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## ORIGINAL ARTICLE

# Hospital-based school for children with chronic illness in Taiwan



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## KEYWORDS

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special education

**Background/Purpose:** To provide educational support and avoid unwanted damage that may impede learning for children with chronic illness, the learning environment should be friendly and safe. There is a need to establish schools inside hospitals, however, which may be neglected in a highly efficient health care system. A study was conducted to identify hospital-based schools for sick children in Taiwan, and to explore the barriers for implementation.

**Methods:** The data were collected by structured telephone interview and retrieval of hospital web information. The study targeted social workers and nurses in the pediatric wards of 29 hospitals, plus officials from the Education Bureau in Taiwan. The interviewers inquired about the availability of a formal educational program inside hospitals and the barriers (if any) in providing educational supports.

**Results:** Taiwan has only one hospital-based informal school and eight hospitals with rotating bedside teachers. Education inside hospitals occurs mostly through voluntary teaching in informal education models. Information about special educational resources has not been widely distributed to patients and health care providers. Professional personnel in Taiwan are not well aware of the needs to establish a hospital-based school.

**Conclusion:** The educational needs of children with chronic illness can be easily neglected even in an industrialized country. The establishment of policy and the enrichment of professional education on advocacy are necessary to eliminate educational inequities and benefit sick children.

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## Introduction

For an individual, education can improve quality of life, increase employment opportunities, and advance economic status. Through learning, people may find meaning in life and thus happiness. Educating children with illnesses can assist them in dealing with their own sickness and sharing the responsibility of taking care of themselves, thereby leading to improved disease outcome.

School is a key environment of learning. Children with chronic illness are hospitalized for a long time or visit hospitals frequently for treatment, which may impede their school attendance. It is widely accepted that there is a correlation between children's health and school performance. Taras and Potts-Datema<sup>1</sup> reported that diabetes, sickle cell anemia, and epilepsy affect student school achievement and ability.<sup>2</sup> Moser et al<sup>3</sup> found that children with end-stage renal disease and end-stage liver disease show a mild cognitive deficit compared with the population norm. Additional reported factors of attention problems in sick children can impair their school performance.<sup>4</sup> During the hospitalization period, child patients are actually isolated within a limited space in a hospital, and their interactions with the world and their peers are profoundly diminished. Furthermore, children with chronic illness may have low self-esteem and feel forgotten by the world. These children have the right to be educated equally in a way tailored to their needs, as long as their health allows it.

To eliminate the barriers that impede learning in children with chronic illness, many special programs have been established in regular or special schools. However, these special programs, when conducted in schools outside of a hospital, entail other problems derived from the illness. These problems spring from the frequent transportation back and forth, children's physical and mental disabilities, and threats from unexpected and immediate medical problems. To avoid unwanted damage or factors that may impede learning for children with chronic illness, the learning environment should be friendly and safe, as well as close to medical facilities. Therefore, there is a need to establish schools inside hospitals.

A hospital-based school is a child-centered service that provides an educational environment tailored to the specific needs of sick children, and offers formal programs that fulfill the educational standards in a certain area. In many developed countries, educational support for children during their hospitalization or treatment periods is considered an essential component of hospital services.<sup>5</sup> Taiwan, which has one of the most efficient health systems in the developed world, spent only 6.55% of its gross domestic product in 2011<sup>6</sup> and provided nationwide coverage and quality health care. Because of the high cost of special education, along with the appearance of reduced spending and highly efficient health system in Taiwan, there have been concerns of the possible inequality on the education opportunity offered inside hospitals. The aim of this study was to identify hospital-based schools for sick children in Taiwan and to explore the reasons/process of their establishment, if any, as well as the barriers to implementation. Finally, the degree to which health care personnel are aware of the needs of establishing a hospital-based school was assessed.

## Methods

This study used public information and interviews to collect necessary information on the educational support for sick children inside hospitals in Taiwan. Structured interviews were conducted by telephone, and relevant information was retrieved from hospital websites. The telephone interviews targeted two populations: (1) social workers and head nurses in the pediatric wards of 29 hospitals in Taiwan and (2) officials from the Education Bureau in Taiwan. Hospitals that were awarded an accreditation level of "excellent" by the Department of Health of Taiwan were included. The criteria of an "excellent" level hospital are defined by the Taiwan Joint Commission on Hospital Accreditation.<sup>7</sup> Other hospitals were excluded from this study because of small service volumes and inadequate facilities for pediatric patients; for these institutions, formal educational services were considered unfeasible. In this study, a "hospital-based school" is defined as a space inside hospitals that has classrooms for educational purposes and implements formal programs of various levels parallel to those in Taiwan schools.<sup>8</sup> A formal educational program is a systematic and organized education model, administered according to a given set of laws and norms, presenting a rather rigid curriculum as regards objectives, content, methodology, and assessment. A formal program can advance students to the next learning stage, and confer degrees and diplomas.

