Teleintervention for Infants and Young Children Who Are Deaf or Hard-of-Hearing

abstract

Advancements in videoconferencing equipment and Internet-based tools for sharing information have resulted in widespread use of telemedicine for providing health care to people who live in remote areas. Given the limited supply of people trained to provide early-intervention services to infants and young children who are deaf or hard-of-hearing, and the fact that many families who need such services live significant distances from each other and from metropolitan areas, such “teleintervention” strategies hold promise for providing early-intervention services to children who are deaf or hard-of-hearing. Unfortunately, little is known about the cost-effectiveness of such teleintervention services. In this article we outline the rationale for using teleintervention services for children who are deaf or hard-of-hearing, describe a teleintervention program that has been serving relatively large numbers of children in Australia since 2002, and summarize what we know about the cost-effectiveness of such an approach. We conclude by summarizing the type of research needed to decide whether teleintervention should be used more frequently with children who are deaf or hard-of-hearing and the potential relevance of the teleintervention approach for the development of intervention systems in the United States. Pediatrics 2010;126:S52–S58

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KEY WORDS
deaf, hard-of-hearing, early intervention, newborn hearing screening

ABBREVIATIONS
DHH—deaf/hard-of-hearing
RIDBC—Royal Institute for Deaf and Blind Children

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Approximately 3 newborns per 1000 are born deaf or hard-of-hearing (DHH), which makes it the most frequent birth defect in the United States.¹ Fifteen years ago, children who were DHH were typically not identified until they were 2 to 3 years of age.² In those states in which newborn-screening programs have been effectively implemented, the average age at which DHH children are identified has been reduced from ~30 months to 2 to 3 months of age (see Fig 1). Consequently, over the past 2 decades there has been a large increase in demand for early-intervention services for young children who are DHH. Most DHH children who are identified early and provided with appropriate early intervention are able to progress at age-appropriate rates.¹³⁻¹⁵ As a result, there are substantial cost savings, mostly in reduced need for special education services;¹⁶,¹⁷ and 43 states have passed legislation that requires newborn hearing screening.¹⁸

Still, there are many DHH children and their families who do not receive appropriate services.¹⁹ In fact, a recent letter sent to all state early-intervention programs from federal officials at the Department of Education and the Department of Health and Human Services noted that there is a “growing national crises in the provision of essential early intervention and health care services for infants and toddlers with hearing loss.”²⁰ That letter went on to state:

“Although efforts to identify and evaluate hearing loss in young children have improved, there is still anecdotal evidence to suggest that many young children with hearing loss may not be receiving the early intervention or other services they need in a timely manner that will enable them to enter preschool and school ready to succeed.”

One of the reasons that many young children who are DHH do not receive the early-intervention services they need is that although deafness is a more frequent than any other birth defect, it is still a relatively low-incidence condition. Consequently, many children who are DHH live a great distance from the specialized services they need and there are often few DHH children living in the same area, which makes it difficult for many educational systems to find appropriately trained people to deliver services.²¹

THE POTENTIAL FOR “TELEMEDICINE” TYPES OF SOLUTIONS

A potential solution for this problem is to use 2-way videoconferencing to provide early intervention services to children who are DHH who do not live in heavily populated areas. As telecommunication technologies have improved and costs have declined, many people have become convinced that telemedicine enables us to provide high-quality health care in situations in which it is difficult or unnecessarily expensive to have the health care provider and the patient in the same room at the same time. The rationale for the expanded use of such telemedicine solutions is that it can be used to provide high-quality care, save money through improved care management and coordination, and reduce patient costs.

A typical application of telemedicine involves a patient at a health care facility in a rural or medically underserved area, which is similar to the situation faced by many infants and young DHH children and their families. Telemedicine uses videoconferencing to link an expert located at a “hub site” with a patient located at a “spoke site.” Widespread conceptual support for telemedicine has lead to hundreds of applications. As pointed out by Wootton, most of these have

“...been in the form of feasibility studies and pilot trials. As a result there is little convincing evidence of the cost-effectiveness of many applications.... Various feasibility studies ... have been driven by the hope that care of chronically ill patients can either be provided more cheaply or be of a higher quality.... Although these studies indicate that patient satisfaction is not a problem, little hard evidence on cost-effectiveness has been obtained”²² (see also refs 23–25 for similar assessments).

