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ACCEPTANCE OF TELEMEDICINE IN PEDIATRIC RHEUMATOLOGY

A National Survey of Pediatricians

A Thesis Submitted to the

Yale University School of Medicine

in Partial Fulfillment of the Requirements for the

Degree of Doctor of Medicine

by

Kathleen Jo Elayda Corbin

2010

ACCEPTANCE OF TELEMEDICINE IN PEDIATRIC RHEUMATOLOGY: A NATIONAL SURVEY OF PEDIATRICIANS. Kathleen Jo E. Corbin, Lisa G. Suter. Section of Rheumatology, Department of Internal Medicine, Yale University School of Medicine, New Haven, CT.

The specific aims of this study were to characterize: 1) the impact of the pediatric rheumatology workforce shortage from the perspective of pediatric rheumatologists and general pediatricians, and 2) the acceptance of telemedicine, including both video conferencing and "store and forward" technology, as a potential solution for the pediatric rheumatology workforce shortage. We hypothesized that physicians practicing in settings with decreased access to pediatric rheumatology would perceive a greater impact of the workforce shortage and would be more likely to accept telemedicine as a substitute for face-to-face patient care. A web-based survey was distributed to members of the American Academy of Pediatrics (AAP) Section on Rheumatology, American College of Rheumatology Section on Pediatric Rheumatology, and a geographically representative sample of AAP state chapters. In addition to responses from 141 pediatric rheumatologists and 613 general pediatricians, we also received responses from 140 other pediatric subspecialists. Rheumatologists were significantly more likely than general pediatricians and other subspecialists to report that the workforce shortage adversely affected their patients (79.2% vs. 61% and 42.2%, respectively; all $p<0.001$). Delay of diagnosis was identified as one of the most important consequences of the workforce shortage by 64.5% of rheumatologists, 43.7% of general pediatricians, and 30% of other subspecialists. Rheumatologists and general pediatricians practicing in predominantly

rural states were more likely than those in urban states to report their patients were affected by the workforce shortage (90.9% vs. 73.5%, p=0.039 for rheumatologists, 71.6% vs. 46.6%, p=0.001 for general pediatricians). A minority of rheumatologists, general pediatricians, and other subspecialists accepted video conferencing as a substitute for face-to-face patient care for routine new (23.4% vs. 30.8% vs. 25%, respectively), routine follow-up (31.2% vs. 38.5% vs. 37.1%, respectively), and urgent visits (34% vs. 35.7% vs. 35.7%, respectively). Similarly, a minority of all respondents accepted "store and forward" telemedicine as a substitute for face-to-face patient care. In multivariable analysis adjusting for technology use, number of years in practice, and concern about liability, general pediatricians practicing in predominantly rural states were significantly more likely to accept video conferencing (e.g. OR 1.70, 95% CI 1.16-2.48 for new visits). For rheumatologists and general pediatricians, concern about liability was significantly negatively associated with acceptance of video conferencing (e.g. OR 0.43, 95% CI 0.23-0.80 and OR 0.68, 95% CI 0.52-0.90, respectively for new visits) as well as "store and forward" telemedicine (e.g. OR 0.35, 95% CI 0.14-0.87 and OR 0.54, 95% CI 0.38-0.76, respectively for new visits). Open-ended responses highlighted the need for experienced examiners at the remote end of telemedicine consultations as well as the potential educational value of telemedicine. Our data suggest that telemedicine would best be utilized for the care of children with rheumatic diseases in under-resourced areas, either for urgent triage decision-making or in the context of multidisciplinary care to allow for communication and education with both providers and parents. In addition, telemedicine cannot be effectively adopted on a large-scale basis until liability concerns regarding remote care are addressed.

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Table of Contents

Introduction 1

Research Aims 17

Methods 19

Results 28

Discussion 48

References 54

Appendices:

Appendix A: Survey Instrument for Rheumatologists

Appendix B: Survey Instrument for General Pediatricians

Appendix C: Survey Invitation Cover Letter

Introduction

Burden of Pediatric Rheumatic Disease

Rheumatic diseases are among the most common chronic illnesses of childhood. Approximately 294,000 children in the United States are affected by autoimmune inflammatory conditions such as juvenile idiopathic arthritis (JIA), systemic lupus erythematosus (SLE), juvenile dermatomyositis, and spondyloarthropathy.(1) JIA, the most common pediatric rheumatic disease with a prevalence of 7 to 401 per 100,000 children, occurs as commonly as juvenile diabetes mellitus and four times more commonly than cystic fibrosis.(2, 3) SLE affects patients of all ages, but approximately 20% of cases are diagnosed in children.(4, 5) The prevalence of SLE in children is estimated to be 10 to 20 per 100,000 children.(6)

These diseases are associated with a significant burden of disease and disability. The hallmark of JIA is joint inflammation, which can cause joint destruction, abnormal growth, and decreased physical functioning. Patients can also have extra-articular manifestations, such as uveitis, which occurs in 10 to 20% of patients and can lead to cataracts, glaucoma, and vision loss.(3, 7) Some patients with JIA are unable to participate in normal childhood activities, including school. One study of 155 Canadian children with JIA found 56.7% missed at least one day of school per year compared to 29.6% of age-matched controls ($p<0.05$).(8) Additionally, studies have shown that a significant number of patients continue to have active disease into adulthood. A 2002 study of 259 adults an average of 28.3 years after diagnosis of JIA found that 43.4% had clinically active disease and 42.9% had severe disability as measured by the Stanford

Health Assessment Questionnaire, a validated tool for measuring health status in arthritis patients.(9, 10)

SLE is a systemic inflammatory disease affecting multiple organs. In children, the most common manifestations are dermatologic (rash, photosensitivity), renal (nephritis), neuropsychiatric (headaches, cognitive dysfunction, psychosis), and musculoskeletal (arthritis, arthralgia). Pediatric SLE typically presents as severe disease requiring high-dose corticosteroids and immunosuppressive therapy.(4, 11) Patients with SLE also experience impaired functioning and inferior quality of life. A 2009 study comparing 98 pediatric SLE patients with healthy controls found the disease was associated with lower physical and social functioning scores on the Child Health Questionnaire.(12) A 2008 study of adolescents with SLE found 67% of patients had high levels of fatigue and impaired aerobic fitness compared to age-matched controls.(11)

JIA, SLE, and other rheumatic diseases are not only a burden on patients and their families, but also represent a significant burden on the health care system. Pharmacologic treatments for these conditions include non-steroidal anti-inflammatory drugs (NSAIDs), corticosteroids, disease-modifying anti-rheumatic drugs (DMARDs), anti-malarial drugs, and immune-modulating drugs such as cytokine inhibitors, all of which are associated with potential morbidity and require close monitoring. Based on national data from ambulatory health care visits from 2001 to 2004, the Centers for Disease Control estimates that patients with JIA and other forms of childhood arthritis make approximately 827,000 ambulatory health care visits per year, including approximately 83,000 emergency department visits per year.(13) A 2006 study of the economic impact of pediatric SLE on the U.S. health care system calculated the annual direct cost of care

to be $16,134 per patient per year, or approximately $146 million to $650 million annually for the population of children with SLE.(14)

Clinical Benefits of Specialty Rheumatology Care

Involvement of rheumatologists in the care of patients with rheumatic diseases has been linked to improved outcomes in patients of all ages. In a prospective study of 282 adults with rheumatoid arthritis by Ward, et al.,(15) patients treated regularly by a rheumatologist had significantly lower rates of functional disability progression (measured by the Health Assessment Questionnaire Disability Index) compared to patients treated intermittently by a rheumatologist or those never referred to a rheumatologist. The differences in disability progression were associated with more aggressive treatment, including second line anti-rheumatic medications, intra-articular steroids, and joint surgery. In another study by the same group, increased frequency of visits to rheumatologists correlated with decreased pain and less disability (measured by Health Assessment Questionnaire Disability Index) in 127 adults with rheumatoid arthritis.(16)

In pediatric patients, improved outcomes are particularly linked to early diagnosis as well as continued treatment by specialists. A study of 356 Canadian children with JIA found that shorter time from symptom onset to diagnosis correlated with inactive disease after six months and better quality of life scores.(17) Early treatment of JIA patients with intraarticular steroids was associated with less leg length discrepancy compared to patients not receiving treatment in a retrospective study of 30 children in Washington and North Carolina.(18)

Recent advances in treatment of rheumatic diseases are likely to further increase the benefits of early specialty care. In the past decade, 10-year survival rates in pediatric SLE have risen as high as 85 to 90%, compared to 75% in the 1980s.(5, 6, 19) This improvement in survival parallels the maturation of the field of pediatric rheumatology, including the addition of board certification as well as dramatic improvements in medical therapy for rheumatic diseases during this time period. As studies have found that the greatest risks of morbidity and mortality in pediatric SLE are associated with delay of diagnosis and treatment,(4) there may be even greater outcome disparities between children with ready access and those with reduced access to pediatric rheumatology care.

Clinical Benefits of Specialty Pediatric Care

In other specialties, treatment of children by pediatric-trained specialists is associated with improved quality of care and outcomes. A 1986 study of 463 pediatric patients with respiratory failure and head trauma in Washington and Oregon found that admission to a hospital with a pediatric intensive care unit and pediatric subspecialists was associated with increased survival.(20) The odds of mortality for patients admitted to hospitals without a pediatric intensive care unit or pediatric subspecialists was significantly higher after adjusting for severity of illness (OR 1.10, 2.36, and 7.71 for low, moderate and high severity of illness, respectively).

A national study of all children with end-stage renal disease undergoing dialysis in 1990 found that pediatric patients were twice as likely to receive peritoneal dialysis (which has been associated with improved outcomes in children) than hemodialysis when

treated in a dialysis facility with greater pediatric experience, compared to facilities with less pediatric experience.(21)

A review of 1,797 children admitted to Cook County Hospital from 1987 to 1993 found that mortality was significantly lower for children suffering blunt trauma who were treated in their Pediatric Trauma Center compared to the national norms established by the Major Trauma Outcome Study, a study of the collective outcomes of 139 North American trauma centers.(22) Similarly, a study of all ureteroneocystostomies performed from 1990 to 1993 at the Primary Children's Medical Center in Utah found significantly lower hospital costs, shorter length of stay, and lower complication rates when the procedure was performed by a pediatric urologist as compared to a general urologist.(23)

Pediatric Rheumatology Workforce Shortage

Rheumatology is one of the smallest subspecialties in pediatrics, and the workforce of pediatric rheumatologists in the U.S. is insufficient to meet the clinical needs of the population of pediatric patients with rheumatic diseases. Since certification by the American Board of Pediatrics first became available in 1992, 237 physicians have become board-certified pediatric rheumatologists and approximately 220 are currently practicing.(24) The U.S. Department of Health and Human Services estimates that at least 337 pediatric rheumatologists are needed to provide adequate clinical care for the population of children with rheumatic diseases in this country.(7) The American Academy of Pediatrics Section on Rheumatology estimates the current need at approximately 400 pediatric rheumatologists.(25)

In a 2004 survey by the Arthritis Foundation (AF) and American College of Rheumatology (ACR), 64.4% of responding pediatric rheumatologists reported a local shortage of pediatric rheumatology providers, and all respondents reported a national shortage.(7) A 2004 survey of pediatric residency directors found that 41.7% of respondents felt that there was an inadequate supply of pediatric rheumatologists in their catchment area, and 48.8% felt there was an inadequate supply in their state.(7)

