

A Study of Video Narratives of Caregivers of Children with Cancer Through the Lens of Media Geography

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Abstract

The purpose of this study was to analyze the narrative content of anti-cancer videos posted by caregivers of children with cancer on the Jieyin platform. Through coding and analysis of 192 anti-cancer videos posted by 10 caregivers, it was found that these videos focused on four main areas: documenting the child's cancer journey, expressing the emotional stress associated with caregiving, raising public awareness of childhood cancer, and raising money for charity. The study suggests that the Shakeology platform is not only a tool for caregivers to document and share their sick child's treatment process, but also an important avenue for emotional catharsis, social support, and raising financial resources. These anti-cancer video contents have contributed positively to raising public awareness and understanding of childhood cancer, while helping families of children with cancer to better cope with life's challenges.

Keywords: health communication, caregivers of children with cancer, Shakeology platform

1. Introduction

Cancer ranks as the ninth highest cause of childhood disease burden globally (Murre J M J, 2015). Between 2018 and 2020, a total of approximately 121,145 cases of cancer in children and adolescents will be diagnosed in China (Ni X. 2022). Caregivers (e.g., parents or guardians) of children with cancer face the challenge of coping with caregiving issues and medical decision-making related to their child's medical care, as well as coping with their own psychological distress throughout the treatment process. Numerous studies have shown that caregivers experience stress, anxiety, and decreased quality of life throughout the diagnosis, treatment, and recovery from childhood cancer (Best, M, 2001; Boman, K, 2011; Boman, K, 2000; Salvador, Á, 2015; Vrijmoet-Wiersma, C, 2008), and during the child's treatment period, caregivers must find a balance between their existing family and work in order to cope with the new caregiving and emotional demands of being a caregiver for a child with cancer (Trask PC, 2003; Hoekstra-Weebers JE, 1999; Hoekstra-Weebers, 2012; Martin S, 2011). Increasing access to social support for caregivers of children with cancer can help them effectively manage their psychological stress and other needs. For example, caregivers of children with cancer express a need for emotional and informational support (Adams, E, 2009; Eysenbach, G, 2004; Love, B, 2012; Kerr, L. 2007). Due to the intensive nature of pediatric cancer treatment, many families are removed from their existing social networks (Gage E, 2012), which may make social media a convenient and effective way to share experiences, communicate with others, and connect with supporters.

Space is the basic material of geography, and space under the study of media geography goes beyond the usual physical attributes. Physical space is the definition of the scope of the real environment, and real environments such as cities, regions, and countries exist in a certain physical space. However, the space in media geography is transformed into a sphere of interpersonal communication based on social and media constructs, and space has become a variety of scenarios for human communication in the media communication environment. The society we live in has become an interconnected society with various layers constructed around the media. The information in the society is transmitted by the media as the core brain, forming a socialized space full of media information.

Merowitz suggests that electronic media breaks the traditional relationship between physical space and social scenes, creating new scenes and breaking up old ones (Merowitz, 2002).

Under the effect of mass media, the space we live in is no longer limited to the original natural space, but more inclined to the psychological space with social attributes. According to Simmel, the sense of space is something that everyone can perceive, and it represents the distance between people (including the physical-geographical distance and human psychological distance). People's interaction activities are the filling of many spatial senses (Simmel, 2002).

Along with the development of the Internet, social media platforms have gradually become an important platform for patients with various diseases and their caregivers to present themselves and exchange health information. As a top streaming short video software with unique platform attributes, Jieyin provides a new "stage" for cancer patients to present themselves and build social networks. Social media platforms such as Jieyin are embedded in the daily lives of caregivers of children with cancer, expanding the living space of the general public. In order to understand whether Jieyin can be a useful source of support for meeting the needs of caregivers of children with cancer, it is necessary to first understand the use of social media sites by caregivers of children with cancer. The purpose of the current study was to describe the content analysis of caregiving videos posted by caregivers of children with cancer in the Shakeology platform.

