

# 行政院國家科學委員會補助專題研究計畫成果報告

運用多元方法探討慢性病兒童就學問題、  
影響因素及預測因子 (3/3)

Application of multi-method in Examining Problem, Factor and  
Predicators of Children with Chronic Illness in School

計畫類別：個別型計畫    整合型計畫

計畫編號：NSC90-2314-B-002-289-

執行期間：90年8月1日至91年7月31日

計畫主持人：陳月枝

共同主持人：高碧霞

計畫參與人員：王惠玉、林寶玉、詹惠婷

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執行單位：台灣大學醫學院護理學系

中華民國九十一年十月三十一日

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#### 一、中英文摘要

本研究乃以50位一般兒童、50位氣喘兒童及15位癌症青少年，來探討慢性疾病兒童之就學問題及影響因素。研究結果顯示氣喘兒童對整體自我概念、家庭概念及身體自我概念均低於一般兒童，氣喘兒童之運動負荷與整體自我概念成正向相關，但疾病之嚴重度、罹病期間、缺席天數及學業總成績均和整體自我概念無關。癌症青少年可因護理指導改善其自我照顧行為及能力，進而降低感染發生率、天數及嚴重度。因此，醫療團隊成員可協助學校教師、校護與病童之同儕，增進對病童之疾病了解，因藉此協助病童在校園發展正向之人際關係、自我概念以達成有效之自我照護成效。

#### 關鍵詞：

慢性病學童、就學問題、自我概念、自我照顧、護理指導

#### Abstract

This study aimed to explore the schooling problems and related factors for school-age children with chronic illness, 50 healthy children, 50 school-age children with asthma and 15 adolescents with cancer were recruited. Asthmatic schooler present lower self-concept in the general scale, family subscale and physical subscale than health schoolers. Asthmatic schoolers with good exercise endurance showed higher self-concept, while their self-concept was not significantly correlated to severity, duration

of illness, school absence and academic performance. Nursing instruction to adolescents with cancer could enhance their self-care capabilities to decrease the rate duration, severity of infection. Indeed, the positive infection from health team workers to teachers, school nurses, and peers for children with chronic diseases will lead the positive interpersonal relationship, self-concept for children, and then attain effective self-care outcomes for children in school.

#### Keywords:

Children with chronic illness, schooling problem, self-concept, self-care, nursing instruction

#### 二、緣由與目的

近年來，雖然社會經濟的進步及醫療科技的發達提供兒童健康照護較佳的初期預防(primary prevention)，但仍不可避免地仍有病童與其家庭蒙受先天性、長期性及慢性健康問題威脅。惡性腫瘤帶給兒童的健康威脅最大，是5至14歲兒童死因之第二位，所佔人數有24.9%之多(Chen & Chao, 1991; 陳等, 民81); 而氣喘病童的發生率以謝貴雄教授對7-15歲台北市學童之研究，自1974年的1.3%已提高至1994年的10.79%之多(謝, 民81, 周, 民84)。另外，環保署在1995年的國中學童盛行率調查結果有8.8%的學童罹患氣喘，已較WHO在1996年的調查結果7.7%高出許多(譚,

民 85)。由上述資料顯示，慢性疾病兒童照護的次級及三級預防(secondary and tertiary prevention)及照護工作室在醫療科技進步之際，仍不忽視的重要環節。

「慢性疾病兒童護理」是兒童健康照護的重要一環，目前即將來的慢性疾病兒童護理，宜朝向整體性的兒童照護體系發展(高及陳，民 87)。讓慢性疾病兒童的照護在醫療機構、居家護理及學校護理均有合適的轉介諮詢管道，並能夠重視兒童生長、發育、認知、社會心理及情緒等的發展特性，且注重家庭中心式護理以協助病童及其家人共同面對健康問題的衝擊及適應調整(Miller & Wood, 1991; Weitzman, Walker, & Gortmaker, 1986; Chen & Chao, 1991; 陳等，民 81; 高及陳，民 87)。

研究指出，慢性疾病學童面臨著許多亟待克服的衝擊及困難，其包括：就學恐懼症、高缺席率、注意力集中困難、學習障礙、體力較差及自我保護傾向等(Deasy-Spinetta, & Spinetta, 1980; Klopovich, 1983; Lansky, Lowman, Vats, & Gyulay, 1975; Lansky, Chairns, & Zwartzes, 1983, Weitman, Walker, & Gortmaker, 1986)。因重症需長期住院的病童需克服自己明顯的身體外觀變化，感受到自我心像及人際互動關係的焦慮感(Moore & Triplett, 1980)。

