

# ***A Study on the Current Situation of Education of Rural Children with Serious Illnesses Who Go to the City for Medical Treatment***

## ***—A Case Study of WuJiaNong in Hefei City***

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**Abstract:** This study analyzes the current situation of family education and school education of special children with major illnesses such as leukemia and malignant tumor who travel to the city specifically for medical treatment in rural areas, taking WuJiaNong in Hefei as an example. After understanding the economic pressure, mental pressure, and social support of these special groups, and taking into account the situation of local voluntary organizations, the current situation of family education and schooling of children with leukemia in WuJiaNong, Hefei City is clarified, and the causes of their education problems are analyzed in the light of various factors, to draw the attention of the society and improve the current situation of the lack of family education and schooling of children with major diseases in rural areas.

**Keywords:** children with leukemia, family education, school education, current situation, reason analysis

## **1. Introduction**

WuJiaNong is located at the intersection of Tongcheng South Road and Wangjiang Road in Hefei, Anhui Province, an urban village adjacent to Anhui Children's Hospital. This urban village is home to families of children with leukemia from different counties around Hefei, who rent rooms here for a long time to provide treatment for their children.

With a little-known history, WuJiaNong has now become synonymous with "leukemia" on the Internet. In the eyes of many people in Hefei, WuJiaNong is just an ordinary urban village with small two-story buildings as the standard construction, temporary "overnight buildings" that are also very dense and have a hundred and one lanes. The reality is that WuJiaNong is indeed an ordinary urban village, if there is anything special, it is adjacent to the Provincial Children's Hospital. It is for this reason that WuJiaNong has gradually become a gathering place for some children with leukemia.

If you walk into the village, you will find a special feature here, there is a special group of "angels" living here, they all have one thing in common - shaved heads and thick masks, which is the sign of chemotherapy. There are more than 60 families of children with leukemia and malignant tumors living here all year round, some of them are rich, but because their children have to be treated all year

round, they have to live in a dilapidated urban village for a long time to save money and be close to the hospital. For parents and children, the hospital and the small village, which are only one wall away, are all they have to live on.

## **2. Reasons for the Formation of WuJiaNong**

### **2.1. Economic Reasons**

Most of these families are from the rural areas around Hefei City. When their children first develop the disease, the parents choose to go to the county and town health clinics or the nearby community hospitals for treatment, but due to the backward medical conditions in these institutions, the disease is not thoroughly investigated, and they choose to seek treatment in big cities such as Beijing and Shanghai. However, most families eventually choose to come to Hefei, the nearest provincial capital city, for treatment due to economic conditions and difficulties in cross-provincial reimbursement.

More and more families with children from rural areas are coming here. Although leukemia is not incurable, its treatment cycle and recovery period are very long, so housing has become an urgent problem for them to solve. Most of the families choose to rent a room in the WuJiaNong next to the hospital because they can go to the hospital whenever the child is in danger, such as when he or she suddenly contracts a high fever or needs chemotherapy and checkups. The housing conditions by the provincial hospital in the center of the city are superior, but the average monthly rent is as high as 1,500 yuan, which is undoubtedly an added burden for these families who are not rich and have to bear the high cost of treatment for their children, while the average rent in the urban village of WuJiaNong is about 300 yuan. Because of these factors, families who go to the city for medical treatment choose to gather in this urban village, and gradually the originally cold urban village becomes “lively”.

### **2.2. Social Prejudice**

Leukemia is not an incurable disease, but many people have little knowledge about it and are prejudiced. During the interviews, some parents said that their neighbors in their hometowns heard that their children had leukemia, and when they saw the children wearing heavy masks, they thought it was an infectious disease and gradually distanced themselves from them, refusing to interact with them. These children wear masks to isolate the germs to prevent infection, and leukemia itself is not contagious.

These social prejudices caused them to have little contact with the outside world, but when they came to WuJiaNong, there were many families with leukemia in the same situation, and they formed a cohesive force and found a sense of belonging among them. During the interviews, some of the parents talked about how they faced a “different look” from their neighbors when they returned home, and how, over time, the talk of returning home caused them a great deal of psychological burden. (This “centripetal force” formed in WuJiaNong (a sense of relative deprivation) kept them together and reduced some of the prejudice from society.