2. Methodologies

In this paper, we selected the anti-cancer videos posted on Jieyin by caregivers of children with cancer as the research object. By using the search terms "children with cancer", "anti-leukemia children" and "childhood leukemia" to identify the video content pages on Jittery Voice platform, we filtered out hospital accounts, After filtering out hospital accounts, doctors' accounts, public welfare organizations' accounts, and irrelevant content such as handling and explanation, the bloggers were identified as caregivers of children with cancer, and the bloggers' Jitterbit accounts were observed for a long period of time (December 2022-April 2024). In order to make the selected sample more representative and persuasive, this paper sets criteria for secondary screening:(1) The number of videos posted by the blogger's account needs to be more than twenty to ensure the positivity and continuity of the selected sample. (2) Self-filmed and posted video content by caregivers of children with cancer. A total of 72 cancer child caregiver bloggers and a total of 12,065 video contents were obtained as of April 26, 2024 after screening. It was observed that different children with cancer caregivers had different activity levels on Shakeology and posted different amounts of video content. Accordingly, in this paper, based on the purposive sampling method, 10 cancer child caregiver bloggers whose caregivers' children are in different age groups, have different types of cancers, and have a higher number of anticancer video contents posted on Shakeology, and have been used for a longer period of time, will be selected as the study subjects among the observation subjects. After that, all the video contents posted by the research subjects on Jieyin were captured from the first update about their children's cancer posted by the research subjects to the deadline of the researcher's data collection date, and 192 valid data were obtained after data de-emphasis and cleansing. After determining the study sample, the video samples posted by the caregivers of children with cancer were imported into Nvivo12 software for multilevel coding.

In this paper, we coded the data according to Strauss's three-process coding, starting with "open coding," in which the researcher used the original words of the caregivers in the videos as much as possible in order to be close to the original intention of the caregivers of the children with cancer. When the coding reached saturation, a second round of "spindle coding" was conducted to summarize the initial coding and categorize the words according to the content of the video to make the coding more logical. The third round of "selective coding" was conducted to further integrate the decentralized content into the research questions.

3. Study Finds

Based on the statistics of the content of the study participants' video postings, it was found that the themes of the video narratives posted by bloggers who are caregivers of children with cancer on the Jitterbug platform can be categorized into four areas: (1) documenting their child's cancer journey, (2) sharing the emotional stress associated with caregiving, (3) raising awareness and advocacy for childhood cancer, and (4) raising money for charity.

3.1 Documenting Your Child's Cancer Journey

One of the main ways in which carers of children with cancer use Jitterbug is to document the journey of the child's cancer treatment; although the carers do not have cancer, they experience the physical experience of cancer through the experience of caring for a child. In this case, the caregiver becomes the sick child's "surrogate self," standing in for the caregiver's own self and telling the sick child's narrative of suffering as if it were their own story (Knepper,

K, 2018). Carers live through different stages of treatment and celebrate milestone moments related to cancer. Carers make videos to share the story of their child's cancer diagnosis, updates on treatment progress, and the results of recent tests. For example, one caregiver described their intention to create a Shakeology account in the information section of their Shakeology homepage.

Hello everyone I'm [sick child's name], 2020 was diagnosed with leukosis, three years of anti-leukodystrophy, relapse after one year of junction therapy, the current Hebei transplant for three months, in the anti-rejection, every video in the real record of the anti-leukodystrophy process, thankful to meet, like the friends to leave us a concern. I'm not sure if you're going to be able to get it right! I'm not sure if you're a good person, but I'm sure you're a good person.

