Network Practice of Rare Disease Bloggers and Life Narrative: Take ALS as an Example

Jiaxin An[1,a,*]

[1]Institute of Literacy and Journalism, Sichuan University,West Port Street, Chengdu, China
a. ajx5110@163.com
**corresponding author*

Abstract: As a healing method, narrative is widely concerned by the medical community. The characteristics of "Hyper-temporal", "sharing" and "personalized" of new media provide convenient conditions for the self-performance of rare disease groups and also encourage them to re-choose narrative content and strategies. This paper adopts in-depth interview and text analysis to analyze the network practice and narrative behavior of Amyotrophic lateral sclerosis (ALS) web celebrities. The study found that the online narrative of ALS is not only the life practice of bloggers' self-healing, self-persuasion and self-empowerment, but also their positive response to real family and social responsibilities. At the same time, the online celebrity career of rare disease bloggers reflects their life courses in a certain sense. The social media accounts of rare disease bloggers are an important carrier for them to enrich themselves and place their feelings and expectations, and the continuation of their digital life has brought new philosophical and ethical thinking.

Keywords: rare disease, web celebrity, life narrative.

1. Introduction

Rare disease is a general term for a disease with a very low prevalence rate and a small total number of patients. Although the number of patients with a single rare disease is small, as a population, they cannot be ignored. There are about 1,400 kinds of rare diseases known in China, and the total affected population is expected to exceed 20 million[1]. Despite the large number of rare diseases in the group, the voice of the group is weak in single. They have been on the social fringe for a long time, and lack public attention and support.

In recent years, short video has increasingly become the dominant medium for people to understand the world and express themselves in cyberspace. According to the 50th Statistical Report on Internet Development in China, by June 2022, China had 962 million short video users, accounting for 91.85 percent of the total Internet users[2]. The huge scale of short video users has boosted the development of the web celebrity economy. According to the 2024-2028 China Web Celebrity Economic Investment Planning and Prospect Forecast Report released by the Industry Research Institute, the market scale of China's web celebrity economy will reach 1.3 trillion yuan in 2022, and it is expected that the market scale of China's web celebrity economy will exceed 1.6 trillion yuan by 2023, with a year-on-year growth of 23.8%[3]. With the rise of new media platforms such as TikTok and Weibo, many patients with rare diseases have joined the online marketing army. They take the initiative to create content, share their activities, release their voices, express their demands, and actively integrate into contemporary society.

The research of rare disease bloggers is the cross-content of web celebrity research and health communication. For Amyotrophic lateral sclerosis (ALS), which attracts high social attention and has no effective treatment, the expression from individual patient not only avoids the disadvantages of mechanical analysis of data theory and the third-party control and fills the gap of current medical analysis materials; but also connects the sick group with the new media technology to explore the secondary empowerment of marginal groups in the real society, and provides a valuable reference for researchers to think about the support and impact of technology philosophy to the whole society.

Therefore, this study chooses ALS patients as an example, which is relatively known by the public. The author conducted a thematic narrative analysis and depth of interview to discuss the ALS web celebrity narrative behavior and network practice.

2. Literature review

2.1. Narrative research

"Narrative" contains the basic structural experience of individual level and social level, and is a way of knowledge organization and basic thought mode of individual and even human beings. By describing individual life and deconstructing and reconstructing individual life stories, narrative research can obtain an explanatory understanding of individual behavior and experience, and find the meaning hidden in the individual's daily life[4].

As a kind of human behavior, narrative refers to the behavior of connecting characters, events, results, and other elements into a relatively complete plot, and telling it through oral, text, video, and other forms[5], has important effects on information transmission, cognitive change, and behavioral incentives.

Narrative research focuses on the whole process of narrative subject, narrative relationship, narrative content and narrative framework, spanning many disciplines, and occupies an important position in the fields of pedagogy, sociology, psychology, medicine and communication. Since the 20th century, with the development of network technology and the popularization of infrastructure construction, more and more people choose to express emotion and record life in cyberspace. Network narrative becomes the norm of network practice, technical innovation and new media features also affect the user's narrative content and narrative strategy, guiding the narrative to fragmentation, linear and surreal direction.

As a specific direction of health communication research, health narrative focuses on the experience and feeling that diseases bring to patients and their families[6], providing individuals with the opportunity to express themselves and understand their own situation[7]. Marginal groups are the main object of Western health narrative research, including children and adolescents, women, immigrants and minorities[8].