The small number of pediatric rheumatologists is accentuated by their uneven geographic distribution, which leaves a large portion of the pediatric population with limited access to specialty rheumatology care. A 2003 workforce study by Mayer, et al. found that 98.7% of pediatric rheumatologists are clustered in metropolitan areas, and only 3% of U.S. counties had one or more pediatric rheumatologist.(26) According to the American Board of Pediatrics, 13 states had no pediatric rheumatologist in 2008, including Arkansas, Louisiana, and Nevada, which are each home to more than half a million children.(24) This distribution leaves nearly half (45.8%) of the pediatric population in the country more than 50 miles away, and one-quarter (26.4%) of the pediatric population more than 100 miles away from a pediatric rheumatologist.(26) The mean distance from a child to a pediatric rheumatologist is 60 miles; in contrast, the mean distance to a pediatric cardiologist is 22 miles, and to a pediatric endocrinologist or hematologist/oncologist is 26 miles.(27)

Most pediatric rheumatologists practice in an academic setting and are involved in research and educational activities in addition to clinical care, which further limits accessibility to patients. The 2004 AF/ACR survey found that 89.3% of pediatric rheumatologists practice in an academic setting, and on average, pediatric

rheumatologists spend only 52% of their time involved in patient care.(7) Previous surveys by the ACR and Mayer, et al. showed similar findings.(28, 29) According to ACR membership records, approximately one-third of pediatric rheumatologists report that patient care is not their primary professional activity.(7)

According to pediatric rheumatologists, limited access has adverse consequences for patients. In the 2004 AF/ACR survey, 89.4% of pediatric rheumatologists reported delay of diagnosis and 94.2% reported delay in treatment as adverse outcomes of the workforce shortage.(7) Additionally, more than 85% of pediatric rheumatologists reported the workforce shortage results in misdiagnosis and inappropriate treatment of patients.

The workforce shortage also has consequences for pediatric rheumatologists, especially increased workload. In about 60% of states with a pediatric rheumatologist, the number of children with rheumatic diseases exceeds 1,000 patients per specialist.(7) Workforce studies have found that in addition to traditional clinical duties, pediatric subspecialists spend large amounts of time providing telephone consultations which are generally not compensated.(30)

General pediatricians have not yet been surveyed about the workforce shortage in pediatric rheumatology. In other specialties, primary care pediatricians and specialists agree about workforce shortages. In a 2005 survey of child neurologists, 83% felt that the supply of child neurologists was inadequate.(31) In a 2009 survey of pediatricians, 79% of respondents felt the supply of child neurologists in their area was inadequate, and 90% felt the national supply was inadequate.(32)

Potential Solutions to the Workforce Shortage

(1) Internist Rheumatologists as Substitute Providers

Internist rheumatologists serve as recourse for some children with limited access to pediatric rheumatologists. A study of children with rheumatic diseases in Missouri in 1998 found that two-thirds of children with a known rheumatic disease received care from an internist rheumatologist.(33) A 2004 survey of California rheumatologists found nearly half (46%) of pediatric rheumatology patients in the state were cared for by internist rheumatologists.(29) A survey of rheumatologists in Washington in 1996 found that 62% of internist rheumatologists treated pediatric patients.(34) A national survey of rheumatologists in 2003 found that approximately one-quarter of internist rheumatologists provide care to children.(26) This survey found the likelihood that an internist rheumatologist saw pediatric patients significantly increased with increasing distance from a pediatric rheumatologist. Compared to internist rheumatologists practicing within 10 miles of a pediatric rheumatologist, the odds of treating children were higher for those practicing 10 to 50 miles from a pediatric rheumatologist (OR 1.49), and were more than double for those more than 200 miles from a pediatric rheumatologist (OR 2.25). The California and Washington studies also found distance to be an important determinant in treating pediatric patients.(29, 34)

Participation of internist rheumatologists increases the availability of rheumatology care to children. More than half (53.2%) of children in the U.S. live within 10 miles of a pediatric rheumatologist or internist rheumatologist who treats children.(26) However, internist rheumatologists provide care for only a subset of children. The 2004 California survey found that approximately half of pediatric patients treated by internist

rheumatologists were adolescents.(29) Of 78 internists who reported caring for children in that survey, fewer than 5% were involved in the care of patients younger than 12 years of age. Given that the majority of pediatric rheumatic diseases have their peak onset in children less than 10 years old, with the exception of SLE which occurs most commonly in adolescents, this practice pattern likely excludes a large number of children in need of rheumatologic care.(6)

The quality of care internist rheumatologists provide for children has not been studied, but evidence suggests some internists may not be adequately trained to treat children. Nearly two-thirds (65.8%) of California internist rheumatologists providing care for children reported minimal or no exposure to pediatric rheumatology during their fellowship training.(29) In the Washington study, 12 of 31 internist rheumatologists caring for children reported minimal or no pediatric rheumatology training.(34)

In both the California and Washington studies, the majority of internist rheumatologists who saw children reported comfort treating common conditions like JIA and SLE, but comfort levels were lower for less common rheumatic diseases and those usually diagnosed in younger children. In California, 80.8% of internist rheumatologists involved in the care of children reported comfort treating polyarticular JIA, pauciarticular JIA, and psoriatic arthritis, and 72% reported comfort with SLE.(29) In contrast, only 24.7% were comfortable with Kawasaki disease, 43.8% were comfortable with polyarteritis nodosa, and 56.2% were comfortable with dermatomyositis. Findings were similar in Washington, where 89% of internist rheumatologists who cared for children were comfortable with polyarticular and pauciarticular JIA, 83% were comfortable with psoriatic arthritis, and 77% were comfortable with SLE, but only 36% were comfortable

with Kawasaki disease, 44% were comfortable with polyarteritis nodosa, and 52% were comfortable with Wegener's granulomatosis.(34)

(2) Increase the Supply of Pediatric Rheumatologists

Instead of relying on substitute providers, the optimal solution to the workforce shortage in pediatric rheumatology would be to increase the number of pediatric rheumatologists. However, a number of factors indicate that the workforce shortage is likely to continue. Although the number of trainees in pediatric rheumatology fellowship programs has more than tripled from 24 in 1998 to 88 in 2008, at least one-fourth of available fellowship positions have remained unfilled in recent years.(7, 24) Low levels of interest in pediatric rheumatology may be due to limited opportunities for exposure to the field in residency curricula. A 2004 survey of pediatric residency directors found that only 70 of 127 responding programs had one or more pediatric rheumatologist on staff, and 20.5% of programs did not offer a pediatric rheumatology rotation, either on- or off-site.(35)

Additionally, there is evidence of considerable attrition of fellows and practicing rheumatologists. From 1998 to 2008 the number of fellows has dropped by an average of 21% between training year one and training year three.(36) The reason for this pattern is not well understood. In the 2004 AF/ACR survey, 26.3% of pediatric rheumatologists reported they had decreased the amount of time they spent in clinical care over the past five years, and 31.7% reported plans to decrease their time in clinical care over the next five years.(7) The primary reason for decreasing clinical time was research obligations, followed by retirement. Taking these circumstances into account, it is projected that in

the year 2025 there will continue to be a need for more than 100 additional pediatric rheumatologists,(37) which represents a nearly 50% increase over the current national workforce.

Analysis of practice location of pediatric rheumatologists suggests that the uneven geographic distribution of specialists is also likely to continue. A 2003 study by the American Board of Pediatrics found that 80% of recent graduates of pediatric rheumatology fellowships practice in a county with at least one more experienced pediatric rheumatologist.(7)

(3) Increase Access to Pediatric Rheumatologists Using Telemedicine

In a growing number of medical specialties, telemedicine has been used to increase access to care. Telemedicine is broadly defined as the use of electronic communications technology for the provision of patient care.(38) Two major categories of telemedicine currently being used for specialty consultations are “store and forward” telemedicine, which involves electronic transfer of digital information, and video conferencing, which allows for live interaction with real-time audio and video. Examples of both types of telemedicine have been successfully implemented in pediatrics.

Both “store and forward” telemedicine and video conferencing have been used to increase access to pediatric cardiologists. A 2006 Canadian study found that pediatric cardiologists were able to differentiate between innocent and pathologic murmurs from digitally recorded heart sounds of 55 children with a mean sensitivity of 0.93 and mean specificity of 0.86.(39) In a 2002 study, pediatric cardiologists at Children’s National Medical Center in Washington, D.C. used video conferencing to remotely guide

sonographers and interpret neonatal echocardiograms at two community hospitals.(40) Of 500 studies performed in this way, the telemedicine diagnosis was altered for only three cases on subsequent review. Telemedicine also eliminated the need for face-to-face consultation for 194 patients.

More than half (54%) of pediatric dermatologists reported using either "store and forward" telemedicine or video conferencing in a 2006 survey.(41) Evidence suggests telemedicine is diagnostically reliable and accurate when compared with traditional face-to-face consultation with a dermatologist. One study comparing diagnosis by digital photograph with face-to-face diagnosis for 135 patients at Children's Hospital of Wisconsin pediatric dermatology clinic found 69% agreement when the photographs and live patients were evaluated by two dermatologists, and 82% agreement when photographs and live patients were evaluated by the same dermatologist.(42) In another study, a review of 429 pediatric teledermatology consultations in a private dermatology practice in San Francisco found that in only 6% of cases did the dermatologist feel an additional in-person consultation was necessary.(43)

Telemedicine has also been shown to improve outcomes of children with asthma. A study of a school-based video conferencing system for 96 children with asthma in inner-city San Francisco found that after three telemedicine appointments scheduled over a 32-week period with an asthma specialist at San Francisco General Hospital, subjects demonstrated significant improvement in asthma knowledge, as well as physical and social functioning as measured by the Child Health Survey of Asthma.(44) Additionally, a trend toward a decrease in the number of asthma attacks was observed among study subjects. A smaller study of asthma patients in Texas seen at school via video

conferencing with a pediatric asthma specialist found an 83% increase in the number of symptom-free days and 44% reduction in symptom score severity over a 24-week period.(45) Improvement in quality of life was reported by patients and caregivers.

Telemedicine is especially important in bringing specialty care to children in rural areas. Approximately 20% of the U.S. pediatric population lives in rural areas, but only 11% of physicians practice in those areas. The majority (54%) of physicians practicing in rural areas are primary care providers,(46) and pediatric subspecialists in particular tend to practice in academic centers and metropolitan areas.(27, 30)

In rural areas of Georgia and California, initial studies have shown that video conferencing effectively facilitated remote consultation for children with special health care needs (CSHCN) with subspecialists in tertiary medical centers. In Georgia, 333 telemedicine consultations were performed from 1995 to 1997, most commonly for patients with asthma and seizure disorders.(47) When surveyed, 48% of pediatricians involved in the study reported they felt telemedicine was adequate for initial consultations, and 84% felt telemedicine was adequate for follow-up consultations. Participating pediatricians were found to have more positive attitudes as they gained more experience with telemedicine. In California, 130 specialty telemedicine consultations for CHSCN were carried out from 1999 to 2002.(48) The most common specialties consulted were endocrinology, psychiatry, and gastroenterology. Of the 81 physicians involved, 79 rated their satisfaction with telemedicine as “excellent” or “very good.” Almost all (98%) of parents/guardians stated they wished to continue telemedicine consultations rather than travel to specialty clinics for routine face-to-face appointments.

