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Understanding the experience of family caregivers of patients with leukemia: a qualitative analysis of online blogs

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Although family caregiving is a demanding task, it has the potential to increase the significance and satisfaction of the caregiving process, while also enabling better response to the patient's condition. This study aims to qualitatively explore, describe and analyze the experiences of family caregivers who are taking care of patients with leukemia. With an inductive thematic analysis, data collected from 997 online blog posts generated by 32 Chinese family caregivers of both adult and pediatric patients with leukemia were thoroughly examined. Through a detailed analysis of the blog posts, three main themes were identified: (1) family caregivers' (FCGs') reactions to the leukemia diagnosis, (2) challenges faced in caregiving, and (3) effective coping strategies. The study reveals significant implications for improving the quality of life for family caregivers and enhancing health services for patients with leukemia. Gaining a comprehensive understanding of challenges and hardships faced by FCGs can shed light on enhancing the current medical services. A detailed account of the financial and psychological burdens experienced by FCGs offers valuable insights that can influence the decision-making of healthcare institutions and policymakers, facilitating the implementation of effective medical reforms. The findings underscore the importance of addressing the psycho-social needs of family caregivers, thereby suggesting the need of improved implementation of effective psycho-social support to enhance their overall quality of life. It is recommended that future research focus on developing more socially integrated approaches specifically tailored for family caregivers of patients with leukemia. While this study is primarily exploratory and descriptive, it forms a foundation for further investigation and understanding of the comprehensive family caregiving system for patients with leukemia.

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Introduction

Leukemia is one of the most common cancers (Bray et al., 2018; H. Wang et al., 2016). In 2020, 474,519 new cases of leukemia were diagnosed worldwide, with an incidence rate of 2.5% and 311,594 new deaths of this disease were reported in the same year, with a mortality rate of 3% (Sung et al., 2021). Despite the high incidence and morbidity, there has been substantial advancement in the clinical treatment of leukemia during the past few decades regarding the patients' five-year survival rate. The five-year survival rate of patients with leukemia was 19.6% in 2003–2005, and it increased to 25.4% in 2012–2015 in China (H. Wang et al., 2016). Family caregivers (FCGs) are seen as a crucial component of the survivorship process, which takes into account the physical, emotional, and financial aspects of cancer (National Cancer Institute, 2019).

Although FCGs are important sources of support for patients, they must also deal with the burden and stress that come with providing care. Studies revealed that marital status (Arab et al., 2020) and psychological status (Grover et al., 2019) were contributing factors of the caregiver burden. Family function, social support, household income and the type of leukemia were important predictors of FCGs' quality of life (C. Wang et al., 2020; Yu et al., 2018). Excessive burden and psychological stress would negatively affect family caregivers' quality of life (Jia et al., 2015; Li et al., 2019; M. Wang et al., 2022; Y. Wang et al., 2021). However, those FCGs had insufficient resources to manage the stressors and underwent negative psychological, behavioral, and physiological effects, resulting in negative impacts on family relationships (Yucel et al., 2021).

FCGs experienced great burden and psychological distress in caring for their family members diagnosed with leukemia. To offset these experiences, a growing number of FCGs have been sharing their experience of coping with illness online by keeping blogs. Online blog narratives can offer space for both patients and their family caregivers to share knowledge and information of the disease and its treatment, exchange information regarding various aspects of illness and feeling, and form new relationships regardless of temporal or geographic presence (Heilferty, 2009; Shah and Robinson, 2011). The blog provides a low-cost, worldwide, and immediate data collection method (Hookway, 2008; Hookway and Snee, 2017). As a consecutive, unique and rich source of data, blogs have been used by empirical health researchers for gathering information about caregivers' experiences, perceptions, and feelings (E. Wilson et al., 2015). As a result, there has been an increasing number of studies based on blogs written by caregivers of geriatric patients with chronic diseases such as dementia (Anderson et al., 2017, 2019; Kannaley et al., 2019; McLennon et al., 2021).

However, there is a lack of research on illness blogs written by family caregivers of patients with leukemia. Furthermore, prior

research on FCGs of patients with leukemia tends to focus more on the negative effects of caregiving. Although caregiving is a demanding task, it can increase sense of meaning and satisfaction in the caregiving process and help FCGs better cope with the patient's condition (Desields et al., 2016; Papastavrou et al., 2012). Existing studies have primarily examined the quality of life and burden of FCGs, but there is a significant gap in understanding their emotions, feelings, concerns, needs, advice and other meaningful experiences among Chinese FCGs of patients with leukemia. Moreover, Chinese traditional culture and Confucianism prioritize family care over other forms of care (Ge et al., 2011; Tang and Chen, 2002). In China, family members have a strong sense of obligation (Yu et al., 2018). The care provided by Chinese FCGs for patients with leukemia, both at home and in hospitals, far exceeds that delivered by nurses in Western countries (Ge et al., 2011; Tang and Chen, 2002; Yu et al., 2017, 2018).

To bridge the research gap and effectively address the concerns and social needs of Chinese family caregivers of patients with leukemia, we deem it is crucial to gain a comprehensive understanding of this particular group and their caregiving experiences. Therefore, by describing and analyzing the narratives shared by Chinese family caregivers of patients with leukemia in their blogs, this study aims to delve into their unique caregiving experiences and, in turn, amplify the often-overlooked voices of this vulnerable group.

The unsolicited nature of the blog itself eliminates the potential of recall bias (Anderson et al., 2017). This distinctive characteristic sets blogs apart from other more conventional methods, such as interview, focus group, or survey, commonly used to explore personal experiences with illness (Heilferty, 2009). Additionally, we refrained from providing a pre-set topics for the narratives to ensure that they accurately and genuinely reflect the real daily experience of leukemia caregiving, devoid of any researcher influence or bias (Kannaley et al., 2019).

The research questions investigated in this study are listed as follows: How do FCGs of patients with leukemia describe their caregiving experience? What discernible patterns can be drawn from their narratives?

Method

Study design. By focusing on how blog authors used their self-initiated narratives being created online, this study employs thematic analysis to examine the perspectives and experience of Chinese family caregivers of patients with leukemia.

Data collection. A purposive sampling method was employed to collect data from blog texts created online by Chinese family caregivers of patients with leukemia. Blog texts were selected from *Red* (*Xiaohongshu* in Chinese, literally "little red book"), a

Table 1 Inclusion and exclusion criteria of blog posts by family caregivers of patients with leukemia.

| Inclusion criteria | Exclusion criteria |
|--|--|
| 1. All blogs selected for this study were published publicly, not password-protected, and easily accessible via in-app search. | 1. Blogs were written in language other than Chinese. |
| 2. The blog was written in Chinese by an individual who was described as a family caregiver of a patient with leukemia. | 2. Blogs kept by associations, organizations, or companies that provided health care services were excluded since these blogs were not supposed to be purely first-person account of caregiving. |
| 3. The blog posts were closely related to the experience of caregiving for a family member with leukemia. | 3. Contents irrelevant to the caregiving experience, for example, posts of commercials, pure science news, were disregarded. |
| 4. Blogs with at least 10 posts, each with a text length of over 100 words, were included, in consideration of the continuity of detailed accounts of caregiving experience. | 4. Blogs with less than 10 posts or each post with a text length of less than 100 words were excluded. |
| 5. The blog was published between 2019 and 2021. | 5. Videos, pictures, hyperlinks or comments were not included. |

smartphone application oriented to posting, discovering and sharing experiences of daily life through a wide variety of media such as images, texts, videos, and livestreaming. The search was conducted on the application between January 4, 2022 and February 18, 2022. Using key words such as “leukemia”, “leukemia diary”, “leukemia blog”, “fighting against leukemia”, and “fighting leukemia diary”, all researchers collected the samples eligible for the research objective. Embracing as much relevant content as possible, the data were collected based on the inclusion and exclusion criteria, as displayed in Table 1.