Others have been more optimistic. For example, McConnochie et al compared:

“...two groups of children that were almost identical, but one had access to their doctor's office, the emergency department and telemedicine technology for care, while the second had only the first two options.... (The first group of families, which had access to telemedicine for their children, did in fact access care for illness overall nearly 23% more often than the second group. But since the children with telemedicine access had 24% fewer Emergency department visits, which cost about seven times the cost of a doctor office or telemedicine visit, the telemedicine group ultimately still cost insurers less per child over a year.)²⁶

Although more studies are needed, there is growing support for using...
telemedicine types of solutions to provide early-intervention services to children who are DHH. For example:

“It is the position of the American Speech-Language-Hearing Association (ASHA) that telepractice (telehealth) is an appropriate model of service delivery for the profession of speech-language pathology. Telepractice may be used to overcome barriers of access to services caused by distance, unavailability of specialists and/or sub-specialists, and impaired mobility. Telepractice offers the potential to extend clinical services to remote, rural and underserved populations.”

The following are some examples of how teleinterventions have been implemented to address issues similar to those experienced by children who are DHH.

- Sicotte et al.28 implemented a teleintervention program to treat stuttering in children and concluded that (1) it was feasible to provide services to families in remote areas, (2) families participated frequently and consistently, and (3) there was high rate of client and provider satisfaction.

- Hill et al.29 explored the feasibility of using teleintervention for assessing motor speech disorders with acquired neurologic impairment and determined that although it was feasible, additional refinement of the technology and assessment tools was needed.

- Jessiman30 compared speech and language assessments via a telehealth system to an in-person system and also evaluated the progress that school-aged children made in articulation and language treatment when it was provided via telehealth. He concluded that children “progressed in their speech and language goals quickly over the 12 sessions.”

- Forducey31 used 2-way interactive teleconferencing to deliver speech treatments to students throughout the state of Oklahoma and concluded that the program was successful.

- Carpenedo32 used real-time interactive video technology to provide speech services as an adjunct to traditional in-home speech-treatment visits and concluded that it improved patient services.

- Xu et al.33 evaluated the costs of providing pediatric otolaryngology services using videoconferencing compared with conventional outpatient services and found that it was more economical to provide services via videoconferencing; however, they did not assess patient outcomes.

Studies such as these are used to suggest that teleintervention might be used to address the barriers created by the shortage of trained early-intervention providers and the high costs of providing services to geographically dispersed families of DHH children. However, it is important to note that there is not enough systematic, rigorously collected evidence to demonstrate that such services would really be less costly or equally effective as the face-to-face services that are typically provided currently. Before teleintervention should be considered a viable tool for addressing the problems noted above for infants and young children who are DHH, better data are needed about the costs and effects of such services compared with currently available alternatives.

The largest and most comprehensive teleintervention effort yet undertaken to deliver early-intervention services to children who are DHH has been operational in Australia for a number of years. As a first step in deciding whether teleintervention should be used more broadly for providing services to US children who are DHH, it would be useful to consider what can be learned from the Australian experience.

AUSTRALIA’S TELESCHOOL PROGRAM

Since 2002, the Royal Institute for Deaf and Blind Children (RIDBC) in Australia has been using 2-way videoconferencing to provide early-intervention services to more than 100 children per year who are DHH, deaf-blind, or visually impaired. These children are receiving all of their educational services via the RIDBC Teleschool (www.ridbc.org.au/services/teleschool.asp). According to a recent evaluation study (K. Dally and R. Conway, Invest to Grow Local Evaluation Report for RIDBC Remote Early Learning Program, unpublished report from the University of Newcastle, Callaghan, Australia, 2008), most professionals and parents participating in this program have agreed that it provides high-quality services with which parents are very satisfied and that children seem to be progressing as well as they would if they were enrolled in a traditional program in which providers visit the family in their homes. Unfortunately, the authors did not collect data to compare the developmental outcomes of children participating in the RIDBC Teleschool with those of similar children who are receiving face-to-face services. On the basis of the limited cost data that were collected, the report concluded:

“At present the cost of the remote delivery of services appears to be slightly higher than the cost of face-to-face service delivery. However, the costs of the telephony and remote technology connections are likely to decrease in the future . . . (and) the motor vehicle costs for the local service delivery are likely to rise if fuel prices continue to escalate. Thus, at present, the remote program appears to be cost comparative with face-to-face service delivery and, over time, may become even more cost efficient than local delivery options.”