At the end of 2009, a total of 29 hospitals were rated "excellent". The nationwide interviews were conducted from February 2010 to April 2010. There were two interviewers—the author and a trained university student who conducted interviews independently. The interviewers first phoned the social workers in the 29 hospitals, inquiring about the availability of a formal educational program or presence of a school inside the hospital. If none was available, the interviewers then asked the social workers and also the head nurses in pediatric wards of the hospitals about the availability of informal bedside education. The interview questions are listed in [Table 1](#). Using event analysis, the verbal data derived from the structured interviews were abstracted and described. When necessary, a descriptive narrative, such as quotes from participants, is provided to support the arguments. In December 2012, a follow-up telephone interview was conducted for the existence of a hospital-based school.

## Results

The 29 "excellent" hospitals had bed numbers ranging from 297 to 3666. The biographic data on the 29 hospitals and a portion of the survey results are summarized in [Table 2](#). The national survey showed that only one hospital provided classrooms for hospitalized children. Another hospital offered space for schooling specifically for deaf children, whose ties with hospitals are not due to "illness". Health care providers in eight hospitals indicated that bedside teachers rotated across hospitals, but there were no classrooms equipped for educational purposes inside the hospitals. These hospitals with rotating bedside teachers were all located in Taipei and Kaohsiung.

**Table 1** Questions that were used to interview social workers and nurses in 29 hospitals.

- (1) Is there a formal school (or educational program) inside the hospital?
- (2) Does the hospital or an institution offer any bedside educational support (other than a hospital-based school)?
- (3) Given any of the above educational support offered inside the hospital, please continue to answer the following questions:
  - (i) When was the school/program established? How long was the preparation period for establishment?
  - (ii) Who (or what department) was involved with the preparatory work? Who (or what department) was the initiator?
  - (iii) How is the job of educational supports shared?
  - (iv) What illnesses of children raise the needs for educational support inside a hospital? What are the demands from the patients?
  - (v) How does the hospital identify sick children who need educational support inside hospitals? Who initiates the application for education? What are the application procedures?
  - (vi) How does the school/program operate? What are the teaching modalities?
- (4) Have children with chronic disease and their families who stay frequently or for a long term in the hospital raised concerns about the children's education?

The first and only hospital school (in Chang Gung Memorial Hospital, Kaohsiung branch) was officially launched in February 2009. The project of the hospital school was initiated by the superintendent, with the goal of providing educational support to sick children who require long stays in a hospital. The program is a collaborative effort between the hospital and a neighborhood elementary school. The former supplied school materials and facilities, whereas the latter provided volunteer teachers. Requests for admission were initiated by the families, and in response to the requests, the hospital performed a series of professional reviews for acceptance. The reviews examined the contagiousness of the disease, and the patients' adaptability to illness and activities, and their physical condition. The children commonly received one-on-one tutorials with an "informal" course. During the implementation years, the student enrollment size has been always low, and none of the students were conferred with diplomas through a formal long-term program. A social worker stated, "Parents were so eager to see the child recover that they hesitated to put any academic pressure on the children...and the parents tended to be over-protective." The social worker added, "Parents might violate the principle that children should have a voice in matters concerning themselves."

The people interviewed, even the health care providers, were unaware of the importance of continued learning during hospitalization. Of the participants asked whether the educational needs of children with chronic illness were raised by the patients or their parents, only one social worker, who worked in the hospital that has a hospital school, reported such inquiries. None of the social workers/nurses from the other 28 "excellent" hospitals described the importance of or need for education. In addition, the personnel who worked in hospitals without educational support appeared to be confused by any consideration of educational concerns. Several social workers even pointed out that hospitals are places that provide health care for the patients, not educational institutions, and expressed wonder that a school might be necessary. One social worker, who actually worked in one of the eight hospitals with bedside educational programs, knew nothing about the educational resources and responded, "That should be the business of the Education Bureau." In the 2012 follow-up, the existence of a hospital-based school remained the same.

The personnel in the Education Bureau who were interviewed about the educational resources reported that only Taipei and Kaohsiung had programs offering bedside teachers. All the hospitals were allowed to apply for the services of rotation teachers. The number of teachers allowed is determined by the number of hospital beds and the number of sick children with educational needs. Teachers would also deliver educational services in the patients' homes when necessary. Government organizations outside of the two major cities provided resources only for the underserved and the impoverished, such as the "Hand-in-Hand" project.<sup>9</sup> The Educational Ministry provided subsidies to obtain education, rather than the education itself, to poor families. The patients themselves would then have to find educational opportunities through charity institutions in the community.

## Discussion

It is widely accepted that education plays a role in reducing poverty, protecting children from crime and delinquency, promoting the well-being of the individual, and maintaining the welfare and stability of the society. When children are confined to a hospital due to illness, they must not be deprived of their right to pursue happiness through education. "Learning to live and living to learn" are both effective in enhancing happiness, even during the "dark days" of illness.<sup>10</sup> Education also enhances understanding of the disease and thus may improve a patient's compliance to treatment, which in turn may have a positive effect on disease outcome.<sup>11</sup> For sick children who are hospitalized for long periods, learning inside hospitals would greatly reduce the time spent on transportation and protect physically vulnerable patients from injury. Advocacy to ensure that the voices of weak children be heard has become an essential component in pediatric care.