慢性病兒童在校園中的直接照顧者是班級教師與健康中心校護，Checkryn, Deegan 及 Reid(1987)指出，學校教師位因應慢性疾病兒童的就學問題，面臨了：(1)調整對學童的學業期望；(2)獲得相關兒童疾病資訊；(3)取決合宜的紀律管理方式；(4)調整給予病童的情緒支持等困難。而 Moore 等人(1980)的調查發現，極少教師有接受過轉診及照顧過癌症兒童的經驗，大部份的校護極需要有關於兒童癌症的相關資訊，尤其針對癌症孩子的身體健康狀態的照顧、發展要務的考量、人際關係的維

持、身體心像的調整、以及面臨孩子的死亡問題等。不論如何，癌症孩子在學校中最常互動的教師正扮演著重要的復健者角色(Spinetta & Lansky, 1982)，而面臨愈來愈多的學童長期照護問題，學校的護理人員亦需積極地扮演著癌症學童就學中的照顧及復健者角色(張，民 85; 陳，民 85; Moore & Triplett, 1980)。

高、李、曾和陳(民 85)曾針對台北縣市中小學兒童癌症在校園常見健康問題之現況初步調查中，指出氣喘、心臟病、癲癇、腎臟病、蠶豆症、疝氣、肢體殘障、糖尿病及癌症等均是校園常見的慢性疾病。慢性疾病兒童容易因治療過程而請假休學或是隱瞞病情不敢讓學校教師或同學知道，而受到排擠或被拒絕入學或建議轉校(高等，民 85; Weitzman, 1986)。

慢性疾病兒童的就學問題，也出現在氣喘兒童身上。氣喘是校園中罹病率最高，且發作時間、地點最不可預測的慢性疾病，高氏等人評價氣喘兒童之校園學習情形，發現約有 82% 會因發作而請假，65% 以上的兒童會每個月請假 5 天，更有人達到 21 天之久(高、洪，民 85)，可見氣喘對兒童的學習情形有很大的影響。在余、陳及高(民 85)所舉辦之校園慢性病護理研討會中，發現許多的學校護理人員及教師會因不了解病童健康狀況，而無法有效地提供病童之校園學習生活指導及照護。

在面對慢性疾病兒童的就學問題，家庭，尤其是父母親也是扮演重要角色。高等人之結果發現癌症兒童父母對病童就學的考慮因素包括「學校可運用的資源」、「孩子可獲得的關照」、「孩子的體力恢復情形」及「孩子的就近性照顧」。而「學校可運用的資源」因素中，發現父母相當重視校護提供照顧方法、事前與校護、校長及老師的聯絡(高等，民 88)。延續此研究結果，中華民國兒童癌症基金會在教育部指導下，於民國 87 年 4 月 13 日至 15 日

舉行學校行政人員兒癌研習會(高及陳, 民87), 更加強學校輔導系統、保健系統、社區居家照護與醫療機構網共同來提供癌症兒童整體性照護的重要。

研究目的:

本研究旨在藉由過去之癌症兒童及氣喘兒童臨床照護及研究經驗, 來整合醫療照護體系, 以增加慢性疾病病童學校生活之有效性、持續性及整合性照護。也能藉由此研究結果作為醫療諮詢、照護系統、學校保健教育、輔導系統等提供慢性疾病兒童照護的重要參考, 因此本研究之目的包括下列幾點:

1. 了解慢性疾病學童面對就學問題之自我概念及自我照顧;
2. 探討慢性疾病學童就學問題之影響因素;
3. 評價慢性疾病學童之護理指導成效服務;
4. 提昇慢性疾病兒童的學校學習及照護品質。

### 三、研究結果與討論

本階段之研究, 乃以橫斷式調查方式, 針對 50 位中高年級之學齡期的氣喘兒童及其 100 位同儕(平均年齡  $10.5 \pm 0.9$  歲)及 15 位青少年癌症病童(平均年齡  $13.5 \pm 1.5$  歲)為對象, 追蹤其照護情形。學齡其氣喘兒童之研究結果歸納如下: 1. 氣喘兒童及一般兒童的自我概念有顯著的差異, 氣喘兒童對整體的自我概念、家庭自我概念及身體自我概念均低於一般兒童。2. 氣喘兒童上體育課的情形, 和運動上的限制與整體的自我概念有顯著相同, 尤其是體育課全部參加及可以負荷任何運動項目而不喘的學童, 其整體自我概念為最高。3. 基本屬性疾病嚴重度, 罹病期間、治療狀況、有無使用吸入型藥物、有無參加氣喘衛教指導及最近一學年的缺席天數和學業總成績等, 均和其整體自我概念無關。青少年癌症兒童之研究結果歸納如下: 1. 癌症青少年可以藉由護理指導來顯著地改善, 尤其是在接受護理指導後的第二週, 其自我照顧認知得分數高。癌症青少年於化學治療繼

