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Original Article

Caring in nursing: Investigating the meaning of caring from the perspective of Chinese children living with leukemia

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ABSTRACT

Background: Effective communication between nurse and patient is paramount in establishing the relationship on which patient care is based and influences the quality of nursing care leading to improved health outcomes for patients. It is necessary for nurses to understand children's perspectives of nurse–patient communication in order to choose appropriate communication skills to promote effective communication and a sweet relationship.

Purpose: To explore the communication status of children who were in the early stages of living with leukemia and their perspectives of nurse–patient communication.

Method: In-depth interviews were conducted with Chinese children with leukemia using a descriptive qualitative research method, and the data were analyzed using Krippendorf's content analysis.

Results: Twenty-nine children with leukemia were interviewed. Three communication states were identified among children in the first three months of living with leukemia: totally unwilling to communicate, reduced communication with others and increased communication with parents. Nurse–patient communication for children with leukemia formed three themes: content, form and occasion of communication.

Conclusions: With a better understanding of children's communication status and their expectations of communication, nurses can promote effective nurse–patient communication strategies to meet children's psychological needs and build harmonious relationship.

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1. Introduction

Leukemia is the most common pediatric malignancy, with approximately 15,000 new cases in children under 15 years of age diagnosed annually in China [1], and treatment for childhood leukemias has advanced rapidly: for example, the long-term event-free survival of Acute Lymphatic Leukemia (ALL) has risen to 75%–80% [2,3]. More and more children are in remission, and therefore have needed to experience long-term hospitalization. Current treatment for standard and high-risk ALL consists of chemotherapy lasting about 30 months for girls and 36 months for boys [4], and treatment for Acute Myeloid Leukemia (AML) lasts about 18 months [5]. In China, the first hospitalization period for children with leukemia needs to be 2–3 months to achieve induced remission and for the first (and even second) course of treatment to be consolidated. During the remission stage, children need to be in hospital for about two weeks of every course according their treatment schedule. During the first 3 months, children always showed negative emotions. [6]. It is helpful for nurses to understand the nature of children's communication to promote their adjustment. The length of time involved for the treatment enables the children to develop long term relationships with the nurses. To do this effectively the nurses need a good understanding of the children's perspectives of communication. The purpose of this study was to explore the communication status of children who were in the early stages of living with leukemia and their perspectives of nurse patient communication (Table 1).

2. Background

The importance of nurse–patient communication has been well documented and that relationship is an important part of daily nursing practice. [7,8] Effective communication between nurse and patient is paramount in establishing the relationship on which patient care is based and influences the quality of nursing care leading to improved health outcomes for patients [9,10]. In the nurse–patient relationship, communication involves more than the transmission of information; it also involves transmitting feelings, recognizing those feelings and letting the patient know that their feelings have been recognized [11]. Nurse–patient communication is an interaction defined by socially and culturally derived processes [12,13]. Because the interaction between a nurse and a patient is a shared process, both the patient and the nurse are involved in constructing, interpreting, and defining each other's actions. Several researchers have explored nurses' perspectives of communication [14–16], while other studies' have focused on the patients' viewpoint [10,17–20]. Many communication skills were explored and educed for nurses, especially patient-centred communication [17]. However, studies of patients almost all involved adults or elders, and few studies have focused on school-aged children living with leukemia. School-aged children have a high level of communication skills, and they can express themselves frankly [21]. It is necessary for nurses to understand children's perspectives of nurse–patient communication in order to choose appropriate communication skills to promoting effective communication and a sweet relationship. This paper reports one part of a research project exploring the experiences of Chinese children living with leukemia and the nurse–patient communication needed during their hospitalization.

3. The study

3.1. Aim

The aim of this study was to explore the communication status of children who were in the early stages of living with leukemia and their perspectives of nurse patient communication.

3.2. Design

A descriptive qualitative study design was adopted, and face-to-face individual in-depth interviews with an intervier schedule with outline questions were used to collect data.