Dad: [personal contact details of carer shown here]

Carers use Jitterbug as a way to keep up-to-date information about their child's health throughout the cancer treatment process. Carers would share details of their child's diagnosis and treatment, upcoming appointments and surgeries, and their child's current treatment plan through videos on the Shakeology platform. For example, one caregiver recorded a video of her child on the day of his bone piercing, where the child showed nervousness before departing from home, and the caregiver gently reassured the child to ease the child's anxiety; after the child's bone piercing was over, the caregiver gave the child a thumbs-up encouraging him to be the bravest little warrior, and took out the toys prepared in advance to give to her child as a reward, and at the end of the video the family gave a thumbs-up to the camera, and the family gave a thumbs-up to the camera, and the family gave a thumbs-up to the camera. At the end of the video, the family gives a thumbs up to the camera, sending a message of positivity and optimism to netizens watching the video. Like this caregiver, caregivers use Jieyin to share updates on their children's health as part of the largest portion of their videos.

Carers also share videos on Jitterbug to celebrate monumental moments in their child's cancer treatment, such as the anniversary of their child's cancer diagnosis, their child's birthday, and their partner's birthday. One caregiver shared the first anniversary of his child's diagnosis in a video in which he, as the child's father, prepared flowers for the child as well as the child's mother (the primary caregiver) and personally made a commemorative cake to celebrate this monumental occasion. The video shows many fragments of the child's journey from the diagnosis to the present day, with the first half of the video showing the caregiver accompanying the child for treatments, infusions, and looking after the child's The first half of the video shows caregivers accompanying the child for treatments and fluids, taking care of the child's daily routine, and the second half of the video shows him making a cake, preparing flowers, and everyone eating the cake together. The video received 6,138 likes and 512 comments in support of the caregiver organizing such a celebration. For example, the owner of the flower store saw the video and commented, "I should have given you guys a discount". Another commenter commented "My son grew up with poor health and spent many nights in tears, when things got tough, I always thought of [video maker] and it gave me strength again. I wish [the video maker] a sweeter and sweeter life for the family!" .

Videos documenting the journey of a child with cancer usually present the caregiver's perspective on their child's and family's fight against cancer, presenting mostly events related to the disease. This type of narrative reflects the ongoing active observation and interpretation of the caregiver of a child with cancer. As a tool of confrontation, digital media, on the one hand, brings together caregivers' individual narratives of their children's life experiences and becomes a common mediated memory for the cancer community; on the other hand, it constructs a memory space for a diverse group (Xie Zhuoxia, 2020).

3.2 Share Emotional Stress Related to Nursing

The openness, integration and interactivity given by the Internet have significantly increased the breadth of mass communication and interpersonal communication, and the space constructed by it has become more and more a place of communication, where users can express and communicate through operations such as liking, commenting and retweeting, etc.; and the text, which serves as a symbol to convey meanings, has also become more and more a tool for users to recognize and understand.

A child suffering from leukemia is like a bolt from the blue for the caregiver of the child, a heavy psychological burden and huge financial pressure comes instantly, plus accompanying the child to and from the home and the hospital frequently, tired of running around, not enough time for rest and relaxation, and also constantly raising money from all over the world. At the same time, the sick child suffers from various chemotherapy side effects due to intensive chemotherapy, and the caregiver is in a state of high stress physically and mentally while taking care of and worrying about the child, and the caregiver is facing great psychological pressure. Although family and friends are the objects that the caregiver can communicate with directly, the high or low family communication orientation (Lu, H, 2020), social alienation caused by the disease (Yang, XY, 2020), and other factors will affect

the caregiver's ability to communicate with the family and friends, and the caregiver will not have enough time to rest and relax. 2020) and other factors can affect the rate of interaction and the quality of communication between members, so the caregiver's emotions will not be fully and completely represented in their presence. Caregivers expressing these emotions through videos can help them reduce their inner pressure and avoid related psychological problems. At the same time, sharing their experiences on Shakeology often results in receiving encouraging comments from other users.

