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Using Telemedicine to Provide Pediatric Subspecialty Care to Children With Special Health Care Needs in an Underserved Rural Community

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ABSTRACT. *Objective.* For children with special health care needs (CSHCN) that live in rural, medically underserved communities, obtaining subspecialty care is a challenge. Telemedicine is a means of improving access to these children by addressing rural physician shortages and geographic barriers. This article reports a medical-needs assessment of parents/guardians with CSHCN and the status of a telemedicine program for CSHCN as well as the results of parent/guardian and local provider satisfaction with the telemedicine program.

Design. We report the results of a pretelemedicine medical-needs survey conducted in March 1999 by using a convenience sample of CSHCN living in a rural, medically underserved community located 90 miles north of the University of California Davis Children's Hospital (Davis, CA). In April 1999, a telemedicine program was initiated to provide consultations to CSHCN and has continued since. We also report the parent/guardian's perceptions of the appropriateness and quality of telemedicine consultations and the local provider's satisfaction with telemedicine consultations completed from April 1999 to April 2002.

Results. The pretelemedicine medical-needs assessment demonstrated several barriers in access to subspecialty care including traveling >1 hour for appointments (86% of parents/guardians), missing work for appointments (96% of working parents/guardians), and frequently relying on emergency department services and/or self-regulation of their child's medications. From April 1999 to April 2002, 130 telemedicine consultations were completed on 55 CSHCN. Overall, satisfaction was very high. All the parents/guardians rated satisfaction with telemedicine care as either "excellent" or "very good," and all but 2 of the rural providers' surveys reported satisfaction with telemedicine as "excellent" or

"very good." The frequency of telemedicine consultations has increased with time.

Conclusions. Pediatric subspecialty telemedicine consultations can be provided to CSHCN living in a rural, medically underserved community with high satisfaction among local providers and parents/guardians. Telemedicine should be considered as a means of facilitating care to CSHCN that, relative to the customary delivery of health care, is more accessible, family-centered, and coordinated among patients and their health care providers. *Pediatrics* 2004;113:1–6; *telehealth, telemedicine, children, pediatrics, rural health, medical home, children with special health care needs, subspecialties, referral and consultation.*

ABBREVIATIONS. CSHCN, children with special health care needs; UCDC, University of California Davis Children's Hospital.

Residents living in rural communities are confronted with significant inequities in access to health care compared with residents living in urban and suburban communities.¹ Rural residents face a relative shortage of specialty and subspecialty physicians and show several inferior measures of health status. Children who reside in rural and medically underserved regions experience disparities in access because there are relatively fewer pediatric specialty and subspecialty services available, and those services that are available are typically distant from their rural residence.¹ Moreover, for children with special health care needs (CSHCN) living in rural communities, obtaining specialty or subspecialty care is especially challenging because these children require more frequent routine and urgent medical assessments.

In 1999, the Center for Health and Technology at the University of California Davis Medical Center and the University of California Davis Children's Hospital (UCDC, Davis, CA) established a tele-

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medicine program to a rural and medically underserved community with the objective of providing pediatric subspecialty telemedicine consultations to CSHCN.² This project was begun to improve access to specialty care for CSHCN and as a step toward our nation's Healthy People 2000 and 2010 goal of providing a medical home for all CSHCN.³ Telemedicine has become an increasingly viable solution to address the physician shortages and geographic barriers that rural residents face and has been implemented successfully to provide adult and pediatric consultations in specialties such as dermatology,⁴ psychiatry,⁵ cardiology,⁶ home health care,⁷ radiology,⁸ and pediatric specialty care.⁹ Additionally, the use of telemedicine to provide specialty consultations for CSHCN with their primary care provider in their own community can facilitate care that is more accessible, family-centered, and coordinated, thereby reinforcing other efforts in providing a medical home.^{10,11}

Before implementing the telemedicine program, a prospective medical-needs survey of CSHCN and their parents/guardians was conducted. The first objective of this study was to report the results of the medical-needs assessment including the parent/guardian's perceived role that telemedicine could play in the care of their children. The second objective was to assess the success of the telemedicine program and report the parents/guardians' perceptions of the appropriateness and quality of telemedicine consultations for their children after the telemedicine program was initiated.