The goal of the RIDBC Teleschool is to provide families who live in rural areas of Australia with the same level and quality of service they would receive if they lived in a metropolitan area.
Videoconferencing equipment is used so that a specially trained early-intervention specialist can work with the child and teach the parent how to deliver effective early-intervention services in between these virtual home visits. Participating families live all over Australia (an area roughly the size of the continental United States but with less than one-tenth as many inhabitants). Videoconferencing sessions are typically held 1 hour/week or 2 half-hours/week depending on the family’s schedule and the child’s needs.

Videoconferencing equipment is set up in the family’s home so that the child and caregiver can view the specialist in real time on a television screen or computer monitor (and vice versa). An example of this setup is shown in Fig 2. Materials necessary for the instruction are sent to the families via the postal service or over the Internet. Examples include educational resources such as books, toys and puzzles, lesson plans that outline specific goals for the child, information sheets about hearing and vision loss, and regular progress reports.

Before beginning the RIDBC Teleschool program, families are strongly encouraged to schedule a visit to the RIDBC central campus in Sydney. Financial assistance for travel expenses and free on-site accommodation are provided to families to make it easier to complete this visit. Families are able to access a wide range of services during this initial visit:

- diagnostic assessment of the child’s developmental status;
- meeting with the specialist who will be providing the RIDBC Teleschool services for their child and participating in several face-to-face intervention sessions;
- meeting with other professionals who will assist with their child’s educational program, including audiologists, speech-language pathologists, occupational therapists, psychologists, etc;
- learning about and using educational resources from the RIDBC library; and
- participating in a practice videoconference session so that they can experience and discuss the differences between face-to-face and videoconference sessions.

Typically, videoconferencing equipment is placed in the family’s home to reduce travel time, allow flexibility in scheduling, and provide the opportunity for other family members to participate in the weekly sessions. In-home videoconferencing also allows RIDBC Teleschool staff to observe activities in the home and teach parents how to enhance their child’s natural learning environment by encouraging interactions with the people and resources to which they have access. Weekly videoconferencing sessions enable the specialist to observe the family’s interactions with the child, monitor the child’s progress, and offer suggestions for further expanding the child’s skills.

A typical videoconference includes:

- parent feedback on previous activities;
- specialist modeling of new activities and skills;
- specialist coaching of the parent during parent/child interactions;
- review of video footage from previous videoconferences;
- suggestions for generalizing the goals to the home environment; and
- discussion of test results and reports from other professionals.

Other family members such as grandparents or siblings or local professionals such as specialists or speech-language pathologist may also attend the session. Videoconferencing sessions are also recorded and made available to families so that they can review or share previous sessions with other family members or professionals. In addition, specialists may use this video footage to help parents reflect on their own skills and to better understand their child’s abilities. Such sessions help parents improve their observational skills so that they are able to watch their child’s responses and accurately report on the child’s abilities and progress.

Before each RIDBC Teleschool session, the specialist sends an educational package to the family. This package consists of a lesson plan that outlines specific goals from the program, a description of activities for achieving the
goals, and relevant resources for completing the activities such as books, toys, puzzles, DVDs, and craft material. Many families also use videoconferencing to access courses in specific skills that are not available in their local area, such as sign language instruction. Also, parents are introduced to other families via videoconference and are often able to establish support networks.

Since 2002, RIDBC Teleschool services have been provided to more than 170 families. Although a comprehensive evaluation of the children’s developmental outcomes and the cost-effectiveness of the service has not been performed, participants have reported that teleintervention has provided an effective method of delivering a personal, immediate, and specialized service to them and their child. According to Dally and Conway (K. Dally and R. Conway, Invest to Grow Local Evaluation Report for RIDBC Remote Early Learning Program, unpublished report from the University of Newcastle, Callaghan, Australia, 2008), families value the immediacy of teleintervention services, which are less susceptible to waiting lists, travel arrangements, and unforeseen obstacles such as weather or illness. Participants also reported better satisfaction with teleintervention services compared with telephone and correspondence services, because the early-intervention specialist is able to directly observe the parent-child interactions and provide responsive feedback that can be applied immediately. Early-intervention providers in the teleschool program have also noted that parents seem to acquire skills more rapidly than in a traditional face-to-face model. In a face-to-face session, the early-intervention specialist may regard the child as the primary participant and engage more often in modeling activities and strategies directly with the child and involving the parents only occasionally. In a teleintervention setting, the roles shift because the early-intervention specialist has limited physical access to the child and must now regard the parents as the primary participants. This shift seems to change the focus of the session from teaching the child to coaching the parent(s) in implementing appropriate educational activities with their child.