In recent years, video conferencing has been increasingly used to enhance pediatric care in the acute setting. From 2006 to 2008, 63 telemedicine consultations between rural emergency departments in Vermont and upstate New York and pediatric intensivists at the University of Vermont resulted in transfer of 61 critically ill patients to a tertiary care hospital.(49) Consultations were most commonly made for respiratory distress/failure, seizures, and infection. Referring physicians and intensivists reported they felt that patient care was improved by telemedicine use 88% and 89% of the time, respectively. A 2006 study comparing video conferencing with in-person consultation for 492 acute visits to the primary care center or emergency department at the University of Rochester found telemedicine diagnosis was accurate in 89% of cases.(50)

Acceptance of Telemedicine as a Solution to the Workforce Shortage

An important part of implementing telemedicine is acceptance on the part of the physicians involved. Acceptance of telemedicine is influenced by many factors. As described above, studies show that some pediatricians feel telemedicine is an adequate way to provide clinical care. There is also evidence, however, that physicians are concerned about the reliability of clinical care provided via telemedicine. In the Georgia study of telemedicine specialty consultations for CSHCN, only 42% of participating pediatricians, including both general pediatricians and specialists, reported confidence in recommendations made via telemedicine.(47) This concern is common throughout the telemedicine literature. In a study of 128 teledermatology consultations at the Massachusetts General Hospital dermatology clinic, two remote dermatologists reported a mean certainty ranging from 7.0 to 7.6 on a scale of 0 to 10, with 10 indicating the

greatest level of certainty, compared to a mean certainty of 8.5 for office-based dermatologists.(51)

Individual and practice characteristics also play a role in physicians' acceptance of telemedicine. In a study of 87 primary care providers involved in the treatment arm of a randomized clinical trial of telemedicine for Medicare patients with diabetes, acceptability was higher among physicians practicing in rural locations compared to urban locations.(52) Rural physicians reported a mean acceptability of 31.9 on a scale of 0 to 36, with 36 representing the greatest level of acceptability, compared to a mean acceptability of 29.0 for urban physicians ($p=0.044$). This study also found that younger age was associated with higher satisfaction with telemedicine in multivariable analysis.

Barriers to acceptance of telemedicine also include systems-level issues such as reimbursement and legal concerns. Reimbursement for telemedicine in the U.S. is greatly variable. Medicaid policies for telemedicine reimbursement are currently in place in only 34 states, and only five states have legislation about private payer reimbursement for telemedicine.(53) A 2003 survey by the American Telemedicine Association found that telemedicine reimbursement by private payers is highly unpredictable.(53) In the 2006 survey of pediatric dermatologists, 86% of respondents reported they were not regularly reimbursed for "store and forward" teledermatology consultations.(41)

Several sources report legal barriers to adoption of telemedicine, especially concern regarding malpractice laws and state-based licensure.(54-56) Respondents to the 2006 pediatric dermatology survey reported medicolegal ramifications as a significant barrier to the use of telemedicine.(41)

Other systems-level barriers to acceptance of telemedicine include the cost and manpower associated with implementing and supporting the technology. A 2009 survey of health information technology use in 109 U.S. children's hospitals found that 25.3% of responding chief information officers cited lack of financial support, and 29.2% cited insufficient staff as major barriers to adoption of various types of health information technology.(57)

Summary and Goals

The current supply of pediatric rheumatologists is not sufficient to address the needs of children with rheumatic diseases. While data suggests pediatric rheumatologists generally agree about the adverse consequences of the pediatric rheumatology workforce shortage, to our knowledge no data exists examining the attitudes and opinions of general pediatricians regarding the impact of the workforce shortage.

Telemedicine provides a means to overcome barriers to access in a number of pediatric specialties and poses a potential solution to the workforce shortage in pediatric rheumatology. To date, no study has examined the use of telemedicine in this field. An important first step is to explore attitudes and opinions of both general pediatricians and pediatric rheumatologists about the possibility of using telemedicine in pediatric rheumatology.

The goal of this work is to address these gaps in knowledge.

Research Aims

Specific Aim 1

Characterize the impact of the workforce shortage in pediatric rheumatology from the perspective of pediatric rheumatologists and general pediatricians.

Hypotheses:

(a) Pediatric rheumatologists and general pediatricians agree about adverse consequences of the workforce shortage, e.g. long wait times for appointments, delay of diagnosis, misdiagnosis, delay of treatment, inappropriate treatment.

(b) Physicians in an academic practice setting perceive a lesser impact of the workforce shortage than physicians in a private practice setting.

(c) Physicians practicing in areas with decreased access to pediatric rheumatologists (e.g. states with a predominantly rural population, states with few or no pediatric rheumatologists) perceive a greater impact of the workforce shortage.

(d) Pediatric rheumatologists who experience a greater burden from "workarounds" (e.g. uncompensated telephone consultation) will perceive a greater impact of the workforce shortage.

Specific Aim 2

Characterize pediatric rheumatologists and general pediatricians' acceptance of telemedicine as a potential solution for the workforce shortage in pediatric rheumatology.

Hypotheses:

(a) Physicians who have prior experience with technology are more likely to accept telemedicine.

(b) Younger physicians, measured by number of years in practice as a surrogate for age, are more likely to accept telemedicine.

(c) Physicians practicing in areas with decreased access to pediatric rheumatologists are more likely to accept telemedicine.

(d) Pediatric rheumatologists are less likely than general pediatricians to accept telemedicine due to increased concern about potential barriers.

(e) Pediatric rheumatologists who experience a greater burden from "workarounds" will be more likely to accept telemedicine.

Methods

To achieve the Specific Aims listed above, a survey instrument addressing physician attitudes about the impact of the pediatric rheumatology workforce shortage and the role of telemedicine to address the workforce shortage was developed and administered to a national sample of pediatric rheumatologists and general pediatricians.

Survey Development

The survey instrument was developed using a combination of literature review and expert opinion. A literature search was performed using MEDLINE to identify English-language publications pertaining to the pediatric rheumatology workforce, telemedicine use and acceptance, and physician attitudes toward those topics. The search included combinations of the following MeSH terms: pediatric rheumatology, workforce, pediatric rheumatic disease, childhood arthritis, juvenile arthritis, telemedicine, telehealth, attitudes, acceptance, barriers. The literature search was performed by the author.

Prior surveys examining physician attitudes toward the pediatric rheumatology workforce shortage are summarized above in the Introduction. Many of the issues identified, such as previously recognized consequences of the pediatric rheumatology workforce shortage, were incorporated into the survey.

The literature search found no studies examining attitudes toward the use of telemedicine in pediatric rheumatology. Studies examining attitudes toward telemedicine in other specialties identified a number of factors affecting telemedicine acceptance, which are summarized above in the Introduction. Systems-level barriers to the adoption

of telemedicine, including lack of financial and technological support for installing and maintaining telemedicine technology, were consistent across specialties and among both pediatric and adult patient populations. Another recurrent barrier was concern about the reliability of clinical information obtained via telemedicine. Because these issues are well documented, we chose to exclude them from the survey and focus on topics that might be specific to the care of children with rheumatic disease.

Expert opinion was compiled from interviews with two community-based general pediatricians, two academic pediatric rheumatologists, two health informatics specialists, and one physician investigator who specializes in pediatric workforce issues. All interviews were conducted by the author. Each individual was asked to identify facilitators and barriers to the use of telemedicine in clinical practice. Clinicians were asked open-ended questions about their experiences caring for or referring patients with suspected or known rheumatologic disease. Themes identified during these interviews included: workarounds to compensate for the pediatric rheumatology workforce shortage and specific barriers to telemedicine use including comfort with technology, liability, and reimbursement.

Using the core issues identified in the literature search and interviews, a preliminary version of the survey instrument was written by the author. This was presented to both generalist and specialist pediatricians at the General Pediatrics Research Conference at Yale University School of Medicine in September 2008. The survey instrument was also pilot-tested with three rheumatologists and three general pediatricians. The survey instrument was revised by the author in conjunction with the research team to incorporate feedback from these two review processes.

Separate versions of the survey instrument were generated for pediatric rheumatologists and general pediatricians. Each final survey was composed of 42 questions. Demographic information, practice characteristics, experience with technology, and physician attitudes about telemedicine were assessed using multiple-choice questions. Physician attitudes about potential barriers were asked using three-point Likert scales. Open-ended questions asking about physician attitudes were also included.

The decision was made to use an internet-based survey to allow for rapid, cost-effective communication with a large number of physicians. Additionally, we felt using email and the internet would allow us to sample a group of physicians most open to adopting new technology such as telemedicine. Internet-based versions of the surveys were generated using SurveyMonkey, an online survey tool.(58) Print versions of the survey instruments are included as Appendices A and B.

Sampling Strategy

Inclusion criteria for all survey subjects were the following: physicians currently providing primary or rheumatologic care for pediatric patients in the U.S. for whom email or telephone contact information was available. All responses were collected between December 2008 and June 2009. Participation was voluntary and anonymous. The Yale University Human Investigations Committee granted approval for this study.

To identify physicians providing rheumatologic care for pediatric patients, the author first contacted the Section on Rheumatology of the American Academy of Pediatrics (AAP). Access was granted to the section's email list-serve. Two of 123 members were excluded: one was a member of the research team, and another was an

international physician. The remaining 121 members represent approximately 51% of U.S. pediatric rheumatologists. In addition, the author identified 95 members of the Section of Pediatric Rheumatology of the American College of Rheumatology (ACR) who met inclusion criteria and had not already been contacted through the AAP.

To our knowledge, there are no existing publicly available lists of general pediatricians' email contact information. The AAP and American Medical Association recommended purchasing email addresses through an approved third-party marketing firm (Medical Marketing Services, Inc., Wood Dale, IL). The cost for these services was prohibitively expensive. Therefore, to obtain a national sample of general pediatricians' email addresses, the author chose to contact state chapters of the AAP.

As outlined above in the Research Aims, we hypothesized that geographic region, proportion of the population living in rural areas, and availability of pediatric rheumatologists would impact our findings. Therefore, we stratified our sample by those three parameters:

1) Geographic region: We used U.S. Census definitions of geographic region to divide the 50 states into four groups: Northeast, South, Midwest, and West. (59)
2) Proportion of population in rural areas: Based on the national median percent rural population of 27.2%,(59) we stratified states as "Urban" (defined as low proportion or $\leq$ 27% of the population located in rural areas) versus "Rural" (defined as high proportion or > 27% of the population located in rural areas).
3) Availability of pediatric rheumatologists: Based on the median pediatric rheumatologist per 100,000 children ratio of 0.2, (24) we defined "Low"

availability states as those with a ratio $\leq$ 0.2, versus "High" availability states with a ratio > 0.2.

States were stratified first by geographic region, then proportion rural population, and finally by availability of pediatric rheumatologists.

States within each stratification were assigned random numbers using a random number generator, and state chapters were then contacted based on random number order until one to two state chapters per stratification had agreed to participate. Seven of the 31 state chapters contacted agreed to participate: Colorado, Connecticut, Florida, Georgia, North Carolina, North Dakota, and New Jersey.

