

The Psychological Impact of a Dying Child on Chinese Family Members

Alice Cheng Lai, Thomas Wong, Zhi-xue Zhang & Ida M. Martinson

Abstract This study aimed to examine the psychological impact of a dying child on Chinese family members. Twelve parents of children with fatal illnesses were interviewed in hospital by a nursing doctoral student. The data were analysed by methods used in grounded theory research and common themes regarding family's responses were identified. They were: (1) parents' feelings of shock and disbelief, including the Chinese concept of yuan; (2) parents' depression and uncertainty; (3) parents' feelings of dissatisfaction; (4) family's conflicts and confusion including the use of Chinese herbs; and (5) healthy siblings' responses and feelings of being ignored. The impact on family functioning included decreasing participation in social activities, the family's being afraid of their future lives affected by fengshui and having more family conflicts. Whether parents were able to adjust well depended upon their marital relationship, the availability of social support, individuals' endurance, and their commitment to religious practices. The findings have implications for nursing practices in counseling dying children and their family members, in teaching communication skills to parents, and working with teachers at schools.

INTRODUCTION

The diagnosis of cancer impacts on family members resulting in: emotional disturbances such as anxiety, depression, loneliness, helplessness, and hopelessness (Van Dongen-Melman, et al., 1986, Dahlquist, et al., 1993, Manne, et al., 1995); heavy domestic and caregiving role demands (Lewis, 1986), and interpersonal crises (Oberst & James, 1985). Research on the psychosocial impact of cancer on family members has been increasing (Biegel, et al., 1990). Some investigators have examined the impact of children's cancer on their families. They have found that the diagnosis of cancer in a child not only results in a variety of stressors for parents (Kalnins, et al., 1980, Sawyer et al., 1993), but also has a devastating impact on the adaptive functioning of the entire family (Adams, 1978; Lindamood & Wiley, 1983; Fife, et al., 1987). The impact of cancer on family members is generally moderated by social support and coping styles. Social support has a direct effect on people's psychological well-being, and protects

individuals from psychological distress (Andrews, et al., 1978; Aneshensel & Stone, 1982; Turner, 1981). For example Northouse (1988) reported that psychological distress was related to social support for breast cancer patients and their husbands, while Morrow, et al. (1984) suggested that parents of children with cancer with socially supportive relations tend to adjust much better. Despite increased attention paid to the impact of cancer on families, there is limited knowledge about the impact of a dying child in Asian families. In particular, no research has been conducted in Chinese societies to examine the psychological influence of children with cancer on family functioning. Further, comprehensive data pertaining to families' psychological responses, obtained from in-depth interviews and qualitative analysis are relatively scarce, so this study provides an in-depth descriptive account of the Chinese family's psychological responses to the fatal illness of the child, which will help to enhance the quality of nursing practice for patients and their family members.

Alice Cheng Lai, Thomas Wong, Zhi-xue Zhang, *School of Nursing, The Hong Kong Polytechnic University, Hong Kong*
Ida M. Martinson, *Department of Family Health Care, School of Nursing, University of California, San Francisco*
(Requests for reprints can be addressed to Dr. Alice Cheng-Lai, School of Nursing, The Hong Kong Polytechnic University, Hong Kong, e-mail:hsalai@inet.polyu.edu.hk)

All families at two leading pediatric cancer centers meeting the criteria for the study were invited to participate. Twelve families refused to participate. There were 97 families willing to participate in this study, representing families where the children with cancer were either newly diagnosed, or under treatment and doing well, or were off treatment, children who were dying as well as families where the child had died. This article presents the data from parents whose child was dying.

METHOD

Participants

Twelve parents (three fathers and nine mothers) were interviewed. Their children (eight boys and four girls) had fatal illnesses and would not live. The mean age of the participants was 40.83 (SD=7.09), and their educational levels ranged from primary school to tertiary undergraduate. All nine mothers were housewives. One of the three fathers was a skilled worker, another was an accountant, and the other was unemployed. Seven of the 12 parents did not believe in any religion, but the other five had different religious faiths (two Buddhists, two Catholics, one Christian). The ages of their ill children ranged from one to 13 years old. Three of the 12 children were single children, five had one sibling, and four had two siblings.