In addition, feelings of isolation and anxiety are often quite strong for families who live in remote areas. Participants have reported that teleschool offers emotional support and reassurance by providing a weekly face-to-face contact with a specialist who can provide information and guidance about how to enhance their child’s development.

Anecdotal evidence has also suggested increased participation by fathers and other family members as well as fewer cancellations by families. This increased level of engagement is probably attributable to greater ease of attendance and flexibility of scheduling. Teleschool sessions are offered from 8 AM to 8 PM and on Saturday mornings. Furthermore, the effort of bringing a child to a center-based activity or of hosting early-intervention staff in their own homes is often a cause for city-based families to cancel scheduled visits. For remote families, the in-home videoconferencing approach seems to reduce both the effort and the cost of accessing appropriate services.

**DISCUSSION**

Evidence about the cost-effectiveness of using teleintervention to provide services to children who are DHH is similar to the conclusions regarding telemedicine made in 2004 by Hailey et al. who noted that “good-quality studies are still scarce.” Because of critical needs for services and the shortage of trained and qualified providers, it is easy to assume that teleintervention services are as good as face-to-face services and can be delivered at lower cost. The feasibility of using 2-way real-time videoconferencing to deliver the types of services needed by infants and young children who are DHH has been demonstrated a number of times, including in large-scale implementations such as the RIDBC Teleschool program in Australia (K. Dally and R. Conway, Invest to Grow Local Evaluation Report for RIDBC Remote Early Learning Program, unpublished report from the University of Newcastle, Callaghan, Australia, 2008). Nonetheless, we do not yet have good evidence that the outcomes for children or the costs of delivery are comparable to those with face-to-face services.

As telemedicine was first gaining popularity, Hersh et al. made an observation that should be kept in mind as the use of teleintervention to serve DHH children and their families is considered:

“Despite the widespread use of telemedicine in virtually all areas of health care delivery, there is only a small amount of evidence that interventions provided by telemedicine result in clinical outcomes that are comparable to or better than face-to-face care. . . . Large-scale RCTs [randomized, controlled trials] must be done to identify the health outcomes whose benefit appears most promising. If the goal is to show comparability to usual care, then studies must provide adequate statistical power to show that the lack of a difference truly exists.”

What is needed are randomized comparisons of teleintervention services and face-to-face services for relatively large numbers of infants and young children who are DHH. To have adequate statistical power, such studies should include at least 100 children in each group and at least 2 years of service so that longitudinal data about the children’s language, cognitive, social, and functional development can be col-
lected. Data collection should be performed by people who do not have a vested interest in the outcome of the study (and preferably would not even know that the children are participating in a randomized, controlled trial). To control for the effects of teacher experience and skill, it would be best if all teachers participating in the study provided early-intervention services to an equal number of children in both the teleintervention and the face-to-face conditions.

In addition to collecting data about children’s outcomes, the study should examine the actual costs of delivering both types of services, including equipment, materials, staff time, travel, and administrative support. Such an analysis should also include information about parent time and opportunity costs as well as the impact of each kind of service on parent employment and access to health care and other social services. Economic-analysis techniques such as discounting, sensitivity analyses, amortization of costs over time, and alternative cost allocations should be included in the cost-effectiveness analyses.

Parent and staff satisfaction with the program should be assessed, as should the scalability of the teleintervention program. In addition, effects of the program on other parts of the system should be considered. For example, does the use of teleintervention improve or hinder the family’s relationship with other providers and/or families, and does it lead to greater or less understanding of what other services are available for their child?

CONCLUSIONS

Using 2-way videoconferencing to deliver services in rural and remote areas to children who are DHH is a potential solution to one of the biggest obstacles to effective services identified in the US national evaluation of newborn-screening and intervention programs described elsewhere in this supplement issue26: the severe shortage of appropriately trained teachers and clinicians in many parts of the country. However, although the potential benefits are great, much more systematic data are needed to determine the costs and effects of such services compared with face-to-face services for DHH infants and young children and their families. The US could consider introduction of a pilot program to test the feasibility of the teleintervention approach for this population. The United States could also be an ideal site at which to carry out a randomized, controlled trial of teleintervention versus traditional face-to-face services.

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