The chronicity of children's illness had been found to significantly affect their school attendance, which prevents them from earning degrees or diplomas.<sup>12</sup> The consequences of school absence deriving from chronic illnesses may raise concerns in terms of educational inequalities. According to the 2008 annual report from the Department of Health, Executive Yuan, R.O.C.,<sup>13</sup> the top two diseases in

**Table 2** Summary of the 29 “excellent” teaching hospitals and the survey results on the existence of a hospital-based school.

Location	No. of hospitals	No. of beds	Educational concerns raised	Hospital-based school	Rotating bedside teachers
Taipei	8	297–3121			4
Kaohsiung	4	1200–2650	1	1 (informal) <sup>a</sup>	3
Taichung	4	562–2023			
Tainan	4	445–1276			
Hsinchu	2	332–819			
New Taipei	2	1028–1096			
Taoyuan	2	739–3666			1
Changhua	1	1389			
Hualien	1	935			
Miaoli	1	1177			
Total	29		1	1	8

<sup>a</sup> Informal program is not a systematic and organized education model that parallels the curriculum of a regular school, and can advance students to the next learning stage, and confer degrees and diplomas.

children in Taiwan that cause the longest hospitalization stays are neuropsychiatric diseases and cancers. The other chronic illnesses that require frequent hospital visits include chronic renal disease, rheumatism, asthma, other airway problems, heart disease, physical/hearing/mental disability, and diabetes.<sup>2,13</sup> Osteogenesis imperfecta is another example of a childhood genetic disease that causes weak bones that break easily; as a result, these children are vulnerable to physical damage in regular school activities. In 2000, a senior high school male with osteogenesis imperfecta died because of an accidental fall while in school, which highlighted the importance of establishing a hospital-based school.<sup>14</sup>

The purpose of attending a hospital-based school is to minimize the effects of a child’s medical problems on his/her learning. However, regardless of how much effort and money are involved, the interaction with peers, learning experiences, and school facilities in a hospital-based school remain very limited. Both hospital-based schools and the special program inside of a regular school cannot replace each other. The caretakers and health care providers should take into consideration the balance between the pros and cons of schooling inside or outside a hospital.

To address the issue of educational supports for sick children, there is a need to involve education and health care policy, the practices, and resources. The educational support that the government of Taiwan offers for sick children is detailed in the “Special Education Act”<sup>15</sup> and “Special Educational Support Network”, which provides rotation bedside teachers and supplemental education from the community. These programs are intended to provide not only educational supports, but also mobility aids, transportation, and some daily needs. Furthermore, the educational network encourages collaboration between educational institutions and hospitals, and serves as an information provider and a communication platform. However, the educational needs of sick children who are vulnerable to damage in a regular educational institution and who spend much time traveling between hospitals and schools have not been met. In order to pursue academic advancement, these children need a safe educational environment, a place that is accessible to medical facilities

while they learn. Currently in Taiwan, children with chronic illnesses have barely any opportunity to attend a hospital-based school, and found only limited educational resources outside of formal schools. The results of this study identified several possible barriers that prevented the establishment of a hospital-based school. The Taiwanese government and health care providers are not aware of the importance of formal education inside hospitals. Information about the resources of special education has not been widely disseminated to patients and health care providers. It is not known if there are no such needs in Taiwan or if the voices of sick children have been heard. The reasons underlying this phenomenon deserve future study.

In the majority of developed countries, many hospital-based schools have existed successfully for decades, with educational programs across educational levels from elementary to senior high schools.<sup>16</sup> The Hong Kong Red Cross Hospital School, one outstanding example, was first established in 1954 and has expanded to 18 schools since then (Hong Kong Red Cross Hospital School, 2011).<sup>16</sup> Furthermore, many other schools are spread around North America, Australia,<sup>17</sup> and Europe.<sup>18</sup> The majority of these schools were built as formal schools in terms of space, facilities, administration, teachers, and teaching activities. Most of the students are patients with chronic physical illnesses, emotional/behavioral problems, neurological diseases, mobility or other physical disabilities, hearing impairment, and visual impairment. Compared to the situation in Taiwan, these foreign hospital-based schools evidently have had provided better educational supports.

In summary, unlike other developed countries, the learning opportunities for children with chronic illness have been considered inadequate in Taiwan. Scant educational resources are offered inside hospitals. When education is delivered to sick children in hospital settings, most of the teachers are volunteers and the education programs are informal. Because of the lack of financial support, space, and teaching manpower, as well as a weak desire for such services by the patients’ families, the educational services in hospitals were difficult to maintain. Policy and professional education on advocacy are necessary to benefit sick children.

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