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Health Communication and Social Support for the "Butterfly Baby" Rare Disease

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Abstract

"Butterfly baby" skin like butterfly wings, blowing, flicking, there is a risk of fragmentation, the medical specialty called hereditary herpetic epidermolysis bullosa (Epidermolysis Bullosa, EB), is a group of extremely rare hereditary skin diseases characterized by increased skin fragility, is one of the most painful of the rare human diseases. It is one of the most painful of the rare human diseases. From the perspective of health communication, social support activities for "Butterfly Babies" can help the public understand more about the patient group and related diseases, stimulate the public's sympathy and understanding, and make the public accept the "Butterfly Babies" group, so that the "Butterfly Babies" group can be more familiar with the disease. This will help the public to accept the "Butterfly Babies" group, so that the "Butterfly Babies" group can normally integrate into the social life, and provide them with respect and support.

Keywords

Rare diseases, Health communication, Butterfly babies.

1. Introduction

Rare diseases, which refer to those diseases with extremely low incidence, have received increasing attention in recent years. At present, there are about 7,800 recognized rare diseases, accounting for about 10% of human diseases. Most of the rare diseases are mainly caused by defects in genes, resulting in congenital disorders, about 80% of which are inherited. The combined impact of rare diseases is enormous. With China's huge population base, many rare diseases have become less "rare" in China. It is estimated that there are about 20 million people with rare diseases in China, and the number of diseases continues to grow, with about 250 new diseases added to the list every year.

In recent years, the Chinese government has launched a number of policies and promoted a number of projects in an attempt to gradually solve the problems faced by patients with rare diseases in terms of disease diagnosis and treatment, drug accessibility, and payment security, including the Rare Disease Catalog of 121 diseases, such as albinism, amyotrophic lateral sclerosis, Gosheimer's disease, congenital scoliosis, Fabry's disease, hemophilia, and idiopathic cardiomyopathy, and to identify and gradually improve the registration system of patients with rare diseases throughout the country. gradually improved, and the establishment of 324 hospital-based treatment networks. However, the relevant policies are not sufficient to meet the needs of most patients with rare diseases, and there are still many types of rare diseases for which there is a lack of effective medication and treatment programs, and "Butterfly Baby" is one of them.

"Epidermolysis Bullosa (EB), a group of extremely rare genetic skin diseases characterized by increased skin fragility, is one of the most painful of the rare human diseases. One of the most painful of the rare diseases, patients are usually born with the disease, with blisters or blood blisters occurring on mucosal tissues of the skin, eyes, mouth, esophagus, and respiratory tract

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when subjected to minor friction or for no apparent reason, resulting in traumatic ulceration. In China the disease was officially listed in the First Catalog of Rare Diseases in 2018. According to the Butterfly Baby Care Center, a public welfare organization, the number of registered EB patients in China is currently close to 700, most of whom are children. Due to the lack of epidemiological data, the probability of the disease is estimated to be nearly 10,000 people in China.

EB is categorized as simplex, junctional, dystrophic, and Kindler syndrome.

The simplex form (EB simplex EBS) is the most common form of EB, which can range from mild (not too painful) to severe (very painful), and the blisters rarely scar after healing. The blisters are located within the epidermis, and most simple forms are inherited in an autosomal dominant manner, caused by dominant negative missense mutations in the basal cell keratin genes KRT5 and KRT14.

The junctional type (Junctional EB JEB) results in blisters in the mouth and respiratory tract. It is rare and can range from moderate (uncomfortable, mildly painful) to severe, with the blisters located in the center of the zona pellucida and basement membrane bands. Autosomal recessive inheritance. There is generalized blistering at birth with extensive exfoliation, severe oral involvement with characteristic perioral and perinasal hypertrophic granulation tissue, vesicles persisting for many years, nail dystrophy or nail loss can be seen, tooth deformities are common, and laryngeal and bronchial damage can lead to respiratory distress or even death. Other systemic damage includes skeletal and muscular deformities, gastrointestinal damage, and urogenital damage. Most children die within 2 years of age.

Dystrophic EB DEB, in which the blisters are located underneath the dense plate, leads to blisters in the middle layer of the skin (dermis), which can range from mild to severe. There are two modes of inheritance, autosomal dominant and autosomal recessive, usually manifested as autosomal dominant with milder symptoms, while autosomal recessive, usually with worsening symptoms, most patients will have defective skin from the front of the calf to the foot after birth, and blisters and maculopapular blisters will recur on friction areas such as elbows and groin, and blisters, after healing, will remain in the majority of patients with atrophic skin After the blisters have healed, most patients will be left with skin atrophy that looks like parchment, and flexion contractures of the fingers and toes are usually present as well.