3.3. Participants

Data collection was conducted in two of the largest general teaching hospitals in Beijing, China, between October 2008 and July 2009. The inclusion criteria were: (1) at least 3 months

Table 1 – General information about the children living with leukemia (n = 29).

Item	n	F (%)
Sex		
Male	16	55.2
Female	13	44.8
Age (years)		
7–8	7	24.1
9–12	15	51.8
13–14	7	24.1
Education		
Primary school grades 1 to 2	7	24.1
Primary school grades 3–6	11	37.9
Junior middle school	11	38.0
Birthplace		
Beijing	6	20.7
Other places	23	79.3
Having siblings		
Yes	7	24.1
No	22	75.9
Status of study		
Attending school	4	13.8
Absence from school	25	86.2
Stage of disease		
ALL remission	26	89.7
AML remission	3	10.3
Course of disease (month)		
4–12	15	51.7
13–24	9	31.0
24–30	5	17.3
Living status in the treatment interval		
Living in home, Beijing	6	20.7
Renting house in Beijing	14	48.3
Living in hometown	9	31.0

since clinical diagnosis of acute leukemia; (2) being of school-age; (3) having no difficulty in communicating verbally; and (4) being willing to join the study. Participants were recruited using purposive sampling to give variation in sex, age, birthplace, education level, acute leukemia sub-type and course in order to increase the richness of the data. The ward head nurses nominated suitable participants. Data were collected until no new themes emerged, and it was judged that data saturation was achieved. The final sample size was 29 children: 16 boys and 13 girls, ranging from 7 to 14 years old. They were all chaperoned by their biological parents during hospitalization (Table 1).

3.4. Data collection

Data were collected using Semi-structured interviews that were tape recorded and lasted an average of 20 min. Each interview began with the researcher asking the participant to describe his/her experiences of how nurses communicated with her/him during their time as an inpatient and then letting them recall their communication status during the early stage.

3.5. Ethical considerations

Approval to conduct the study was obtained from the university and the two hospital ethical committees. All children and their parents were fully informed about the purposes of the study, and that the interviews would be tape-recorded; that their anonymity would be maintained; and that their participation in the study was voluntary so they were free to withdraw from the study at any time.

3.6. Data analysis

The data were analyzed using qualitative content analysis methods for descriptive qualitative studies, including the five following procedures [22]: transcribing qualitative data, breaking down data into smaller units, coding and naming the units, categorizing, deriving themes. Two researchers in the study team were assigned the tasks of analyzing the data independently, and wrote memos and notes [23]. Then, the two researchers together with the master's student's supervisor collaboratively reviewed the codes, categorized them, and identified the emerging themes through regular group meetings.

4. Findings

4.1. Communication status of children in the early stages of living with leukemia

There were three communication states of children in the first three months of living with leukemia: Totally unwilling to communicate, reduced communication with others and communication with parents increased. However most of the children actively wanted others to communicate with them during this stage. See Fig. 1.

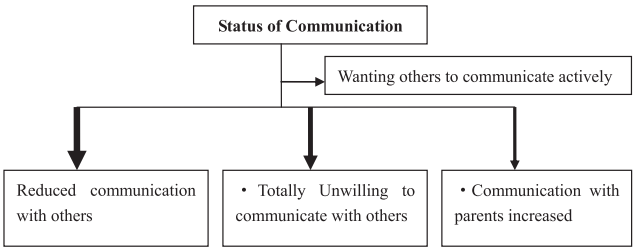

Fig. 1 – Communication status of children in the early stages of leukemia.

4.1.1. *Totally unwilling to communicate*

This means that children would not actively communicate with parents, health professionals, or other children in the ward, and they just passively answered doctors' questions. There were 10 children who recalled that they refused to say anything during the first 3 months of hospitalization except when they had to answer doctor's or nurses' questions. Four of these were younger, aged 7–8 years old, and the other 6 children were 12–14 years old.