2.2. Online narrative of disease patients

"Disease" (disease) and "disease pain" (illness) are two different concepts[9]. Disease means physiological change, and disease and pain include the understanding of the patient and his social relations and even the whole society. In the context of "disease and pain", patients with disease are not only the victims, but also play a unique subject role. They can adjust the relationship between themselves and disease and the outside world through narrative behavior, so as to heal themselves, reshape themselves and even heal others[10]. In this process, the narrator and the listener are often involved together.

In terms of narrative types of disease patients, scholar Li Feifei summarized Frank's classification method, which divided narrative types into three categories: "recovery narrative", "chaotic narrative" and "exploration narrative" from the perspective of storytelling methods."Recovery narrative" is optimistic about the disease and believes that it will be better; "chaotic narrative" revolves around "I will never get better again"; and "exploring narrative" focuses on the results of the development of the disease[11].

In terms of the content and characteristics of the narrative, the overall narrative style is different in different media types. In terms of rare disease groups, there are more positive attitudes in TikTok platforms, and the overall number is more. However, in the microblog platform, the negative attitude is mostly expressed, and with the deterioration of the illness of several rare diseases "big v bloggers", the number of works is relatively less.

Multiple studies have been conducted focusing on the narrative behavior of patients with the disease. Du Yizhu and Xu Kaibin pay attention to the construction of narrative meaning, spiritual sustenance and emotional support of patients in the cancer online forum "Dancing with Cancer"[12]. Liu Ying and Sun Yang took the hepatitis B forum " as the content and used an analysis method to investigate the emotional support, information support and companionship support in the network community[13]. However, the current domestic academic research focuses on a disease type with a large patient population, and there is not enough research focusing on the online narrative of rare disease groups. Although the overall number of rare diseases groups is large, the social attention is small. As the weak position of this group is more obvious, there is a stronger demand for attention in promoting the process of social equity. Based on this, this study focuses on the network practice and narrative behavior of rare disease groups in online communities.

3. Research design

This study selected ALS bloggers who actively conduct web use practices to research. ALS is a more well-known disease in the list of rare diseases. Compared with other rare disease bloggers, ALS bloggers have higher social popularity, more interaction with fans and richer research texts. In this paper, two new media platforms TikTok and Weibo were selected as research fields, and two approaches are adopted in the selection of research objects: one is to select ALS bloggers with contact information on "TikTok" and "Weibo" according to their nicknames and personal profiles, and obtain 5 respondents through the introduction of the contacted respondents. Telephone interviews and face-to-face interviews were conducted, and each interview lasted more than 50 minutes.

The basic information of the interviewees is shown in Table Table 1.

Table 1: Basic information of the interviewees

Number	Interviewee	Sex	Age	Domicile	Use the platform	Fans (one)
1	WSQ	man	31	Taizhou,Zhejiang	TikTok	3607
2	LJ	man	37	Sichuan Ganzi	TikTok	4237
3	ZZJ	man	50	Shaanxi ankang	Weibo	3506
4	HXB	man	30	Guang'an,Sichuan	TikTok	40021
5	ZDH	man	35	Guang'an,Sichuan	TikTok	2006
6	CJY	woman	37	Guang'an,Sichuan	TikTok	2825
7	FJC	man	33	Nanjing,Jiangsu	Weibo	1779
8	ST	man	41	Wuyi, Hebei	Weibo	31002
9	DJF	man	39	Baoji, Shaanxi	Weibo	43

This study combines the in-depth interview method and the text analysis method. The main content of the in-depth interview involves the network image presentation, account operation reasons, work theme content and network practice experience of the ALS groups, so as to better understand the account operation characteristics and network communication behavior of the interviewees. The researchers also used text analysis to analyze the short video accounts of ALS bloggers and the comments below, and used keyword retrieval methods to observe all the accounts containing the word "ALS" on the TikTok and Weibo platforms.

4. Research finding

Rare disease groups are marginal groups that are not seen in the social discourse system. The information revolution brought by new media technology has changed the ways and rules of social communication in the past, expanded living space for marginalized groups, rebuilt social relations and gained opportunities to gain social support, and continued their wishes and expectations in the real world. Due to the different physical states, purpose appeal and capital value, the network practice behavior of rare disease bloggers has a distinct particularity compared with that of general web celebrity bloggers.