### **2.3. Social Relations**

The resettlement of the urban leukemia families in quasi-groups (quasi-groups are communities that are not organized but have some connection between people, have some degree of common concern, and may form groups at some point, but are not currently organized) is, to some extent, the result of population movement due to urbanization. As a rural population seeking medical care in the city, the chances of establishing communities that form voluntarily are increased. Once fragile and helpless groups scattered in different parts of the city, they are now beginning to group in a small corner of a

large city, with physical and spiritual ties between them as “healing the children” becomes the central task of the family, and sharing information and resources makes these ties stronger for a time. However, there is no tightly organized structure so far, because of the regular mobility of the population, the lack of infrastructure, and unclear responsibility relationships within the group, resulting in the inefficient allocation of organizational resources.

### **3. Analysis of the Current Situation and Causes of Family Education for Children with Leukemia in WuJiaNong**

#### **3.1. Current Situation of Family Education for Children with Leukemia in WuJiaNong**

There are about 60 families with leukemia in WuJiaNong, which is the most concentrated place for children with leukemia in Hefei. Among the 36 families with children with leukemia surveyed, 6 children were 0-3 years old, 30 children were 4-14 years old, and school-age and preschool-age children accounted for 83.3%. In terms of the education level of the survey respondents, the guardians of children with leukemia in WuJiaNong generally had low education levels and their occupations were mainly farming. The family is the main place for children’s growth and socialization, where children form a sound personality and acquire certain social skills. The lack of educational function in the family of children with leukemia in WuJiaNong will hinder the socialization process of children with leukemia and cause a series of social problems [1].

##### **3.1.1. Lack of Subject Education for School-Age Children with Leukemia**

The school-age period is an age period from the age of 6~7 when children enter elementary school to the age of 12~14 when they enter puberty. At this stage, children should be in a critical period for receiving knowledge and developing skills. However, during the critical period when they need to receive cultural knowledge, they cannot normally enroll in school and receive systematic subject education, and family education cannot make up for the lack of school education, as shown by the fact that children with leukemia have no time to learn cultural knowledge while receiving treatment, and fighting against the disease has consumed most of their energy; even if parents have spare energy to tutor their children to learn knowledge at home, the children lack an Even if parents have spare energy to tutor their children at home, the children will develop many bad study habits due to the lack of clear learning purposes and scientific learning methods, and the function of family education cannot completely replace the function of school education.

##### **3.1.2. Children with Leukemia Are More Likely to Commit Crimes as Adults**

As the treatment of children with leukemia deepens, parents’ energy is increasingly shifted to the treatment of their children, and their attention to the education of their children’s thoughts and behaviors gradually diminishes or even disappears. “From the moment they learn of their child’s illness, the parents’ first task is to get their child well, and the focus of their lives is shifted to their child’s illness, and at this point, the child’s education seems to become a ‘non-issue’. irrelevant’.” The treatment period for leukemia is very long, and during this period, children with leukemia lack effective management and educational guidance from their parents, and when these children with leukemia enter society after recovery, they lack the guidance of correct values and thoughts when facing the bad phenomena in society, and are easily misled by the thoughts and behaviors of socially undesirable people, and commit transgressive behaviors such as delinquency [2].

### **3.1.3. The Phenomenon of “Intergenerational Education” Is Common in Families of Children with Leukemia**

In WuJiaNong, about 80% of children are accompanied by their parents, while other children are accompanied by grandparents and other people. Most of these children are in a critical period of psychological and personality development and need parents' care and proper guidance. Due to the huge financial burden of families with children with leukemia, some parents have to work outside the home to reduce the financial burden of the family, leaving the task of caring for the affected children to the grandparents. According to the survey, among the 36 leukemia families surveyed, nearly 40% of the children with leukemia were cared for by their grandparents, who often spent all their energy on caring for the children's living and medical treatment. In the interview, Xiaoying (a pseudonym) is 6 years old and has been suffering from leukemia for three years. Her father works in Zhejiang, her mother takes care of her 2-year-old brother in Zhejiang, and her grandmother is the only one who takes care of Xiaoying's life in WuJiaNong. During the interview, it demonstrates that the grandmother's education level was only elementary school level, and the huge economic and mental pressure made her unable to take care of Xiaoying's education, and she was always ready to respond to Xiaoying's requests.