We hypothesized that in addition to pediatricians, family physicians might offer a unique perspective about the pediatric rheumatology workforce shortage and the use of telemedicine. We attempted to construct a secondary sample of state chapters of the American Academy of Family Physicians (AAFP); however, the response from these organizations was consistently low, and therefore only one state, Montana, was surveyed.

Survey Distribution

The AAP Section on Rheumatology sent invitations to its members through the section list-serve. Members of the ACR Section of Pediatric Rheumatology were contacted individually by the author via email and/or telephone. All subjects contacted by email received an electronic cover letter with an embedded link to the survey (Appendix C). Subjects contacted by telephone were offered the opportunity to complete the survey over the telephone or to receive an electronic survey. In addition to the initial invitation, subjects received up to three reminder emails.

Six of the seven AAP state chapters sent the electronic cover letter to their own member list-serves. One AAP state chapter and the Montana AAFP chapter gave the author permission to send personal emails containing the cover letter and survey link to their members. In addition to the invitation email, two reminder emails were sent to all chapter lists.

Due to low response rates after the initial distribution period, the survey was reviewed by the research team and truncated to a length of 18 questions, and participants were offered the opportunity to enter into a prize drawing as an incentive to complete the survey. Prizes offered were a one-year membership to the winner's choice of the AAP, ACR, or AAFP, or an equivalent value retail gift certificate. After these changes were made, one to two additional emails were sent to all subjects. The Florida AAP chapter opted not to send the additional emails to its members after these changes were made.

Statistical Analysis

Responses to the two survey instruments were collected in online databases through SurveyMonkey. Data were downloaded and entered into PASW 18 (SPSS Inc., Chicago, IL) for statistical analysis. All analyses were performed by the author.

Unexpectedly, responses from AAP state chapter membership included responses from non-rheumatologist subspecialists (e.g. pediatric infectious disease specialists) in addition to general pediatricians. Because other subspecialists are sometimes in the position of referring patients to rheumatologists, we decided to include these responses in our analysis as a separate group ("Other Subspecialists"). For the purposes of our primary research objectives, these responses were compared to those of pediatric rheumatologists.

Where appropriate, comparisons between responses from general pediatricians and other subspecialists were also performed.

Responses from AAFP members were initially analyzed separately; however, we found that that there were no statistically significant differences (aside from the differences in residency training) when responses from family physician responses were included versus excluded with the responses from general pediatricians. Due to this finding, as well as the small number of responses from AAFP members, we chose to include the family physician responses in the general pediatrician group for the analyses presented here.

Descriptive statistics were used to summarize respondent characteristics, including training and practice characteristics, geographic location, availability of pediatric rheumatologists, and experience with technology. Comparisons of these characteristics were made between responses from rheumatologists and 1) general pediatricians and 2) other subspecialists using Chi-square and Fisher's exact tests.

Our first Specific Aim, physicians' perception of the impact of the pediatric rheumatology workforce, was assessed by asking subjects if they felt the workforce shortage adversely affected their patients. Subjects were also asked about specific consequences of the workforce shortage. These answers were summarized using descriptive statistics, and comparisons were made between rheumatologists and 1) general pediatricians and 2) other subspecialists using Chi-square and Fisher's exact tests. Bivariate analyses were performed within each specialty group to explore the relationship of respondent characteristics and the perceived impact of the workforce shortage. Two-

and three-way tables were constructed to identify trends and Chi-square tests were used to explore significance.

To further investigate factors affecting perceived impact of the workforce shortage, multivariate analysis was performed using step-wise logistic regression. All variables found to have trends and significant associations ($p<0.05$) in the bivariate analyses described above were included in the regression model.

Our second Specific Aim, acceptance of telemedicine, was assessed by asking subjects if they would accept various telemedicine scenarios as a substitute for traditional face-to-face consultation. Telemedicine scenarios included in the survey instrument were consultation by telephone, text-only email, transfer of digital photos or images (referred to as "store and forward"), and video conferencing. Because "store and forward" telemedicine and video conferencing are the major forms of telemedicine currently proposed as viable alternatives to face-to-face care in pediatrics today,(60) we chose to focus our analyses on those telemedicine scenarios. Telemedicine acceptance was summarized using descriptive statistics, and comparisons were made between rheumatologists and 1) general pediatricians and 2) other subspecialists using Chi-square and Fisher's exact tests. Bivariate analyses were performed within each specialty group to explore the relationship between respondent characteristics or perceived impact of the workforce shortage and telemedicine acceptance. Two- and three-way tables were constructed to identify trends, and Chi-square tests were used to explore significance.

To further investigate factors affecting telemedicine acceptance, multivariate analysis was performed using step-wise logistic regression. All variables found to have trends and significant associations ($p<0.05$) in the bivariate analyses described above

were included in the regression model. In addition, we anticipated that several variables (such as use of email, internet, and electronic medical records) would be highly correlated, and thus possibly redundant. We therefore performed sensitivity analysis to examine the impact of systematically eliminating highly correlated variables from the regression model.

Formal qualitative analysis of the responses to open-ended questions was not performed. Open-ended questions included in the survey instrument asked respondents to: 1) identify specific examples of consequences of the pediatric rheumatology workforce shortage, and 2) recommend the optimal role for telemedicine in the care of children with rheumatic diseases. Responses were reviewed and categorized by the author and Dr. Suter. Novel recommendations for addressing the workforce shortage or for the application of telemedicine in pediatric rheumatology are included in the Results section.

Results

Responses

Responses were received from 136 of the 216 pediatric rheumatologists contacted (63%). In addition, responses were received from 784 AAP and AAFP members, including 145 pediatric subspecialists. Our goal was to survey general pediatricians, but because our sample also included subspecialists, the true response rate from general pediatricians is unknown. Based on estimates provided by participating AAP chapters, we believe approximately 80 to 90% of the 6,927 emails sent to those organizations were received by general pediatricians. Thus, the response rate from all pediatricians was 11.3%, and that from general pediatricians alone, approximately 10 to 12%.

Of the 784 AAP and AAFP responses, 26 were excluded because they did not meet inclusion criteria: four respondents were not physicians, one was not in clinical practice, and 21 did not practice in one of the eight targeted states. As mentioned above, 145 responses were from pediatric subspecialists, most commonly allergy/immunology, infectious disease, and cardiology. Five subspecialists were rheumatologists, and their responses were included in the rheumatologist group. Final numbers included in the analysis were: 141 pediatric rheumatologists, 613 general pediatricians, and 140 other pediatric subspecialists.

Respondent Characteristics

Training, Practice Setting, and Years in Practice

Training and practice characteristics of respondents are listed in Table 1. The majority of respondents in all groups completed residency in pediatrics. Other residencies

represented were internal medicine-pediatrics and family medicine. A small number (5.7%) of rheumatologists completed internal medicine residency. While the majority of rheumatologists completed pediatric rheumatology fellowship, 20 (14.2%) completed adult rheumatology fellowship. Additionally, 5.7% of rheumatologists completed allergy/immunology fellowship. Fellowship training of other pediatric subspecialists included allergy/immunology, infectious disease, cardiology, and critical care.

Rheumatologists were significantly more likely than either general pediatricians or other subspecialists to practice in an academic setting (93.5% vs. 51.2% and 78.6%, respectively; all $p<0.01$). Just over half of all respondents (56.4% of rheumatologists, 59.9% of general pediatricians, and 51.1% of other subspecialists) were in practice 20 or fewer years. There was no significant difference in the number of years in practice among specialty groups.

Table 1: Training and Practice Characteristics for Rheumatologists (Rheum), General Pediatricians (Ped), and Other Subspecialists (Subspec).

	Rheum n (%)	**Ped** n (%)	**Subspec** n (%)
Total responses, N	141	613	140
Residency training			
Pediatrics	110 (78)	539 (87.9)	121 (86.4)
Internal Medicine-Pediatrics	14 (9.9)	14 (2.3)	5 (3.6)
Family Medicine	0 (0)	38 (62)	0 (0)
Internal Medicine	8 (5.7)	0 (0)	0 (0)
Rheumatology specialty training			
Pediatric Rheumatology fellowship	112 (79.4)	--	--
Adult Rheumatology fellowship	20 (14.2)	--	--
Academic affiliation[A]	130 (93.5)	304 (51.2)	103 (78.6)
Years in practice[B]			
Less than 5	23 (16.4)	99 (16.6)	17 (13)
5-10	21 (15)	100 (16.8)	17 (13)
11-20	35 (25)	158 (26.5)	33 (25.2)
21-30	47 (33.6)	160 (26.8)	40 (30.5)
More than 30	14 (10)	79 (13.3)	24 (18.3)

A: Total responses received for this question: Rheum N=139, Ped N=594, Subspec N=131
B: Total responses received for this question: Rheum N=140, Ped N=596, Subspec N=131

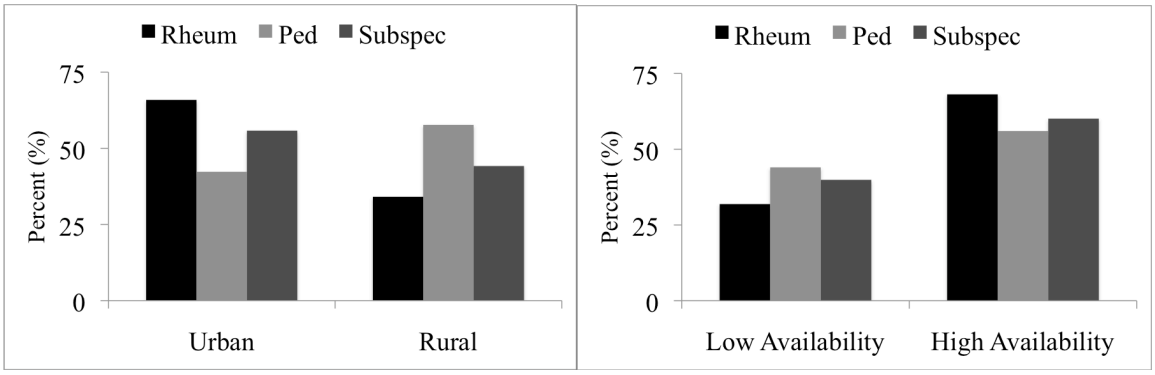
Practice Location and Availability of Pediatric Rheumatologists

Rheumatologists practiced in 33 states and the District of Columbia. The majority of rheumatologists (65.9%) and other subspecialists (55.8%) practiced in predominantly

urban states, while the majority of general pediatricians (57.7%) practiced in predominantly rural states (Fig. 1). The majority of all respondents practiced in states with high availability of pediatric rheumatologists (68.1% of rheumatologists, 56% of general pediatricians, and 60.1% of other subspecialists).

Nearly one-third (31.6%) of general pediatricians reported the nearest rheumatologist was more than 50 miles away, and 17.9% reported the nearest pediatric rheumatologist was 100 miles away. Only 8.3% reported the nearest rheumatologist was in a different state. In contrast, 83.1% of other subspecialists reported the nearest rheumatologist was within 50 miles. The majority of rheumatologists (73.1%) reported that less than half of their patients traveled over 50 miles to see them.