METHODS

The telemedicine clinic for CSHCN was established in Oroville, CA, a community located 90 miles north of the UCDC in Sacramento. The city of Oroville and surrounding communities are designated health professional shortage areas. The population of Oroville is 13 000, and the population of the greater Oroville area is 45 000. The telemedicine connection linked 2 adjacent local primary care offices (one office with 2 general pediatricians and one physician assistant and another office with one general pediatrician and one physician assistant) caring for local CSHCN to an established UCDC pediatric subspecialty clinic office with telemedicine capabilities. Although specific clinical criteria were not established to define a child as having special health care needs, all children participating in the telemedicine program were documented by their primary care pediatricians, familiar with the Maternal and Child Health Bureau definition, as CSHCN because of their requirement for health and related services of a type or amount beyond that required by children generally.

Pretelemedicine Survey

In March 1999, a survey was designed to assess the medical needs of CSHCN and assess the parents/guardians' perceptions of the feasibility and extent to which telemedicine could help meet their children's medical needs. Before the initiation of the telemedicine clinic, a convenience sample was identified by the UCDC of pediatric patients who received subspecialty consultations at the UCDC in fiscal year 1998 and resided in Oroville. An a priori decision was made to survey 25% of this convenience sample randomly. A single attempt at a telephone contact was made during working hours to conduct the telephone survey. Participants were included if they were able to understand and speak English.

The pretelemedicine survey consisted of several questions designed to inquire about certain aspects of the utilization of primary and subspecialty health care services: the logistics of attending medical appointments; alternative care obtained (including self-regulation) in the absence of direct access to the subspecialists;

and, after providing a standardized description of outpatient telemedicine, questions regarding the parents' perceived advantages and disadvantages of using telemedicine for specialty consultations and the likelihood that they would agree to use telemedicine to obtain specialty consultations for their child (survey is available on request).

Telemedicine Program

After the medical-needs assessment was completed, the telemedicine program started in April 1999 and has continued since. A part-time telemedicine site coordinator was hired shortly after April 1999 for this and other telemedicine clinic coordination in Oroville. The telemedicine connection utilizes 3 ISDN lines (384 kilobits per second) providing fully live, interactive video and audio and a peripheral general patient examination camera. For each telemedicine consultation, the patient, the patient's parent/guardian(s), the referring health care provider (physician or physician assistant), and the UCDC subspecialist participate in the entire encounter. At the end of the encounter, either a handwritten or dictated consultation note from the subspecialist is faxed to the Oroville site to be included in both the Oroville and UCDC medical records.

Standardized, pretested satisfaction surveys were administered to the parents/guardians of the CSHCN as well as to the Oroville physician or physician assistant who accompanied the patient during the examination.² Satisfaction surveys consist of eight 5-point Likert scale questions with answers as excellent, very good, good, poor, and very poor. Surveys were administered after each individual telemedicine consultation independent of whether the parent/guardian had completed a survey after a previous visit. The data reported here are from 36 consecutive months (until April 2002) of consultations.

Statistics

Descriptive statistics were used to summarize the demographic, diagnostic, and survey data. Comparisons between median Likert scale satisfaction scores were performed by using the Mann-Whitney *U* 2-sample statistic. Statistical significance was determined at the *P* = .05 level. The Human Subjects Review Committee at UCDC approved the study.

RESULTS

Pretelemedicine Survey

A total of 154 pediatric patients with SHCN whose primary residence was in Oroville were identified as requiring pediatric subspecialty consultations during fiscal year 1998 at the UCDC. This cohort had a significant degree of pediatric subspecialty needs, requiring annual totals of 412 outpatient visits and 46 inpatient admissions. Forty-two (27%) of the parents/guardians were selected randomly, contacted, and asked to participate in the telephone survey. All the parents/guardians that were contacted agreed to participate in the telephone survey.

Baseline characteristics for the surveyed population are shown in Table 1. The age range of the children whose parents/guardians participated in the survey was 1 to 16 years old (mean: 8 years). Twenty-five (60%) were male, and 28 (67%) of the patients had Medicaid as their sole health insurance. A majority of the CSHCN (54%) had been receiving subspecialty care for ≥ 3 years. Diagnoses included asthma, leukemia, epilepsy, diabetes mellitus, cerebral palsy, congenital heart disease, a digestive disorder, or a coagulation abnormality.

