers (N=8) agreed their child would not have received diabetes specialty services without telehealth, but 36% of the caregivers strongly disagreed (N=5). However, all the caregiver's (N=14) surveyed agreed telemedicine allowed their child to see a physician sooner. In addition, all the caregivers reported they were very satisfied with the overall quality of the diabetes telehealth visit, agreed that the telehealth visit was as good as a regular in-person visit, and are willing to have their child be seen with telehealth again in the future.

Caregivers were given an opportunity to leave additional comments or suggestions for improvement at the end of the survey regarding the telemedicine visit (N=4). Additional comments written from one of the caregivers were "Very useful. Trip to Washington or Annapolis takes up entire day. Telemedicine allows us to only spend hour or so, very satisfied with quality of video/audio. Easy to understand." Another caregiver commented

“Very useful, great attitude, understanding, convenient. Loved it.” Other caregiver comments were "This is great" and "I like this and it really was helpful. Keep up the good work."

Caregiver satisfaction survey results discussion. The TDCSS supports that caregivers were satisfied with telehealth visits as an alternative to traditional office visits. While a third of the caregivers reported that they would have received services without telehealth, they acknowledged that telehealth offered them the option and convenience of not having to travel to a tertiary care center. Caregivers appreciated seeing a diabetes physician specialist sooner and are optimistic that their child will receive the services they need due to telehealth. Thus, telehealth provides these families increased access to care and the utilization of quality diabetes prevention services closer to their homes. The results emphasize the importance of the role telehealth has in reducing access to care barriers.

Limitations and future QI metrics. A limitation of the TDCSS is a small convenience sample of 14 participants collected over only a two month period at implementation of the project. Another limit is that this QI project was based on a self-reported nine item caregiver satisfaction survey for a single pediatric clinic pilot program. Future QI outcome measures could include larger sample size and longer studies with clinical metrics such as HbAIC, and health care cost related to the utilization of services, hospitalizations and emergency room use. Psychological considerations could be explored, including caregiver burden and quality of life of these children and their families. Health-related quality of life (HRQL) is an important outcome, linked to better clinical outcomes (HbA1c), and better psychosocial health (Naughton, 2014).

Pediatric Diabetes Telehealth Program Evaluation

Telehealth program benefits and facilitators. The benefits of telehealth program were immediate patient access, reduced service gaps, improved quality, additional clinical support, better patient and caregiver satisfaction and improved adherence to care standards.

CNMC tertiary center has an established partnership with PRMC remote rural site and 14 years of experience in the field of telehealth technology with the vision to improve health outcomes of underserved and at risk children. Senior leadership in both organizations supported the clinical innovation to improve patient care. The leadership team provided effective management for continuous improvement of patient care and provided the necessary support in terms of financial resources and training. Communication was maintained through regular project meetings with the APRNs and team members. Progress of the project was measured by collecting feedback from caregiver's satisfaction with the telehealth services and provider/staff buy-in. After only two months, the demand for telemedicine pediatric diabetes visits had doubled requiring the clinic to add another telemedicine day to accommodate these needed appointments.

Telehealth program barriers. An Identified problem to the implementation of the telehealth program was the local school nurses and primary care pediatricians expressed they wanted more education on pediatric diabetes management and telehealth. A regional pediatric diabetes symposium was coordinated and conducted by APRNs to overcome this barrier to provide community education on pediatric diabetes management and telehealth services with over 100 interdisciplinary providers in attendance. Another barrier to the program implementation included growing pains of not enough space and supporting staff for the demand of referrals for care and future vision to expand services. Next steps include the expansion of the clinic to accommodate the increase in patient services and the expansion to other specialty areas, including infectious disease, asthma, psychology and high risk pregnancies.

Role of APRNs in Telehealth Implementation

APRN leadership. Integral to the quality of telemedicine clinic initiative was the multidisciplinary collaborative teamwork, continuous QI, and dependable technology.