4.1. Self-performance of suffering and life

4.1.1. Life role: Pain is a part of what I can't hide

In the context of the digital age, image performance has gradually become an important way for individuals to realize self-empowerment. With the help of intelligent technologies such as beauty and face change, individuals not only realize the fine beautification of their external image, but also can obtain more social support and social capital. However, for patients with rare diseases, the pain and its physical damage can not be covered. On the contrary, the image of the pain should be enlarged, so as to confirm their identity and obtain the ticket to enter the community, start the community performance and accumulate social capital:

"At first, people didn't believe I was unhealthy and different from normal people, so they said I was a liar. When I got into a wheelchair in the back, and then my muscles shrank a little. Only at this time they could see that I was sick, and people believed that I was really sick."

The pain image of the sick blogger is closely related to the development of the disease and shows a significant trend of change. They gradually developed from the seemingly healthy image at the beginning of the disease to the image of muscle atrophy, bone deformation, and need to move in a wheelchair, and finally only to maintain a relatively healthy head, needing to rely on a ventilator to maintain life. This process is usually anywhere between 3 and 5 years.

The development of the disease not only reflects the significant changes in the patient's physiology, but also is the process of the blogger's self-identity and reinforcement. In the face of disease and pain, rare disease bloggers can gradually accept and adapt to their own patient image through their own self-narrative and image performance. This process is accompanied by their recognition and acceptance of their new image and new identity, reflecting their psychological adjustment and identity reconstruction in the process of their struggle against the disease:

"I didn't want to accept that at first. I was a strong man before. I did business and I was the mainstay of my family. Later because of this disease, I went home, there was no way for me. Behind that, I took a wheelchair and slowly accepted the fact. There are neither things to cover up, nor can cover up."

Rare disease bloggers face a role shift from an important family workforce to patients who should be cared for, which is an inevitable stage of life. This profound identity change is skillfully integrated into their online works. Through the dual narrative strategy of image presentation and image narration, they complete the network performance of self-disease and pain.

From resistance and rejection at the beginning of illness to self-acceptance and active life in the middle of illness, many rare disease bloggers gradually regard illness as a vital part of their body, thinking deeply about how to adjust their lifestyle to the new patient status. In this process, the image of pain is no longer the physical defect they try to avoid, but the focus they desire to be concerned and understood by the public. They thought this as an important window to show the social blind area.

Some rare disease bloggers interviewed said there is "nothing to hide". The change of attitude comes from the acceptance of patient’s position and rare disease, and also from their expectation and hope for being concerned and understood: " I hope you can see us, so that we can have more hope of healing.”

4.1.2. Life scene: I am not confined to the hospital bed

The concept of scene originated from the field of film and television drama, which refers to a behavior occurring in a specific time and space, or an occasion and environment of characters' activities. The life scenes of rare disease bloggers constitute the basic elements of their self-performance and self-narrative. By showing daily life scenes, rare disease bloggers tell their netizens and fans about their unique and rare life, win social attention, correct network cognitive bias, and empower their own network practice.

Different from sudden diseases such as cancer, the disease development of ALS patients is gradual. Their original life will not be permanently stagnant due to the intervention of the disease, but needs to constantly adapt and adjust, and living with the disease has become the daily state of patients with rare diseases.

Although in the case of physical disability, the daily life of patients with rare diseases is often misunderstood by the outside world as "staying at home" or even "never leaving in bed", in fact, the disease does not limit their physical activity ability to a large extent. However, they still maintain their love and pursuit of life. Through self-performance and narrative, the sick blogger showed to the outside world a group image who loves life and works hard:

"I met a patient in the city center today and talked to him for half a day. Everyone is not easy, we got this disease, and now we are families.”

"The pickled pickles and duck eggs have already been sent to the delivery station. Consumers will receive them soon. Thank you all for your support and help.”

In patients with rare diseases whose physical condition is not so serious that have to rely on medical equipment auxiliary stage, they still maintain their daily travel activities, through the way of narrative subject, directly showing and describing their life scene, effectively avoiding the patient group of third party screening and prejudice, thus more real, directly presents the image of patients with rare diseases and the inner world. This kind of self-display and narrative not only helps the outside world to have a deeper understanding of the living conditions of patients with rare diseases, but also helps to dispel misunderstanding, eliminate estrangement, enhance the social understanding and acceptance of patients with rare diseases.

In addition to offline social networking and revenue activities, patients with rare diseases will also have some leisure activities and upload the scene to the Internet:

"Sometimes I also take some beautiful scenery, some sunsets, some crops and rivers in the countryside. I hope to cheer everyone by doing this. Of course, my mood will be a little better, too.”