Due to the smartphone-based nature of *Red (Xiaohongshu)* and its personalized search results, the search results page does not display a fixed quantity of information. Instead, it would dynamically display the relevant content based on the key words used for search. Thus, we could only access images on the application after conducting the initial search using the aforementioned keywords. To obtain eligible data, we took the following steps: (1) Initially, we captured the screenshots of search results pages and put them into a Microsoft word file. (2) Then, we searched the homepages of bloggers by clicking their publicly displayed user names, which were gleaned from the file of captured screens. Consequently, we identified a total of 53 bloggers. (3) Next, since the targeted group was the family caregiver of patients with leukemia, we perused the blog contents to exclude 21 bloggers who were not family caregivers of patients with leukemia. This left us with a final sample of 32 bloggers. (4) Finally, following the inclusion and exclusion criteria, we identified 997 blog texts from the 32 bloggers.

Ethical issues. Institutional review board approval was requested and the protocol was exempted because informed consent is not required when it applies to public and published material (Bruckman, 2002; Hookway and Snee, 2017). There is a growing consensus among researchers that if Internet data are freely and publicly accessible, then they can be used for considered research without prior approval (Anderson et al., 2017). To protect confidentiality and ensure anonymity, we removed all personal identifiers such as real or nick names, locations of the patients with leukemia and their family caregivers within the blog posts. Each blog author was coded using letters and numbers such as Bloggers 1, 2, 3.

Data analysis. The data were analyzed with a thematic analysis method. Thematic analysis is a valuable approach for analyzing naturally occurring data (Clarke and Braun, 2018). Its primary objective is to employ a data-driven approach to understand events, experiences, opinions, viewpoints, and other salient aspects from the participants’ own perspective and determine what matters to them (Kiyimba et al., 2019).

In the data pre-processing stage, all data from selected blogs were saved as html files along with the capture of the “about me” pages of bloggers. Then, data from the html files were saved as a single file in Microsoft word. The text of all blog postings was analyzed according to the six phases of thematic analysis under Braun and Clarke’s guidelines (Braun and Clarke, 2006, 2022). In phase 1, all researchers familiarized themselves with the data by perusing the whole dataset. Phase 2 was the coding process, in which each researcher worked independently to embark on line-by-line open coding of basic units in the data. Due to the unsolicited nature of blog narratives, the coding process was driven by an inductive orientation to data (Braun and Clarke, 2022). All researchers then compared their code lists to identify similar codes, and discrepancies were discussed and revised until consensus was reached to guarantee consistency. No more analysis was furthered until new codes were identified. In phase

3, codes were grouped into meaningful themes. In thematic analysis approach, themes are defined by meaning-unity and conceptual coherence, and each theme has its own distinct central organizing concept (Braun et al., 2014), which might be evidenced at a semantic or latent level (Braun and Clarke, 2006). In phase 4, all researchers checked the candidate themes against the coded information and the whole dataset, to confirm that they recorded a persuading and coherent story regarding the data and the research objective. In phase 5, all researchers fine-tuned the analysis by sorting out the extension of each theme, making sure that each theme was distinct from the others and was based on a compelling central idea. Themes were thus further developed, which sometimes involved them being split, combined, or discarded. The last phase was an integral phase, requiring the writing-up of a thematic map for reporting purposes as well as a final assessment of the codes and themes. Since the process of thematic analysis is not strictly linear, but recursive (Braun and Clarke, 2006), the codes and themes were iteratively evaluated and frequently discussed throughout the analytical process to compare the findings.

Rigor. Credibility, dependability, confirmability, and transferability were addressed to ensure the study was conducted in a rigorous manner (Houghton et al., 2013; Lincoln and Guba, 1985). Credibility was controlled by peer debriefing (Lincoln and Guba, 1985) across the processes of initial coding, theme identifying, theme reviewing, theme naming and writing up (Nowell et al. 2017). Audit trail and reflexivity are used to determine dependability and confirmability (Houghton et al., 2013). Audit trail was maintained through a detailed and comprehensive chronology of research activities to ensure the analytical process was coherent and transparent, for example, taking analytical memos related to the contextual background of the blog data and notes of the themes (Morrow, 2005). Reflexivity was maintained through keeping a reflective journal that included the researchers’ views on the daily logistics of the study, and the impetus and rationale for all methodological decisions (Houghton et al., 2013; Nowell et al., 2017). Transferability was ensured by the purposive sampling with inclusion and exclusion criteria to obtain a homogeneous sample.

Results

Demographic profile of family caregivers and patients with leukemia. All researchers independently examined the posts from the smartphone application *Red (Xiaohongshu)* and identified 997 posts from 32 bloggers that met the selection criteria. The posts included in the study were authored by 31 women and one man. Although demographic information is not compulsory for bloggers when signing up for their accounts of social media, some of the information can be gleaned from the “about me” pages or within the post texts. Table 2 reveals the demographic

Table 2 Demographic characteristics of family caregivers of patients with leukemia.

| | Family caregivers (n = 32) |
|--|----------------------------|
| Gender | |
| Male | 1 |
| Female | 31 |
| Relationship to patients with leukemia | |
| Mother | 25 |
| Father | 1 |
| Female spouse/partner | 5 |
| Aunt | 1 |

characteristics of family caregivers of patients with leukemia. Information with respect to the relationship of family caregivers to the patients with leukemia whom they supported can be found in Table 2. Table 3 displays the demographic characteristics of patients with leukemia.

Qualitative findings. The key themes derived from inductive thematic analysis centered on the caregiving experience of family caregivers of patients with leukemia. The themes identified were (1) FCGs’ reactions to the leukemia diagnosis, (2) challenges faced in caregiving, and (3) effective coping strategies, as displayed in Table 4.

Theme 1: FCGs’ reactions to the leukemia diagnosis. In the early stages of their caregiving journey, FCGs experienced three dis-

tinct emotional responses when faced with their care recipients’ leukemia diagnosis. Initially, they found it hard to come to terms with the diagnosis and accept it as reality. Then, they engaged in self-reflection to understand the reasons behind their care recipients’ leukemia. Finally, they reached a point of acceptance.

Failure to confront the reality of being diagnosed. The initial difficulty in accepting the diagnosis had a profound impact on FCGs, leaving them feeling desperate and struggling to face the reality. The failure to confront the reality contributed to FCGs’ experience of emotional breakdown and trauma during the early stage of the diagnosis. FCGs described the diagnosis as “nightmare” or “thunderstorm” [Blogger 1]. Blogger 10 recalled “I couldn’t accept the reality and felt it was the work of the devil.” Blogger 17 wrote, “Even after 47 days, I still couldn’t accept the reality.”

Reflection upon causes of leukemia. To gain a deeper understanding of the health status of their loved ones and improve their prevention and management efforts, FCGs tended to self-examine the possible causes of leukemia. Relentless in their pursuit of the possible causes, many FCGs listed a series of factors, including the newly renovated houses, new furniture, water supplies, plush toys, green plants and flowers, food, nail polish, hair dye and X-ray, but still had no idea. As Blogger 15 described, “We didn’t live in a new house after the birth of my elder son, so it was not due to formaldehyde or the alike. But I still have no idea, so I really don’t know why it is my son.” Blogger 23 even blamed herself, “Which step was not done properly, making you get infected?” A handful of FCGs managed to identify gene mutation as the exact cause after consulting with the physicians. For example, Blogger 1, a family caregiver of a patient with Acute Lymphoblastic Leukemia Type B, attributed the condition to “mutation in E2A-pBX1 gene.”

