

# Asian Families in their Response to Childhood Cancer and Related Death

November 28<sup>th</sup>, Hong Kong

# Asian Families

■ Taiwan- 3 studies	196
■ South Korea	87
■ Japan	18
■ China-3 studies	129
■ Hong Kong	93

# Family Care

- Family care is concerned with the experience of the family over time
- Family care considers the community and the cultural context of the family group
- Family care looks at the relationships between and among the family members
- Family nursing involves both the healthy and sick members of the family

# When does family care begin? When does family care end?

- Even before diagnosis of the illness, family care begins.
- Even after death family care does not end.

# Culture: Overt issues

- Material aspects including the country's economy and technology
- Symbolic aspects including beliefs and religion
- Social dynamics including health care and the structure of the family

# Modern technological economic practices

- Japan clearly reflected the highest stage of economic and technological development and China the lowest (the coastal areas of China are changing fast).
- Japan is almost totally urbanized while China is primarily a rural society.
- Taiwan has changed from a primary rural to a country with rapid technological development.
- South Korea and Hong Kong were both basically established urban centered societies when the studies were done

# Traditional & religious values

- China reflected the greatest degree of secularization of values in spite of resurgence of religion in much of China
- Japan reflects a strongly secularized value system despite present of new religions. Diffuse traditional values of Shinto, Confucian and Buddhist were in evidence with Christianity a small presence.
- South Korea traditional values were evident of Confucian, Shamanist and Buddhist values but the strongest single religious presence was of Christianity.

# Health Care Systems

- China has a highly integrated system of traditional Chinese medicine with Western medicine
- Taiwan there was clear distinctions between Western and Chinese medicine with additional health system in the temples
- South Korea-mainly Western
- Hong Kong-both are available

# Family structures

- Taiwan retained remnants of the traditional extended family
- China while overwhelmingly rural but extended family no longer functioned effectively
- South Korea had a dominance of the nuclear family
- Japan while nuclear families predominated responsibility for older generation remained
- Hong Kong basically nuclear

# Taiwan-Cultural illustration

- The influence of culture was illustrated most clearly in the extended family and the religious response of the families at diagnosis, during treatment of cancer and in death rituals if the child died.

# Taiwan-How Children Dealt with their illness & treatment

- Children with cancer frequently knew they had cancer

# Assistance to Child & Family

- Parents in Taiwan are the major source of support & assistance to children with cancer.
- Childhood Cancer Foundation in Taiwan has made major improvement in survival rates as well as in the care of the children

# Quotes from family members in Taiwan

- 6 year old girl with ALL: "Mother, what can I do so you won't cry?"
- 9 year old boy with ALL: "I know I will die but its okay to go to heaven but I would be very scared if I go to hell"
- Sister said "If I had cancer, I know what I would do. I would commit suicide, because of the money that it costs my family for treatment even my children will have to pay the debt. Secondly, I could not bear the pain my brother has to endure."

# China, PRC

- One out of six people in the world are Chinese and most likely there are more children with cancer in China than any other country of the world based on their population

# Cultural illustration from China

- We noted that parents often remained in hospital with their child for many months without any involvement from other parents

# How children dealt with illness & treatment

- Many expressed the hope that they would recover rather than die. One boy wanted to comfort his younger brother so he would not feel bad when he died. An adolescent girl was anxious because if her treatment continued her parents would totally exhaust their financial resources

# Assistance to child & family

- Clearly funds are needed for the essential medical treatment to cure children with cancer and to provide long-term quality of life to others. Pain control was not achieved for most children with cancer in China.

# Quotes

- 13 year old boy with optic glioma: "May my eye become smaller, may I see things and may I return home."
- 3 year old girl with leukemia: "May my mother not cry."
- 13 year old expressed his wishes: "May I be cured from my disease, may I grow up and may I go to school."

# South Korea

- Population of around 42 million of which 11 million are children under the age of 15
- Health care insurance policy has plans to expand to cover the cost of care for 12 months each year (at the time of study the coverage was only for 6 month each year)

# Cultural Illustration

- Over one-third of the country is Christian. Churches are very active in providing support to families in need. In our study, families identified religious beliefs as a positive influence.
- Mothers frequently blamed for the child having cancer

# How children dealt with their illness & treatment

- Majority of Korean children knew they had cancer but did not fully comprehend the consequences
- Pain control was a problem

# Assistance to the child and family

- Treatment centers usually far from home so difficult for families (several moved to Seoul to be near medical center)
- Economic hardships due to high cost of long term medical and hospital care

# Quotes from South Korea

- 5 year old girl with leukemia: "Help me I am going to die. I know that I will be with God. No more shots. I will be good."
- The mother of a 6 year old boy with sarcoma: " Why did I experience these bad things? I tried to live a good life and tried to share with other people. I feel guilty for my child having this disease. I feel responsible and I can't bear this guilt."

# Japan

- First non-Western country to develop universal social insurance plans for all citizens including children
- Very active Japanese Association for Childhood Cancer

# Cultural Illustration

- The priority of the male head of the family lies above all in his moral authority and this is expressed socially through the obedience of the wife and filial attitude of the children toward the father

# How children deal with their illness and treatment

- Children remain in the hospital for extended periods of time with the mother usually with the child
- Very limited discussion of their illness with the child
- Parents would get very upset if children asked questions

# Assistance to the child & family

- Mother is the primary caregiver for the sick child
- Japanese Cancer Foundation and the governmental coverage for childhood cancer the financial issues were minimum for families in Japan

# Quotes from Japan

- Mother said "The doctor didn't tell me that leukemia was a life-threatening disease. I knew it was serious but I thought she would be cured. I never thought that she would die."
- 10 year old brother "Sometimes I worry that I may get the same illness. I don't tell my mother about my worries."