Scene communication is a communication activity with the scene as the core, and the key is to present the scene. The sick bloggers carry out some daily leisure activities, and upload and share these scenes through the online platform. This scene display on the Internet not only enriches the life experience of patients with rare diseases, but also provides a platform for them to show themselves, communicate and interact, which helps to further promote the social attention and understanding of patients with rare diseases.

By moving their personal life from the background to the front desk, rare disease bloggers incorporate their own life and production scenes into the image performance, effectively shortening the psychological distance between the audience and bloggers, and strengthening the emotional communication and interaction between bloggers, fans and netizens. This diversified scene narrative strategy not only fully shows the multi-dimensional appearance of the life of bloggers with rare diseases, but also creates a three-dimensional, complete and human image of patients with rare diseases. When the audience resonates with the scene and the emotions, they will have deep empathy for the role played by the blogger and their life experience, and then actively respond to the behavior and expectations of the blogger, forming a virtuous cycle of interaction.

4.1.3. Life story: Family is the fate that I can't give up

When faced with the challenge of serious illness, the recovery and life of patients with rare diseases are often inseparable from the deep care from their families, which makes family stories become an important basic material for sick bloggers to describe their daily life on the online platform. Many rare disease bloggers take family stories as the core content, and integrate them into the network image performance. They convey a complex and sincere emotional experience by describing their warm moments, their deep emotions and their inseparable blood ties. This narrative method not only enriches the self-expression of rare disease bloggers, but also enhances the reality of their network image, and helps to deepen the public's understanding and attention to the life of rare disease patients and their families.

A blogger who has been ill for more than a decade wrote: " I am lucky. I don't have to do anything now. My mother will take care of all of my life. I am now an idle person. I did not expect to become the one who was taken care of again. But my mother is nearly 70 years old and has to take care of me every day. My mother is really great."

It is not necessarily the elders who support sick bloggers. Another blogger said, " My wife divorced me and my 12-year-old child take care of me while going to school now. My son learned to face difficulties and learn to be fearless in such a young age, which made me ashamed."

Through the in-depth narration of kinship and family stories, the sick blogger expressed the complex feelings of dependence and gratitude for his family, but also revealed his inner guilt and contradictions. This narrative approach not only provides a platform for bloggers to express their guilt and gratitude, but also highlights the importance of the family as an indispensable spiritual pillar and safe haven for bloggers.

In addition, relatives also actively participate in the life narrative of rare disease bloggers as narrative subjects. Given that it is difficult to create, shoot and edit the video content independently, relatives often play a helping role in the process. They not only appear in the family stories as actors, but also play the role of collaborative creators, building and presenting these emotionally deep stories together with the bloggers.

A rare disease blogger's husband wrote: " We should enjoy the sweet age, but my wife found ALS in 2018. Her body has been frozen, with saliva cough, difficulty swallowing, and basic can't talk, began to live in a race against time. But from now on, honey your life no longer belongs to your own, but belongs to the people who love you. Good luck."

In the family story narrative, the family members give the rare disease bloggers rich spiritual support and stable physical support, which becomes a powerful motivation for the rare disease bloggers to overcome the difficulties. Relatives also constantly express their expectations for the blogger in the narrative, hoping that the blogger can relieve the physical pain and live a healthy life in the next life.

4.2. Disease-resistance philosophy in the protracted war

4.2.1. Race with life: cherish the present and plan for the future

Autobiographical narrative is a special form of narrative designed to understand people's autobiographical stories in a cultural context[14]. ALS is a chronic disease with no effective treatment options, and patients have to witness gradual deterioration until death. But unlike cancer, ALS is diagnosed very early, and the death cycle takes years or even decades, which means that patients have a relatively longer time to cherish the present and plan for the future.

A sick blogger said:

"It's a race against life, a race against disease. If you can catch up with drug development, you can live as long time as possible. There are a lot of things to do, so I can not waste."

Cherish the present reflects the positive response of sick bloggers to the real world. They transform their dissatisfaction with suffering and the injustice of fate into a positive force to fight against fate and pursue greater life value.

On the other hand, the behavior that rare disease bloggers take the initiative to choose their self-image to shape and display, and strengthen their strong spirituality is also a response to life responsibility. It also involves the sick blogger's planning for the future life. Many rare disease bloggers who have already had children believe the faith that recording life and inspiring their children is a vital reason for releasing daily videos.