Acceptance of the reality. FCGs, regardless of their knowledge of leukemia causes, eventually experienced a shift in their mindset from resistance to acceptance of the harsh reality. As Blogger 3 said, “though it was like a dream, I had to accept the fact.” Blogger 29 mentioned, “The initial sorrow and anger turned into acceptance of the fact, and we tried to persuade each other that everything would be fine!” Blogger 6 embraced the reality without resentment, “I become more open to communicate with fellow

Table 3 Demographic characteristics of patients with leukemia.

| | Patients with leukemia (n = 32) |
|-----------------------------------|---------------------------------|
| Gender | |
| Male | 22 |
| Female | 10 |
| Location | |
| China | 31 |
| Japan | 1 |
| Disease status | |
| Newly diagnosed | 28 |
| Relapsed | 4 |
| Age of first diagnosis | |
| <1 year old | 6 |
| 1-5 years old | 12 |
| 6-10 years old | 5 |
| Grown-ups | 5 |
| Not specified | 4 |
| Type of leukemia | |
| Acute lymphoblastic leukemia, ALL | 16 |
| Acute myelogenous leukemia, AML | 11 |
| Juvenile myelomonocytic leukemia, | 2 |
| JMML | |
| Not specified | 3 |

Table 4 Key themes and subthemes derived from family caregivers’ blogs.

| Themes | Subthemes |
|---|--|
| FCGs’ Reactions to the Leukemia Diagnosis | Failure to confront the reality of being diagnosed Reflection upon causes of leukemia Acceptance of the reality |
| Challenges Faced in Caregiving | Difficulties in seeking medical treatment Desperate shortage of support FCGs’ deteriorating health condition Adversities brought by COVID-19 pandemic Heavy financial burden Overwhelming psychological burden Pressure from multiple caregiving roles |
| Effective Coping Strategies | Efforts to reduce financial burden Efforts to reduce psychological burden Spiritual practice Cautious optimism about caring and life Proactively reporting needs and seeking support Support from family, friends and peers Humanistic care from healthcare providers Goodwill from strangers and cybercitizens |

patients in the ward, I believe it's a different way of approaching life.”

Theme 2: challenges faced in caregiving. The rapid acceptance of the diagnosis was closely intertwined with the prompt assumption of new responsibilities. FCGs took more proactive steps to assist their care recipients in managing and coordinating medical care. However, the journey of FCGs' caregiving life was marked with numerous trials and tribulations. Difficulties in seeking medical services, a desperate shortage of support, the deteriorating health condition of FCGs and the adversities brought by COVID-19 pandemic were persistent challenges for caregiving. In addition, FCGs also experienced excessive financial and psychological burdens and endured considerable pressure as a result of their numerous caregiving responsibilities throughout the course of leukemia.

Difficulties in seeking medical treatment. FCGs experienced untold and unparalleled hardships in seeking affordable medical treatment. The process of contacting the hospital was not smooth. “Good baby, I heard from the doctor that there were two rehabilitation hospitals in City H that would accept seriously ill babies. I contacted one of them, but it would not accept babies as young as you, and there was another one whose phone had been out of order” [Blogger 23]. On certain occasions, FCGs had to travel long distance for better treatment provided by hospitals with higher qualifications, as Blogger 32 related, “...luckily, I can still surf the Internet, ask around, and do my best to send you here! From City Z, to City J, from City J, to City L, and finally to the last stop for leukemia – Hospital Y.”

Consequently, referrals and transfers from one place to another were not rare. Seeking medical treatment in different locations had further compounded the problems of medical insurance reimbursement, as Blogger 11 articulated, “When I consulted medical insurance issue over the phone, I was asked to do out-of-pocket payment first and then go back to my home city for reimbursement. Not to say that the reimbursement amount in my home city will be less, but the point is that the waiting time is too long, at least two to three months. We have already spent 490,000 *yuan* (67,855 USD) on hospitalization, and we look forward to quicker reimbursement of this sum of money so as to pay for the ensuing treatment.”

Desperate shortage of support. A desperate lack of emotional and social support was observed from FCGs' online narratives. Some FCGs reported a lack of emotional support from family members because family members showed no concern. Feeling abandoned, FCGs told their tales of woes where there was a lack of communication and mutual understanding and they nursed grievance towards such indifference. “The elders of the family don't carenot a word of comfort, but they say it's none of their business...their attitude is breaking me down, and our wardmates are supported by their families, but we have to fight alone. When it comes to the so-called family it's really bitterly disappointing” [Blogger 12]. In some cases, in-laws of FCGs even tried to persuade FCGs to give up treatment, as Blogger 19 reported, “My child's grandparents didn't support for further treatment, my father-in-law said we couldn't let a child affect the life of their later years.” A lack of support from the patient's school was also observed, as Blogger 24 remarked, “To treat my son, we lost all our fortune, and my child was suffering every day, but the school didn't show any concern, just talking about the procedures of withdrawal from school.”

FCGs' deteriorating health condition. Long-term caregiving required intensive and attentive nursing, bringing FCGs physical

pains, fatigue and sleep deprivation, which had worsened their physical health condition. Blogger 22 articulated how she was debilitated by the care recipient's suffering, “These days have been really tough. My kid has been throwing tantrums and crying, we had quite enough of this. My heart has been feeling uncomfortable for the past two days... my husband has let me go home to have a good rest. While sitting in the car, I suddenly felt a terrible pain in my chest.” Blogger 13 wrote how she suffered from insomnia, “Now it's 2:05 am, I've been holding you like this for three nights. On average, I can only manage to have about two hours of sleep in sporadic increments within a 24-h period. I'm already exhausted, on the verge of going crazy.”

Adversities brought by COVID-19 pandemic. The COVID-19 pandemic led to a shortage of medical resources, bringing unprecedentedly formidable challenges. As Blogger 15 wrote, “Because of the pandemic, there had been a blood bank shortage, causing a long delay for blood transfusion, but it couldn't be waited for a child who needed to be saved.” Blogger 11 shared the experience of how her husband managed to buy ice packs to reduce the patient's fever, “Ice packs were out of stock at hospital. Due to the pandemic, it was so difficult to buy ice packs that Papa went to three pharmacies to get only three.” During the pandemic, the paper report of nucleic acid within 48 h was required for hospitalization. FCGs stated that treatment thus became more time-consuming than ever before, leading to the results of “delaying the transplant” [Blogger 28] and “keeping families from reuniting” [Blogger 24].

Heavy financial burden. As the treatment course progressed, the medical expenses, including costs of examination, hospitalization, chemotherapy, transplantation, and out-of-town travel, became ever higher or even unaffordable for FCGs. Particularly, they noted that Caspofungin, Propecia, PICC membranes, and targeted drugs were self-funded and could not be reimbursed by health insurance. “The targeted drug is just launched in April this year, not yet included in the medical insurance, it's a self-funded drug, one dose for 70,000 *yuan* (9791 USD) and can only be taken for 21 days. My kid would take it for at least one year. Then, the drug alone would cost 1.2 million *yuan* (168,161 USD). Besides, if we calculate the expense on transplant rejection, maintenance treatment, intravenous immunoglobulin (IVIG) and multiple examinations, we would be homeless under considerable strain” [Blogger 17]. Pressure to raise money for medical bills had left FCGs and their families in straitened circumstances. Some of them even sold their fixed assets. Being almost penniless, Blogger 24 described her added stress, “every day I'm worrying about how to raise all the deposit, my only car is also sold... the large sum of money for transplant surgery has not been settled. Then, I consider loans, to get mortgage on the house, but the only house of mine has no real estate license, how should I settle the matter?”

Overwhelming psychological burden. Enduring persistent anxieties and struggling with mental conflicts, FCGs were overwhelmed by a variety of psychological burdens. FCGs were particularly concerned about the patient's physical health condition, including the ongoing fear of heightened infection risk, adverse physical reactions, intolerable pain, and leukemia relapse. On life-threatening situations, FCGs even dreaded their care recipients “would die someday” [Bloggers 7, 23, 27]. FCGs also worried about the psychological health of the patients. Meanwhile, FCGs hoped their care recipients could feel more comfortable so as to improve the quality of caregiving, but on the other hand, they considered to submit to the demanding treatment requirements which would render the patients uncomfortable: “When I see you becoming better, I desperately want to make every effort to give you better

treatment so that you can stay by my side, but when I see you in immense suffering, I would break down and want to make you suffer less” [Blogger 23]. FCGs expressed a growing concern about explicitly showing their suppressed negative emotions to others. As a result, FCGs opted to internally keep their sorrows hidden in order to protect others from distress. “Every day, I’m preoccupied with caring for her in the hospital...I just pretend to be relaxed when I chat with other patients, I’m constantly anxious about releasing negative feelings” [Blogger 11].