PROCEDURE

Data collection

Before the main interviews began, the interviewer contacted the pediatric oncologist, obtained the families' agreement for the interview, and acquired the relevant medical information.

A trained interviewer, who was an experienced pediatric oncology nurse, was employed to carry out semi-structured interviews according to a schedule specifically developed for this project. Pilot interviews were carried out so that the interviewer could become familiar with the schedule and procedure, and obtain adequate interview skills. Based on the pilot interviews, necessary modifications and refinements to the interview guide were made.

Each of the parents participated in an in-depth, semi-structured, audiotaped interview. All of the interviews were conducted in Chinese, and the length ranged from 90 to 120 minutes. The interviews with parents reviewed the history of the child with the illness and the family's responses after the diagnosis and during the treatment, and examined relevant aspects of the family's functioning. The interviewer collected information from parents about their emotional responses and personal changes. Demographic data on each family were also acquired.

Data analysis

The data consisted of nearly 20 hours of audiotapes which were transcribed verbatim and translated into English. The database consisted of over 310 pages of transcriptions. Approximately 30 pages of the English translation were checked for accuracy and completeness with the Chinese interview by a member of the research team competent in both English and Chinese. The third author immersed himself in the texts and identified the textual units (words, sentences, and paragraphs) pertaining to family members' psychological reactions to the illness of the child. Memos to the document were written to enrich the analytical process. The respondents' descriptions were coded and category labels were developed. These categories were compared and contrasted, producing inclusive categories that could account for the whole data. Following this procedure, common themes regarding the impact of dying children on family functioning were identified.

RESULTS

The Ill Children and Parents' Perceptions of the Illness

The ill children of the 12 Chinese participants had different kinds of cancer. Six children had brain tumors, two had hepatocellular carcinoma (HCC), and the other four children had acute myeloblastic leukemia, juvenile chronic myelogenous leukemia, neuroblastoma, and osteogenic sarcoma, respectively. These ill children were typically characterized by disability in self-care, cognitive impairment, emotional disturbance, and behavioral problems. Although none of these children was expected to live, some Chinese parents still

believed that their child could be cured. Since most of the children had kept very close relationships and pleasurable interactions with family members, their illnesses exerted considerable influence on the whole family. One mother (Case 10) described her child like this: He is very good compared to other kids. He does his homework himself, without our requesting him to; and he keeps his school bag very neat. He is very smart... very ... very sweet. Also, this kid teaches me a lot of things too... He is not the same as other kids... he is much smarter. Because of that, he is born to be my child not just by chance. In Buddhism, it is yuan.

When they were asked to rank the order of their child's illness among the ten most serious things that have happened in their families, all 12 interviewees indicated that the illness of their child was the most serious thing in their family. One mother (Case 3) commented:

Family members, life, relatives and the people around us changed once he got this illness. We have to take care of him and it is a big trouble. His father had to take leave for several months. The maid stayed with him. His brother and sister got poor grades and needed a tutor. The expenses are getting bigger and are continuous. It is a very serious thing.

When asked to nominate three wishes, all the parents said their first wish was that their ill child could be cured and would be healthy, or that their child did not have the illness. Five participants said this was their only wish. Their other wishes included: the ill child could go to school like normal children; the ill child wouldn't affect her/his siblings' schoolwork; the disease wouldn't cause too much harm to the child; the family could have harmony; the whole family would not have the disease; and the ill child would not have to stay in hospital for too long.

THE PSYCHOLOGICAL RESPONSES OF CHINESE FAMILY MEMBERS

The participants' statements suggested the emergence of five kinds of responses. The first four represented the parents' responses, whereas the last was the healthy siblings' response. The

five responses were: (1) feelings of shock and disbelief, (2) a high level of depression and uncertainty, (3) dissatisfaction with professional and medical conditions in the hospital, (4) extreme psychological conflicts and confusion, and (5) healthy siblings' miserable responses and feelings of being ignored.