APRNs provided the technology expertise and leadership for the coordination and interdisciplinary collaboration with other healthcare providers in their use and application. Significant coordination was required to ensure all necessary information was available to the diabetes physician specialist at the time of the clinical encounter and process of workflow. See figure 1 for program implementation multidisciplinary team collaborative workflow.

Telehealth teamwork workflow. The APRNs needed to first make sure equipment was set up and functional and having an alternate plan if technology problems presented. Before the videoconferencing telehealth visit, the child's history since last visit was obtained, and recent HgA1c and other labs, VS and the child's measurement data were compiled and uploaded into the EMR and transmitted to CNMC. Next the child's home blood glucose meter data was uploaded into electronic medical record (EMR) and transmitted to CNMC. During the visit, the APRNs reviewed the data with the diabetes CNMC physician specialist via two-way real time videoconference, performed the physical exam (including eye, thyroid, injection sites) synchronously on screen in the exam room and communicated findings to CNMC physician specialist. In-between telemedicine visits required a high level of collaboration for acute illnesses between school nurses, clinic nurse practitioner, CNMC diabetes specialist, emergency room physicians, CNMC pediatric hospitalist at remote site, and CNMC emergency line for after hours.

Interdisciplinary coordinated care and policy. Finally, the interdisciplinary communication of the treatment plan and coordination of care with primary care providers, school nurses, dietician and diabetes educator was crucial to maintain integrated care coordination. Future community needs were identified to provide leadership to expand telehealth services to school-based health to include other pediatric chronic disease management (childhood obesity, asthma, and psychiatric illnesses). These telehealth visits could further increase community capacities to provide these limited pediatric services in

remote areas. For this to be realized, APRNs are serving on the state Rural Health Council and telehealth clinical advisory board to expand legislation regarding reimbursement, nursing licensure and credentialing. APRNs are actively continuing to advocate for legislation that impacts nurses' abilities to deliver safe, effective, and affordable telehealth nursing practice in the state.

Future Nursing Implications

Future nursing implications are to recognize the impact of telehealth and APRNs leadership role to help implement these innovative programs into rural communities to improve access to care, health care cost and outcomes. APRNs can conduct translational research to establish best practices for telehealth. Such information will contribute to new telemedicine practice guidelines and protocols to improve patient outcomes and reduce health care cost. Furthermore, telehealth principles could be incorporated into not only doctoral nursing curricula but also into all undergraduate and graduate nursing programs. The curricula could include information about telecommunications, informatics, information management, interstate licensing and regulations, and health information privacy. For example, the use of simulation immersion experiences could be employed to increase the telehealth nursing knowledge and skills of all pre-licensure registered nurses and APRNs.

Increased access to coordinated self-management care requires a new orientation towards effective telehealth models which incorporates family-centered prevention education and chronic disease monitoring to maintain health status and quality of life. This new innovative delivery model of care implemented will empower patients and their caregivers with self-management skills for optimal glycemic control. The National Association of Pediatric Nurse Practitioners (2009) further affirms children's health care delivery should be family-centered, accessible, comprehensive, coordinated, culturally sensitive, compassionate, and focused on the overall well-being of children and their families. Value-based medical

home models are becoming the standard to reach the Institute of Medicine's (IOM) triple aim to improve the experience of care and health outcomes, and to reduce healthcare costs (Berwick, Nolan & Whittington, 2009). Partnerships between community health care systems and families through telehealth and APRNs leadership will improve pediatric health outcomes and prevent complications in a cost-effective manner.