Pressure from multiple caregiving roles. In addition to work, FCGs noted that they juggled the family commitments of caring between the patients with leukemia and other family members. With intense caregiving responsibility, FCGs’ life became more stressful. Apart from taking care of the patient, Blogger 15 depicted, “Being overloaded, we have pressure to take care of aging parents, meanwhile, we have to live our own life, but we can never exhaust our family’s fortune.” Seventeen days after her younger son’s transplant, Blogger 24 recalled how anxious she was to go home to see her elder son, “I just wish for my baby to get better soon so that I can go back home to take care of your elder brother.” When other family members were diagnosed with refractory diseases, for example, uremia, cerebral infarction, bladder cancer, prostate cancer, high blood pressure, and heart disease, FCGs felt they were under considerable role strain. “We still don’t have enough money for transplant surgery.....Dad has uremia and can’t take care of himself, grandpa and grandma have cerebral infarction and can’t take care of themselves, either. You have misfortune and so do I, all the pressure is on me, what should I do?” [Blogger 32].

Theme 3: effective coping strategies. This theme captured how FCGs navigated the barriers and adapted to the strains to effectively cope with caregiving. They strove to reduce their financial and psychological burdens. Despite constant exposure to hardships, FCGs demonstrated resilience by adapting positively, expressing their specific needs and actively seeking support. Meanwhile, they also received social support from various sources.

Efforts to reduce financial burden. With rigor in their control of expenses on living and medicine, FCGs exerted themselves to the utmost to reduce financial burden. “To be honest, I seldom eat fruit now, the food price here is really high, so I’ll save whenever possible” [Blogger 11]. Quite a few FCGs revealed that they had purchased health insurance for their care recipients and this had remarkably alleviated their financial burden. As Blogger 28 described, “Had it not been for the commercial insurance purchased in January, we really wouldn’t have been able to approach leukemia in a calm mindset as a normal family! Anyhow, although my husband suffered from this disease, the combination of medical insurance, commercial insurance and critical illness compensation basically will not add too much to my own burden.” By means of communicating effectively with healthcare providers, FCGs endeavored to optimize options for treatment, contributing to saving medical expenses. On the 15th day after transplant, Blogger 24 wrote, “Yesterday, the number of cells just increased a little bit, so I contacted the doctor. After negotiation, I quickly completed the discharge procedures. By doing so, I could save the expense for one day.”

Efforts to reduce psychological burden. FCGs attempted to buffer the stress on psychological health on their own and with others’ assistance. Because of the pains brought by treatments, many young patients with leukemia were often crying in anguish, leading to FCGs’ emotional turmoil. Through cathartic

experiences, either writing these experiences in words and posting them online publicly or bursting into tears privately, FCGs felt themselves freed from the emotional burden. Turning negative feelings into words to share them online via the smartphone-based application *Red (Xiaohongshu)* was a common way to vent grievances, as Blogger 23 wrote in the blog, “But baby do you know, every day when you have gastrostomy and gas incision to change gauze, the pains are unbearable not just to you but also to me. I’m sorry, baby, when I was changing the gauze for you today, my emotions came to a head, I hid in the bathroom and turned the tap, burying my head into the running water, weeping bitter tears uncontrollably.” Communicating with others was reported to be an effective way to handle the emotional disruptions, from which FCGs found inner peace. “For these days in the hospital, I have already started to relieve. After talking to mothers of other patients here, I feel as if this disease is not as horrible as imagined” [Blogger 10].

Spiritual practice. Relying on spiritual practices such as maintaining religious beliefs, reflection on past and prospects for future, FCGs gained will power for further treatment. FCGs and their families often prayed to Buddha or other gods in temples, in the hope that their care recipients would be blessed with excellent health. “When I became energetic, I changed my name. In the temple, I was given the Dharma name C.Y., meaning ‘long and good’. I believe, to change the name is to change the fate. Mom will promise you, praying for your peace and health” [Blogger 17]. FCGs’ vivid recollections revived at the sight of familiar places or photos and possessions of patients with leukemia, which evoked the good times they spent together and brought them a joyful mood. Gazing at the photos taken before being diagnosed, Blogger 8 noted, “I really love you. I miss the scenes when I was busy cooking in the kitchen and you were waiting for me.” Sustaining a sense of hope, FCGs also looked forward to the promising future of care recipients, imagining the days “when you (the patient) would get well and come back home to have a reunion” [Blogger 5].

Cautious optimism about caring and life. Optimism was expressed by FCGs as actively learning nursing skills, finding the meaning of life through adversity and encouraging the care recipients. Inasmuch as patients with leukemia were exceedingly vulnerable to various infections, FCGs took extreme caution in caring with scrupulous attention to detail. The desire to enhance the quality of daily care stimulated FCGs’ motivation to acquire specialized knowledge of nursing and pharmacology regarding leukemia, which was obtained online, or gained from health professionals or wardmates. Blogger 23 wrote how she taught herself the nursing skills, “In the past two days, I also learned much about nursing skills of gastrostomy, tracheotomy tube and long-term bed-ridden care, I believe I’ll take good care of you.” Blogger 24 described how she meticulously attended to the patient’s diet based on the strict requirements of the hospital, “After transplant, I have a particular fear for my baby’s dietary issues. I’m more than careful in high-temperature sterilization of the bowls and chopsticks which will be brought to the hospital.”

FCGs also plucked up themselves in navigating the meaning of life from the bittersweetness of their caregiving experience. They believed everything would be fine if they took an optimistic outlook towards life. Blogger 4 emphasized the significance of optimism, “If parents have prolonged self-doubt, it will instead affect the child’s emotions ...and the effectiveness of the treatment. So, what parents need to do is have better self-management of their own emotions, and live a positive life.” FCGs not only nerved themselves to live positively but also encouraged the care recipients to persevere in grappling with

leukemia. Blogger 9 expressed her encouragement to her care recipient, “Baby, you are cherished by so many people, hang in there!”

Proactively reporting needs and seeking support. With various difficulties and excessive burdens, a sense of helplessness was often expressed by FCGs when delivering care due to their limited knowledge of therapeutic techniques and their inability to plan or make informed decisions. FCGs wrote about the challenges regarding the knowledge and sought support to address their needs. Primarily, they reported informational needs about treatment, including information of transplant, nursing, cross-province treatment, chemotherapy, and prevention for infection. They often sought medical advice from their blog readers. For example, Blogger 5 asked other blog users for advice of methods to lower a fever, “During myelosuppression period, it’s impossible to avoid fever or diarrhea. After medication, there’s no sign of the fever going down. It’s difficult for me to let such a little baby take montmorillonite powder. Do other mommies have any brilliant ideas?” FCGs also expressed emotional needs. “I’m too sentimental and fragile. I hope I could have a shoulder to lean on” [Blogger 1]. In an effort to relieve the financial burden, FCGs often posted their fund-raising needs via social networks, including smartphone applications like *Red (Xiaohongshu)*, *WeChat*, *Alipay*, and fund-raising platforms such as *Shuidichou* and Red Cross. “I put the donation channel on the top of my homepage. Thank you all for a small favor for saving such an ordinary life” [Blogger 8].

Support from family, friends and peers. The tireless efforts of FCGs played a crucial role in overcoming barriers and relieving stress. In addition, seeking financial, emotional, and technical support from wider social context proved to be a significant contributing factor in overcoming these challenges. FCGs received support from various sources, including family members, friends, peers, health care professionals, strangers, and cybercitizens.

FCGs’ family members shared the burden of caregiving, preparing and delivering meals, purchasing drugs, and providing assistance in moving things around between home and hospital. Often, family members took turns to attend to the patients. Some even stopped work temporarily to share the caregiving responsibility. Many FCGs received financial support primarily from their parents or parents-in-law. “My father-in-law has always put me at ease. I fight against the disease in the frontline together with my partner and my father-in-law would provide funding for us” [Blogger 31]. Emotionally, FCGs were backed up by their spouses or partners via mutual understanding and support, as Blogger 14 related, “The sadness in my heart defies description. As a mom, my husband and I rely on mutual encouragement and support.”

Friends and peers were the source of emotional support as well. Blogger 23 described how she was heartened by the cheerful words of one wardmate, “She said to me, you should have the conviction that your baby will be fine. Because of the special bond between mother and child, as long as you have the conviction, he’ll definitely be fine.”