"During the early stage, I did not will talk with anyone, and just answered when the doctor asked me how I was feeling. I felt very uncomfortable at that time, and I did not want to say anything". "I was irritable during the first time I was in hospital and I did not talk about my feelings with others even my mother. I laid on my bed, and just extended my arms when nurses came to do intravenous transfusion, without saying anything".

4.1.2. *Reduced communication with others*

This means that the children with leukemia showed less communication than before their illness, especially pouring out feelings and emotions decreased. There were thirteen children who expressed that they would seldom communicate with others, and these children were not informed about the disease or their parents avoided discussing their questions about the disease.

"I did not talk with my parents at first. Although I talked with my mother something, it was little. At that time, I would not talk about my feelings with my mother anymore, just hiding it in my heart". "I talked with mama occasionally in the beginning, I always lost my temper and cried. I was unhappy and in bad mood during the first months, but I did not communicate my emotion with anyone".

4.1.3. *Communication with parents increased*

This means that compared to when the child was healthy the communication with parents increased and the content of communication was richer than before. There were two 7–8 years old and four 12–14 years old children said they talked about more things with parents than before, and their relationship was more intimate. These children were always informed about their disease from the start, and parents could deal with their doubts about the disease positively.

"Maybe there was more free time in hospital than at school, I played with mum in bed, and watched TV all day long. I talked with her more than before". "I liked to talk with my parents after I had this disease, and we talked about

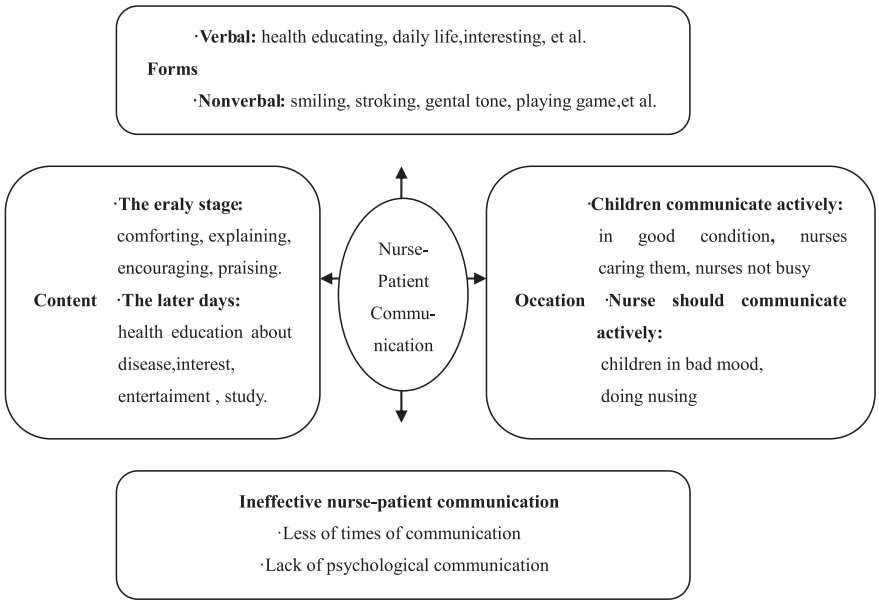

Fig. 2 – Nurse–patient communication of children with leukemia.

everything, such as what I would I do after being cured, imagining my future". "I became less independent at the beginning in hospital, and I depended on my parents a lot. Sometime I felt it brought me into trouble, and I told mom that I was unlucky. They comforted me and made me feel at ease about the long term treatment".

4.1.4. *Hoping others would actively communicate*

This means that children hoped others around them in hospital could initiate conversation with them, encourage and comfort, and help them adjust emotionally, although they did not want to talk with others at that time. All of interviewed children expressed that they liked others to actively talk with them.