Feelings of shock and disbelief

The reactions of Chinese parents at the very beginning were characterized by shock and disbelief, during which denial and anger were commonly reported responses. Typically, parents were stunned, shocked, or disbelieving when they were informed of the definite diagnosis of the fatal illness. One father (Case 9) described his feelings when he was told that his child had cancer cells in her liver: "It was like the end of the world... I heard this, like a time bomb!...So sudden! I didn't know what to say. So scared! I have only one daughter." After her son was diagnosed with neuroblastoma, one mother (Case 1) said, "That moment, my reaction was terrible shock. I cried, feeling extremely down. I could not accept it. He's so little, how could something so unreasonable happen? It should not be. Even now I cannot believe it." Parents reported that they felt emotionally drained and excessively sad. They were very fidgety and cried all the day after their child's disease was diagnosed.

When asked what was the hardest time for them, five of the parents said when their child's disease was diagnosed and they were informed of the bad news. Parents were shocked by the sudden bad news, and they had to conceal their feelings from their ill child. One respondent (Case 4) recounted that, "at the beginning when she didn't know her situation, it was the hardest. Because you couldn't show any worry in front of her."

After that, parents understood the severity of the disease, and they gradually accepted the fact. They began to do their best to care for the child and tried all possible ways to cure their ill child or have death postponed. During the treatment of the ill child, parents often encountered great physical and psychological discomfort. They still experienced a high level of anxiety, depression (hopelessness, emotionally drained), and feelings of uncertainty. They usually kept on worrying about their child, and were afraid of bad things

happening to him/her. As one father (Case 9) said, "It has been really difficult till now. It is difficult and miserable for me every day. Every day I keep on worrying about her all day... Really anxious. I worry every day without having a good day."

Depression and uncertainty

Some parents reported that they were so depressed during this period that they could not do anything. Among the 12 interviewees, five of them stopped work after their child developed the fatal illness. Four of the five parents could not work because of their very bad moods produced by their children's illnesses. One father (Case 9) said that he was so sad about his daughter's illness that he could not concentrate on his work when he thought of her. He reported that he often dreamed and seemed to lose something when he woke up. In Case 2, the father was a taxi driver. He did not work and became silent after his son got cancer. He used to take photographs, but now he felt "miserable" and did not do it anymore. He bought a lot of film in the past, but now he had thrown it all away. He neither took part in any social activity nor talked with others even on the phone. He said he "is never in a good mood."

Parents were also preoccupied with a feeling of uncertainty. They did not know what their future would be like and could not arrange anything. One mother (Case 6) uttered, "The most difficult thing for me to handle is ... now, for every moment, I think of what will happen after doing the bone marrow transplant ... I don't know what the result will be ... I don't know what the result will be like."

Dissatisfaction with professionals and medical conditions

Since parents as caregivers had to stay in the hospital, they could not sleep well for a long time, and thus became very tired. During this period, parents not only wished that their children could be cured, but also expected the health professionals to provide them with information regarding the progress of their children's illnesses; they were very concerned about the treatment given to their children and were highly sensitive to the professionals' attitudes. For this reason, parents easily complained about the medical

conditions and professionals in the hospital. One mother (Case 10) reported her attitude towards doctors and professionals. After her child's brain cancer was diagnosed, she took her child to see a Chinese herbalist. From the mother's point of view, the Chinese herbalist was very selfish because he did not give good medicine to her child. After that, her child was admitted to hospital, and the mother felt that the doctor there was not good either. She said, "...her attitude was so bad and it really made me feel bad... Her attitude really made me sick". So she took her child to another hospital, and commented that "the doctors there are quite nice, but the environment was very bad".

Psychological conflicts and confusions

The greatest problem for parents at this stage lay in the psychological conflicts and confusions they experienced. In Case 6, the son was diagnosed with leukemia. The father worked in Indonesia and could not return to Hong Kong, and the mother had to deal with all the difficulties. At first, the doctor decided to do a bone marrow transplant from the ill child's elder sister. But the operation proved unsuccessful and the mother felt very sad and angry. A second transplant operation from the elder brother's bone marrow was needed, but the elder brother carried Hepatitis B. The mother understood the operation was very dangerous, and she was very confused. Since it was very difficult to find another person to donate marrow, the mother decided to have another transplant performed using her daughter's marrow. The father in Indonesia worried very much about his daughter's health. The father's relatives did not agree with the mother's decision either. The doctor suggested the operation be postponed until the sister was on summer holiday. However, the ill child's condition became worse and worse. The mother said:

I could not decide which way I should go, which way was better, whether or not to do the operation. I think I am dizzy now. I have not decided which way to go. Sometimes I want the doctor to arrange it all for me...but I don't know what the result will be.