Humanistic care from healthcare providers. Out of compassion, by offering humanistic care, many healthcare providers would make things easier for both patients and FCGs whenever possible. According to FCGs, physicians “helped to reach out to rehabilitation hospitals and gave advice on rehabilitation” [Blogger 23], and “helped to reserve beds when healthcare resources were limited” [Blogger 21]. FCGs also received technical support from nurses who sacrificed their own breaks to teach skills about nursing. “The nurse said she would teach me some nursing skills

tomorrow when she could’ve been off from work and she also told me to contact her if I had any questions after transferal” [Blogger 23]. The succor healthcare professionals offered was not limited to technical support, but also encouraging words and comforts. “The doctor said to other doctors, ‘But I really hope he’ll get better soon’. Before I showed my gratitude, I’d already been moved to tears welling up” [Blogger 23]. Blogger 7 described how she was encouraged by the consolation of a physician, “It turned out to be a relapse of leukemia, and I was just dumbfounded, I kept asking the doctor the reason of relapse to see if I hadn’t taken good care of my kid. I really blamed myself. Then, I was comforted by the doctor and I was able to pick myself up again.”

Goodwill from strangers and cybercitizens. Some strangers and cybercitizens offered timely help to treat the disease. FCGs often felt moved or touched by these people’s charitable deeds such as rendering free goods or services. Blogger 3 received “benefit of free cleaning offered by housekeeping personnel.” Blogger 1 reported “receiving a discount of the grocery offered by a vendor.” Blogger 11 shared the experience of being helped by staff from furniture removal carriers, “After moving, he helped us to search for house till late at night. We wanted to pay him higher service fee but was declined. I was so touched.” FCGs also felt indebted to financial support offered by other blog users. “Quite a few mothers added me as a contact on the app *Red* to make donations” [Blogger 8].

Discussion

In this study, we make a significant contribution to the existing body of knowledge by employing qualitative thematic analysis of unsolicited online narratives. This approach allows for a detailed examination of the nuanced experience encountered by family caregivers of both adult and pediatric persons with leukemia. Our qualitative analysis highlights the diversity of family caregivers’ perspectives, capturing the complexity of family caregiving for patients with leukemia.

It is found that in the initial stage of their caregiving journey, FCGs often struggled to confront the reality of their care recipients’ initial diagnosis, and it was the same with FCGs who had experienced their care recipients’ leukemia relapse. This news could bring about severe emotional shock for FCGs. The initial devastation found in our study corroborates the results that the news of being diagnosed with leukemia can be a difficult and traumatic experience for family caregivers (Peterson et al., 2020; M. Wang et al., 2022; M. Wilson et al., 2009). This is due to the life-threatening nature of leukemia (Bozo et al., 2010). Notably, our study has made an important distinction from prior research by highlighting a unique aspect of FCGs’ initial response to the leukemia diagnosis. We have identified that FCGs also contemplated the potential causes of leukemia. Their eagerness to understand the exact causes of leukemia may arise from their concerns regarding future disease management, preventive awareness and genetic counseling, and even family planning considerations among young parent bloggers. These findings have implications for designing effective educational interventions that provide information about the causes of leukemia.

The heavy financial burden reported by FCGs of patients with leukemia found in this study is consistent with findings from prior studies (Arab et al., 2020; Grover et al., 2019; Yucel et al., 2021; Zeidan et al., 2016). Patients with leukemia need prolonged treatment and intensive care, leading to frequent hospitalizations that further increase the burden faced by families, potentially disrupting the overall family equilibrium (Panganiban-Corales and Medina, 2011; Perricone et al., 2012). As the results show,

out-of-pocket (OOP) medicines also placed an undue burden on families, which aligns with the finding from previous research that the share of OOPs still accounts for more than 30% of total health expenditure (Mao et al., 2017). In China, the drugs required to increase the survival rates of patients with leukemia are frequently imported and necessitate long-term usage. However, these medications are not covered by medical insurance (Kong et al., 2022). Low reimbursement rates and coverage further increased OOP expenses for caregivers, substantiating the conclusions drawn from previous research (Zhang and Zhang, 2022). It is our expectation that the government will exert more efforts to provide significant contribution to reducing the OOP medical payments for patients with leukemia.

Another significant finding pertains to the inconvenience caused by the interregional medical insurance reimbursement. Obstacles such as reduced reimbursement rates, ineligibility for immediate reimbursement, and prolonged waiting time as a result of cross-regional reimbursement hindered medical efficiency for patients with leukemia, which aligns with the finding of a previous study (Zhan et al., 2022). The establishment of instant reimbursement mechanism for cross-regional medical services occurred gradually between 2009 and 2014 (Zhang and Zhang, 2022). It is worth noting that due to variations in healthcare insurance systems across different regions in China, when an individual participates in medical insurance in one province but seeks medical services in another, it necessitates interregional medical insurance reimbursement. This process entails coordination and information sharing between different regions and encompasses two aspects: (1) reimbursement for hospitalization expenses in a different province, and (2) reimbursement for outpatient expenses in a different province. Families of patients with leukemia often travel considerable distance across various regions in search of better medical services. However, the procedures involved in interregional medical insurance reimbursement can be relatively complex and time-consuming, especially for patients with leukemia who require prolonged care. Previous research has found that immediate reimbursement significantly increases the likelihood of patients seeking outpatient treatment in China (Zhong, 2011). Therefore, simplifying procedures and improving the efficiency of interregional medical insurance reimbursement are vital for enhancing the rate of health service utilization by patients with leukemia who seek cross-regional healthcare. These efforts aim to improve treatment outcomes for these individuals.

FCGs were found to have experienced tremendous psychological stress, which aligns with findings from previous investigations into the emotional experiences of family caregivers of patients with leukemia (Dionne-Odom et al. 2019; Malpert et al., 2015; Sannes et al., 2019). The immense psychological pressure has adverse effects on the physical health of FCGs (M. Wang et al., 2022), thereby affecting their overall quality of life (Malpert et al., 2015; Yu et al., 2017). The demanding nature of caregiving tasks further contributes to the psychological burden that FCGs bear. In addition to the physical challenges, FCGs also experienced distress while witnessing the patients' physical suffering, especially during bone marrow transplant surgeries. This often led to increased stress, depression, and burnout among family caregivers, which confirms an earlier study suggesting caregiving can be particularly intense during hematopoietic stem cell transplantation, with FCGs assuming many responsibilities to take on a variety of medical tasks and struggling to adapt their schedules to the patient's care needs (Dionne-Odom et al., 2019). Although psychological distress was commonly observed in previous research (Pailler et al., 2015; Peterson et al., 2020), our investigation draws attention to an underappreciated aspect of FCGs' mental struggle: self-denial of overt displaying emotions.

This indicates their compassion and considerations of maintaining harmonious family relationships even in times of crisis. This finding highlights the importance of knowing about the impact of FCGs' emotion on family system, contributing to future interventions on providing better psycho-social care.

The research findings indicate that FCGs not only experienced psychological burden but also faced role strain, which has been consistently reported in prior studies on family caregiving for cancer patients (Cooke et al., 2011; Eldredge et al., 2006; Muriuki et al., 2023). FCGs prioritized the various needs of patients over their own ambitions and aspirations to ensure adequate care. We deem that FCGs' perception of their caregiving roles that they would sacrifice their own goals for the sake of their care recipients' needs, is influenced by traditional Chinese family culture. In this culture, self-sacrifice for betterment of family members is regarded as a crucial aspect of filial piety. Filial piety is highly praised and inherited as a fundamental moral precept that remains profoundly ingrained in Confucianism (Yiu et al., 2021).

Furthermore, the findings highlight that FCGs actively engaged in efforts to reduce financial and psychological burdens, keeping a positive attitude towards caregiving and seeking assistance from others. These coping strategies align with previous studies that have reported positive coping mechanisms among family caregivers (Albrecht et al., 2022; Jacobs et al., 2020; M. Wang et al., 2022; M. Wilson et al., 2009). Our research also presents unique ways of effective coping mechanisms. For instance, FCGs' proactive engagement in active communication with healthcare providers resulted in reduced medical payments; FCGs' tireless efforts in acquiring medical knowledge played a crucial role in reducing their sense of helplessness; practices like writing and shedding tears served as avenues for catharsis, providing solace for FCGs and relieving their psychological stress to a certain extent. Our findings on FCGs' positive coping strategies to relieve their emotional burden differ from a study conducted in the US, which identified maladaptive strategies such as overeating or self-medication with psychoactive substances to provide comfort (Albrecht et al., 2022). We postulate that the underlying reason for the distinctions of the findings can be associated with Chinese traditional social values that emphasize self-esteem and self-respect.