"At that time, I really hoped to hear encouraging words. I wanted the nurses to say some blessing, such as I could get rehabilitation soon, I could go back home after I was cured. I wanted my parents to comfort me. Although I never answered them, I hoped they would tell me that there is no problem, it will be OK". "Although I did not talk with nurses or doctors, I hoped they could come to comfort me, tell me about my body condition and the daily notes, and give me more hope". "I wanted to be cheerful at that time, and I wanted someone who could tell me some happy things and some humour".

4.2. *Nurse–patient communication of children living with leukemia*

Three themes emerged from the data analysis, these were content, form and occasion of communication and these themes varied according to the different situations. Communication in children's wards was found to be ineffective on two counts: communication time was short and communication failed to meet psychological needs. See Fig. 2.

4.2.1. *Contents*

(1) The content of nurse–patient communication in the first three months: In the acute stage of the disease when the symptoms were severe the children's condition was bad at this time. During this stage, children were always nervous, worried or anxious, and they hoped the nurses could give them comfort, explanation, encouragement, and praise according their state of health or illness and the course of therapy. They felt this would enable them to feel connected to the nurses.

"I know that nurses care for me freely, but if they could say some encouraging words, such as 'your disease can be cured', 'you have performed well recently', 'you will get better and be able to go back to school again ', it would make my mind at ease". "My nurses often came to ask about my feelings, How are you feeling? 'Do you feel any better than the other day', and they came to comfort me many times when I got fever. Their action in comforting me created my warm emotion"."Nurses sometime praised me for my good protection of PICC. I was happy and acted bravely".

(2) The content of nurse–patient communication in the later days: In the remission stage, the children's condition was more stable and better than previously. They had more energy to notice their situation and environment, and they wanted to communicate with the nurses about various topics, such as health education about their disease, interests, entertainment and study.

①Health education about disease: This means that children got systematic information about therapy and rehabilitation, such as drug action, course of therapy, body's condition and daily notes. "Sometime, I asked nurses about some problems I could not

understand, such as "Why do I have to have injections? What were those drugs I have had and what were their effects?". Nurses would tell me about my condition and the lasting effects of the therapy, these things helped me to understand the overall situation". "Nurses would talk with me about my condition, the disease, the treatment of my disease and the drugs' side effects. I wondered what I could do to be healthy quicker, and when they had time I would will ask nurses or doctors for some advice about daily life".

②Interest and entertainment: When the children's condition was better, they would like to talk with familiar nurses about interesting topics, and started playing with them. "Of course, I like nurses who speak to me at my level. Just like before, nurses talked with me about Japanese Cartoons, or TV idol. Those children all liked to watch them, and I would chat with nurses for a short while when they were not busy". "I hope to get along with the nurses as friends, we can have a good discussion on trivial matters, such as 'how old are you aunty? Do you have boyfriend?'. One day, I chatted with aunty Jia about a beauty skirt that my mom wanted to buy, it was too expensive, and then we discussed the price like old friends". "When nurses are not busy, they play with me with my toys, and then we chat. We talk about anything, for example, guessing riddles".

③Study: Children would choose trusted nurses to communicate their thoughts about study, future plans and aspirations. "I particularly like the head nurse, and tell her my thoughts, especially talking about life before at school and imagining going back to school again. When I was in a bad mood, she would comfort and encourage me like a friend". "I trust aunty Wang. She often came to chat with me, about my dreams. I tell her my mood and secret thoughts, and she always encouraged me".

4.2.2. *Forms*

(1) Verbal communication: "I hoped nurses would come to my bed and speak with me. Because they are experts in my disease, I believe what they tell me, and that puts my mind at ease". "My favorite nurse is Miss Wang. She smiles and says hello actively when I meet her. And she often cracks jokes for us, this makes me happy and makes our relationship closer".

(2) Non-verbal communication: This includes using facial expressions and gesture to convey a message "One nurse on this ward impressed me deeply when I was in hospital the first time. She always smiled when she came to our room, and I soon remembered her. Her smile lifted my mood, comforted me and let me relax. It seems that she could pass on her good mood". "I once cried because I was homesick, the head nurse came to sit on the bed, held me for a while and stroked my head with her warm hands. She understood how I felt. I would see the head nurse like my mom from then on".