Eighty-three percent of the parents/guardians stated that total travel time to the specialist's office at the UCDC exceeded 1 hour. Forty percent of all parents/guardians and 96% of working parents/guardians typically missed work to attend their chil-

TABLE 1. Baseline Characteristics of Patients and Caregivers of CSHCN Participating in Telephone Survey Needs Assessment

Baseline Characteristics (<i>n</i> = 42)	No.
Average age of CSHCN, years (SD)	8 (4.8)
Male, %	60%
Average time receiving UCDCH specialists care, years (SD)	4.9 (3.8)
Average number of annual visits, mean (SD)	
Local primary care provider	6.8 (6.3)
UCDCH specialist	3.9 (3.6)
Dietician	6.8 (6.8)
Physical therapy	15.6 (21.2)
Case manager	8.6 (13.7)
Emergency department	5.1 (6.2)

SD indicates standard deviation

dren's appointments. Fifty-two percent of the parents/guardians considered themselves as primarily responsible for coordinating care among the different medical services for their children. In the absence of direct access to their subspecialist provider, a majority of the parents/guardians reported that they relied on emergency department services and/or self-regulation of medications for their children.

Perceived advantages and disadvantages of receiving subspecialty care using telemedicine varied substantially. Positive comments about telemedicine included: "could see 2 doctors at one time," "saves time and gas," "wouldn't have to miss work," "access specialists right away," "we could see the same doctors we always see and not have to reexplain things to new doctors," and "if there is a doctor who knows more and is far away, I would do it to get the best care." Comments made about the perceived disadvantages of telemedicine included: "if it is an emergency, I would rather be face to face with the doctor," "they would not be able to do physical examinations," "potential failure of the electronic system," "if I'm not talking face to face, [the doctor] is not going to tell me the truth," and "I prefer face-to-face meetings. . . I want to talk with [the doc-

tor] with nothing in between us." Twenty-one caregivers (50%) indicated that they would be "very likely" to use telemedicine in the future when available, 15 (36%) indicated that they would be "likely" to use telemedicine in the future, and 4 (9%) stated it would be "unlikely" for them to use telemedicine when offered in the future. There were no comments reported from 2 parents/guardians.

Telemedicine

During the subsequent 36-month telemedicine period (April 1999 to April 2002), 55 pediatric patients with SHCN received a total of 130 telemedicine consultations from pediatric subspecialists. The frequency of telemedicine consultations has increased since the program's inception (Fig 1). The median number of visits per individual was 2 (range: 1–12). The ages of the patients ranged from 1 to 18 years with a mean age of 11.2 years. Forty-eight percent of the pediatric patients were male. A majority of the 55 patients (72%) had either no medical insurance or Medicaid.

During the 36-month period, 207 telemedicine appointments were scheduled. One-hundred thirty (63%) patients kept their appointments, 36 (17%) failed to show up at their appointed time, 17 (8%) rescheduled the appointment, and 24 (13%) called to cancel scheduled appointments. The proportion of patients failing to arrive for their scheduled telemedicine appointment (17%) is very similar to what is experienced by the UCDCH pediatrics subspecialty clinic (mean semiannual failure to show rate of 14.8%; range: 8.8%–22.8%). The principal diagnoses responsible for the telemedicine consultations are listed in Table 2. The variety of illnesses that affected these groups of patients warranted different pediatric subspecialty consultations including pediatric endocrinology-obesity (*n* = 99), psychiatry (*n* = 17), gastroenterology (*n* = 6), hematology-oncology (*n* = 4), nephrology (*n* = 3), and infectious disease (*n* = 1).