Among the various sources of support, the primary source identified in this study was family, friends and peers, which is consistent with prior research (Bozo et al., 2010; Dionne-Odom et al., 2019). However, what distinguishes this study is the observation of the support from strangers and cybercitizens, which is less commonly seen in prior research on family caregiving for patients with leukemia. We believe that this can be attributed to the blogger identity of the FCGs. By writing blogs and interacting with their readers, they were able to receive financial and psychological support online. Our research brings attention to a particular dimension that is important yet underexamined in China: peer support. As the findings show, FCGs were encouraged by the emotional support from their wardmates who had similar experience of caregiving. By virtue of sharing firsthand information, peers offer FCGs health advantages such as increased psychological well-being and enhanced coping, promoting hope and adjustment (Sannes et al., 2019; Yu et al., 2017). One-on-one volunteer peer supporting delivered in one recent study conducted in Denmark (Husted Nielsen et al., 2022) has been proved to be a feasible and safe intervention with high satisfaction. We believe it is essential to explore and adapt this successful peer support model in Chinese context.

FCGs of this study reported they received humanistic care from healthcare providers, which supports the finding from prior studies highlighting the support provided by formal healthcare providers to informal caregivers in order to relieve their

psychological burden (Laudenslager et al., 2015, 2019). It is crucial to recognize that FCGs' caregiving experience affects the entire family system rather than solely the patient with leukemia. Although the family has been considered as the optimal source of care for patients with leukemia (Karimjejad et al., 2021), relying solely on the family members is insufficient. Formal care providers, who are strangers but possess authority, serve as an extension of the caregiving system (Waldrop, 2006). Enhanced care coordination is crucial and family caregivers highly appreciate continuous connections with healthcare professionals (Harrison et al., 2022). Therefore, it is necessary for the leukemia clinicians to understand the impact on the family system. This requires effective communication between families and healthcare professionals to address FCGs' unmet needs, easing their sufferings.

Although FCGs' positive adaptation and the social support they received have reduced their financial and psychological burdens to a certain extent, they still face challenges (Schulz et al., 2018). Therefore, it is essential for policy makers and healthcare organizations to gain a comprehensive understanding of these FCGs and to formulate interventions and support programs that can effectively alleviate their stress levels and improve their overall well-being.

Implications

Blogs play a pivotal role in enhancing our comprehension of the impact of leukemia on patients and family caregivers. The findings in this study can be effectively implemented in real-world scenarios by adopting a comprehensive and multi-faceted approach. The intractable economic challenges, surrounding high medical costs and the inefficient cross-regional medical reimbursement system, hold significant importance in guiding future healthcare institutions and policymakers towards enacting impactful and efficient medical reforms. It is important to advocate for financial assistance measures, such as reducing out-of-pocket medical payments and establishing caregiver-friendly policies, in order to alleviate the economic burdens faced by patients and caregivers. Additionally, incorporating family caregiver assessments into standard healthcare practices is recommended to identify and address their specific needs and challenges. The expressed anxieties and pressure faced by family caregivers have practical implications for implementation of effective psychological support, including targeted psychological counseling and relief services aimed at enhancing coping skills and resilience among family caregivers. The wide range of support sources received by FCGs highlights the need for future research on effective communication between informal and formal caregivers. Healthcare providers are encouraged to engage with bloggers of FCGs through blogs as a means of online communication. This facilitates improved health literacy, empowers them to make personalized treatment decisions and predict care recipient outcomes. Online blogs can also offer education and training programs for FCGs and their families to increase awareness and understanding of the trajectory of leukemia. By implementing these strategies, healthcare systems and policymakers can effectively support the well-being of family caregivers and improve the overall quality of care provided to patients with leukemia.

Strengths and limitations

Like all methods of qualitative social research, blogs as data have both benefits and pitfalls. Illness blogging provides an innovative and valuable method of documenting the authentic experience of family caregiving. This research utilized naturalistic data, which included the unfiltered, in-depth experiences of family caregivers of patients with leukemia. A rich investigation of delicate matters

of this vulnerable group is made possible by the perceived anonymity of the Internet, which permits family caregivers to freely and openly communicate their emotions and thoughts that may be sensitive and challenging to share in clinical settings. The in-depth exploration of online blogs using thematic analysis has generated understanding of the plights and challenges faced by family caregivers of patients with leukemia and how they employed effective coping strategies to resolve those problems.

Limitations to this study should also be noted. Only Chinese family caregivers were included, which would limit the scope of this study and leave out some significant global nuances of family caregivers' perspectives towards caregiving for patients with leukemia. Furthermore, the data were extracted from only one social networking mobile application. Meanwhile, a set of key words used to identify an eligible sample of blog narratives in data collection may make it possible that some blogs and some issues pertinent to family caregiving for patients with leukemia would have gone unnoticed. The low diversity in participants (only one man) and some missing demographic information not presented by the bloggers were another limitation of the study. These factors limit the generalizability and transferability of the present study's findings.

Conclusion

This qualitative study employed a thematic approach to explore the experiences shared in online blogs by Chinese family caregivers of patients with leukemia. The findings indicate that despite the financial and psychological burdens they faced, family caregivers coped with the challenges positively with their own endeavors and social support from others. The process of coping and psychological adaptation for caregivers was complex, as FCGs grappled with various concerns regarding the overall family system. This research highlights the need for the healthcare system reforms as well as a deeper understanding of the functioning of informal caregivers in order to address their needs. It also calls upon healthcare professionals to offer appropriate support. Further studies in this field should systematically examine the development of interventions for informal caregiving, with the aim of enhancing healthcare outcomes for family caregivers and ultimately improving the quality of life for patients with leukemia.

Data availability

Datasets were derived from public resources. The data of the study were extracted from the mobile phone application *Red (Xiaohongshu)* accounts identified as Chinese family caregivers of patients with leukemia.

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References

- Albrecht TA, Hoppe R, Winter MA (2022) How caregivers cope and adapt when a family member is diagnosed with a hematologic malignancy: informing supportive care needs. *Cancer Nurs* 45(6):E849–E855. <https://doi.org/10.1097/NCC.0000000000001063>
- Anderson J, Eppes A, O'Dwyer S (2019) "Like death is near": expressions of suicidal and homicidal ideation in the blog posts of family caregivers of people with dementia. *Behav Sci* 9(3):22. <https://doi.org/10.3390/bs9030022>
- Anderson JG, Hundt E, Dean M, Keim-Malpass J, Lopez RP (2017) "The church of online support": examining the use of blogs among family caregivers of persons with dementia. *J Fam Nurs* 23(1):34–54. <https://doi.org/10.1177/1074840716681289>
- Arab M, Bernstein C, Haghshenas A, Ranjbar H (2020) Factors associated with caregiver burden for mothers of children undergoing Acute Lymphocytic