Figure 1: Responses from Urban vs. Rural States and States with Low vs. High Pediatric Rheumatologist Availability.

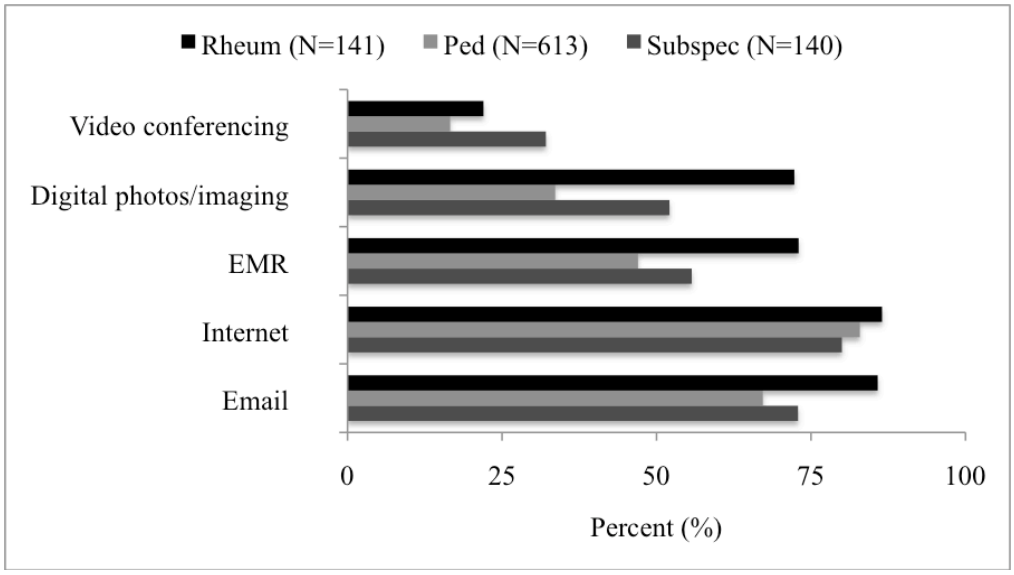


Total responses: Rheumatologists (Rheum), N=138; General Pediatricians (Ped), N=612; Other Subspecialists (Subspec), N=138.“Urban” states had proportion of rural population $\leq$ 27% vs. “rural” states with rural population >27%. The majority of rheumatologists and other subspecialists practiced in urban states, while the majority of general pediatricians practiced in predominantly rural states. “Low” availability states had pediatric rheumatologist per 100,000 children ratio $\leq$ 0.2 vs. “high” ratio > 0.2. The majority of all respondents practiced in high availability states.

Experience with Technology

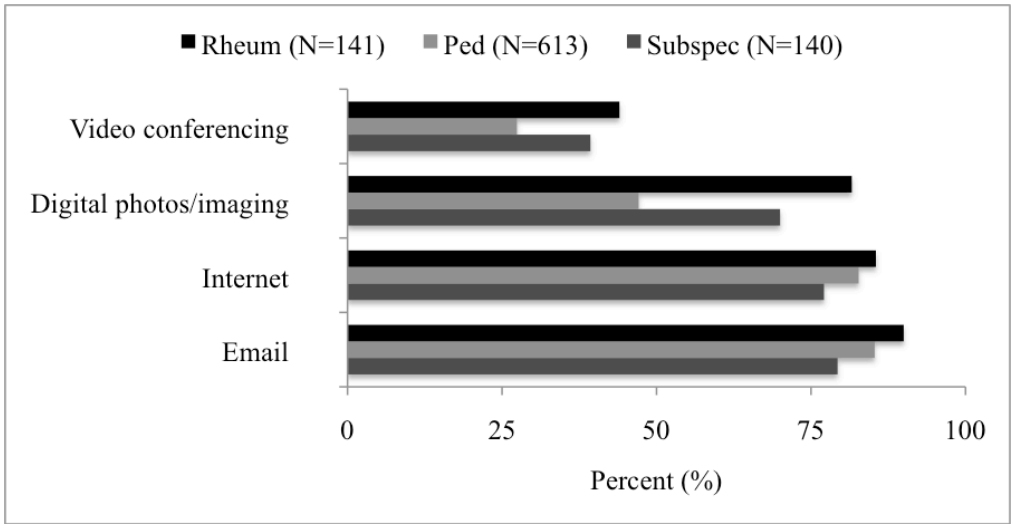
Respondents were asked about experience with technology in their medical practice, i.e. the "professional setting," as well as outside of medical practice, i.e. the "personal setting" (Fig. 2 and 3). There were no significant differences in internet use. Rheumatologists were significantly more likely than both general pediatricians and other subspecialists to use email, electronic medical records, and digital photos or imaging in the professional setting. Rheumatologists reported more use of video conferencing in the professional setting than general pediatricians (22% vs. 16.6%), but this difference was not statistically significant. In the personal setting, rheumatologists were significantly more likely than general pediatricians to use digital photos or imaging (81.6% vs. 47.1%, $p<0.001$) and video conferencing (44% vs. 27.4%, $p<0.001$).

Figure 2: Experience with Technology in the Professional Setting.



Respondents were asked if they used email, internet, electronic medical records (EMR), digital photos/imaging, or video conferencing in their medical practice, i.e. the "professional setting." Rheumatologists (Rheum) were significantly more likely than both general pediatricians (Ped) and other subspecialists (Subspec) to use email, electronic medical records (EMR), and digital photos/imaging (all $p<0.01$).

Figure 3: Experience with Technology in the Personal Setting.



Respondents were asked if they used email, internet, digital photos/imaging, or video conferencing outside of their medical practice, i.e. the "personal setting." Rheumatologists (Rheum) were significantly more likely than general pediatricians (Ped) to use digital photos/ imaging and video conferencing (all $p<0.001$).

Specific Aim 1: Impact of Pediatric Rheumatology Workforce Shortage

Adverse Consequences of the Workforce Shortage

Rheumatologists were significantly more likely than general pediatricians and other subspecialists to report their patients were affected by the workforce shortage (79.2% vs. 61% and 42.2%, respectively; all $p<0.001$). Rheumatologists were also significantly more likely than general pediatricians and other subspecialists to rank delay of diagnosis, delay of treatment, misdiagnosis, and inappropriate treatment as one of the top three consequences of the workforce shortage (Table 2). General pediatricians were more likely than rheumatologists (28.9% vs. 18.4%, $p=0.012$) to include increased parental anxiety as one of the top three consequences of the workforce shortage.

Rheumatologists and general pediatricians disagreed about the average time their patients waited to be seen for an urgent rheumatology referral (Table 3). Rheumatologists

were more likely than general pediatricians to report the average wait time for an urgent referral appointment was 24 hours or less (34.1% vs. 15.5%, p<0.001). In contrast, general pediatricians were more likely than rheumatologists to report the average wait time was more than four days (46.2% vs. 30.2%, p=0.001). There were no significant differences between wait times to urgent referral appointments reported by rheumatologists versus other subspecialists.

Table 2: Most Important Adverse Consequences[A] of the Pediatric Rheumatology Workforce Shortage.

	Rheum n (%)	**Ped** n (%)	**Subspec** n (%)
Total responses, N	141	613	140
Lengthened wait times for appointments	64 (45.4)	277 (45.2)	40 (28.6)[B]
Delay of diagnosis	91 (64.5)	268 (43.7)[C]	42 (30)[C]
Delay of treatment	77 (54.6)	242 (39.5)[C]	38 (27.1)[C]
Misdiagnosis	31 (22)	34 (5.5)[C]	7 (5)[C]
Inappropriate treatment	32 (22.7)	29 (4.7)[C]	4 (2.9)[C]
Increased parental anxiety	26 (18.4)	177 (28.9)[D]	23 (16.4)

A: Respondents were asked to rank the top three consequences of the pediatric rheumatology workforce shortage from the above list. These numbers reflect the number of respondents who ranked a specific consequence as the first, second, or third most important consequence among the six listed options.
B: p<0.01 (All p-values represent analyses comparing the annotated group to rheumatologists.)
C: p<0.001
D: p=0.012

Table 3: Average Time to Appointment for Urgent Rheumatology Referral.[A]

	Rheum n (%)	**Ped** n (%)	**Subspec** n (%)
Total responses, N	129	561	105
24 hours or less	44 (34.1)	87 (15.5)[B]	35 (33.3)
2-3 days	46 (35.7)	215 (38.3)	36 (34.3)
4-7 days	30 (23.3)	123 (21.9)	20 (19)
More than 7 days	9 (7)	136 (24.2)[B]	14 (13.3)

A: Respondents were asked to identify the average wait time (from the time intervals listed above) for a patient in their practice to be seen for an urgent rheumatology referral.
B: Rheumatologists vs. general pediatricians, $p<0.001$

Compensation for the Workforce Shortage via "Workarounds"

Nearly half (46.9%) of rheumatologists reported spending at least 30 minutes on the telephone each week consulting on patients they never see. Fourteen rheumatologists (10.7%) reported spending more than an hour per week, and two (1.5%) reported spending up to two hours per week on such telephone consults. Nearly half (48.5%) of rheumatologists reported traveling at least once a month to a site other than their primary practice to provide rheumatologic care to children.

Factors Affecting Perceived Impact of the Workforce Shortage: Bivariate Analysis

1) Rheumatologists

Rheumatologists practicing in states with low availability of pediatric rheumatologists were significantly more likely than those in high availability states to report the workforce shortage affected their patients (90.2% vs. 74.4%, $p=0.039$). Rheumatologists practicing in predominantly rural states were significantly more likely

than those in urban states to report the workforce shortage affected their patients (90.9% vs. 73.5%, p=0.039). Longer time to urgent referral was significantly associated with increased perceived impact of the workforce shortage. The percentage of rheumatologists reporting the workforce shortage affected their patients increased with greater amounts of time spent in telephone consultations, but this trend was not statistically significant. Factors that did not affect the perceived impact of the workforce shortage for rheumatologists were practicing in an academic setting and traveling to additional sites to provide rheumatologic care.

2) General Pediatricians

General pediatricians practicing in academic settings were significantly less likely than those in private practice to report the workforce shortage affected their patients (54.1% vs. 67.8%, p=0.001). General pediatricians in rural states were significantly more likely than those in urban states to report the workforce shortage affected their patients (71.6% vs. 46.6%, p=0.001). Greater reported distance to the nearest pediatric rheumatologist and longer time to urgent referral were significantly associated with increased perceived impact of the workforce shortage. Factors that did not affect the perceived impact of the workforce shortage for general pediatricians were state availability of pediatric rheumatologists and reporting that the nearest pediatric rheumatologist was in a different state.

3) Other Subspecialists

Longer time to urgent referral was also significantly associated with increased perceived impact of the workforce shortage for other subspecialists. Similar to rheumatologists and general pediatricians, more subspecialists practicing in rural states

compared to urban states reported the workforce shortage affected their patients (52.1% vs. 33.3%), but this trend was not significant.