The sick child's caregiver posted her own understanding of the disease on the Shakeyin platform, and with the video as the center, the information continued to spread and extend, and the degree of interaction with other users as a scale, forming a heterogeneous social network of strong and weak relationships, and this interactive behavior, in fact, also constructed a virtual interactive space. In this space, through the function of commenting, users not only form a direct dialogue with caregivers of sick children, but also further construct a narrative space (Chen, 2021).

One caregiver described it in the ShakeOut after the results of her child's bone puncture came back and she couldn't have a transplant but had to undergo a fourth chemo mindset:

The mindset is really coming apart

Since [sick child's name] has been sick, she has always been optimistic and positive, because she doesn't want others to look at her with pity, so she shows her best side every time, and everyone thinks she is in good shape and doesn't look like a sick child. I myself also think that she will definitely be able to get well, but it is only costly and time-consuming, but it does not matter as long as she is there.

At first in Nanchang that the conditions are not good to take her to the better Wuhan Union Medical College Hospital, myeloid leukemia most of the need for transplantation in order to allow her to live a normal life or decided to go to the preferred transplantation Lu Daopei Hospital.

Full of hope after playing the third treatment smoothly through each bone marrow suppression period, are waiting for 3 treatment can be prepared for transplantation, bone penetration results came out that - moment of heart collapse, why ah

Why is it that when everyone else has 2 treatments and 3 treatments and everything turns negative and is in remission and can enter a position, she doesn't quite get 4 treatments

Through this kind of emotional sharing, on the one hand, the carers' emotions can be released, and the support from the netizens' likes and comments and listening will give them energy and courage to continue to move forward, and under this kind of quasi-social relationship, the carers will feel that they are not alone in their struggle. On the other hand, emotional sharing posted by caregivers in social media is more emotional than specific emotional stories posted in traditional media, thus triggering deeper feelings among netizens.

Therefore, by constructing their own perception of their children's pain and suffering, the caregivers symbolize and narrate their unique cognitive attitudes and emotional experiences, which become the basis for establishing group identity and emotional ties, thus creating an "emotional field". And through the emotional confession and communication, the pain can be effectively alleviated through "emotional sharing", and the depression in the heart can be dissolved.

3.3 Childhood Cancer Awareness and Sensitization

Through short-form video platforms, children with cancer as a group are removed from their original birthing space, and for viewers of this type of video, the images of sick children in videos produced by caregivers of children with cancer are not the same as the mysterious and plain images of children with cancer that have been reported in traditional media.

In traditional media, images of children with cancer are often shaped and disseminated by media organizations, and the voice and control of the patients themselves may be limited. Traditional media may be more inclined to report on stories with specific emotional or dramatic overtones, resulting in a homogenized or stereotyped image of the sick child being reported on. Stories tend to be time-lagged and information may not be updated in time to reflect the latest situation of the sick child, and there is limited interaction between the sick child and the viewer, with a lack of immediate feedback and communication. The traditional media, due to the limitation of the length and form of the report, may express emotions superficially and lack depth.

Compared with traditional media, caregivers on the ShakeMedia platform usually have greater autonomy and initiative to show their children's treatment status, and they can decide the content, format and frequency of sharing, thus providing a more realistic reflection of the experience of a sick child's fight against cancer. Caregivers can

update their children's status and treatment progress in real time, and viewers have access to the most up-to-date and timely information. The Jitterbug platform provides a highly interactive online environment for the caregiver community. On this platform, caregivers can directly interact with viewers through video comment sections or live streams to receive feedback and support. This highly participatory feature helps to build and strengthen the sick child's support network. Caregivers have the opportunity to showcase the uniqueness of the child as an individual, for example, by showcasing the child's drawing, dancing, singing and other specialties in the video, which removes the limitations of the traditional label of "child with cancer" and reveals a richer picture of the child's personal attributes and outlook on life.