Some parents did not want their ill child to suffer from pain or trauma. They gave up or stopped chemotherapy and sought the help of Chinese herbalists instead. If the ill child suffered very

much during the hospitalization, the parents hoped that his or her life would end earlier and be free from too much pain. However, they anticipated that they would miss the child very much after he/she passed away. Accordingly, some parents experienced serious conflicts.

Healthy siblings' miserable responses and feelings of being ignored.

Most interviewees reported that their healthy children did not show overt concern about the ill child, but some described their healthy children's responses. One mother (Case 4) with another two children reported that her elder son sometimes had insomnia after his younger brother was diagnosed, but her younger daughter was not affected at all. In Case 6, the mother recounted that both her elder son and daughter were concerned about their ill brother. When they learned that their younger brother had been diagnosed with cancer, both of them cried. The sister of the ill child donated her bone marrow to her younger brother. However, later it was found that the abnormal cells had not been cleared. The sister felt miserable and she felt pain in her bone and waist. She wondered why her younger brother did not accept her marrow. In this family, there was a period during which the mother could not go to hospital, and the elder brother, who had just finished his Form 7, went to work and returned to the hospital every day to take care of his younger brother. In our interview, the mother reported that her elder son experienced great pressure, and that he always cried. The brother always thought of his younger brother and he was occupied by a negative mood while he was working. The daughter was dissatisfied with her mother's neglect of her and could not concentrate in class.

Several parents admitted that the other child(ren) in the family was/were neglected during the illness. Since parents spent much time taking care of the ill child, some siblings had feelings of being neglected and were jealous of the sick child. One mother (Case 5) recounted that her ten-year-old elder son cried on the day his younger brother had the operation. Since the parents spent much time caring for the ill brother, the elder one was jealous of his brother, and his academic performance at school became worse. This healthy child became frightened and could not sleep well.

Influences on Family Functioning

Since the whole family life generally centered on the ill child, and both parents and siblings sacrificed time, money, and energy for the ill child, the illness caused changes to family functioning. According to participants' descriptions, the impacts on family functioning included: decreasing social participation; being afraid of the future; bad fengshui and; more family conflict.

Decreasing social participation.

Family members withdrew from friends, and considerably lessened their participation in social activities after one child developed a fatal illness. In a typical family, one parent stayed in hospital most of the time to take care of the ill child, while the other parent had to work to make a living for the whole family. Since the ill child occupied almost all of their time, they could not engage in social activities. On the other hand, some parents were so sad that they had no interest in any social activity.

Being afraid of the future.

Family members were afraid of their lives or did not know how to plan their future. One couple decided not to bear another child because they were afraid that the new child would have an illness like the ill child (Case 11). In Case 6, a mother with three children said that when she saw her ill child, she became worried about the health of the other two healthy children. This mother reported that after the child got cancer, her elder son felt so miserable because he did not know what his future would be. Some parents attributed their children's illnesses to the bad fengshui of their flat and thus moved out. Like many Chinese people, these parents believed it was the location of their flat that brought them bad fortune and caused the illness of their child. One family repainted the gate, did not sleep in certain places, and changed the flat according to a fortune-teller's suggestions.

More family conflict.

The illness with the child resulted in more conflict in most of the families, with parents experiencing more role conflicts and role strains.

The child's fatal illness influenced the relationship between parents. Impaired marital relations were reported by most of the interviewees. One father and three mothers reported that after their child became ill, they had a lot of quarrels with their spouse. Since they were in a bad mood, they often argued with each other over very small things. One mother (Case 1) recounted:

I always try to hold back my bad temper, but I really can't. I always quarrel with my husband.... I mean it's better to minimize our contact with each other. It was better when I stayed in the hospital. Actually, I think that I just want to find some outlet. I have nowhere to express my feelings. Even when there is only a trivial matter/issue, I scold him. He becomes irritated and gets in a bad mood. We start to quarrel.