Factors Affecting Perceived Impact of Workforce Shortage: Multivariate Analysis

Multivariable analysis included all variables with statistically significant associations ($p<0.05$) with our outcome variable, reporting that the workforce shortage affected one's patients, in the logistic regression models. For rheumatologists, after adjusting for state availability of pediatric rheumatologists, factors significantly associated with reporting that the workforce shortage affected their patients were practice location in a rural state (OR 3.43, 95% CI 1.06-11.10) and longer time to urgent referral (OR 1.95, 95% CI 1.07-3.57). For general pediatricians, after adjusting for practice in an academic setting, factors significantly associated with reporting that the workforce shortage affected their patients were: practice location in a rural state (OR 2.03, 95% CI 1.38-2.99), longer time to urgent referral (OR 1.98, 95% CI 1.60-2.46), and greater reported distance to the nearest pediatric rheumatologist (OR 1.19, 95% CI 1.05-1.34). For other subspecialists, no factors were significantly associated with reporting that the workforce affected their patients in multivariable analysis.

Specific Aim 2: Acceptance of Telemedicine

A minority of all respondents accepted video conferencing or "store and forward" telemedicine for: 1) routine new visits, 2) routine follow-up visits, and 3) urgent visits (Table 4). Although rheumatologists consistently reported lower acceptance than general pediatricians and other subspecialists, the only statistically significant difference found

was acceptance of "store and forward" telemedicine for routine follow-up visits. General pediatricians were significantly more likely to accept "store and forward" telemedicine in this context than rheumatologists (34.4% vs. 18.4%, p<0.001).

Table 4: Acceptance of Telemedicine as a Substitute for Face-to-face Consultation, by Type of Patient Visit.

	Rheum n (%)	**Ped** n (%)	**Subspec** n (%)
Total responses, N	141	613	140
Video conferencing			
Routine new patient	33 (23.4)	189 (30.8)	35 (25)
Routine follow-up patient	44 (31.2)	236 (38.5)	52 (37.1)
Urgent issues	48 (34)	219 (35.7)	50 (35.7)
"Store and forward" telemedicine			
Routine new patient	13 (9.2)	97 (15.8)	20 (14.3)
Routine follow-up patient	26 (18.4)	211 (34.4)[A]	39 (27.9)
Urgent issues	28 (19.9)	126 (20.6)	27 (19.3)

A: Rheumatologists vs. general pediatricians, p<0.001

Perceived Barriers to Telemedicine

The majority of rheumatologists reported concern about liability (83.3%) and reimbursement (78.1%) as potential barriers to the use of telemedicine (Table 5). Rheumatologists were more likely than general pediatricians and other subspecialists (33.3% vs. 19.7% and 13.4%, respectively; all p<0.001) to report they were "very

concerned" about liability. Rheumatologists were also more likely than other subspecialists (27.3% vs. 16.1%, p=0.036) to report they were "very concerned" about reimbursement. The majority of respondents reported they were not concerned about crossing state lines, i.e. issues of medical licensure.

Table 5: Concern About Potential Barriers to Telemedicine.

	Rheum n (%)	**Ped** n (%)	**Subspec** n (%)
Liability[A]			
Not at all concerned	22 (16.7)	140 (25.1)[B]	30 (26.8)
Somewhat concerned	66 (50)	308 (55.2)	67 (59.8)
Very concerned	44 (33.3)	110 (19.7)[C]	15 (13.4)[C]
Reimbursement[D]			
Not at all concerned	29 (22)	131 (23.6)	35 (31.3)
Somewhat concerned	67 (50.8)	276 (49.7)	59 (52.7)
Very concerned	36 (27.3)	148 (26.7)	18 (16.1)[E]
Crossing state lines[F]			
Not at all concerned	75 (57.3)	338 (60.8)	72 (64.9)
Somewhat concerned	39 (29.8)	173 (31.1)	31 (27.9)
Very concerned	17 (13)	45 (8.1)	8 (7.2)

A: Total responses received for this question: Rheum N=132, Ped N=558, Subspec N=112
B: p=0.040 (All p-values represent analyses comparing the annotated group to rheumatologists.)
C: p<0.001
D: Total responses received for this question: Rheum N=132, Ped N=555, Subspec N=112
E: p=0.036
F: Total responses received for this question: Rheum N=131, Ped N=556, Subspec N=111

Factors Affecting Telemedicine Acceptance: Bivariate Analysis

1) Rheumatologists

Generally, experience with technology in both the professional and personal settings made rheumatologists more likely to accept telemedicine as a substitute for face-to-face care. Rheumatologists reporting use of EMR in the professional setting were significantly more likely to accept "store and forward" for urgent visits (24.3% vs. 7.9%, p=0.031). Those reporting use of video conferencing in the personal setting were significantly more likely to accept video conferencing for urgent visits (43.5% vs. 26.6%, p=0.035). Interestingly, however, rheumatologists who reported use of video conferencing in the professional setting were less likely to accept video conferencing for urgent visits (25.8% vs. 36.4%), but this trend was not significant. This pattern was consistent but not necessarily statistically significant for routine new and follow-up visits.

A number of other factors showed trends with increased telemedicine acceptance: rheumatologists practicing in rural states, those reporting the workforce shortage affected their patients, and those reporting increased time in telephone consultation. In contrast, rheumatologists were significantly less likely to accept video conferencing for urgent visits if they reported concern about reimbursement (41.7% vs. 17.2%, p=0.015), and showed a similar trend for concern about liability. Again, these patterns were consistent but not necessarily statistically significant for routine new and follow-up visits. Factors that did not affect rheumatologist acceptance of telemedicine included number of years in practice, academic practice setting, state availability of pediatric rheumatologists, reported time to urgent referral, and concern about crossing state lines.

2) General Pediatricians

General pediatricians reporting professional and personal use of technology were also significantly more likely to accept telemedicine as a substitute for face-to-face care. For example, general pediatricians reporting professional use of digital photos or imaging were more likely to accept video conferencing for urgent visits (45.6% vs. 30.7%, $p<0.001$), and those reporting personal email use were more likely to accept "store and forward" telemedicine (22.8% vs. 7.8%, $p=0.001$).

General pediatricians in practice less than 20 years were more likely to accept video conferencing for urgent visits than those in practice greater than 20 years (41.7% vs. 28.9%, $p=0.001$). General pediatricians in rural states were significantly more likely to accept video conferencing for urgent visits (41.4% vs. 28.2%, $p=0.001$). Additionally, trends toward increased acceptance of telemedicine were also noted with increased distance to the nearest rheumatologist, longer time to urgent referral, and report that the workforce shortage affected their patients. In contrast, concern about liability was associated with lower telemedicine acceptance. General pediatricians reporting concern about liability were less likely to accept "store and forward" telemedicine for urgent visits (19.6% vs. 30%, $p=0.011$). These patterns were consistent but not necessarily statistically significant for routine new and follow-up visits. Factors that did not affect acceptance of telemedicine for general pediatricians included state availability of pediatric rheumatologists, academic practice setting, and concern about crossing state lines or reimbursement.

3) Other Subspecialists

Other subspecialists were also more likely to accept telemedicine if they reported experience with technology. Those reporting professional email use were significantly more likely to accept "store and forward" telemedicine for urgent visits (23.5% vs. 7.9%, $p=0.037$), and those reporting personal internet use were more likely to accept video conferencing for urgent visits (43.5% vs. 9.4%, $p<0.001$).

Trends toward increased telemedicine acceptance were noted among subspecialists practicing in rural states, those reporting longer times to urgent referral, and those who reported the workforce shortage affected their patients. Concern about liability was associated with decreased acceptance of telemedicine. These patterns were consistent but generally not statistically significant for routine new and follow-up visits. Factors that did not affect acceptance of telemedicine for other subspecialists included academic practice setting, years in practice, state availability of pediatric rheumatologists, distance to the nearest pediatric rheumatologist, and concern about crossing state lines or reimbursement.

Factors Affecting Telemedicine Acceptance: Multivariate Analysis

A priori multivariable analysis included all variables with statistically significant associations ($p<0.05$) with our outcome variables, acceptance of video conferencing and "store and forward" telemedicine, in the logistic regression models. Due to the fact that we explored several aspects of technology use and access to pediatric rheumatologists, several variables showed significant inter-variable correlation. We performed sensitivity

analyses by replacing the multiple related variables with one representative variable in logistic regression models. These analyses produced insignificant changes in our results.

For example, in the regression model for general pediatricians' acceptance of video conferencing for urgent visits, we first included all variables representing use of technology (e.g. professional and personal use of email, internet, digital photos or imaging, and video conferencing) that were significantly associated with acceptance of telemedicine. When all technology variables were included, the odds ratio of accepting video conferencing for general pediatricians practicing in a rural state was 1.67 (95% CI 1.12-2.48). We then replaced the related variables with one representative technology variable, professional use of email, which had the greatest statistical association with other technology use variables. When only the representative technology variable was included, the odds ratio of accepting video conferencing for general pediatricians practicing in a rural state was 1.63 (95% CI 1.13-2.35).

Similarly insignificant differences were noted when all variables reflecting access to pediatric rheumatology (i.e. practice location in a rural state, distance to the nearest pediatric rheumatologist, state availability of pediatric rheumatologist, time to urgent referral) were replaced with one representative variable, practice location in a rural state. Therefore, below we report the results of regression models using these two variables, professional use of email and practice location in a rural state, to represent technology use and access to pediatric rheumatology variables, respectively.

1) Acceptance of Video Conferencing

For rheumatologists, concern about liability had a significantly negative effect on acceptance of video conferencing for new (OR 0.49, 95% CI 0.26-0.94) and follow-up

visits (OR 0.30, 95% CI 0.54-0.97) after adjusting for professional use of email and practice location in a rural state (Table 6).

For general pediatricians, concern about liability was also negatively associated with acceptance of video conferencing for new, follow-up, and urgent visits after adjusting for professional use of email, practice location in a rural state, and years in practice (Table 6). Increasing number of years in practice also had a significantly negative effect on general pediatricians' acceptance of video conferencing for follow-up (OR 0.78, 95% CI 0.67-0.88) and urgent (OR 0.85, 95% CI 0.74-0.98). In addition, odds of accepting telemedicine remained significantly increased for general pediatricians practicing in rural states and those reporting professional use of email in this model. For other subspecialists, only practicing in a rural state was found to have a significant effect on acceptance of video conferencing for new visits.

2) Acceptance of "Store and Forward" Telemedicine

For rheumatologists, concern about liability had a significantly negative effect on acceptance of "store and forward" telemedicine for new (OR 0.35, 95% CI 0.14-0.87) and urgent visits (OR 0.50, 95% CI 0.26-0.93), after adjusting for professional use of email and practice location in a rural state. For general pediatricians, concern about liability also had a significantly negative effect on acceptance of "store and forward" telemedicine for new (OR 0.54, 95% CI 0.38-0.76), follow-up (OR 0.56, 95% CI 0.43-0.74), and urgent visits (OR 0.60, 95% CI 0.44-0.82) in the multivariable model. Professional use of email had a significantly positive effect on general pediatricians' acceptance of "store and forward" telemedicine for new (OR 2.31, 95% CI 1.26-4.25) and follow-up (OR 1.68, 95% CI 1.10-2.55) visits. For other subspecialists, only practice

in a rural state was found to have a significantly positive effect on acceptance of "store and forward" for new visits (OR 3.43, 95% CI 1.18-10.03).

Table 6. Factors Affecting Acceptance of Video Conferencing as a Substitute for Face-to-Face Consultation, by Type of Patient Visit.