For example, an ALS mother said:

"I want to use my colding story to let my son know that no effort will be wasted. As long as I don't give up my life, I will have infinite possibilities, even I can contend with my fate. How I hope I can accompany my son to grow up."

Some of the mothers, who were also ill with their son, said:

"What can I do otherwise? I am still a mother of two children. I can only think in the long run."

When it comes to imagining the later stages of the illness, many bloggers " want to do more when they are in better shape. "One blogger said in his vlog:" When we really met our wardmate face to face, we were much more touched than watching them online. He is now on a ventilator but he took it off in order to talk to me. I looked at him breathing in miserably, as if I would be tortured and suffocated in the future."

In this regard, she hopes to "record life while resisting freezing, in order to leave no regrets. Hoping that these works can be left for the family in the future."

Planning for the future is an important practical reason for rare disease bloggers. Disease bloggers expect their living videos, especially some positive videos can inspire and comfort the living, continue to play a role in influencing reality in their departed future, and respond to the needs and expectations of the living.

4.2.2. Spiritual power transmission: the doctor-patient relationship is absent and the strength among the patients rise

Patients with rare diseases rarely have long-term interactions with doctors due to their rare condition, few cases, lack of treatment experience, poor curative effect, and high long-term hospitalization costs. Doctor-patient relationship narratives are not common in the work of ALS bloggers. In the absence of the doctor-patient relationship, experienced wardmates can not only provide relatively rich treatment experience, but also give play to the group advantage of group heating, and occupy a high position in the interpersonal relationship of patients.

CJY, the patient's family member, expressed the help and support from her son's wardmate HXB: " He doesn't go out. He is afraid of being laughed at, so he doesn't go out. Then XB came and said

‘Fear what? And I would dare to go out’. XB came to see him to encourage him and call him to come out. Tell him repeatedly that he has to accept the reality.”

Emotional support between patients naturally and uniquely meets the basic need of "understanding and resonance", which is an emotional comfort that no other group, including family and non-patient friends, can replace. As a "companion" group of rare disease patients, almost all the rare disease bloggers have expressed the original intention of encouraging their wardmates. Patients are also very willing to transfer positive energy and encourage each other through sharing, so as to enhance the overall strength of their comrades.

For example, some bloggers who regain confidence in life will have a more sober and thorough understanding of the difficulties and troubles in life, and even develop a set of their own philosophy of life. They are willing to share these "insights" or "long-thinking" life experience with others. They are willing to calm network rage with their own inspirational life and sunshine mentality digestion, to inspire troubled patients, and give others positive emotional support: " I hope to bring everyone sunshine and encourage everyone. Now the online anger is too heavy, I hope everyone can face life actively.”

Relational narratives emphasize shared subjectivity. In the shared discourse, the narrative subject is not only the individual blogger, but also the sick patients interacting with the blogger. The narrative story is not limited to the blogger's own story, but the common story among the patients. In this process, the mutual narrative between patients also helps the blogger to further relieve the theme of suffering in the narrative, so as to convey a more positive value orientation and guide the expression of the work to a more positive direction.

The emotional support structure among patients is affected by the strength of psychological energy, forming a relatively clear classification of social capital in the network of patients. Generally speaking, bloggers who enter the career early, have good operations, and also take more responsibility in the patient group are more likely to support their emotional support to convey love and hope to other patients.

In the mutual verification of consciousness and unconsciously among patients, the narrative subject has developed from a single blogger to a patient group based on the identity logo of "similar", the emotional mutual assistance and social support in the patient relationship network have also become important themes of the narrative.

For example, "WSQ" is the "big brother" of one group of fellow bloggers. His imagination of emotional support is not limited to online mutual encouragement, but also extends to offline and future considerations, and even generates an idealistic future expectation:

"I want to do a good job of the account, when I become a big boss, those who can not take care of themselves can be picked up. We can live with our wardmates and ask nannies to take care of.”

4.3. The web celebrity process accompanied by life

4.3.1. Narrative healing: another help beyond drug therapy

Health narratives are believed to help patients with illness, pain or trauma by expressing emotional and personal experience. As Frank argued in his book The wounded Narrator: The Body, Disease, and Ethics, patients give meaning to encounters and are cured in narration[15]. The process of sick bloggers participating in online practice and starting the web celebrity career is also a process of self-healing for bloggers as patients.

