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Go Home and Get Better: An Exploration of Inequitable Educational Services for Homebound Children

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Abstract

This paper explores the inequitable educational services afforded to homebound children with chronic illness in the US. Even though this vulnerable population is growing due to increased survival and incidence rates, neither federal nor state guidelines address their educational needs. Even the Individuals with Disabilities Education Act (IDEA) does not provide guidelines for this population in our public school systems. Traditional educational services afforded to this population consist of 4-5 hours per week of home instruction. In addition to receiving inequitable educational services, being homebound isolates them from important social interaction with their peers. We are currently conducting a national study on virtual inclusion via interactive technologies and the equity and inclusion challenges of this practice. This paper details this problem and then examines the use of innovative technologies that may offer inclusion of these children in traditional schools (e.g., videoconferencing and telepresence robots).

Author Keywords

Telepresence; education; human-computer interaction; chronic illness; education; social inclusion.

ACM Classification Keywords

H.5.m. Information interfaces and presentation (e.g., HCI): Miscellaneous

Introduction

Attending school is a significant aspect of normal life for children. Their learning, interaction with teachers and peers, lessons and activities are part of the comprehensive school experience that occurs within their familiar educational environment. Homebound students with chronic illness are typically traditional students until symptoms of illness and treatments cause prolonged disruptions in their school attendance. Being removed from school and losing contact with peers for significant periods of time may create anxiety and fears about disrupted friendships and falling behind academically [2,13]. Current educational practices of home instruction, hospital schools, and online schools may provide academic material, but do nothing to alleviate their physical segregation and social isolation. Many of these children have physical limitations (due to medical condition) but are cognitively capable of learning both academic and social lessons. They need equitable access to their local schools, for both academic and social lessons and connection with their peers.

Background

Inclusive education

The federal government has made provisions for inclusive educational practices for children with disabilities through the Individuals with Disabilities in Education Act (IDEA) [14]. Unfortunately, homebound children do not always receive services under the IDEA. Whether they receive services or not is left up to local school districts. As a result, opportunities for inclusive education and engagement in meeting fundamental needs for healthy social and academic development remains a challenge for homebound children with chronic illness.

Population size

In the United States, the number of children with at least one chronic illness has grown dramatically in recent years. National figures from 2008 that estimate 17% of all students under the age of 18 suffer from a chronic illness that affects their performance in school [4].

Current Services

Home instruction

Traditional services afforded to homebound students by educational systems in the U.S. have not changed much, if at all, since the 1930's [5]. The standard of educational services for homebound children consists of home instruction services. The number of hours allocated to a student for at-home instruction varies according to state and school district recommendations but is typically 4-5 hours per week.

Hospital schools

Improvements in medical treatment and decentralized approaches to healthcare mean that a majority of these children spend shorter periods of time in hospital and longer periods of time recuperating or receiving treatment at home [11]. Many children's hospitals have school services within the hospital but students who are discharged from the hospital and recovering at home typically receive no continuing access to these hospital schools. At the same time, students who are recovering at home may not be well enough to physically attend their traditional school. As a result, many homebound students are caught in a gap between the services afforded to them by the hospital and the services available to them from their local school system.

Online schools

The Center for Online Learning and Students with Disabilities (COLSD) expresses a commitment to Universal Design for Learning (UDL) that re-affirms the importance of providing curricular and instructional support to all students. However, even though the COLSD subscribes to the 2001 reauthorization of the Elementary and Secondary Education Act (ESEA) that measures, for accountability purposes, the achievement profiles of students receiving public education services online, it still does not recognize students with chronic illness or on homebound status as a population within the school system and thus does not provide reports on the effectiveness of online educational services for this population [1]. This lack of awareness and attention to this population contributes to longstanding inadequate educational services.

Innovative Approaches

There is both a limited amount of *research* addressing the educational needs of these children and attention directed toward determining *present practice* in the delivery of services to students with chronic illness [12]. The following innovative technologies have attempted to provide educational services to these children.

Telepresence solutions

Video-conferencing

Several studies have explored the effectiveness of teaching and learning via videoconferencing [3,6,7], but most of the studies are about bringing new material to those in the classroom, not homebound children to experience classroom activities. In 2001, an early study of real-time video-conferencing to connect children with chronic illness to their classroom was conducted in Canada using a non-mobile telepresence robot called PEBBLES (which stands for Providing Education by Bringing Learning Environments to Students) [15]. However, because PEBBLES was not mobile, it needed assistance when moving from one class to another. Research has shown this may create social debt towards classmates and that classmates are not always happy to help carry the robot [9].

Mobile telepresence robots

Telepresence robots, essentially videoconferencing on a wheeled platform under control of the remote user, allow the homebound student to pilot or navigate a physical presence in school. The homebound student is not dependent on the assistance of others for mobility and is enjoys the same kind of autonomy as other students in selecting who to talk to, where to go, and the distance they are from others in various situations (e.g., whether they "sit" at the front or the back of the classroom, how close they go to something to examine it). They also experience physical access to school buildings comparable to that of a student in a wheel chair. Mobile telepresence robots also give the student actual presence in the classroom. The homebound student on the robot is referred to by name and is often "dressed" in a t-shirt or other decorations to represent their identity

Innovative approaches to this problem have been limited by the availability of alternative methods for including these children in traditional schools and privacy concerns over allowing interactive technologies in the classroom [8]. There is also a lack of consistency in both state and federal policies to identify and subsequently meet the needs of these students.

Discussion

It is a moral imperative to end the physical segregation and social isolation of these students from their school communities and begin the complex work of exploring opportunities to finally include them. The United States has local networks of home instruction, hospital schools, and online schools that receive state and federal funding but there is no data currently available to evaluate how many homebound students utilize these programs. The use of interactive technologies to provide these students with school experiences is also limited. However, findings from our research [10] suggest the use of telepresence robots to be promising. [10] Future research will address the following:

- 1) What are the affordances of telepresence robots for this population?
- 2) What are the robot design features that matter for both academic and social learning?
- 3) How can we best evaluate this use of technology by a small number of diverse learners for such a wide-range of potential educational, social, and medical outcomes?

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