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Table 1: Telehealth Diabetes Caregiver Satisfaction Survey (TDCSS) (N=14)

Survey Questions	Strongly Disagree *n* (%)	Disagree	Neutral	Agree	Strongly Agree *n* (%)
Communication Quality/Privacy					
1. I was able to talk comfortably with the diabetes doctor on the television screen.	0 (0)	0 (0)	0 (0)	0 (0)	**14 (100)**
2. I felt confident that my child's information was not heard by others outside the room.	0 (0)	0 (0)	**2 (14.3)**	**1 (7.1)**	**11 (78.6)**
3. I was able to understand the diabetes doctor's recommendations for my child.	0 (0)	0 (0)	0 (0)	**1 (7.1)**	**13 (92.9)**
Increased Access to Care					
4. Telemedicine allowed my child to see a diabetes doctor sooner.	0 (0)	0 (0)	0 (0)	**5 (35.7)**	**9 (64.3)**
5. My child would not have received services from a diabetes doctor without telemedicine.	**5 (35.7)**	0 (0)	**1 (7.1)**	**4 (28.6)**	**4 (28.6)**
6. My child will receive the help he/she needs because of our diabetes telemedicine visits	0 (0)	0 (0)	**2 (14.3)**	0 (0)	**12 (85.7)**
Quality of Telemedicine Services					
7. The diabetes doctor telemedicine visit was as good as a regular in-person visit.	0 (0)	0 (0)	**1 (7.1)**	0 (0)	**13 (92.9)**
8. I am willing to have my child see the diabetes doctor with telemedicine again in the future.	0 (0)	0 (0)	0 (0)	0 (0)	**14 (100)**
9. Overall, I am very satisfied with the quality of the diabetic telemedicine visit.	0 (0)	0 (0)	0 (0)	0 (0)	**14 (100)**

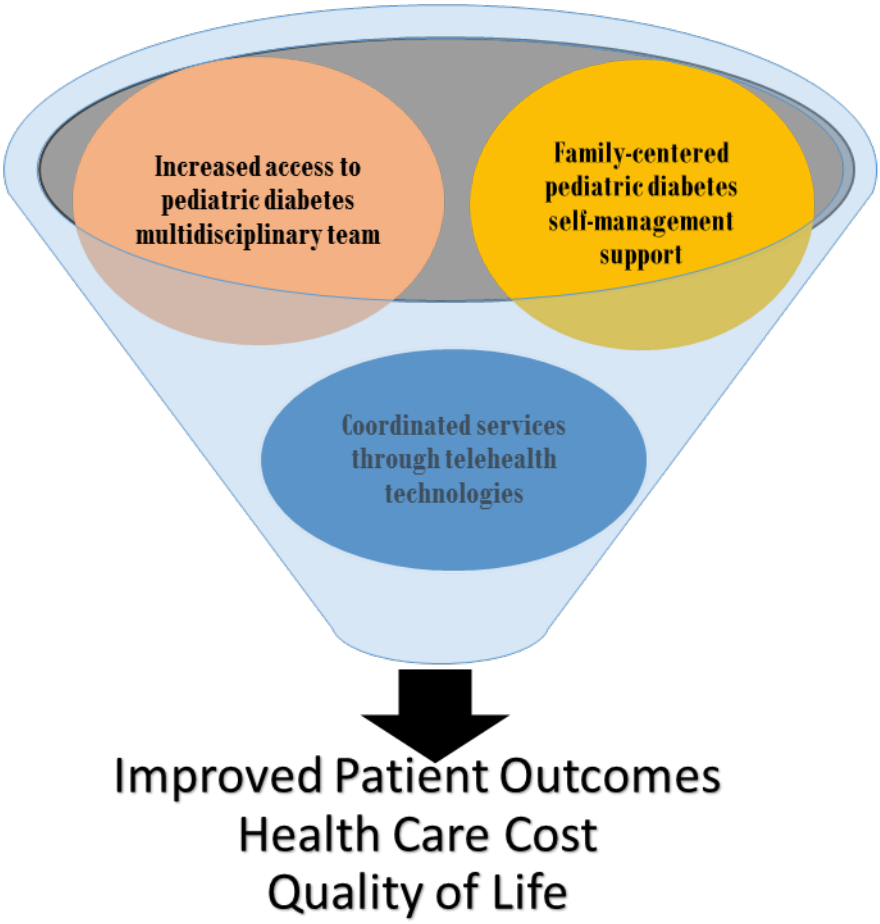

Figure 1: Modified Chronic Care Model for Pediatric Diabetes Telehealth Delivery of Care (Wagner & Austin, 1996).