發性感染, 高峰期時的自我照顧行為較改善。3. 在接受護理指導後, 個案之繼發性感染發生率、發生天數及嚴重度均獲改善。4. 在感染高峰期時, 青少年之自我照顧認知及自我照顧行為呈正向相關。

### 四、研究之自評及建議

綜合上述的發現, 可以提供以下的未來努力方向: 1. 醫療團隊成員宜重視慢性病兒童的自我概念, 以期使病童積極地參與自我照顧態度及行為。2. 加強與學校的校護、老師的聯繫雙向溝通, 以協助學校師生對慢性學童的正確了解, 以使病童在校園中的生活及學習「正常化」。3. 成立校園內的「同儕病友團體」, 將有助於病童在校園中的正向人際關係, 藉由同儕的相互鼓勵, 而增加自我照顧意願。4. 醫療機構之醫療人員與校園師生間的聯繫溝通, 與轉介溝通網的建立是刻不容緩之服務事項。

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# PROMOTING HEALTH CARE FOR CHILDREN WITH CANCER IN TAIWAN

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In Taiwan cancer has become the second leading cause of death of children in late 1970's, subjecting health care professionals to new challenges in carrying out their duties. Not only is the treating long, but relapses often occur, requiring expensive, repeated hospitalization and appropriate care. By November 1982 the Childhood Cancer Foundation (CCF) of the Republic of China became a government-sanctioned reality, with a board of directors comprising physicians, nurses and business leaders. CCF's primary concern has been to provide individualized and continuing care. In 1991, a comparative study was done to compare the differences in health care for children with cancer in 1981 and 1991 in Taiwan. The concept of a well-established health care delivery system, including accessibility, continuity, efficiency, dynamism, and integration, served as the conceptual framework for the study. The results showed that: a). medical care improved—the length of time between symptom and diagnosis was shorter, the number of clinic visits before diagnosis decreased, and the length of time hospitalization was much shorter with most children receiving their health care in hospital near their own town; b). pain control at the terminal stage improved with 70% of mothers stating that their child's pain had received appropriate care; and c). the role and function of the physician and the nurse were more recognized by patients.

It was evident that CCF did make great contribution to health care for children with cancer in Taiwan in 19 years. We are currently conducting a longitudinal study in 2001. The results will be the base of the pediatric oncology care in the 21th century.

# PROMOTING HEALTH CARE FOR CHILDREN WITH CANCER IN TAIWAN

## Introduction

Cancer has become a major threat in the Republic of China since the late 1970s. It is the leading cause of death in adults and the second leading cause of death in children. It has had a profound impact on children and their families. Thus, health professionals, especially nurses, face the new challenges of meeting the special needs of children with cancer.

The annual incidence of childhood cancer is about 13 per 100,000 children. No statistics on childhood cancer incidence in the Republic of China were available for the earlier study in 1981. In 1990, the childhood Cancer Foundation found 437 newly reported cases. There were 6 million children under 14 years of age in Taiwan, and thus the incidence was 7.3 per 100,000 children. The leading types of childhood cancer were leukemia (39.5%), brain tumor (19.9%), and lymphoma (8.2%).

Treatment of cancer usually continues for 2 to 3 years. Many factors affect the effectiveness of treatment; of these the appropriateness and continuity of the therapeutic regimen are most important. The 1981 study showed that having a well-established health care delivery system, in terms of accessibility, continuity, efficiency, dynamism, and integration is imperative. With the efforts of the CCFROC, since its founding in 1982, the network of the health care delivery system has been gradually established.

In 1991, a comparative study was done to compare the differences in health care for children with cancer in 1981 and 1991 in Taiwan. The information obtained from this study would be useful for further planning in order to establish a well-organized health care delivery system for families who have children with cancer. It would also give insight on the changes that may have occurred over the previous 10 years in treating children who have cancer.

## Materials and Methods

**Patients.** The sample consisted of 75 children with cancer in 1981 and 121 children in 1991. Children were divided into 3 groups in 1981 and 5 groups in 1991.

The 1991 sample included:

Group I. Children who were newly diagnosed, within the previous 1-3 months (n=25).

Group II. Children who had received treatments for 1-3 years (n=25).