4.2.3. *Occasions*

(1) Occasions when children actively communicate: If children were in good condition, they would communicate actively with nurses when nurses did normal nursing duties for them or nurses were not busy. "When I got better and I didn't need to lie in bed, I would chat with the nurses. Sometimes I went to their office and sometime they came to the ward to play with me". "I will say a few words to the nurses when they came to do puncture for me. And they came to our ward several times a day for normal nursing duties, I will talk with them for a while every time". "Because there are too many children in the ward, the nurses are always busy and have no time to play with us. Sometime I want to chat with the nurses, but I see they are too busy, so I have to go away. I wonder if the nurses could talk with me for a little longer when they are not busy".

(2) Occasions when nurses should communicate proactively: Children wished that nurses could be proactive in communicating with them when they were in a bad mood, and hoped nurses would take more time for deeper communication when they gave nursing care. "I will not talk with nurses when my mood is bad, but I hope that there is a good friend to sharing my feeling. If the nurse who I trust has time to sit down beside me, I will talk with her about my emotion". "They always ask 'How are you feeling at the moment?', and I say ' 'I'm OK'. Maybe they are busy so they rarely say more than one or two words. But 'it's OK' does not means 'I am feeling good', it just means 'II can cope with my situation right now'. If nurses could take more time to talk with me about my condition that is really caring about me!"

4.2.4. *Ineffective nurse–patient communication: examples and reasons*

(1) Little time spent on communication: Children believed that there were too few opportunities for communication. There were two reasons for this: one related to the nurse and one to themselves.

①Nurse's reasons: Being too busy and not actively communicating are the two main nurse's reasons which led to few occasions of nurse–patient communication. "Nurses have no time, and they go away after completing the injection. So I do not talk with them, I just saying hello sometime, and they do not have time to stop to talk with me for a while". "It's not strange that I rarely talk with the nurses,, maybe I do not initiate conversation with them. But if nurses could come to talk with me actively, I am happy to chat with them".

②Reasons within the children: Three children believed that their introverted nature was the main reason that they did not communicate. They would not initiate communication with nurses. " I am always introverted, and I was also like this at school. I rarely spoke to others, so I will not talk with nurses actively. That is my reason".

(2) Lack of psychological communication: Although children acknowledged that they occasionally spoke with the nurses, they believed there was no psychological and emotional communication. There were also two reasons.

①Reasons within the nurses: Nurses not initiating an interaction and their poor practical skills resulted in the children not communicating their emotions. "I would not even think of telling the nurse about my mood. Because they have never asked I would not think of telling them. If they have time to sit beside me and talk with me, maybe we will be good friends and talk about anything". "I rarely talk with nurses, and do not speak my mind to them. That's because some nurses' have poor skills: sometime they puncture me several times before they can get in, so then I am not in the mood to speak with them. I like to talk with the nurse who has good skills and make me feel little pain".

②Reasons within the children: Three 12–14 years old boys considered that there was no necessary to tell nurses their thinking. These children had been in junior middle school, and they believed themselves introvert. "I do not want to talk with them about my mood or emotion. It is not necessary, and that is my own business". One 12 years old girl was too shy to actively share her mind with nurses: "Sometime, I do not want to talk about my mood, I'm a little shy, and I feel embarrassed".

5. Discussion

5.1. *Most Children's communication was reduced during the early stage*

In the early stage of leukemia all the children showed reduced communication, several children did not even want to communicate with others. Although four children's communication with parents increased, they rarely talked with nurses or other children. Emotion effects a person's communication. During this period, children faced the consequences of a life-threatening disease and changes in their living environment and lifestyle, and they had to endure the side effects of frequent diagnostic tests and treatments. Their bodies and minds were affected at the same time. Studies have indicated that children with cancer have a higher propensity for mental and behavioral problems in the early stage. Depression, somatic complaints, social withdrawal, and high anxiety are more commonplace [24,25]. These may effectively reduce children's communication.