- Leukemia (ALL) treatment. *Palliat Support Care* 18(4):405–412. <https://doi.org/10.1017/S1478951519000853>
- Bozo Ö, Anahar S, Ateş G, Etel E (2010) Effects of illness representation, perceived quality of information provided by the health-care professional, and perceived social support on depressive symptoms of the caregivers of children with leukemia. *J Clin Psychol Med Settings* 17(1):23–30. <https://doi.org/10.1007/s10880-009-9177-4>
- Braun V, Clarke V (2006) Using thematic analysis in psychology. *Qual Res Psychol* 3(2):77–101. <https://doi.org/10.1191/1478088706qp0630a>
- Braun V, Clarke V (2022) Thematic analysis: a practical guide. Sage, Los Angeles
- Braun V, Clarke V, Rance N (2014) How to use thematic analysis with interview data. In: Vossler A, Moller N (eds) *The counselling and psychotherapy research handbook*. Sage, London, p 183–197
- Bray F, Ferlay J, Soerjomataram I, Siegel RL, Torre LA, Jemal A (2018) Global cancer statistics 2018: GLOBOCAN estimates of incidence and mortality worldwide for 36 cancers in 185 countries *CA Cancer J Clin* 68(6):394–424. <https://doi.org/10.3322/caac.21492>
- Bruckman A (2002) Studying the amateur artist: a perspective on disguising data collected in human subjects research on the Internet. *Ethics Inf Technol* 4(3):217–231. <https://doi.org/10.1023/A:1021316409277>
- Clarke V, Braun V (2018) Using thematic analysis in counselling and psychotherapy research: a critical reflection. *Couns Psychother Res* 18(2):107–110. <https://doi.org/10.1002/capr.12165>
- Cooke L, Grant M, Eldredge DH, Maziarz RT, Nail LM (2011) Informal caregiving in hematopoietic blood and marrow transplant patients. *Eur J Oncol Nurs* 15(5):500–507. <https://doi.org/10.1016/j.ejon.2011.01.007>
- Deshields TL, Heiland MF, Kracen AC, Dua P (2016) Resilience in adults with cancer: development of a conceptual model. *Psychooncology* 25(1):11–18. <https://doi.org/10.1002/pon.3800>
- Dionne-Odom JN, Currie ER, Johnston EE, Rosenberg AR (2019) Supporting family caregivers of adult and pediatric persons with leukemia. *Semin Oncol Nurs* 35(6):150954. <https://doi.org/10.1016/j.soncn.2019.150954>
- Eldredge DH, Nail LM, Maziarz RT, Hansen LK, Ewing D, Archbold PG (2006) Explaining family caregiver role strain following autologous blood and marrow transplantation. *J Psychosoc Oncol* 24(3):53–74. https://doi.org/10.1300/J077v24n03_03
- Ge C, Yang X, Fu J, Chang Y, Wei J, Zhang F, Nutifafa AE, Wang L (2011) Reliability and validity of the Chinese version of the caregiver reaction assessment. *Psychiatry Clin Neurosci* 65(3):254–263. <https://doi.org/10.1111/j.1440-1819.2011.02200.x>
- Grover S, Rina K, Malhotra P, Khadwal A (2019) Caregiver burden in the patients of acute myeloblastic leukemia. *Indian J Hematol Blood Transfus* 35(3):437–445. <https://doi.org/10.1007/s12288-018-1048-4>
- Harrison M, Darlison L, Gardiner C (2022) Understanding the experiences of end of life care for patients with mesothelioma from the perspective of bereaved family caregivers in the UK: a qualitative analysis. *J Palliat Care* 37(2):197–203. <https://doi.org/10.1177/08258597221079235>
- Heilferty CM (2009) Toward a theory of online communication in illness: concept analysis of illness blogs. *J Adv Nurs* 65(7):1539–1547. <https://doi.org/10.1111/j.1365-2648.2009.04996.x>
- Hookway N (2008) ‘Entering the blogosphere’: some strategies for using blogs in social research. *Qual Res* 8(1):91–113. <https://doi.org/10.1177/1468794107085298>
- Hookway N, Snee H (2017) The blogosphere. In: Fielding NG, Lee RM, Blank G (eds) *The sage handbook of online research methods*, 2nd edn. Sage, London, p 380–398
- Houghton C, Casey D, Shaw D, Murphy K (2013) Rigour in qualitative case-study research. *Nurse Res* 20(4):12–17. <https://doi.org/10.7748/nr2013.03.20.4.12.e326>
- Husted Nielsen I, Piil K, Tolver A, Grønbaek K, Kjeldsen L, Jarden M (2022) Family caregiver ambassador support for caregivers of patients with newly diagnosed hematological cancer: a feasibility study. *Support Care Cancer* 30(8):6923–6935. <https://doi.org/10.1007/s00520-022-07089-0>
- Jacobs JM, Nelson AM, Traeger L, Waldman L, Nicholson S, Jagielo AD, D’Alotto J, Greer JA, Temel JS, El-Jawahri A (2020) Enhanced coping and self-efficacy in caregivers of stem cell transplant recipients: identifying mechanisms of a multimodal psychosocial intervention. *Cancer* 126(24):5337–5346. <https://doi.org/10.1002/cncr.33191>
- Jia M, Li J, Chen C, Cao F (2015) Post-traumatic stress disorder symptoms in family caregivers of adult patients with acute leukemia from a dyadic perspective. *Psychooncology* 24(12):1754–1760. <https://doi.org/10.1002/pon.3851>
- Kannaley K, Mehta S, Yelton B, Friedman DB (2019) Thematic analysis of blog narratives written by people with Alzheimer’s disease and other dementias and care partners. *Dementia* 18(7–8):3071–3090. <https://doi.org/10.1177/1471301218768162>
- Karimjejad H, Ghaljaei F, Kiani F (2021) The effect of education training intervention on the caregiver burden among mothers of children with leukemia: a quasi-experimental study. *Oncol Clin Pr* 17(5):194–199. <https://doi.org/10.5603/OCP.2021.0018>
- Kiyimba N, Lester JN, O’Reilly M (2019) Using naturally occurring data in qualitative health research: a practical guide. Springer International Publishing, Cham
- Kong H, Chang S, Jin Y, Xing Y, Wang Y, Kou J (2022) Research progress on family caregiver burden of children with leukemia. *Chin Gen Pr Nurs* 20(18):2475–2478
- Laudenslager ML, Simoneau TL, Kilbourn K, Natvig C, Philips S, Spradley J, Benitez P, McSweeney P, Mikulich-Gilbertson SK (2015) A randomized control trial of a psychosocial intervention for caregivers of allogeneic hematopoietic stem cell transplant patients: effects on distress. *Bone Marrow Transpl* 50(8):1110–1118. <https://doi.org/10.1038/bmt.2015.104>
- Laudenslager ML, Simoneau TL, Mikulich-Gilbertson SK, Natvig C, Brewer BW, Sannes TS, Kilbourn K, Gutman J, McSweeney P (2019) A randomized control trial of stress management for caregivers of stem cell transplant patients: effect on patient quality of life and caregiver distress. *Psychooncology* 28(8):1614–1623. <https://doi.org/10.1002/pon.5126>
- Li L, Liu C, Cai X, Yu H, Zeng X, Sui M, Zheng E, Li Y, Xu J, Zhou J, Huang W (2019) Validity and reliability of the EQ-5D-5L in family caregivers of leukemia patients. *BMC Cancer* 19(1):522. <https://doi.org/10.1186/s12885-019-5721-2>
- Lincoln YS, Guba EG (1985) *Naturalistic inquiry*. Sage Publications, Beverly Hills, Calif
- Malpert AV, Kimberg C, Luxton J, Mullins LL, Pui C-H, Hudson MM, Krull KR, Brinkman TM (2015) Emotional distress in parents of long-term survivors of childhood acute lymphoblastic leukemia. *Psychooncology* 24(9):1116–1123. <https://doi.org/10.1002/pon.3732>
- Mao W, Tang S, Zhu Y, Xie Z, Chen W (2017) Financial burden of healthcare for cancer patients with social medical insurance: a multi-centered study in urban China. *Int J Equity Health* 16(1):180. <https://doi.org/10.1186/s12939-017-0675-y>
- McLennon SM, Davis A, Covington S, Anderson JG (2021) “At the end we feel forgotten”: needs, concerns, and advice from blogs of dementia family caregivers. *Clin Nurs Res* 30(1):82–88. <https://doi.org/10.1177/1054773819865871>
- Morrow SL (2005) Quality and trustworthiness in qualitative research in counselling psychology. *J Couns Psychol* 52(2):250–260. <https://doi.org/10.1037/0022-0167.52.2.250>
- Muriuki MM, Oluchina S, Mbithi BW (2023) Assessment of role strain among family caregivers of adult patients with cancer at a national referral hospital in Kenya. *Psychooncology* 32(1):42–46. <https://doi.org/10.1002/pon.5868>
- National Cancer Institute (2019) Survivorship. <https://www.cancer.gov/publications/dictionaries/cancer-terms/def/survivorship>. Accessed 7 Aug 2022
- Nowell LS, Norris JM, White DE, Moules NJ (2017) Thematic analysis: striving to meet the trustworthiness criteria. *Int J Qual Methods* 16(1):1–13. <https://doi.org/10.1177/1609406917733847>
- Pailler ME, Johnson TM, Zevon MA, Kuszczak S, Griffiths E, Thompson J, Wang ES, Wetzler M (2015) Acceptability, feasibility, and efficacy of a supportive group intervention for caregivers of newly diagnosed leukemia patients. *J Psychosoc Oncol* 33(2):163–177. <https://doi.org/10.1080/07347332.2014.992086>
- Panganiban-Corales AT, Medina MF (2011) Family resources study: part I: family resources, family function and caregiver strain in childhood cancer. *Asia Pac Fam Med* 10(1):14. <https://doi.org/10.1186/1447-056X-10-14>
- Papastavrou E, Charalambous A, Tsangari H (2012) How do informal caregivers of patients with cancer cope: a descriptive study of the coping strategies employed. *Eur J Oncol Nurs* 16(3):258–263. <https://doi.org/10.1016/j.ejon.2011.06.001>
- Perricone G, Polizzi C, Morales MR, Marino S, Scacco CF (2012) Functioning of family system in pediatric oncology during treatment phase. *Pediatr Hematol Oncol* 29(7):652–662. <https://doi.org/10.3109/08880018.2012.695439>
- Peterson RK, Chung J, Barrera M (2020) Emotional symptoms and family functioning in caregivers of children with newly diagnosed leukemia/lymphomas and solid tumors: short-term changes and related demographic factors. *Pediatr Blood Cancer* 67(2):e28059. <https://doi.org/10.1002/psc.28059>
- Sannes TS, Simoneau TL, Mikulich-Gilbertson SK, Natvig CL, Brewer BW, Kilbourn K, Laudenslager ML (2019) Distress and quality of life in patient and caregiver dyads facing stem cell transplant: identifying overlap and unique contributions. *Support Care Cancer* 27(6):2329–2337. <https://doi.org/10.1007/s00520-018-4496-3>
- Schulz R, Beach SR, Friedman EM, Martzolf GR, Rodakowski J, James AE (2018) Changing structures and processes to support family caregivers of seriously ill patients. *J Palliat Med* 21(S2):S-36–S-42. <https://doi.org/10.1089/jpm.2017.0437>