In the narrative, sick bloggers often adopt positive narrative strategies to express their love for life, express their firm belief in fighting against fate and create new meaning for suffering experiences, so as to construct their own spiritual fortress. This is not a simple spiritual victory, but the patient's self-comfort and self-healing, which is a positive psychological treatment.

In his work, a former dancer, ALS blogger wrote:

"I can no longer deduce the visual beauty, but I can still convey the truth of life and the power of the heart, because of love so I insist."

Self-motivation is a common theme of rare disease bloggers' narratives. Positive autobiographical narrative not only helps patients to understand and accept disease and pain, but also helps to relieve pressure, strengthen spiritual strength, and play a certain healing role while self-motivation. Sick bloggers transcend the bondage of the material body, pursue the strength of the spiritual world, strengthen the meaning of life and the power of the mind in the narrative. They heal their mind by giving themselves full value.

Cyberspace for rare disease bloggers provides a chance to have a new life space. By creating a more positive image, they can remind themselves to pay more attention to happy memories in life to reduce the pain of disease. Life is the reflection of the difficult reality. By enhancing the positive force in the face of suffering, the narrative has played a positive effect in delaying the deterioration of the disease.

Quite a few rare disease bloggers have the idea of "living well" and "having hope for life". They turn their hatred of disease and their dissatisfaction with fate into the motivation to fight against fate, from the weak in the material world to the strong in the spiritual world.

4.3.2. Multi-linear narrative: life perception is always new

The conventional linear narrative structure tells the course of the occurrence and development of events in chronological order[16]. Although it conforms to the general law of the development of events, there are the disadvantages of ignoring personal subjective experience and recalling experience. The multi-linear narrative structure narrates the same event at different times with different narrative clues, expressing the different feelings of the sick bloggers in different periods, and reflecting the blogger's new life thinking. In the practice of web celebrity, the content narrative of sick bloggers revolves around their "disease pain" and "suffering", and has different narrative strategies in different periods of illness.

In the early stage of the illness, the content creation of rare disease bloggers revolves around their "biological life". With the network as the medium and the platform as the basis, rare disease bloggers began to move their offline life and offline performance to the online space, telling the major turning point of their lives in new scenes and contexts. During this period, bloggers' content creation focused on diagnosis information, disease popularization and illness feelings, expressing dissatisfaction with their fate and expecting themselves to be misdiagnosed:

"I really hope this is just a dream. I wake up and I found I was healthy."

With the development of the disease, the body signs caused by the disease gradually revealed, and the scale of fans gradually accumulated. The increase of heat at the same time is also accompanied by the reduction of the increasing difficulty of creation caused by illness. During this period, bloggers no longer limited their content creation to "biological life narrative", but more watched the rest of their lives by observing the irreparable results, expressing their attitude and perception of life through thinking about life, the world and interpersonal relationships. Since then, the narrative content mainly revolves around its "spiritual life" and "social life".

"Live a positive life. When met my friend who is not happy, I would try to persuade them to be positive."

During this period, when the result of biological life could not be changed, the spiritual life gradually broke through the shackles of the physical body and guided the individual to integrate life with reason and value. Thinking about illness and the sense of responsibility for family and society begin to internalize into individual self-awareness, calling for the surge of new life. Spiritual life is born under the "rotten tail" of biological life, highlighting the challenge and resistance to disease and fate.

In addition to their life beliefs, some rare disease bloggers also regard it as their duty to promote disease cure and popularize the diagnosis and prevention of rare diseases. They also make use of their social status, resource advantages and simple experience of becoming a medical doctor to convey kindness to the society and give full play to their social values:

"It is to release some information about refuting rumors. A lot of misdiagnoses, including some media reports, are wrong."

"The public doesn't know much enough about our disease. They think us just like normal disabled people, but not."

"Narrative of social life" is particularly evident in CaiLei, the vice president of Jingdong. Since his illness, CaiLei has actively released news about promoting drug research and development under his major accounts. In addition, "ST" and other bloggers also insist on updating popular science content of ALS, responding to patients' help actively, and giving full play to their social value in the rest of their lives.

4.3.3. Collaboration across time and space: the continuation and immortality of digital life

In the later stage of the disease, due to the loss of mobility, unclear words, difficulty in speaking, the decline of physical strength and energy, and other symptoms seriously, the quality and renewal speed of their work descend. At this stage, the web celebrity career of rare disease bloggers will disappear.