The median encounter time was 30.0 minutes (mean time: 40.0 minutes; range: 15–70 minutes). Some sort of technical difficulty was experienced in

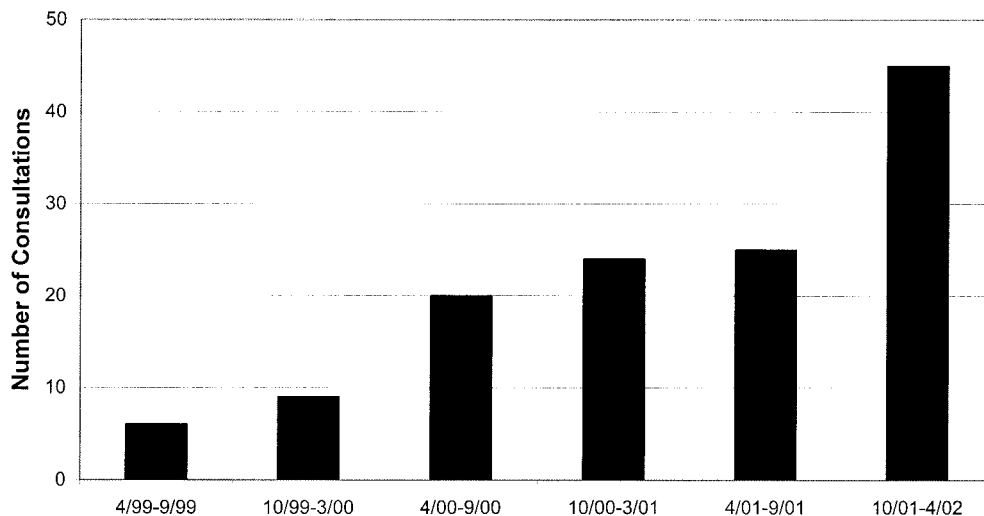


Fig 1. Frequency of pediatric telemedicine consultations.

TABLE 2. Principal Diagnoses for 130 Telemedicine Consultations

Specialty	No.
Endocrinology-obesity (<i>n</i> = 99)	
Obesity	25
Insulin-dependent diabetes mellitus, uncontrolled	29
Morbid obesity with sleep apnea	18
Delay in sexual development and puberty	6
Acanthosis nigricans	4
Precocious sexual development and puberty	3
Chronic fibrous thyroiditis	3
Chronic lymphocytic thyroiditis	3
Hypercholesterolemia	3
Other specified hypoglycemia	2
Nontoxic multinodular goiter	1
Hypertrophy of labia	1
Mixed acid-based balance disorder	1
Psychiatry (<i>n</i> = 17)	
Bulimia	6
Attention-deficit disorder with hyperactivity	3
Posttraumatic stress disorder	3
Obsessive compulsive disorder	2
Manic-depressive psychosis, unspecified	2
Unspecified childhood psychosis	1
Gastroenterology (<i>n</i> = 6)	
Failure to thrive	4
Esophageal reflux	1
Disaccharide malabsorption	1
Hematology-oncology (<i>n</i> = 4)	
Histiocytosis	4
Nephrology (<i>n</i> = 3)	
Nephrotic syndrome	3
Infectious disease (<i>n</i> = 1)	
Erythema multiforme	1

38 consultations (29.2%). In 22 encounters (16.9%), either the subspecialist or Oroville health care provider complained of “pixelation” of the image. Difficulties obtaining quality audio occurred in 10 encounters (7.7%) such that, for one encounter, a simultaneous telephone connection was required for audio. More than one attempt was required in establishing the telemedicine connection in 6 encounters (4.6%). All the encounters where technical difficulties were experienced eventually completed the telemedicine consultation during the scheduled visit. All telemedicine encounters were billed at typical and appropriate consultation rates.

Satisfaction of care provided by the telemedicine consultations is shown in Fig 2 for parents/guardians and Fig 3 for providers. One-hundred thirty parent/guardian surveys (from 55 individual parents/guardians) and eighty-one provider surveys

were collected. Overall, satisfaction was very high, with all the parents/guardians rating satisfaction of telemedicine care as either “excellent” or “very good.” All but one of the surveyed parents/guardians stated that they wished to continue to receive their consultations using telemedicine. Ninety percent of overall telemedicine satisfaction scores ranked as “very good” and “excellent,” and the lowest overall satisfaction reported from one parent/guardian was “poor.”