	Rheum OR (95% CI)	**Ped** OR (95% CI)	**Subspec** OR (95% CI)
Routine new patient			
Concern about liability	0.43 (0.23-0.80)[A]	0.68 (0.52-0.90)[A]	0.86 (0.43-1.70)
Practice located in rural state[B]	2.19 (0.93-5.13)	1.70 (1.16-2.48)[A]	2.93 (1.26-6.82)[A]
Professional use of email	3.98 (0.45-35.1)	1.66 (1.08-2.56)[A]	0.91 (0.25-3.28)
Years in practice	N/A	0.89 (0.77-1.02)	N/A
Routine follow-up patient			
Concern about liability	0.53 (0.30-0.93)[A]	0.65 (0.49-0.85)[A]	1.46 (0.78-2.74)
Practice located in rural state	1.05 (0.48-2.31)	1.81 (1.26-2.61)[A]	2.00 (0.92-4.37)
Professional use of email	2.23 (0.45-11.2)	2.20 (1.45-3.35)[A]	0.82 (0.26-2.61)
Years in practice	N/A	0.78 (0.67-0.88)[A]	N/A
Urgent patient issues			
Concern about liability	0.69 (0.41-1.18)	0.71 (0.55-0.93)[A]	1.42 (0.76-2.64)
Practice located in rural state	0.88 (0.41-1.91)	1.66 (1.16-2.38)[A]	1.48 (0.69-3.20)
Professional use of email	2.63 (0.54-12.9)	1.41 (0.94-2.12)	0.82 (0.26-2.61)
Years in practice	N/A	0.85 (0.74-0.98)[A]	N/A

A: $p<0.05$
B: Defined as proportion of state population in rural areas >27%

Open-Ended Responses

Review of open-ended responses yielded several common themes among all respondents. There were comments both supporting and refuting the use of telemedicine in the care of children with rheumatic diseases. Comments in support of telemedicine highlighted the improved access, particularly for urgent referrals and/or patient triage, as well as for patients located in areas without easy access to a rheumatologist.

One general pediatrician respondent highlighted the value of telemedicine in serving lower socioeconomic rural populations for whom distant travel is particularly burdensome: [The most important role for telemedicine in pediatric rheumatology is] "making consultation available, especially for my lower SES patients who simply cannot afford to travel to the peds rheum clinic (250 miles)." Another noted that video conferencing might provide better remote consultation than traditional telephone calls because "telemedicine avoids the rushed nature and telephone tag of telephonic communication." Other respondents commented that video conferencing may be useful for educational purposes rather than patient care (i.e., educating providers, parents, and/or schools about a child's illness and treatment). Yet a third role identified for telemedicine was to coordinate multispecialty and/or multidisciplinary care, with one general pediatrician stating that telemedicine might have a role "facilitating conversations between multiple subspecialists for discussions on complex patients with multiple comorbidities including rheumatologic."

Comments arguing against the use of telemedicine in rheumatologic care often highlighted the "hands-on" nature of the musculoskeletal examination, noting that any type of telemedicine would be problematic unless a skilled examiner was with the patient.

For example, one rheumatologist noted, “I have a problem without doing a physical exam of the joints, testing muscle strength, [it] really requires hands on evaluation to be done effectively.”

Discussion

This study represents the first national data comparing attitudes of pediatric rheumatologists and referring pediatricians (i.e. general pediatricians and other pediatric subspecialists) about the impact of the workforce shortage in pediatric rheumatology. It is also, to our knowledge, the first national survey examining physician attitudes toward using telemedicine as a solution for the pediatric rheumatology workforce shortage. We found that although rheumatologists perceived a greater impact of the workforce shortage than either general pediatricians or other pediatric subspecialists, they were equally unlikely to accept telemedicine for the care of children with rheumatic diseases.

We hypothesized that physicians practicing in settings with decreased access to pediatric rheumatology would perceive a greater impact of the workforce shortage. As expected, we found that rheumatologists and pediatricians practicing in rural settings and those reporting greater wait times for urgent referral appointments were more likely to report their patients are affected by the workforce shortage.

Similar to a prior survey of pediatric rheumatologists, we found that the majority of rheumatologists reported delay of diagnosis and treatment as adverse consequences of the workforce shortage.(7) We hypothesized that rheumatologists and general pediatricians would agree about the consequences of the workforce shortage. In fact, rheumatologists and general pediatricians often disagreed about the adverse effects of the workforce shortage for patients. When asked to rank from among a list of consequences, both groups ranked long wait times and delay of diagnosis and treatment highly, but rheumatologists were more likely to rank medical errors such as misdiagnosis and inappropriate treatment as consequences, while general pediatricians were more likely to

rank increased parental anxiety as a consequence. This highlights an interesting potential difference in the interpretation of the impact of the workforce shortage between the two groups: the impact of the workforce shortage perceived by rheumatologists seems to be related to clinical measures such as diagnosis and treatment, whereas the impact perceived by general pediatricians seems to be more related to the emotional impact on patients and their parents. Additionally, while both rheumatologists and general pediatricians reported long wait times for appointments as an adverse consequence of the workforce shortage, general pediatricians were more likely to report longer wait times for urgent referrals.

A minority of rheumatologists, general pediatricians, and other pediatric subspecialists reported willingness to accept video conferencing or "store and forward" telemedicine as alternatives to traditional face-to-face patient care. Although acceptance of telemedicine was low among our respondents, we were able to identify that up to 24% of rheumatologists, 39% of general pediatricians, and 37% of other pediatric subspecialists *were* willing to accept telemedicine for the care of children with rheumatic diseases. Characterizing this group may be helpful in identifying early adopters for telemedicine in pediatric rheumatology. Several authors point to the usefulness of finding such "champions" to foster enthusiasm and investment when implementing telemedicine systems.(55, 61)

As expected, we found that rheumatologists and general pediatricians practicing in settings with decreased access to pediatric rheumatology, especially those in predominantly rural states, were more likely to accept telemedicine. These findings are consistent with previous experience of acceptance and adoption of telemedicine in rural,

underserved areas,(47, 48) suggesting that similar models to connect patients in underserved areas with specialists in academic centers might be successful in pediatric rheumatology as well.

In addition to characterizing potential early adopters, however, it is also important to recognize that the majority of respondents did not accept telemedicine for the care of children with rheumatic diseases. Characterizing this group may aid in identifying important barriers to the implementation of telemedicine in pediatric rheumatology. Although there was no significant difference in telemedicine acceptance among specialties, rheumatologists consistently reported lower rates of acceptance compared to both general pediatricians and other subspecialists. This is likely due, at least in part, to the expected finding that concern about potential barriers, especially liability and reimbursement, was higher among rheumatologists. In our multivariable model, concern about liability was a significant deterrent to the acceptance of telemedicine for rheumatologists. As summarized above in the Introduction, this is a common theme in the telemedicine literature, and suggests a need for action at the policy level.

As expected, we found that physicians reporting prior experience with technology were more likely to accept telemedicine. We also found that a greater proportion of respondents were willing to accept video conferencing compared to "store and forward" telemedicine, suggesting video conferencing may be a preferred telemedicine modality for pediatric rheumatology patients. However, an unexpected finding was that rheumatologists reporting experience with video conferencing in the professional setting were less likely to accept video conferencing telemedicine. This contrasts with previous findings that acceptability and satisfaction generally increase as physicians gain more

experience with telemedicine.(47) Although this trend was not statistically significant, it raises questions regarding rheumatologists' opinions about the appropriateness of video conferencing for the care of children with rheumatic diseases.

Responses to the open-ended question about the role of telemedicine in pediatric rheumatology may shed some light on this issue. When respondents were asked about the role of telemedicine in pediatric rheumatology, a common theme raised by those arguing against telemedicine was the inability of a rheumatologist to personally perform the physical examination of a patient via telemedicine. In other specialties, this issue has been addressed by the presence of a trained examiner whom the consulting physician can direct to interact with the patient. In pediatric rheumatology, this role could potentially be filled by internist rheumatologists, as providers who are trained in the musculoskeletal examination and who offer increased access for patients due to their greater numbers and broader geographic distribution.

Acceptance of video conferencing and "store and forward" telemedicine was generally higher for follow-up and urgent visits, which suggests that although respondents feel telemedicine may not be optimal for rheumatologic care, there could be situations in which telemedicine might be more acceptable. Some respondents indicated what these situations might be in their open-ended answers, where a common theme was that the role of telemedicine might be for follow-up or urgent care only. This is a theme already reflected in the telemedicine literature. For example, in the study of telemedicine for children with special health care needs in Georgia, it was noted that specialists reported the most satisfaction when telemedicine consultations were used in conjunction

with on-site visits, suggesting that telemedicine may be more successful as part of an integrated health delivery model.(47)

Our findings may be limited by a number of factors common to survey studies. While our response rate from rheumatologists was consistent with average response rates for physician questionnaires,(62) response from AAP and AAFP members was low. However, this is the first study to examine attitudes of non-rheumatologists (i.e. general pediatricians and other pediatric subspecialists) about the workforce shortage in pediatric rheumatology. By collecting data from other pediatric subspecialists, our data offer insights into a group of physicians straddling both the referring and specialist physician roles. Additionally, the proportion of subspecialists to general pediatricians in our responses is similar to the proportion of subspecialists to general pediatricians in the U.S.,(24) suggesting that our data may be representative of the overall population of pediatricians.

Because participation was voluntary, our data may reflect a bias favoring respondents who had increased interest in the pediatric rheumatology workforce shortage. Given that our instrument was an internet-based survey, respondents may also represent a group of physicians who were more technologically savvy and/or already interested in telemedicine. Thus, telemedicine acceptance for patients with rheumatic diseases is likely to be lower among nonresponders.

Finally, our data may not be generalizable as our novel survey instrument was not previously validated, but we collected data on several aspects of both technology use and access to pediatric rheumatology that showed internal consistency, suggesting the instrument was valid for our purposes.

In spite of these potential limitations, this work represents the first national data on this topic and includes the input of more than 850 pediatricians. Our data suggest that telemedicine would best be utilized in the care of children with rheumatic disease in under-resourced areas, either for urgent triage decision-making or in the context of multidisciplinary care to allow for communication and education with both providers and parents. In addition, telemedicine cannot be effectively adopted on a large-scale basis until liability concerns regarding remote care are addressed. Our data help to illuminate the experience of physicians of all specialties in the care of children with rheumatic diseases and raise important issues about the potential use of telemedicine in the field of pediatric rheumatology.

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Appendix A: Survey Instrument for Rheumatologists

Rheumatologist 2

1.

Introduction

This is a survey about your experience caring for children with rheumatic diseases.
Although individual experiences may vary, please give us your impression of your typical experience with pediatric patients in your practice.

All information collected in this survey will be kept confidential and used for research purposes only.

1. Where is your practice located?

State:

ZIP:

2. Please indicate the training you have completed. Select all that apply.

- [ ] Pediatric residency
- [ ] Medicine-Pediatric residency
- [ ] Internal Medicine residency
- [ ] Family Medicine residency
- [ ] Pediatric Rheumatology fellowship
- [ ] Adult Rheumatology fellowship
- [ ] Other (please specify)

3. How many years have you been in practice?

- ○ Less than 5
- ○ 5-10
- ○ 11-20
- ○ 21-30
- ○ More than 30

2.