Carers of children with cancer often need to acquire highly specialized medical and nursing knowledge in the early stages of their child's diagnosis and treatment, including knowledge of the disease and treatment, and hands-on experience in nursing care, etc. As the caregiver's experience builds up, the caregiver will also disseminate their experience and knowledge of caring for their child in videos, which is important to many other families of children with cancer who are looking for help on media platforms. For many families of other children with cancer who seek help on media platforms, knowing how their "friends" are fighting cancer or the pace of treatment is very important to them, and when their child is diagnosed with cancer, access to information is necessary for every family of a child with cancer, and the Internet provides a platform for the presentation of this information. Although caregivers of children with cancer are not professional healthcare workers, the information, knowledge, and experience they provide based on their status as a caregiver of a child with cancer has a certain degree of credibility and persuasive power, and the information they publish is more likely to be believed by the audience.

Because of the variety of childhood cancer diseases, different morbidity, different treatment options, and different disease conditions of children with cancer, ordinary viewers have little knowledge about childhood cancer. When caregivers post anti-cancer videos on the Shakeology platform, ordinary viewers do not know much about childhood leukemia and tend to ask for explanations of relevant specialized terms in the comment section of the videos, such as, "Why do children get leukemia? What does it mean to enter the warehouse? How long does a transplant take?" etc. The caregivers will popularize these questions to the viewers and raise their awareness of childhood cancer.

When a child's cancer is successfully treated, the family of the child with cancer will return to the hospital where they were treated with gifts on holidays to visit other sick children battling the disease and give them encouragement and support, and they also call on more caring people in the community to care for the group of children with cancer and expand awareness and publicity of childhood cancer.

3.4 Fundraiser

Treatment of childhood cancer usually requires high costs, including surgery, chemotherapy, radiotherapy, medication, etc., which often puts significant financial pressure on the patient and his/her family. Caregivers may not be able to work normally while accompanying the sick child for treatment, resulting in a decrease in overall family income, but basic expenses for family life and hospitalization remain, and may even increase due to the treatment of the sick child's disease (e.g., nutritional supplements, special care, etc.). The low threshold, easy readability, and wide spread of the Jitterbit platform gives caregivers of sick children the opportunity to tell their personal situation to the cyberspace, which enables cancer-stricken families to break through the original identity and spatial limitations, and to rely on the Jitterbit platform to record their lives and obtain help from caring members of the society. Therefore, opening an account on the ShakeMe platform to make cancer videos is one of the ways that many caregivers choose to alleviate their financial burdens.

The caregiver can sell goods through the way of live broadcasting, live broadcasting is usually carried out at night, when the caregiver has finished a day of care life, the use of the leisure time before the rest of the live broadcast selling goods, the audience can support the family of the child suffering from cancer through the purchase of goods, this way to directly convert the traffic into economic income. During the live broadcast, viewers can also support the child's family by giving them virtual gifts from the platform, which the caregiver can then convert into cash.

When a user's fan base has accumulated to a certain level, the Jieyin platform allows the user to open a merchandise window, where the caregiver can display the merchandise window on his or her personal homepage and earn income by selling the merchandise. Some caregivers will write the reason for bringing goods in the information section of their Jieyin personal homepage, requesting netizens to buy goods to show their support for the family.

2023 mid-April lively and lovely [name of the sick child], diagnosed with leukemia, opened the sinful chemotherapy treatment, because of the expensive treatment costs, has spent all the savings, on the road with goods to save the girl, I hope that you can enter the window to look at the need to place an order, every single

one of your family has brought the greatest help, thank you for all the good people, good people live a peaceful life Thank you!

Thank you to Shake Shack for helping the kids!

♥ Thank you to each and every one of you who stopped by the video!

As the number of fans increases, the caregiver's personal account may receive attention from brands (e.g., mother and baby brands), and the caregiver can earn income by cooperating with the brand to publish advertisement content. Some caregivers who have gained enough fans during the treatment of the sick child will choose to continue to carry goods in the form of self-publishing as their professional work after the recovery of the sick child, and according to the positioning of their own fan base, they will still focus on the Mother and baby and household goods.