The survey results from the 3 Oroville physicians (22 surveys) and 2 Oroville physician assistants (59 surveys) were combined after analyses demonstrated similar responses. All but 2 of these provider surveys rated their satisfaction with telemedicine as “excellent” or “very good.” The lowest satisfaction score from these providers was their perception that telemedicine gave an adequate examination to the UCDCH physician. This score was statistically lower than the scores for their ability to understand the consultant and their overall satisfaction with the telemedicine consult ($P < .001$ for both).

DISCUSSION

Our data demonstrate that the vast majority of parents/guardians of CSHCN living in a rural, medically underserved community would be either likely or very likely to receive their children’s subspecialty care using telemedicine. Additionally, our data demonstrate that pediatric subspecialty telemedicine consultations to a rural, underserved community for CSHCN are feasible and considered highly satisfactory by both the parents/guardians and rural health care providers. Ninety-eight percent of the parents/guardians stated that they wished to continue to receive their consultations using telemedicine rather than having to travel to the UCDCH subspecialty clinic for routine fact-to-face appointments.

There are several potential advantages to the use of telemedicine as a means of providing subspecialty consultations to CSHCN living in rural, underserved communities. First, by increasing local access to subspecialty health care expertise, telemedicine may provide a means of supporting a medical home in communities that otherwise have limited access to comprehensive care. Telemedicine may promote increased care coordination between the primary care physicians and subspecialists and allows primary care providers to coordinate and directly participate

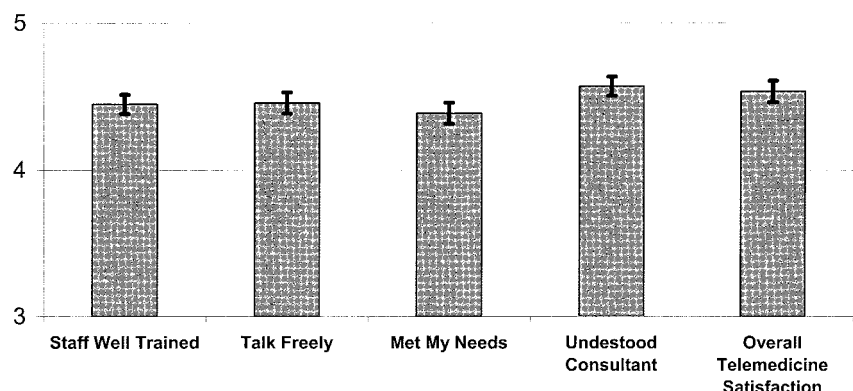
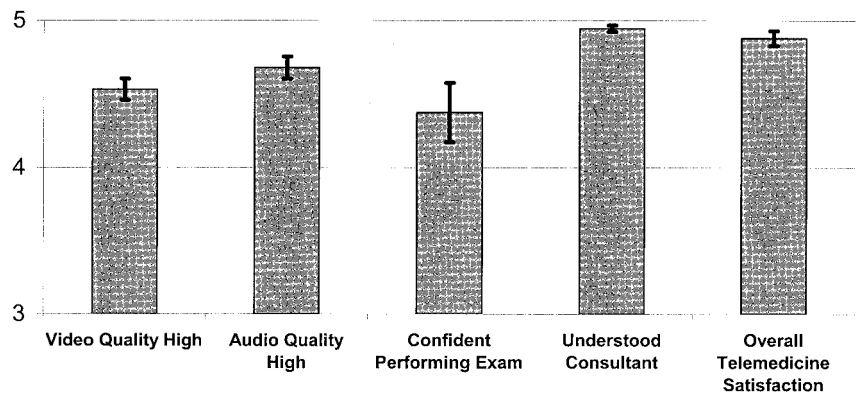


Fig 2. Parent/guardian satisfaction with telemedicine (mean \pm standard error of the mean) recorded by using the 5-point Likert scale (3 = good; 4 = very good; 5 = excellent).

Fig 3. Provider satisfaction with telemedicine (mean \pm standard error of the mean) recorded by using the 5-point Likert scale (3 = good; 4 = very good; 5 = excellent).



in the team management of CSHCN. Telemedicine also may provide an educational benefit to the rural primary care providers, reduce provider isolation, and potentially increase their knowledge in a medical subspecialty. Telemedicine decreases the travel and work-loss burdens for the parents/guardians of CSHCN and potentially lessens the chances for medical errors caused by delayed or lack of communication between the subspecialist and primary care provider. Last, telemedicine allows patients to remain in the care of their primary care physicians, assists community providers in retaining patients, and may improve patient and parent/guardian perception of their primary care providers.