In the meantime of medical research, all walks of life are also contributing to the "Butterfly Babies", for example, in August 2022, Qinhuai District, Nanjing, held an art exhibition created by artists and "Butterfly Babies", 25 paintings were exhibited. Twenty-five paintings were exhibited from 18 "Butterfly Babies". These paintings tell the wishes of the "Butterfly Babies": they want to eat candies, they want to be strong, they want to travel, they want to dance like butterflies, etc. These wishes are easy for normal people to achieve. Wishes that are easy for normal people to achieve are difficult for these "Butterfly Babies" to realize.

2. Theoretical Analysis

2.1. Theoretical Foundations

2.1.1. Health communication

Health communication is a variety of information dissemination activities aimed at promoting people's health. It is the process of cell phone, production, transmission and sharing of health information for the purpose of maintaining and promoting human health through various channels and using various communication media and methods.

In the field of health communication, Lasswell put forward the "5W" model, which mainly refers to the five factors of who communicates, through what channels, to whom, what content, and

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the effect of communication. However, in practical application, the factor that is usually neglected is "feedback", i.e., the action produced by the audience after receiving the information.

2.1.2. Social support

He Xuesong (2017) mentioned in the book "Social Work Theory (Second Edition)" that social support refers to the network of relationships consisting of contacts between individuals, through which individuals are able to maintain their identities and receive emotional, service, information and other support. It is the perceived and actual instrumental or expressive support provided by communities, social networks and intimate partners. In terms of content, social support can be categorized into instrumental and expressive support. Instrumental support refers to guidance, assistance, tangible support and problem-solving actions, etc.; expressive support refers to psychological support, emotional support, self-esteem support, emotional support, and recognition. There are two sources of social support, the first is the formal social support system, the support given by the formal organizations of society (government, charitable organizations); the second is the informal social support system: the support from the interpersonal mutual support network of family, friends, neighbors, colleagues and so on.

2.2. Theoretical Analysis

On the whole, the social support for "Butterfly Babies" includes art and humanistic care and companionship activities such as organizing exhibitions, singing and dancing performances, poetry recitations, making peripherals, caring exchanges, microfilming, etc., as well as material support activities such as charity sales and fundraisers, and professional popularization and dissemination of knowledge about rare diseases.

From the perspective of health communication, social support activities for "Butterfly Babies" can make the public know more about the patient group and related diseases, stimulate the public's sympathy and understanding; make the public accept the "Butterfly Babies" group, and make the public accept the "Butterfly Babies" group, and make the "Butterfly Babies" group more familiar with the disease, so that the public can understand the disease. The "Butterfly Babies" group can be accepted by the public, so that the "Butterfly Babies" group can normally integrate into the social life, and provide them with respect and support; call on caring people in the society to provide material support for the "Butterfly Babies" group; through the activities, gather the patient group, and build up the "Butterfly Babies" and their family members' support network. Butterfly babies" and their families through the activities, to build a social network, to provide the exchange of experience, make friends and other functions; for the public to provide professional knowledge of rare diseases popularization, to promote the prevention of related diseases, and to improve people's concept of medical care.

3. Literature Review

In the research about rare diseases, scholars mainly focus on therapeutic drugs, health insurance system, and social communication events. As for the health communication of rare diseases, the number of studies is scarce, mainly focusing on the communication of rare diseases that have become a hot topic on the Internet, without focusing on other rare diseases; in terms of the social support of rare diseases, the studies are mainly carried out at the macro level, and practice cases are more often used.

Shen Xiaoyan and Zhang Jie [1] studied the causes and effects of the stigmatization of rare disease groups through a large-scale questionnaire survey, and found that the causes of stigmatization mainly include the bias of public cognition, negative stereotypes that generate abnormal emotions, and the expression of curiosity in the mass media in the process of dissemination, and the deliberate use of emotionally charged headlines, etc.; the stigmatization

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of rare diseases causes inconvenience to the patients' lives and brings psychological "outside" stress. The stigmatization of rare diseases may cause inconvenience to patients' lives, bring about psychological "out-group awareness", deepen the sense of social alienation, and internalize the negative evaluation of the outside world into self-depreciation and self-stigmatization. The study applies solid theories, analyzes facts, and fully integrates survey data and social phenomena.

Gao Jiamin and Ma Zheng [2] analyzed the current status of the dimensions of quality of life of patients with rare diseases and their relationship with social support, in order to provide a reference for the improvement of social security policies for patients with rare diseases. Methods:The WHOQOL-BREF scale was used as the evaluation tool, and snowball sampling method was applied to collect data through internet and telephone surveys. t-test analysis was used to compare the data with the Chinese normative data, and a linear regression model was used to examine the relationship between informal and formal social support and the quality of life of patients with rare diseases. It was found that the quality of life scores of patients with rare diseases in all dimensions (physical and psychological, social and environmental) were significantly lower than those of the normal and disease groups in the Chinese normative model, indicating that rare diseases have a significant negative impact on the quality of life of the residents. Informal and formal social support were associated with the quality of life of patients with rare diseases, and the higher the level of informal social support, the better the quality of life of the patients in all domains; the quality of life in psychological and social domains of the patients who had received social support was higher than that of the patients who had not received social support. This has implications for improving the level of social support for patients, improving the social security policy for rare diseases, and for improving the well-being of patients' lives.