5.2. *Children's communication was associated with their knowledge about the disease*

The findings of this study demonstrated that those children who could communicate better with parents or nurses usually get some information about the disease shortly after diagnosis, while children who were not told about the disease, or those who's parents refused to talk about it by avoidance or hiding, always had bad communication during the early stage. In China, because of the severity of leukemia, parents always request that the doctors or nurses hide the disease from the children. This leads to reduced occasions of communication about disease between children and health professionals or parents, and even resulted in children having more emotional problems which could make a communicating barrier between them [26]. Studies have shown that if parents could tell children with leukemia the truth about the disease, and tell them selected information about the illness, such as the duration of treatment, the purpose of various tests and procedures, it can enhance the sense of prognosis, improve children's ability to cope with the disease, and promote communication between children and parents [27,28].

5.3. *The content of nurse–patient communication was associated with children's course of disease*

In the early stage, children with leukemia hoped that nurses could give them psychological support by comforting or encouraging them; in the remission stage, children wanted to communicate with nurses about topics like health education about the disease, interests and study. During the first three months, the severity of the disease and change of environment and life style induced severe psychological problems in the children and they appeared to be in emotional shock [6,24,25]. They particularly needed other's emotional support at that time. In later days, the children were in the remission stage with a stable condition, and they understood the effects of treatment and life of hospital through experience. They paid more attention to life in general and hoped to get more information about their disease [29].

5.4. *Using different forms of communication to promote nurse–patient communication*

There were two forms of nurse–patient communication for children with leukemia and nurses: verbal and nonverbal. Verbal communication included giving about the disease information, chatting about daily life and interests; nonverbal communication included smiling, stroking, using a gentle tone, playing games. Language is the main tool of communication, and nurses' words are the soul-ties of communication between nurses and children; while nonverbal communication also pay an important role, for example, smiling is the beginning of good communication and the medium of getting close to children [30]. When communicating with school-aged children, nurses' use of words, which express comforting, explaining, praising, encouraging, informing, and inquiring, along with suitable body language can improve the effective communication and the nurse–patient relationship [31].

5.5. *Nurses' activity affected nurse–patient communication*

Children considered that nurses' activity was the key of effective communication between nurse and patient, and proactive nurses had harmonious relationships with children and always given emotional support to them. Being too busy and not having enough time to talk with patients is frequently offered as a reason for the low quantity and quality of nurse–patient conversation [32,33]. And for communicating with patient with cancer, nurses' poor communication skills was the main reason of ineffective communication [34,35]. Nurses being proactive in communicating with children while doing their daily duties could relieve children's worry, and easily get them trust.

6. Implications for nursing practice

In the early stage, health professionals should actively initiate communicate with children and discuss with parents the importance of deciding how and how much to tell the children about the disease. Nurses could provide positive information for children and give them confidence. If children are unwilling to speak with others, nurses should take more time to stay with them, explain, enlighten, and encourage them to express their feelings, and make effective nurse–patient communication. Secondly, nurses should prompt parents to communicate with children, and help parents to keep emotionally stable while facing their children in order to prevent transmission of negative emotions. Thirdly, nurses could encourage children to keep connecting with their friends, and promote good emotional expression indirectly. For nurse–patient communication, nurses should choose appropriate content to communicate with children using different mediums as appropriate to the situation. As the course of the disease progresses, nurses should take more time to become involved in children's daily life as friends, giving them emotional and life support.

7. Conclusion

This study describes three states of communication of children in the early stage of living with leukemia; the content, form, and occasion of nurse–patient communication and the reason of ineffective communication. With a better understanding of children's communication status and their expectations of communication, nurses can promote effective nurse–patient communication strategies to meet children's psychological needs and built harmonious relationship.

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