"Now I publish works less because I am getting worse and tired."

"I can't speak easily now, so I can only type to communicate."

As a blogger's life comes to an end, his new media account will be stopped. His account only publish a birthday blessing automatically every year. However, some accounts will continue to have a certain number of fans after the owner die, some of them even extend into a memorial space that bears the blogger's ill-resistance memory, provide virtual places for patients and netizens to mourn, and still play the role of social value such as encouragement and belief for a long time.

For example, in the video of the death of the well-known inspirational web celebrity "Zhuo Jun"'s account, many netizens expressed their grief and wishes:

"Zhuo Jun, go well on your way to haven. I pray you a healthy, safe and happy life."

"Ming, my brother, walk well, tears run up."

The formation of memorial space is a kind of multi-subject cooperative narrative behavior across time and space. Under the account of the sick blogger, netizens from different regions publish contents at different times, thanks and wishes to the blogger or comfort and encourage the blogger's family, which are all the secondary processing and extension of the blogger's original content.

Death is an unavoidable topic of life. In all philosophy and religion, death is not the end of life, forgetting is. Because of this, the memory of the deceased becomes a continuation of the spiritual and social life of the deceased.

The collective digital mourning in cyberspace is a kind of ritual behavior, and the original narrative of the blogger is gradually abstracted into concrete symbols in the collective mourning of netizens, which is constantly lofty and idealized. Through the joint participation of netizens and collective writing, it eventually becomes a collective memory, adding new meaning on the basis of imagination and memory.

As one patient said, "We can be very pleased that every day he lives is surrounded by love. He and his parents created miracles that have warmed and inspired us to move forward, we also seem to see, at this moment, he is smiling and saying to us: come on, you will go further and further."

Digital media technology not only changes the behavior and way of individuals, but also changes the way individuals are remembered. With the massive storage space and the diversity of recording methods, digital media has retained the real images of a large number of bloggers who have died of rare diseases. These images have been constantly added new meanings and value to the cross-space collaboration narrative of netizens, which inspiring later generations. If the work kept under the blogger's private account is also regarded as a memory, then the deceased rare disease blogger gets "immortal" in the digital memory.

5. Discussion and conclusion

This study examines the works as a rare group of ALS blogger network performance behavior through the in-depth interviews and text analysis, disease philosophy expression and web celebrity practice career, and explores the ALS blogger network practice and the uniqueness of network narrative from life and living, social relations and new media technology three levels. The new media technology and web celebrity occupation have expanded the life visibility of rare disease groups, increased the intersection range of rare disease groups and the outside world, and also brought new thinking about life and ethics.

First of all, the development of the web celebrity career of rare disease bloggers is highly consistent with their own life process. Different onset stages not only affect their own demands and desire to express, but also are related to the content, form and attention of their works. With the progression of the disease, the symptoms are increasingly revealed, and the impact of the disease on the physiological function gradually increases. While gaining the trust of fans, the difficulty of the blogger to update his works increased, and intensified the "acceptance" and "stigma" of the blogger psychologically, which has an impact on the identity transformation of the blogger. With the extreme deterioration of the condition and even the death of the blogger, the web celebrity account stopped more, at this time, the digital life gradually emerged.

Second, this paper does not observe one specific online forum. On the one hand, influenced by the actual situation of the selected research subjects, the number of patients with single types of rare diseases is relatively small, and it is more difficult for patients with rare diseases to contact. This study did not deliberately avoid the possibility of contact with other rare diseases, but compared with the fatal diseases such as cancer and hepatitis B with higher social attention, there are few single cases of rare diseases, and there is a lack of practical basis for sharing information among patients with different rare diseases in China. Therefore, there is always a lack of an aggregated online forum similar to "dancing with cancer" online forum. The "weak connection" network established on large social media platforms such as TikTok and Weibo is a more common way to connect and interact among patients with rare diseases in China. Therefore, in this study, the patient established the interview relationship first and then contacted the patients with rare disease web celebrities. Based on this, this research selects two more open new media platforms, which include bloggers, patients, fans and ordinary netizens into the research scope, and takes the private account of the blogger as the platform. In addition, the network practice of rare disease bloggers is generally an external practice, rather than limited to their own group. The identity of their web celebrity stipulates that they must be oriented to the whole society. Therefore, choosing the research mode of selecting online — and offline linkage and multi-platform joint observation has more practical guiding value than focusing on a single patient forum.