## **3.2. Analysis of the Causes of the Family Education Problem of Children with Leukemia in WuJiaNong**

### **3.2.1. The Shackle of Huge Economic Pressure**

Most of the families of children with leukemia living in WuJiaNong, Hefei are from rural areas in the surrounding counties of Hefei, and their families are not rich. This catastrophic medical expenditure has been one of the major causes of poverty and poverty return for families in China. According to the survey, among the 36 families with children with leukemia, 61% of the families spent between 100,000 and 200,000 yuan on medical expenses, and 11% spent between 200,000 and 500,000 yuan. 94.4% of the families chose “chemotherapy” as the treatment option for their children. “, and in the two families that chose bone marrow transplantation, the medical expenses invested were up to 200,000 yuan or more [4].

In the face of tremendous financial pressure, both or one of the parents went out to maintain a meager financial income and to reduce the financial burden on the family. Based on this economic consideration, the child can only be entrusted to the care of grandparents, thus creating a situation where parents are separated from their children, which directly results in a crippled family structure and a lack of family education for the affected children. In the survey process, in families where grandparents take care of children with leukemia, the grandparents' responsibilities are limited to taking care of the children's living and living, coupled with the grandparents' limited education level, lack of knowledge structure, or old-fashioned, and lack of awareness to educate the grandchildren's thoughts and behaviors, which is not conducive to the children's learning life, resulting in a “vacuum” in family education for children with leukemia. This leads to a “vacuum” in family education for children with leukemia.

During the survey, another 60% of parents of children with leukemia chose to take care of their children themselves, but they still had to bear the huge medical expenses and the entire burden of caring for their children. In addition to taking care of their children, they also have to deal with household chores, medical expenses, and reimbursements. All this leads to a lack of time and energy for the parents of children with leukemia to educate their children, and in this case, family education for children with leukemia is not lacking but is in this case, although the family education of children with leukemia is not deficient, it is very defective.

### **3.2.2. Limitations of the Education Level and Ability of the Education Subject**

The education level and social status of the education subject will have a great influence on the family education style, and this influence determines the amount of investment in the education of children with leukemia. This educational investment is reflected in the socialization of children with leukemia in terms of their emotions, behavior, and personality, not only to allow them to receive the indoctrination of knowledge in school education but also to shape their personality and improve their virtues [5].

Families of children with leukemia are mainly educated at elementary school or below, and they generally face the problems of “not knowing how to educate their children scientifically” and “not wanting to let their children study because they are too tired” in the process of educating their children. One of the most important points is that the child is suffering from a catastrophic disease, and after each chemotherapy treatment, the child will have a great physiological reaction due to the drugs, and the child will have a great psychological challenge. The child has to suffer again and again from the pain of chemotherapy, and just fighting the disease has exhausted the child, making the child suffer less from the disease has become the greatest wish of the parents [6]. In the interview, when the person in charge was asked what the most difficult point of the current work was, she replied: ‘The biggest problem of work now is that cannot achieve a change in the concept of these parents, the meaning of the Happy Childhood Reading Workshop is to let the children enjoy the learning atmosphere here even if they cannot receive school education. But parents feel that as long as their children are cured, nothing else matters, so the proportion of children who can come here regularly to participate in learning is not large, and those work will slowly shift to changing parents’ concepts.’

Family education is the first lesson in a child’s growth process and an important part of doing so. At present, most of the family education for children with leukemia is in a vacuum, on the one hand, because parents value their children’s condition and neglect the importance of education, and on the other hand, in the absence of support from governmental organizations and resources and the lack of assistance from relevant family education professionals, family education for children with leukemia seems to have a limited effect [7].

## **4. Analysis of the Current Situation and Causes of School Education for Children with Leukemia in WuJiaNong**

### **4.1. Overview of the “Happy Childhood” Public Welfare Reading Workshop**

According to the survey, almost all of the children with leukemia living in WuJiaNong have to leave school and even go far away from home to receive treatment in the hospital because the most important thing for them is their lives. Most of them could not successfully integrate into school even after the end of treatment, and the reason for this is that these children had no school to attend during the long treatment process, which led to their disconnection from normal school life and even psychological and social problems such as interpersonal communication [8]. But education as well as school life is very important for children’s socialization growth, especially for younger children, school education is more likely to determine their lifelong fate. According to the survey, some of the children in WuJiaNong are in fact “able to go to school” because of the existence of a charity organization called “Happy Childhood” reading workshop.