Group III. Children who had relapsed during treatments (n=23).

Group IV. Children who had received treatments and died 1-15 years prior (n=23).

Group V. Children who discontinued treatments for more than 2 years according to protocol and were in good health condition (n=25).

**Data Collection.** Semi-structured interview guides that were used in the 1981 study on the “ Impact of childhood cancer on the Chinese Family ” were revised for the data collection. Five parts were included in the interview guide.

## Data Analysis

Data were analyzed based on the concepts of a well-established health care delivery system, including accessibility, continuity, efficiency, dynamism, and integration. General information of the children and parents are presented in Table 1 and 2.

There were also similarities in the family structure between the two samples, including the parents' ages and the fact that the main caregiver was the mother. However, there were more working mothers in 1991 than in 1981 and there appeared to be a striking decrease in illiteracy (See Table 2).

**Health Care:** In relation to the place where the children were first diagnosed, there was a statistically significant difference in the location where the children were first diagnosed. In 1981, the local medical doctor played an important role, while in 1991, the place for first consultation related to the diagnosis was the general hospital with a specialized pediatric oncology center ( $x=7.2$ ,  $p<.05$ ) (See Table 3). There was also a significant difference in the number of places consulted before the diagnosis was established in 1991.

Frequency of weekly visits to the clinic weekly decreased from 57.3% in 1981 to 15.7% in 1991. The length of time involved coming to the clinic was decreased significantly ( $p<.001$ ). Visits of less than 8 hours increased from 32% in 1981 to 78% in 1991.

“ Resources of support. ” Families received support in various ways from spouses, relatives, doctors, nurses, and parents of other sick children, although there was very little religious support. Parents also reported more support received from nurses: in 1981, 58% acknowledged receiving a great deal of support from nurses. In 1991 this increased to 82%.



## **Discussion**

A well-established health care delivery system should be accessible, provide continually, be efficient, dynamic, and integrated. The scope of health care includes prevention, treatment, and continuity of care, including hospice care. Different programs in service are adopted based on the priorities of health need in different cultures. More importantly, the health care delivery system should serve different populations and age groups, and treat different kinds of diseases. Setting national health goals and targets in the context of the fiscal crisis is a challenge for a health care decision maker. Evaluation of the performance of health services is thus important, as it is the basis of further planning.

A study on the impact of childhood cancer on Chinese families was completed in 1981 in Taiwan, ROC and several problems were identified: financial burden for medical care, inappropriate health care delivery system, inappropriate pain control for children with cancer at terminal stages, and insufficient support from health care professionals, especially nurses. The results of the study influenced various health care professionals as well as the society, which ultimately lead to changes in the pediatric oncology health care delivery system in Taiwan.

The Childhood Cancer Foundation of the Republic of China was thus established with the support of the general public in 1982. Since then, the CCFROC has played an active role in helping children with cancer and their families.

The results of the 1991 study provide evidence that the evidence that the services for children with cancer in recent years have improved.

## **Conclusion**

In Taiwan cancer has become the second leading cause of death of children in late 1970's, subjecting health care professionals to new challenges in carrying out their duties. Not only is the treatment long, but relapses often occur, requiring expensive, repeated hospitalization and appropriate care. By November 1982 the Childhood Cancer Foundation (CCF) of the Republic of China became a government-sanctioned reality, with a board of directors comprising physicians, nurses and business leaders. CCF's primary concern has been to promote individualized and continuing care. In 1991, a comparative study was done to compare the differences in health care for children with cancer in 1981 and 1991 in Taiwan. The concept of a well-established health care delivery system, including

accessibility, continuity, efficiency, dynamism, and integration, served as the conceptual framework for the study. The results showed that: a). medical care improved—the length of time between symptom and diagnosis was shorter, the number of clinic visits before diagnosis decreased, and the length of time for hospitalization was much shorter with most children receiving their health care in the hospital near their home town; b). main control at the terminal stage improved with 70% of mothers stating that their child's pain had receiving appropriate care; and c). the role and function of the physician and the nurse were more recognized by parents. The results of the study will assist program planner who are helping children with cancer to improve their health care system.

After 1991, the social economic condition changed, National Health Insurance was inaugurated in 1995. CCF's role and function focused more on developing treatment protocols. The survival rate of leukemia is now about 85%. Consequently, quality of life of cancer children has been the core of caring for nurses. It was evident that CCF did make great contribution to health care for children with cancer in Taiwan in 19 years. We are currently conducting a longitudinal study in 2001. The results will be the base of he pediatric oncology care in the 21th century.