The illness of the child also lowered the quality of the interactions between the parents and the other healthy siblings. In Case 2, when the six-year-old son developed cancer his father took care of him. His younger son used to play with the ill elder brother when he was living in the hospital, but did not pay attention in classes, and often forgot things. The teacher gave him bad marks. The father's mood was very bad and he often reprimanded the younger son. The younger son became afraid of his father and did not talk at home. The illness of a child may influence the family functioning in every aspect. In Case 6, the family had one elder son and daughter in addition to the ill boy. The elder son finished his Form 7 and went out to work. Originally, the mother expected this elder son to continue his study, but now she could not afford the school fees due to the financial difficulties. The couple did not have good marital relations. The father who worked in Indonesia did not talk about their child's illness with his wife, which imposed greater pressure on the mother. The mother devoted most of her time to caring for her ill child in hospital, and thus could not do anything for her young daughter. The mother felt very sad and guilty.

Intervening Conditions

Participants' statements indicated that the parents' responses to their children's fatal illnesses were mediated by four categories of factors: marital

relations; social support; personal character; and commitment to religious belief.

Marital relations

Couples in better marriages reported better adjustment. Spouses in a better marriage could share the responsibility and provide assistance physically and psychologically, which lessened the pressure imposed on them. The mother in Case 8 said she could face her young daughter's fatal illness and she did not accept any help from social workers. In talking about her marital relations, she said:

Both of us are very cooperative. He concentrates on his work and I concentrate on the baby... I am responsible for looking after the baby at the hospital and he is responsible for earning money for the family....Actually we don't have big problems and we can handle most things now, we don't have other requests yet.... My husband consoles me and I also console him in return. As this is a fact, we shouldn't blame any one. We share the burden.

Social support

Although spouses served as the central social support source for the parents of ill children, most of the participants recounted that they also received support from other sources including close friends, relatives, church friends, and members of social welfare organizations. One mother (Case 11) reported that after the brain tumor of her son was diagnosed, she talked about it with her friends, and they told her what her child should eat and how to cure the child. Before they decided whether the ill child should receive radiotherapy, their relatives and friends helped them to make the decision. However, after her son was admitted to the hospital, her friends and relatives seldom went to visit the ill child, and this mother became disappointed.

Some families did not discuss disease-related topics with others, but other parents communicated with their friends, relatives, and others. Those who could talk with others usually adapted more easily than those who did not openly express their emotions.

Personal character

Some parents had strong personal characters. They neither talked about the illness of their child with others nor requested any help from them. They were able to deal with the difficulties, and successfully coped with the stress resulting from their ill child. One mother (Case 5) said that when her four-year-old boy's brain tumor was diagnosed, she was able to accept the fact. She asked her elder son to do most things by himself. Her husband continued to go to work. She did her best to take care of her child in the hospital and did not request help from others. She described her feelings as, "I have seen the matter through now. I will not be so sad when he needs to have a surgical operation as I was in the past...I try to keep from crying in front of others." The father in Case 12 did not talk with his friends and relatives about his son's fatal illness because he thought that it was his own family's problem. He believed that others usually caused more trouble instead of helping. Although he had to go to work as well as to the hospital, he arranged everything well. He tried to control himself and do his work well. He commented that, "I arrange my time. If the time is arranged well... there should not be any problem."

Commitment to religious belief

After their child became ill, some parents began to participate in religious practices. These parents tended to attribute their child's illness to reasons pertaining to religious faith. After their child developed a life-threatening fatal illness, they were more involved in religious activities than before. One mother (Case 10) believed that her ill child was paying the debt of his previous life, therefore, she attended worship and read Buddhist scriptures begging Buddha to prolong her son's life. She was confident that her ill child could be cured due to her religious devotion.