The “Happy Childhood” public welfare reading workshop is a non-profit organization that aims to stimulate children’s interest in reading, cultivate children’s reading habits, improve children’s cultural quality and reading ability through the establishment of a library, for the psychological and physical characteristics of children aged 0-14 years old, continuous, planned and purposeful, with services and guidance provided by professional volunteers. It is a non-profit public organization that aims to

stimulate children's interest in reading, cultivate their reading habits, and improve their cultural quality and reading ability.

The predecessor of 'Happy Childhood' is the 'Happy Childhood' Reading Program. The project was initiated by the Anhui Youth Volunteer Association and the Hefei Bloodless Donors Association. During the implementation of the 'Little Warriors for Life project' at Anhui Provincial Children's Hospital for children with leukemia, it was discovered that the hospitalized children especially liked to read books. So, in May 2009, it applied for a grant from the Chen Yixin Family Foundation to set up two library rooms in the hematology and rehabilitation wards of Anhui Provincial Children's Hospital, which are open to all hospitalized children, especially those with leukemia and cerebral palsy, free of charge. The reading activities brought a lot of fun to the hospitalized children and their parents. Subsequently, members of the project rented a few houses in WuJiaNong to provide activities for children with leukemia, as well as a reading workshop and a public canteen, while the daily management of the library and reading tutoring were taken care of by a group of private enthusiasts, including professionals from the children's library, school teachers, full-time mothers, college students, etc. They are collectively called volunteers, and every afternoon, they are active in the WuJiaNong.

## **4.2. Specific Status of Education for Children with Disabilities**

### **4.2.1. Public Welfare Institutions Have Replaced Some of the Functions of Schools**

The service content of the project mainly includes the following aspects: daily courses, including ability development courses, art courses, etc.; outings and festival activities; and parent classes. The growth of human beings cannot be separated from the support of the environment, such as family, school, and society, and the growth process of children is also the process of continuous interaction with the environment. The 'Happy Childhood' Reading Workshop provides such an environment for children with leukemia in WuJiaNong, which is indeed remarkable in that it helps children with leukemia to continue their socialization, improve their ability to adapt to society, and play a transitional role in their future education, playing a more important social role in the lives of these children. The child's right to education is maintained [9].

### **4.2.2. The Long-Term Education of Children with Disabilities Is Not Guaranteed**

The 'Happy Childhood' public welfare reading workshop is only a project initiated by a public welfare organization, which cannot continue to provide education for children with disabilities at the end of the project, resulting in a lack of education for children with disabilities. This will not only cause a great psychological change in the child but also make the child's life return to its previous state, with nothing else to do but watch TV and play games.

### **4.2.3. The Quality of Education for Children with Leukemia Is Not High**

"However, because of the different conditions of children with leukemia, the mobility of the children, and their different ages, the curriculum of the reading workshop can only be designed to educate children with leukemia based on the normal education system. Therefore, the program only fulfills part of the function of mainstream education and plays a transitional role, which has major shortcomings. The most important thing for children with leukemia is to receive treatment, and the 'Happy Childhood' public welfare reading workshop can only provide some basic education for a small number of children who are recovering from leukemia, while more children can only stay at home all day and do nothing due to their illness.

### **4.3. Analysis of the Causes of School Education for Children with Leukemia in WuJiaNong**

#### **4.3.1. Internal Factors**

##### **4.3.1.1. The Current Situation of Family Survival**

First of all, almost all of the families in WuJiaNong are from rural areas, and the existing rural cooperative medical care and major disease relief system is not very perfect, when these children suffer from major diseases, the family members are forced to quit their jobs either voluntarily or because they have to take care of their children, which is undoubtedly an added burden to the families who have to spend hundreds of thousands of yuan on medical expenses. In addition, the treatment process of leukemia is an extremely long process, which is undoubtedly a heavy blow to the parents of the affected children, who lack the care of friends and relatives in the city. Both the financial burden and the mental stress will leave the family with no time to care for them and no energy to focus on their children's education.