After the videos produced by some caregivers to fight cancer for sick children are noticed by local charitable organizations or caring people, the charitable organizations or caring people will visit the families of the sick children offline and give them certain material support. For example, local charitable organizations raise money offline for the families of the sick children and conduct fundraising activities, and caring people go to the hospital to accompany the sick children to do handicrafts and other activities on Children's Day and other festivals. The caregivers record these moments and make videos to thank the caring people or charitable organizations for their help.

4. Research Limitations

Sample limitations: although the study selected 10 caregivers of children with cancer as study participants through specific screening criteria and analyzed 192 videos posted by them, these samples are still limited in number and may not be fully representative of all caregivers of children with cancer.

Platform homogeneity: This study focused only on the Jieyin platform and did not consider similar anti-cancer narrative content on other social media platforms (e.g., WeChat, Weibo, Shuttle, etc.). This limits a comprehensive understanding of how caregivers of children with cancer use social media to express and seek support on different platforms.

Limited time horizon: the study focuses on data up to April 26, 2024, and lacks long-term tracking and follow-up data. Caregivers and their families may have different needs and behaviors at different stages and points in treatment, and these changes are difficult to capture in the short term.

Limitations of the analytical approach: the study primarily used a qualitative coding analysis approach, and while this approach helped to provide an in-depth understanding of the video content, it lacked the quantitative analysis to support the broad applicability of the qualitative findings.

Lack of viewer perspective: Research has focused primarily on the perspectives of caregivers of children with cancer, but has not delved into how viewer feedback and interactions may influence caregiver behavior and psychological states. Viewers' comments, private messages, and supportive approaches may have a significant impact on caregivers' video content and posting behaviors, and this section of the analysis is lacking.

Ethical and privacy issues: although the study describes how caregivers shared sick children's healing journeys and emotional stress on the Shakeology platform, it does not discuss the ethical issues that may be involved in these behaviors, especially how to protect sick children's privacy and dignity in the context of sharing sensitive information about sick children publicly.

These research gaps provide directions for further research in the future, such as expanding sample sizes, increasing platform diversity, conducting longer follow-up studies, adopting mixed methods (combining quantitative and qualitative), analyzing the impact of audience interactions, and delving into ethical issues.

5. Conclusion

By analyzing the narrative content of anti-cancer videos posted by caregivers of children with cancer on the Jieyin platform, this study reveals how caregivers use social media to document their child's journey through cancer, express emotional stress, raise public awareness of childhood cancer, and raise money for charity, among other functions. These videos not only demonstrate the emotional and psychological needs of caregivers of children with cancer during the caregiving process, but also show the important role of social media, such as Jitterbug, in supporting and empowering families of children with cancer.

The study found that the Jieyin platform provides an expressive and documentary platform for caregivers of children with cancer to share their child's treatment process and personal experiences in a more personal and timely

manner. Through these videos, caregivers were not only able to gain sympathy and support from viewers, but were also able to leverage the platform's interactivity and broad user base to seek financial help and social support. These findings suggest that social media platforms play an increasingly important role in modern health communication, particularly in the self-presentation of patient groups and the creation of social support networks.

However, there are some limitations in this study. For example, the study sample was limited in size, focusing mainly on the Jitterbug platform and failing to provide comprehensive coverage of all social media usage. In addition, the study data had a limited time span and lacked in-depth analysis of interactions between caregivers and viewers. Future research could further explore the role of social media in the lives of caregivers of children with cancer by expanding the sample, adding analysis of other platforms, and conducting longer follow-up studies.

Overall, this study emphasizes the key role played by social media platforms in the community of childhood cancer caregivers and calls for more attention to the needs and difficulties of this particular group. It is hoped that this study will draw more attention from the community to families of children with cancer and promote the formulation of relevant policies and the provision of support services.

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