Another mother (Case 1) also reported that she and her family members began to believe in Buddhism after her son developed cancer. They went to a temple in Mainland China on the first and fifteenth days of the lunar calendar. At home, they set up a Buddhist image to worship in the morning and evening. A religious specialist, who they heard had cured other people's illnesses, gave their child Chinese herbal medicine. When the

child was in hospital, the mother stayed in hospital and her husband and relatives went to religious activities. If the ill son was in a favorable condition, they took the child with them. She said:

Maybe my child has a very heavy debt so that he is born to suffer. Maybe we parents have done some bad things and caused our child to suffer. He has to suffer the chemotherapy... I just try to do my best to beg the specialist's help. What else can we do? Just make more effort to pray and don't look at the condition from the worse side. This can give me some confidence. It is the only way.

Religious involvement provided psychological comfort and spiritual well-being for some parents. Some participants reported that participation in religious practices made them feel more comfortable since their child had been diagnosed with cancer. In Case 7, the mother immigrated to Hong Kong from Mainland China, and her husband died in an accident. She had no relatives in Hong Kong and no place to live. She became intensively enthusiastic about religion after her child became ill. She began to read a lot of Christian religious books given to her by a pastor and others. She said:

I feel more peaceful since I came here, mainly because I read the Bible more... more peaceful in my heart...very confused in the past...couldn't do anything...I am much better now.

DISCUSSION

In this study, Chinese family members were found to have extreme psychological reactions to the fatal illness of the child and expressed their reactions. When parents were first informed of their child's cancer, they were generally shocked and could not accept the fact. After that, they gradually recognized the severity of the illness and tried many different ways to cure him/her. Although parents began to face the fact, they still experienced extreme emotional disturbances, with feelings of anxiety, depression, uncertainty and exhaustion. In addition, families generally experienced more family conflict. Relations between couples and the quality of interactions

among family members were impaired. The impact of a dying child on the family members reported by participants in this study is consistent with the findings from past research (Martinson & Cohen, 1988; Sales, 1991).

Some parents were able to adjust after their child became fatally ill, but others experienced depression and sadness for a quite long time. Whether parents were able to cope successfully with the stress produced by the illness of a child depended upon the quality of their marital relationship, the availability of social support, an individual's personal characteristics, and parents' involvement in religious practices.

Our analysis of the participants' descriptions revealed that good marital relations and healthy communication between spouses contributed to parents' adjustment as well as their psychological well-being. These findings echo the results from past research. Both Grandstaff (1976) and Wellisch, et al. (1978) found that couples with good preexisting marital relations were able to alleviate the stresses of mastectomy more easily, and husbands in stronger marriages were more involved in their wives' decision-making pertaining to surgery. Friedrich and Friedrich (1981) documented that marital relations are the major variable in parents' ability to cope with an ill child. Cohen, et al. (1977) suggested that better family communication contributed to better adjustment to bereavement. Vess, et al. (1985) revealed that couples with better communication were more able to deal with role demands, were more cohesive, and indicated less role conflicts, role strain, and family conflicts than other couples did. All of these studies suggest that the quality of marriage and communication between couples may predict better adaptation to emotional problems.

Adequate social support was found to be a significant factor in parents' coping with children with cancer. Those who reported having adequate sources of support generally adapted better. This result is consistent with past research findings. Pearse (1977) found that families without adequate social support had more difficulty coping with the stress produced by illness. Cohen and Wills (1985) suggested that the social support system has a buffering effect for cancer patients. It protects the patient from the full onslaught of the stressor

produced by the disease experience when interpersonal resources are available and responsive to the patient's needs. Our findings indicated that parents who received emotional, cognitive, and material support from others were able to cope better with the stress resulting from the illness of their child.

Some participants were found to be able to weather the stresses and pressures even though they neither had good marriages nor obtained social support from relatives and friends. Findings indicated that personality characteristics and commitment to religion served as important factors for parents in managing their emotional distress. Some parents were more resistant to the stresses they experienced, and they seemed not to become physically or emotionally impaired. These parents generally had a sense of personal control and commitment to personal goals, which has been proven to be the most significant factor for people's resistance to stressful events (Cohen & Edwards, 1989; Wiebe & McCallum, 1986).

Families showed higher participation in religious practices after their child developed the fatal illness. The parents who were committed to religious activities obtained emotional comfort from their religious devotion. This finding is consistent with the senior author's previous research conducted in other areas (Martinson & Martinson, 1988; Martinson, Martinson, & Kim, 1996).