##### **4.3.1.2. The Health Condition of the Child with Leukemia**

In the urban village of WuJiaNong, Hefei, the children with leukemia have a distinctive feature: they all wear masks, and they live in fear of infection. The pain of the disease combined with the inability to attend school and the lack of childhood friends prevented them from spending their childhood like normal children. The pain of the disease is compounded by the pain of regular chemotherapy. It is the poor health of these children with leukemia that makes them unable to devote their minds and bodies to other things, and they do not have the interest or the energy that comes naturally to children. As a result, only a small percentage of these children, who do not receive formal schooling, attend the Happy Childhood Reading Workshop.

#### **4.3.2. External Factors**

##### **4.3.2.1. Deficiencies of the Charity Itself**

First of all, Happy Childhood Reading Workshop is a non-profit public welfare organization, which aims to stimulate children's interest in reading, cultivate children's reading habits, and improve children's cultural quality and reading ability. This reading workshop is only a public welfare project, and there is no guarantee that it will be in existence by the time the project is completed. According to the survey, the main person in charge of the project is already applying for another project called "Halfway House" which provides free temporary (two-week) housing for families of children with leukemia by raising funds to take care of them and invites experienced families of children with leukemia to help calm them and relieve their anxiety and panic (The project is currently being completed). At the end of the current project, likely, the children's right to education will not be guaranteed.

Secondly, as a non-profit organization, the main source of funding is crowdfunding and foundation applications, but the current situation is that the existing classroom is small and the lease is about to expire, so the project leader has rented a new classroom nearby.

Finally, the Happy Childhood Reading Workshop is run by a team of volunteers, whose dedication has allowed the organization to grow and contribute to the education of children with leukemia. However, the volunteers are mainly college students, who have unpredictable free time, so the education of children with leukemia cannot be guaranteed.

#### 4.3.2.2.Social Prejudice

According to the survey, the majority of people in the outside world think of leukemia as an incurable and contagious disease. This is due to the lack of public awareness of leukemia and the misconception that children with leukemia are contagious because they wear masks to prevent infection, which creates a stereotype over time and leads to the isolation of this social group. The lack of recognition and prejudice from the outside world has undoubtedly caused serious psychological and mental pressure on these families, and almost no schools are willing to accept these children with leukemia in education, thus leading to the lack of education for these children.

### 5. Conclusion

In summary, there are still hundreds of these ‘WuJiaNong’ in China, and WuJiaNong in Hefei City is a microcosm of the rural areas where children with serious illnesses go to the city for medical treatment, where a single illness makes an originally wealthy family penniless, an originally happy family sad, and a school-age child who should be enjoying his or her education spends time in the hospital. After the study has enabled the social group to know more about them, it has triggered social concern to improve the current situation of rural children with serious illnesses who go to the city for medical treatment, such as economic pressure, social support, and educational problems. These children who go to the city for medical treatment are not able to receive family education in a normal family, and at the same time, they are not able to enjoy compulsory education at their school age, so the lack of both family education and school education has a great impact on their socialization. This effect will spread to the whole society like water waves, such as the lack of school socialization of school-age children, economic downturn, etc.

Based on this conclusion, the society can set up a social work organization to provide support and guidance to rural children with serious illnesses and their families who go to the city for medical treatment, to relieve their mental stress. The establishment of specific schools or educational institutions to help rural children with serious illnesses who go to the city for medical treatment, so that children of school age can enjoy the education they should enjoy, and school socialization. The media should report more on the incident to arouse more social concern so that more public welfare organizations and caring people can participate in ‘WuJiaNong’ to improve the living environment and conditions of rural children with serious illnesses who go to the city for medical treatment.

Of course, the study has some limitations, only exploring the Hefei WuJiaNong this area, and the exploration time can be longer, the children of tracking research, will be more conducive to the subsequent development.

There is much more that can be done to study children with serious illnesses who go to the city for medical treatment and their families. In the future, researchers can find out whether the relationship between these families and their relatives has changed due to serious illnesses, and what is the difference in the perception of emotions in socialization, and researchers need to know more about this group of people to help them solve their problems in practical terms.

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