Based on the theory of health communication, network community and social support, Xinyue Wang [3] analyzed the social support that rare disease groups received in the network community in terms of information support, emotional support, and companion support. The risks of rare disease groups seeking support in online communities are summarized according to the reality, communication links and group characteristics. Based on the link of "Knowing, Believing, and Acting", the study proposes to optimize the pathway for rare disease patients to seek support in online communities in terms of communication sources, interactive contents, and communication effects.

4. Interview Analysis

The invited guests of this interview are Mr. Zhou, the founder of the Butterfly Babies charity organization, and Ms. He, the mother of the Butterfly Babies patients. Mr. Zhou told us that the reason why he set up the organization was that his daughter unfortunately suffered from the rare disease "Butterfly Babies", and the lower limit of the incidence rate of the disease is 1 in 100,000, and there are more than 10,000 patients in the country. The disease is closely related to the family's financial ability, parents' education and learning ability.

He mother also told the daughter was born after the major hospitals have not seen this disease, Beijing Children's Hospital genetic comparison, three days after the diagnosis but can not be cured. After a month of hospitalization has been home care. Have also searched on Baidu, and then in the country to find, folk recipes and large hospitals, but all useless, and now often being patient group to understand the relevant care knowledge. The child's hands and feet atrophy, can not walk normally, teeth loss, esophagus and mouth is affected, can not chew food, severe malnutrition, vision loss, white eyeballs more than black eyeballs, pimples around the eyes. Drooling in bed, sleep affected. Fingers are bent and hearing is affected. Talking about her family's situation, He's mother told her that her family lives in the mountainous area of Fujian,

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her husband has a Grade 1 disability, and he drives an online car with a monthly income of 3,000 yuan, while she herself works in a factory assembly line with a maximum of 1,000 yuan a month, with a monthly income of only 100 yuan in the off-season. The oldest in the family is a "Butterfly Baby" patient, now 11 years old, a boy, and the second is also a boy 8 years old, normal. The village gives a monthly subsidy of 300 yuan, and the oldest needs about 300 yuan a month to change his medication and take a bath every day. The child's grades are average because of frequent absenteeism, and teachers are afraid to contact him, unable to concentrate. The home is leaky and damp, causing the child's skin to ulcerate. He wanted to go to Beijing for esophageal dilatation surgery, but it was expensive and unaffordable. The child received easy fundraising when he was just born, but it only provided temporary relief. Can't afford better dressings and it hurts to use gauze. Hospitals do not dare to admit, the child can only go to the big city every time there is a problem, very worried, go to the city's Children's Hospital each time four or five thousand, scrape together, and finally to the point of borrowing can not be borrowed.

Ms. Zhou told us that her organization mainly provides financial support for some families, giving away dressings, reimbursing surgery costs, teaching patients' families how to care for wounds; helping to build channels for medical treatment, genetic testing, surgery, nursing care, and docking hospitals; publicizing the rare disease "Butterfly Babies" and trying to let policymakers know that it is covered by health insurance, and promoting the creation of new treatment options. The organization has organized cartoons and short videos. The agency has organized cartoons, short videos and documentaries, but they have had little effect, as the public is not interested in such a sad topic. The news media, Sanlian Weekly, and Ding Xiangyuan are very well read, but only have a social effect and do not bring in many donations, and the news media can't attach links to donations. Last year, there was a public number with a donation link, which brought more than 10,000 donations a month. Ninety percent of the funds raised on the Aurora Platform's Joyful Donation program are used to buy dressings for patients, and ten percent are used for operating expenses. The Butterfly Cup soccer tournament is held once a year, inviting 32 companies to participate in the team entry fee of 10,000 yuan, while a variety of activities to raise funds. Because Butterfly Baby has a lot of patient needs and no protection policy, the chronic disease policy has a clear list, only a few dozen kinds of disease protection, foreign research and development of new drugs can not be introduced, the price is high, the organization has more than 1,300 patients registered, but can only reimburse ten percent of the ten percent of the family's expenses. Teacher Zhou and Mother He both expressed their eagerness for the state to pay attention to the rare disease group, reduce the cost of treatment and include it in the medical insurance, hoping that the children will grow up healthy.

5. Summary

Rare disease patients such as "butterfly babies" and their families have to bear a lot of unimaginable pain, the onset of physical torture and epidermal state of psychological torture that is different from the ordinary people, the diagnosis is difficult to treat the plight of the more difficult and obstacles urgently need to get the whole society to help, so that the "rare" be seen, and the road to break the cocoon into a butterfly needs more attention and protection! Let the "rare" be seen, the cocoon into a butterfly road needs more attention and protection!

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