Limitations of this study should be mentioned. One weakness concerns the limited representativeness of our respondents. Since only a small number of parents were identified as having a child dying, the effects of other factors such as occupation, socioeconomic status, and educational level could not be detected. For example, participants' financial situations have a close bearing on the level of stress they experience, and thus have something to do with their adjustment to the emotional turmoil produced by the illness of their child. However, this relationship could not be examined in this study.

In this study, investigation of the impact of the ill child on the healthy siblings was solely based on participants' reports. Some participants reported that their healthy children did not have negative manifestations. The healthy siblings' responses

may depend upon their age. Very young children had not developed an understanding of the concept of fatal illness and thus did not go through the emotional and behavioral distress of their parents and their elder siblings. However, it is also possible that parents were not sensitive to their healthy children's changes and thus reported no negative impact. The healthy children's changes could be examined through field observation, and whether the ill child has an influence on healthy children in the same family deserves further investigation.

Implications for Nursing Practice

The findings of this study have implications for the improvement of nursing services. First, counseling should be provided for ill children and their family members. Such a service is especially necessary at the beginning when the fatal illness of the child is diagnosed. The majority of the respondents recounted that this was their hardest period because most of them were totally at a loss. Nurses should provide these parents with both relevant information and psychological counseling. When asked what kind of help they needed most, some parents reported that more knowledge about the disease and the expected outcome should be provided, and that psychological counseling should be available for both the ill child and the family.

Second, parents need to be taught to communicate with others. When they were asked whether they would like to take part in an activity which was organized to help them, several mothers reported that they did not know how to interact with strangers, how to communicate with others, and thus would not like to participate in these activities. Other participants stated that they would neither like to talk about their problems with others nor express their feelings in front of strangers. They believed that organizations could not help them, and even thought that such associations would cause more problems instead of giving them assistance and comfort. These parents should be encouraged to share their experiences with others. Training regarding how to overcome their feelings of embarrassment in front of others should be offered.

Two concepts unique to Chinese culture in Hong Kong were identified. The concept of **yuan** means affinity, predestined relationship, or the

cause of a predestined relationship. Rooted in the Buddhist beliefs of predestination and fatalism, **yuan** provides a cultural explanation for the formation of interpersonal relationships on the basis of predestined affinity or enmity (Yang & Ho, 1988). **Feng shui** is related to the idea that living with rather than against nature benefits both humans and our environment and our lives are deeply affected by our physical and emotional environs. Hence the comments from the participants which related to either the illness being predetermined or effected by the environment in some way.

Third, nurses could cooperate with schools to make the ill children feel comfortable when they return to school. Parents hoped their ill children could stay with other normal children after leaving hospital. They were concerned that because their ill child was mentally slower and without hair, they might be discriminated against in school. Several mothers complained that their children were not fairly treated or were discriminated against by the school. They reported that schoolteachers did not have enough knowledge of the ill children and could not fully understand them. Educating the public to hold a supportive attitude toward children with cancer and their families is a demanding task in Hong Kong.

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瀕死病童對華人家庭各成員的心理影響

這項研究旨在探討華人家庭面對瀕死病童時心理的衝擊和克服哀痛的方法。研究由護理博士生於醫院進行，訪問了十二名患有致命疾病兒童的家長，數據以紮根理論的方法分析，並將家長的反應歸類，包括：(一) 家長對病童的情況感到震驚、不接受，並且以中國的「因緣」概念解釋情況；(二) 家長抑鬱及把持不定；(三) 家長感到不滿意；(四) 家庭出現爭吵和混亂(包括在使用中草藥上)；(五) 健康的兄弟姊妹感到受忽略。

面對瀕死病童，家庭的整體功能也受到影響，如家庭會減少參與社會活動、家庭成員會擔心自己的生活及健康，變得較關心「風水」，家庭的爭吵因而增加。家長的婚姻關係、個人忍受能力、信仰及社會支援的多寡，足以影響家長面對病童的適應能力。

此項研究的結果有助發展瀕死病童及其家人的輔導服務，並可應用於教育機構及指導家長的溝通技巧。

摘要