The data from our pretelemedicine survey are consistent with previous studies that investigated the perceived advantages and disadvantages of telemedicine. The issues of missed work, costs and time for transportation, and the time needed to schedule a face-to-face appointment as barriers to specialty and subspecialty services are consistent with the concerns expressed by participants in our study.¹² Similarly, in a survey conducted by Allen and Hayes¹³ on patient satisfaction with telemedicine in a rural clinic, faster and easier access to a subspecialist was noted as the primary advantage of telemedicine. That study reported that patients “would rather see specialists on the TV system than to wait for a few days to see him or her in person.”

Karp et al⁹ reported similar overall parent/guardian satisfaction when using telemedicine to provide subspecialty consultations to CSHCN. Their experience was analogous to ours insofar as only a few subspecialty groups conducted a majority of the consultations. In the report by Karp et al, allergy-immunology and pulmonology accounted for 64% of the consultations, and in our experience, 89% of the consultations were performed by endocrinology-obesity and child psychiatry. These results are consistent with previous telemedicine research that has demonstrated that some health care providers are more likely to adopt and increase their utilization of telemedicine technologies, whereas others are slow to adopt or never adopt such technologies.^{14,15} In our experience, some clinicians prefer to have personal contact with their patients and have variable degrees of comfort with new technologies, which may partly explain why some subspecialists were more or less likely to adopt telemedicine. Other reasons for the

unequal use of telemedicine among subspecialists include the varying need for different subspecialists in Oroville, the families’ willingness to participate in telemedicine, the referring physicians’ preference to refer patients using telemedicine, the subspecialists comfort with using telemedicine, and the frequency with which patients need to be seen for their condition.

Telemedicine, however, is not without its critics. Some authors believe that using telecommunications technology threatens basic components of medical care and urge careful consideration of its use.¹⁶ Stanberry,¹⁷ for example, warned “against excessive reliance on technology to the detriment of traditional clinician-patient relationships and against complacency regarding the risks and responsibilities—many of which are as yet unknown—that distant medical intervention, consultation and diagnosis carry.” He emphasized that, with telemedicine, an intangible aspect about traditional health care is threatened, which is “the comfort and compassion human beings can only bring each other when they are face to face.”

There are several limitations to our data. First, because our pretelemedicine telephone survey was limited to English-speaking parents, biases could have been introduced such that the reported perceived advantages, disadvantages, and proportion of families willing to participate in telemedicine is not reflective of non-English-speaking families. Second, certain subspecialties such as endocrinology-obesity have been relatively more successful at incorporating telemedicine, measured in terms of number of consultations. This variance between subspecialty areas may have been caused by the reluctance of parents/guardians or subspecialty providers, or both, to use and maintain telemedicine because of factors related to their specific subspecialties, respectively. Because of this, the feasibility of this program may not be possible to duplicate in other settings. Additionally, although the referring physicians from Oroville were general pediatricians, one might expect that the perceptions of the need for telemedicine (or subspecialty consultation) would be different between referring pediatricians and/or other primary care physicians. We believe that the success of a telemedicine program depends on financial and personnel resources, patient and parent/guardian attitudes, the referring and consulting health care providers’ commitment to

telemedicine, and the specific medical condition being considered for telemedicine consultation.

Our report of a telemedicine program established to provide pediatric subspecialty services to CSHCN is among the first such reports in the literature. This program should encourage other providers and patients to use and evaluate the use of telemedicine as a means of providing subspecialty care as well as promote similar efforts to attain medical homes for CSHCN living in rural, underserved regions.

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USELESS ROUTINES

“In a series of reports that began in 1989 and is still continuing, an expert committee sponsored by the federal Agency for Health Care Research and Quality, an arm of the Department of Health and Human Services, found little support for many of the tests commonly included in a typical physical examination for symptomless people.

It found no evidence, for example, that routine pelvic, rectal and testicular examinations made any difference in overall survival rates for those with no symptoms of illness.”

Kulata G. Annual physical checkup may be an empty ritual. *New York Times*. August 12, 2003

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