- Shah SGS, Robinson I (2011) Patients' perspectives on self-testing of oral anticoagulation therapy: content analysis of patients' internet blogs. *BMC Health Serv Res* 11(1):25. <https://doi.org/10.1186/1472-6963-11-25>
- Sung H, Ferlay J, Siegel RL, Laversanne M, Soerjomataram I, Jemal A, Bray F (2021) Global cancer statistics 2020: GLOBOCAN estimates of incidence and mortality worldwide for 36 cancers in 185 countries. *CA Cancer J Clin* 71(3):209–249. <https://doi.org/10.3322/caac.21660>
- Tang Y-Y, Chen S-P (2002) Health promotion behaviors in Chinese family caregivers of patients with stroke. *Health Promot Int* 17(4):329–339. <https://doi.org/10.1093/heapro/17.4.329>
- Waldrop DP (2006) Caregiving systems at the end of life: how informal caregivers and formal providers collaborate. *Fam Soc J Contemp Soc Serv* 87(3):427–437. <https://doi.org/10.1606/1044-3894.3548>
- Wang C, Yan J, Chen J, Wang Y, Lin YC, Hu R, Wu Y (2020) Factors associated with quality of life of adult patients with acute leukemia and their family caregivers in China: a cross-sectional study. *Health Qual Life Outcomes* 18(1):8. <https://doi.org/10.1186/s12955-020-1269-8>
- Wang H, Naghavi M, Allen C, Barber RM, Bhutta ZA, Carter A, Casey DC, Charlson FJ, Chen AZ, Coates MM, Coggeshall M, Dandona L, Dicker DJ, Erskine HE, Ferrari AJ, Fitzmaurice C, Foreman K, Forouzanfar MH, Fraser MS, Murray CJL (2016) Global, regional, and national life expectancy, all-cause mortality, and cause-specific mortality for 249 causes of death, 1980–2015: a systematic analysis for the Global Burden of Disease Study 2015. *Lancet* 388(10053):1459–1544. [https://doi.org/10.1016/S0140-6736\(16\)31012-1](https://doi.org/10.1016/S0140-6736(16)31012-1)
- Wang M, Chang M, Cheng M, Zhang R (2022) The psychological adaptation process in Chinese parent caregivers of pediatric leukemia patients: a qualitative analysis. *Cancer Nurs* 45(5):E835–E842. <https://doi.org/10.1097/NCC.0000000000001034>
- Wang Y, Yan J, Chen J, Wang C, Lin Y, Wu Y, Hu R (2021) Comparison of the anxiety, depression and their relationship to quality of life among adult acute leukemia patients and their family caregivers: a cross-sectional study in China. *Qual Life Res* 30(7):1891–1901. <https://doi.org/10.1007/s11136-021-02785-6>
- Wilson E, Kenny A, Dickson-Swift V (2015) Using blogs as a qualitative health research tool: a scoping review. *Int J Qual Methods* 14(5):160940691561804. <https://doi.org/10.1177/1609406915618049>
- Wilson ME, Eilers J, Heermann JA, Million R (2009) The experience of spouses as informal caregivers for recipients of hematopoietic stem cell transplants. *Cancer Nurs* 32(3):E15–E23. <https://doi.org/10.1097/NCC.0b013e31819962e0>
- Yiu HC, Zang Y, Chew JHS, Chau JPC (2021) The influence of Confucianism on the perceptions and process of caring among family caregivers of persons with dementia: a qualitative study. *J Transcult Nurs* 32(2):153–160. <https://doi.org/10.1177/1043659620905891>
- Yu H, Li L, Liu C, Huang W, Zhou J, Fu W, Ma Y, Li S, Chang Y, Liu G, Wu Q (2017) Factors associated with the quality of life of family caregivers for leukemia patients in China. *Health Qual Life Outcomes* 15(1):55. <https://doi.org/10.1186/s12955-017-0628-6>
- Yu H, Zhang H, Yang J, Liu C, Lu C, Yang H, Huang W, Zhou J, Fu W, Shi L, Yan Y, Liu G, Li L (2018) Health utility scores of family caregivers for leukemia patients measured by EQ-5D-3L: a cross-sectional survey in China. *BMC Cancer* 18(1):950. <https://doi.org/10.1186/s12885-018-4855-y>
- Yucel E, Zhang S, Panjabi S (2021) Health-related and economic burden among family caregivers of patients with acute myeloid leukemia or hematological malignancies. *Adv Ther* 38(10):5002–5024. <https://doi.org/10.1007/s12325-021-01872-x>
- Zeidan AM, Mahmoud D, Kucmin-Bemelms IT, Alleman CJ, Hensen M, Skikne B, Smith BD (2016) Economic burden associated with acute myeloid leukemia treatment. *Expert Rev Hematol* 9(1):79–89. <https://doi.org/10.1586/17474086.2016.1112735>
- Zhan C, Wu Z, Yang L, Yu L, Deng J, Luk K, Duan C, Zhang L (2022) Disparities in economic burden for children with leukemia insured by resident basic medical insurance: evidence from real-world data 2015–2019 in Guangdong, China. *BMC Health Serv Res* 22(1):229. <https://doi.org/10.1186/s12913-022-07564-8>
- Zhang X, Zhang L (2022) The impact of instant reimbursement of cross-regional medical services on hospitalization costs incurred by the floating population—evidence from China. *Healthcare* 10(6):1099. <https://doi.org/10.3390/healthcare10061099>
- Zhong H (2011) Effect of patient reimbursement method on health-care utilization: evidence from China. *Health Econ* 20(11):1312–1329. <https://doi.org/10.1002/hec.1670>

Author contributions

All authors made a significant contribution to the work reported, whether that is in the conception, study design, execution, acquisition of data, analysis and interpretation, or in all these areas; took part in drafting, revising or critically reviewing the article; gave final approval of the version to be published; have agreed on the journal to which the article has been submitted; and agree to be accountable for all aspects of the work.

Competing interests

The authors declare no competing interests.

Ethical approval

Ethical approval was not required as the study did not involve human participants.

Informed consent

In line with standard practice for analysis of online social media, informed consent from individual authors was deemed neither necessary nor practicable. Authors posted the blogs available under terms of service, which permit re-use by researchers for academic purposes. Blogs were collected and used in line with the terms of service. Data presentation has been anonymized to avoid linking particular authors to particular blogs.

Additional information

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