4. Do you have an affiliation with a medical school?

- ○ Yes - Faculty member
- ○ Yes - Non-faculty affiliation
- ○ No

Rheumatologist 2

3.

5. How do you usually communicate with primary care providers about the following types of consults?
Select all that apply.

	Routine New Patient	Routine Follow-up Patient	Urgent Issues (New or Follow-up)
Fax or mail	☐	☐	☐
Telephone	☐	☐	☐
Email (text-only messages)	☐	☐	☐
Digital transfer of photos or imaging	☐	☐	☐
Video conferencing (real-time audio and video exchange)	☐	☐	☐

Other (please specify)

6. What is the average time it takes for a pediatric patient to be seen in your practice for an urgent referral?

- ○ 24 hours or less
- ○ 2-3 days
- ○ 4-7 days
- ○ More than 7 days

7. Approximately how much time per week do you spend on the phone with primary care providers discussing pediatric patients *whom you will never see*?

- ○ None
- ○ 1-30 minutes
- ○ 31-60 minutes
- ○ 61-90 minutes
- ○ 91-120 minutes
- ○ More than 120 minutes

4.

Rheumatologist 2

8. Approximately what percentage of your pediatric patients travels more than 50 miles to your practice?

- 0-10%
- 11-25%
- 26-50%
- More than 50%
- Don't know

9. Do you represent the only pediatric rheumatologist in the area where your primary practice is located?

- Yes
- No

10. Approximately how often do you travel to a location(s) other than your primary practice to provide rheumatologic care to children?

- Never
- Less than once a month
- Once a month
- Once every 2 weeks
- Once a week
- More than once a week
- Other (please specify)

5.

Rheumatologist 2

11. Check all that apply. Which of the following types of technology have you used...

	in your practice of medicine?	outside your practice of medicine?
Email (text-only messages)	☐	☐
Digital photos or imaging (including transfer, downloading or processing)	☐	☐
Electronic medical record (integrated EMR including electronic visit notes)	☐	☐
Internet	☐	☐
Video conferencing (real-time audio and video exchange)	☐	☐

Other (please specify)

6.

12. We define "telemedicine" as the delivery of health care using telecommunications technology (e.g. email, digital transfer of photos/imaging, video conferencing), excluding the use of telephone.

How would you describe your level of concern about the following issues with respect to telemedicine?

	Not at all concerned	Somewhat concerned	Very concerned
Liability	○	○	○
Crossing state lines	○	○	○
Reimbursement	○	○	○

13. If the above concerns were not an issue and the technology was readily available, would you be interested in seeing pediatric patients via real-time video conferencing?
(Images during video conferencing are television quality or better.)

- ○ Yes
- ○ No

7.

Rheumatologist 2

14. The 2007 Pediatric Rheumatology Workforce Report by the U.S. Department of Health and Human Services showed a national shortage of pediatric rheumatologists.

Do you feel this shortage has affected patients in your practice?

- ○ Yes
- ○ No

15. In which of the following ways has the pediatric rheumatology workforce shortage affected patient care in your practice?
Rank your top 3 choices, with 1 being the most important.

	1	2	3
Lengthened patient wait times for appointments	○	○	○
Delay in diagnosis	○	○	○
Delay in treatment	○	○	○
Misdiagnosis	○	○	○
Inappropriate treatment	○	○	○
Increased parental anxiety	○	○	○
Other	○	○	○

If "Other", please specify

16. Please use the space below if you would like to elaborate or share any specific examples.

8.

Rheumatologist 2

17. Each answer choice below describes a complete patient evaluation.

If available, which would you find acceptable for evaluation of the following types of consult? Check all that apply.

	Routine New Patient	Routine Follow-up Patient	Urgent Issues (New or Follow-up)
Face-to-face appointment between patient and specialist	☐	☐	☐
Telephone consultation between primary care provider (PCP) and specialist, ***without*** face-to-face appointment	☐	☐	☐
Telephone consultation, *followed by* face-to-face appointment	☐	☐	☐
Email exchange between PCP and specialist, ***without*** face-to-face appointment	☐	☐	☐
Email exchange, *followed by* face-to-face appointment	☐	☐	☐
Digital photo or image transfer between PCP and specialist, ***without*** face-to-face appointment	☐	☐	☐
Digital photo or image transfer, *followed by* face-to-face appointment	☐	☐	☐
Real-time video conferencing (television-quality video or better) with patient, PCP, and specialist, ***without*** face-to-face appointment	☐	☐	☐

Other (please specify)

Rheumatologist 2

18. In your opinion, what is the most important role for telemedicine in pediatric rheumatology?

9.

Thank you for your participation!

In appreciation of your time and contribution, all participants may enter a free drawing for one of the following prizes:
One-year membership dues, American Academy of Pediatrics
One-year membership dues, American College of Rheumatology
$400 gift certificate to Amazon.com or Home Depot

One winner will be selected from all participants. The prize will be the winner's choice. Entry into the drawing will not be connected to your survey responses.

To enter the drawing, please click here.

Appendix B: Survey Instrument for General Pediatricians

Primary Care 2

1.

Introduction

This is a survey about your experience caring for children with rheumatic diseases.
Although individual experiences may vary, please give us your impression of your typical experience with pediatric patients in your practice.

All information collected in this survey will be kept confidential and used for research purposes only.

1. Do you currently provide primary care for pediatric patients?

- ○ Yes
- ○ No

2. Where is your practice located?

State:

ZIP:

2.

3. Please indicate the training you have completed. Select all that apply.

- ☐ Pediatric residency
- ☐ Medicine-Pediatric residency
- ☐ Family Medicine residency
- ☐ Rheumatology rotation during medical school or residency
- ☐ Continuing Medical Education credits related to rheumatology
- ☐ Adult rheumatology fellowship
- ☐ Pediatric rheumatology fellowship
- ☐ Other (please specify)

4. How many years have you been in practice?

- ○ Less than 5
- ○ 5-10
- ○ 11-20
- ○ 21-30
- ○ More than 30

Primary Care 2

5. Do you have an affiliation with a medical school?

- Yes - Faculty member
- Yes - Non-faculty affiliate
- No

3.

6. Which of the following best describes the distance between your practice and the closest pediatric rheumatologist?

- In the same building/complex
- 10 miles or less
- 11-25 miles
- 26-50 miles
- 51-100 miles
- 101-200 miles
- More than 200 miles
- Don't know

7. Is this rheumatologist located in a different state than your practice?

- Yes
- No
- Don't know

8. What is the average time it takes for one of your pediatric patients to be seen by a rheumatologist for an urgent referral?

- 24 hours or less
- 2-3 days
- 4-7 days
- More than 7 days

4.

Primary Care 2

9. How do you usually communicate with your preferred pediatric rheumatologist(s) about patients?
Check all that apply.

- [ ] Do not communicate with a pediatric rheumatologist
- [ ] Fax or mail
- [ ] Telephone
- [ ] Email (text-only messages)
- [ ] Digital transfer of photos or imaging
- [ ] Video conferencing (real-time audio and video exchange)
- [ ] Other (please specify)

10. How does this rheumatologist communicate with you about patients?
Check all that apply.

- [ ] N/A
- [ ] Fax or mail
- [ ] Telephone
- [ ] Email (text-only messages)
- [ ] Digital transfer of photos or imaging
- [ ] Video conferencing (real-time audio and video exchange)
- [ ] Other (please specify)

5.

Primary Care 2

11. Check all that apply. Which of the following types of technology have you used...

	in your practice of medicine?	outside your practice of medicine?
Email (text-only messages)	☐	☐
Digital photos or imaging (including transfer, downloading or processing)	☐	☐
Electronic medical record (integrated EMR including electronic visit notes)	☐	☐
Internet	☐	☐
Video conferencing (real-time audio and video exchange)	☐	☐

Other (please specify)

6.

12. We define "telemedicine" as the delivery of health care using telecommunications technology (e.g. email, digital transfer of photos/imaging, video conferencing), excluding the use of telephone.

How would you describe your level of concern about the following issues with respect to telemedicine?

	Not at all concerned	Somewhat concerned	Very concerned
Liability	○	○	○
Crossing state lines	○	○	○
Reimbursement	○	○	○

13. If the above concerns were not an issue and the technology was readily available, would you be interested in having a pediatric rheumatologist see your patients via real-time video conferencing?
(Images during video conferencing are television quality or better.)

- ○ Yes
- ○ No

7.

Primary Care 2

14. The 2007 Pediatric Rheumatology Workforce Report by the U.S. Department of Health and Human Services showed a national shortage of pediatric rheumatologists.

Do you feel this shortage has affected patients in your practice?

- ○ Yes
- ○ No

15. In which of the following ways has the shortage affected patient care in your practice?
Rank your top 3 choices, with 1 being the most important.

	1	2	3
Lengthened patient wait times for appointments	○	○	○
Delay in diagnosis	○	○	○
Delay in treatment	○	○	○
Misdiagnosis	○	○	○
Inappropriate treatment	○	○	○
Increased parental anxiety	○	○	○
Other	○	○	○

If "Other", please specify

16. Please use the space below if you would like to elaborate or share any specific examples.

8.

Primary Care 2

17. Each answer choice below describes a complete patient evaluation.

If available, which would you find acceptable for the following types of referral? Check all that apply.

	Routine New Patient	Routine Follow-up Patient	Urgent Issues (New or Follow-up)
Face-to-face appointment between patient and specialist	☐	☐	☐
Telephone consultation between primary care provider (PCP) and specialist, ***without*** face-to-face appointment	☐	☐	☐
Telephone consultation, *followed by* face-to-face appointment	☐	☐	☐
Email exchange between PCP and specialist, ***without*** face-to-face appointment	☐	☐	☐
Email exchange, *followed by* face-to-face appointment	☐	☐	☐
Digital photo or image transfer between PCP and specialist, ***without*** face-to-face appointment	☐	☐	☐
Digital photo or image transfer, *followed by* face-to-face appointment	☐	☐	☐
Real-time video conferencing (television-quality video or better) with patient, PCP, and specialist, ***without*** face-to-face appointment	☐	☐	☐
Other (please specify)			

Primary Care 2

18. In your opinion, what is the most important role for telemedicine in the care of children with rheumatic diseases?

9.

Thank you for your participation!

In appreciation of your time and contribution, all participants may enter a free drawing for one of the following prizes:
One-year membership dues, American Academy of Pediatrics
$400 gift certificate to Amazon.com or Home Depot

One winner will be selected from all participants. The prize will be the winner's choice. Entry into the drawing will not be connected to your survey responses.

To enter the drawing, please click here.

Appendix C: Survey Invitation Cover Letter

Dear colleague,

We are writing to invite you to participate in a short internet survey about using technology to improve access to rheumatology care for children. As you are aware, there is a shortage of pediatric rheumatologists in this country. By participating in this brief survey, you will provide the first national data regarding the clinical impact of this workforce shortage and how telemedicine might offer solutions to this access problem. The survey will take 5-10 minutes to complete.

We appreciate your input on this important topic. Please click on the link below, or copy and paste it into your internet browser, to take the survey.

https://www.surveymonkey.com/s.aspx?sm=TMb8XmjMCLCcfIQxtcb6PQ_3d_3d

Sincerely,

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Yale University School of Medicine

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