# Hong Kong

A beautiful city of 9 million people. Many high rise buildings with a excellent health care system

# Cultural illustration

- Mutual protection between the parents and patient
- Protect the elders from knowing about the diagnosis or prognosis unless the elders are involved in taking care of the child
- A taboo to talk about the bad thing (death)

# How children deal with their illness & treatment

- Some children knew their illness, most from being in the hospital

# Assistance to the child & family

- All children are able to receive the medical treatments necessary for best care
- The Childhood Cancer Foundation of Hong Kong is helpful for families who need assistance with costs of travel to and from the hospital etc

# Questions that children in Asia have asked

- What is death like?
- When one dies, where does one go?
- Where did my brother go?
- Am I dying?
- Will you die, too?
- Why am I dying?

# Conclusions

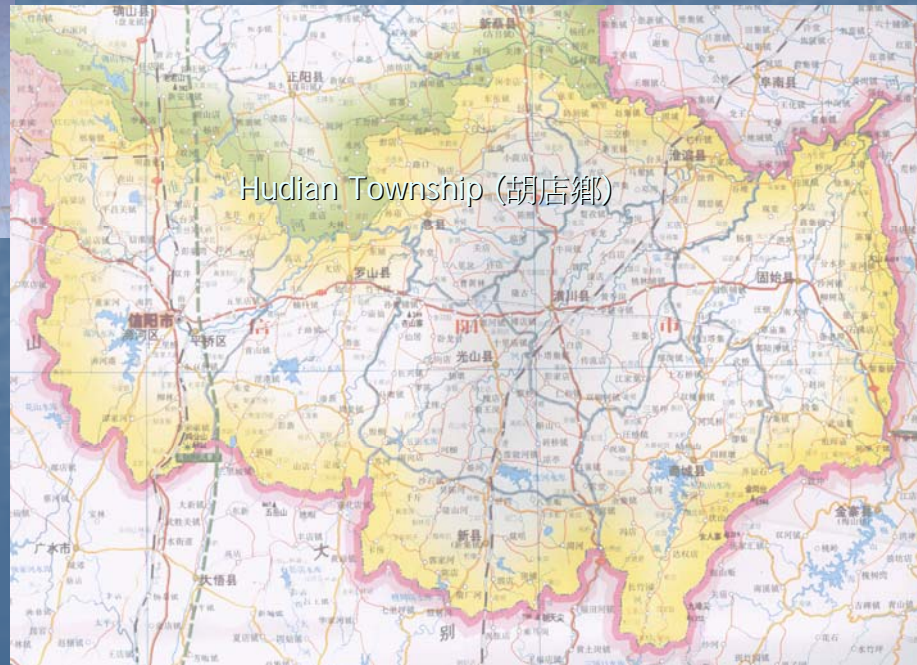
- Financially, the child with cancer in Japan, Taiwan and Hong Kong have the best chance of being cured without a complete financial collapse for the family. South Korea is moving towards full financial coverage while China has the longest way to go.

- In most countries mothers provide most of the care giving but in both South Korea and Japan mothers were often held responsible for not protecting their children from developing cancer. In China, fathers in rural areas frequently accompany their ill child and remain with them during hospitalization.

- In spite of current treatment methods, health care providers must continue to deal with the reality that some children will not survive. Dying children need good care, too. Hospice care for children is available in Hong Kong, South Korea and Taiwan. Neither Japan nor China have yet established hospice care for children.

Our location in:

# Henan Province (河南省)



Xinyang (信陽市)

# The Xinyang City Administrative Region



## Current programs

- Back-to-school----725 rural primary/middle school students
- Nutrition----about 700 rural primary/middle school students, and 100 college students
- Health assessments----600 last year; 300 re-check this year and begin 1 new school
- Libraries begun----in 3-4 primary and 1 middle school; 250 books to Nanguan church library
- Short term (3 weeks) ESL teachers----26 in summer of 2005 teaching 600+, mostly teachers of English
- Long term ESL teachers----1 on site for 3<sup>rd</sup> year, 2<sup>nd</sup> likely
- Sports equipment----selected schools at \$250-375 per school
- Youth encounters----1 event so far
- Upcoming: Computers and Media // Health Education // Medical equipment and supplies

Honored grandfathers, grandmothers, uncles and aunties,

How are you?

I am very grateful for your help to me. I am now very happy that I can again go to school. Our home is very simple and poor. My father got liver cancer when I was small. Even though my mother did her best to earn some money, going everywhere to borrow to pay for dad's illness, in the end he still went and I will no longer see him. After my father's death, we had hardly anything to eat, had debts to repay, and the work in the fields formerly done by dad himself now depends upon mother. Later because of the pressures of daily life, mother had no choice but to have me withdraw from school.

Now it is better. Because of your help, I can go to school again. My grades for my class are not bad. In the school recitation competition I got first place. You can surely imagine that this success didn't come easily. Relying now upon the support of your aid, I think now I can certainly study hard and not disappoint your hopes. And when I grow up I will be a useful person!

Wang Tiantian (a girl)

Grade 2, Zhaomiao Primary School, Hudian, Pingqiao District,  
Xinyang, Henan

July 6, 2003



## Excerpts from another letter

### Thank you Letter

"I could not express my gratitude even with thousands of words . . . I don't know who you are, and you don't know who I am, but . . . you have protected us with your love. I will never forget you, the you from far away . . . I hide my gratitude deep in my heart, deeper than the ocean. I promise I will not fail your expectation. My whole family thanks you. I pray for you quietly."

Wishing you health,

Liu Xin

Assisted by You

July 15, 2003