Of course, sick bloggers are not entirely involved in content creation. While sharing their lives, diseases and insights, many sick bloggers also use online platforms to carry out live streaming or short video sales, selling their hometown agricultural and sideline products and discounted daily necessities, so as to subsidize their families. In the video, their image characteristics, including perseverance and unremitting self-improvement, have also won social attention and social support. Some bloggers with more serious rare diseases will also receive rewards for shorter daily stories or essays, and cooperate with public welfare organizations to provide scientific guidance on rare diseases, etc. This is a normal result of the unique evolution process and the situation of rare disease groups.

It is worth noting that the rare disease groups this paper focused on are patients with muscle weakness and muscle atrophy caused by genetic problems. The remarkable feature is that the disease will gradually lead to physical disability, and the patients without exception will go to the end of life due to illness. However, there are many kinds of rare diseases, and different diseases have different degrees of damage to patients' physiological function and life and health. For example, rare diseases such as albinism do not affect normal life and longevity of patients. Therefore, the conclusions of this study on patients with rare diseases cannot be applied to all patients with rare diseases.

References

[1] *Frost Sullivan, the Pain Challenge Foundation.2023 China Rare Disease Industry Development Report [EB / OL]. Beijing: Beijing Disease and Pain Challenge Foundation, Frost & Sullivan, 2023:9-10.*

[2] *China's government network. The 50th Statistical Report on Internet Development inChina[EB/OL].2022-8-31[2022-09-01].http://www.gov.cn/xinwen/2022-09/01/content_5707695.htm;*

[3] *Ruiguan Industrial Research Institute. China Internet celebrity Economy 2024-2028[EB/OL].2024-04-23[2024.04.23].https://www.reportrc.com/report/20240112/56495.html*

[4] *Fu Min, Tian Huisheng. Educational narrative research:Essence,Characteristics and Methods [J]. Educational Research, 2008 (05): 36-40.*

[5] *Li-bin wang. Exploring the disease expression of cancer patients on the "Zhihu" platform from the perspective of health narrative — An empirical study based on patient self-report [J]. Southeast Transmission, 2021 (01): 127-131.*

[6] *Green, M.C."Transportation into Narrative Worlds: The Role of Prior Knowledge and Perceived Realism." Discourse Processes 38.4 (2004):247-266.*

[7] *Sharf, B.F., & Vanderford, M.L.(2003).Illness Narratives and the Social Construction of Health.In Thompson, T.L., Dorsey, A.M.,Miller, K.I., & Parrott, R.(Eds.), Handbook of Health Communication (pp.16-28).Mahwah, NJ: Lawrence Erbaum.*

[8] *Xu Kaibin, He Yuying. The evolution of the "knowledge picture" of western health narrative research — is based on the analysis of the literature related to SSCI from 1992 to 2018 [J]. University of Journalism, 2021 (05): 1-21 + 121.*

[9] *Kleinman, A.(1988).The illness narratives: Suffering, healing, and the human condition.New York,NY: Basic Books.*

[10] *Høybye, M.T., Johansen, C., & Tjørnhøj-Thomsen, T.(2005).Online interaction: Effects of storytelling in an internet breast cancer support group.Psycho-Oncology,14(3), 211-220.*

[11] *Li Feifei, Wang Cheng Wei. How self-empowerment is possible in women with breast cancer: thinking based on the cancer narrative [J]. Medicine and Philosophy, 2019,40 (06): 17-20.*

[12] *Du izhu, Xu Kaibin."Dancing with Cancer" and "Dancing with Love": the meaning construction of the online cancer narrative [J]. University of Journalism, 2023, (07): 56-70 + 119.*

[13] *Liu Ying, Sun Yang. Research on social support in online virtual communities of vulnerable groups — Take the hepatitis B forum "sincere care" as an example [J]. Journalism and Communication Research, 2011,18 (02): 76-88 + 111-112.*

[14] *Bruner, Jerome. "Life as Narrative." Social Research 71, no. 3 (2004): 691–710. http://www.jstor.org/stable/40971721.*

[15] *Frank A W.The wounded storyteller:Body, illness, and ethics[M].University of Chicago Press, 2013.*

[16] *Xiao-man wang. The humanistic perspective based on health narrative turns to —. Taking the wechat public account "fruit shell patient" as an example [J]. News world, 2024(02):26-29.DOI:10.19497/j.cnki.1005-5932.2024.02.007.*