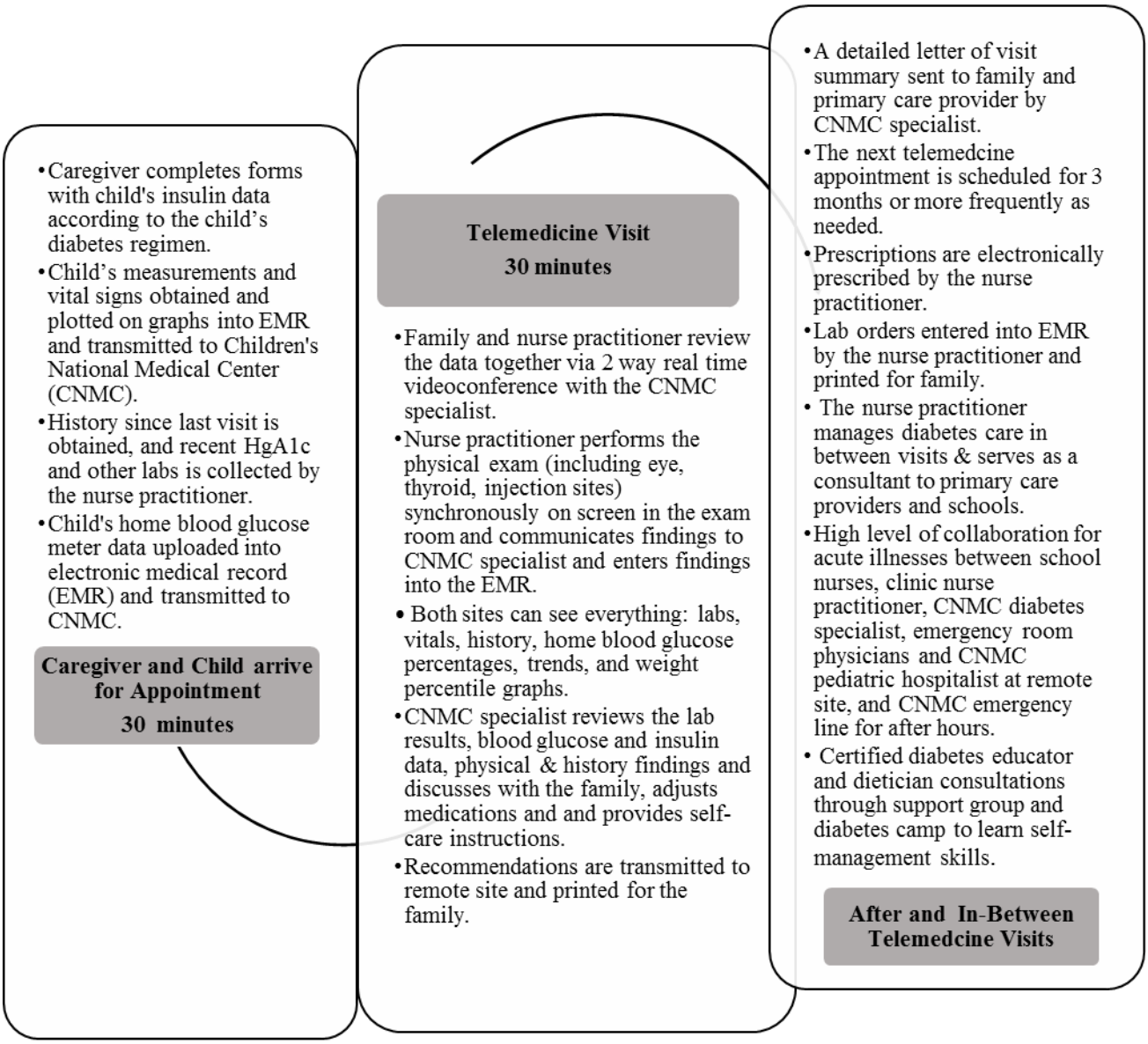

Figure 2: Telehealth Workflow