

Autobiographical Narrative and AI-Mediated Community Dialogue: A Participatory Study of Chinese Only-Child Cancer Caregivers

Keywords

practice-based research; participatory approach; community of practice; communication theory of resilience; autobiographical theory; AI companionship; only children; cancer care; filial piety

Abstract

This practice-based research investigates the predicament of Chinese only children caring for parents with cancer, a generation shaped by the one-child policy and burdened with sole filial and emotional responsibility. These caregivers often experience psychological exhaustion, isolation, and moral conflict while navigating end-of-life care. Although several digital storytelling and peer-support platforms have been developed in Western caregiving contexts, they primarily address dementia or chronic illness and remain culturally misaligned with Chinese caregiving grounded in filial piety and cancer-related uncertainty. In China, most online mutual-aid groups lack ethical guidance and sustained companionship, further intensifying caregivers' stress and misinformation.

This study proposes to explore AI's role as a co-participant in autobiographical narrative caregiving practices, examining how iterative dialogue and collective reflection among caregivers, AI, and the researcher can help co-define the boundaries, roles, and ethical frameworks of AI intervention, thereby making the process of framework creation itself a participatory practice.

1. Introduction

This research stems from my eighteen-year experience caring for my mother with breast cancer, during which I witnessed the profound solitude of Chinese only-child caregivers bearing full filial and emotional responsibilities. Rooted in a culture that discourages open dialogue about death, many caregivers internalize "forced resilience" while suppressing vulnerability, lacking spaces for reflection and shared meaning-making. My mother's passing in 2021 marked the completion of our shared journey of life education, transforming this lived experience into a research inquiry.

Drawing on my professional background as the lead designer of a million-user children's aesthetic education app, I began exploring how digital and dialogic approaches might foster empathy and resilience within caregiving communities. This shift from "caregiver and survivor" to "researcher and witness" marks my transition from personal experience to reflective practice, where technology and the humanities converge to examine the boundaries and ethical frameworks of AI's role in life pedagogy.

The participatory approach is ethically grounded: it seeks to prevent the research from being guided solely by my personal narrative, instead prioritizing co-created understanding through

shared voices and iterative dialogue. A preliminary hospice pilot using art-based co-creation tested the feasibility of participatory engagement, revealing that artistic expression can function simultaneously as data and intervention. However, it also underscored the need for more accessible and dialogic forms of participation to broaden caregiver involvement and critically examine how participatory methods themselves shape change. This need points to AI's potential as an inclusive and responsive medium that can foster trusted self-disclosure and timely support.

2. Research Background and Questions

2.1 Research Background

Affected by China's one-child policy (1979–2015), approximately 224.6 million only children (Li et al., 2018) have now reached middle age, while their parents, aged between 55 and 75, are entering a high-risk period for cancer—the disease with the world's highest incidence and mortality rates in China (Wild et al., 2020). This demographic shift has produced a generation known as the "sandwich generation," uniquely positioned between aging parents and their own children, and now central to the country's emerging caregiving crisis.

Across global contexts, cancer family caregivers face profound physical, psychological, and social challenges. As primary decision-makers and implementers of end-of-life care (Keeley, 2017), they must navigate complex treatment decisions, medication management, and emotional strain, often at the expense of their own wellbeing (Yang et al., 2024; Rezaei et al., 2024). Social isolation is prevalent among caregivers, and some develop the belief that "only I can provide optimal care" as they transition from "novices" to "care experts," while suppressing vulnerability to maintain a sense of normalcy (Schorch, Wan, Randall & Wulf, 2016; Thomas, Morris & Harman, 2002).

For Chinese only children, these burdens are intensified by cultural and structural conditions. Shaped by the legacy of the one-child policy and the ethics of filial piety, they face heightened responsibility and limited support networks. The inversion of traditional parent-child roles during caregiving (Wang, Xiao, Zhang et al., 2023) transforms them from "children" into "caregivers," requiring constant negotiation between emotional intimacy and managerial duty (Yi, Wang, Jen & Xu, 2025).

Fei Xiaotong's Differential Mode of Association theory (Fei, 1992) describes Chinese society as organized through concentric circles of moral obligation centered on the family. Within this moral structure, adult children are positioned as their parents' primary caregivers; failure to fulfill these duties often leads to social criticism and self-reproach. This expectation, reinforced by the dual model of filial piety—the authoritative dimension emphasizing obedience and sacrifice, and the reciprocal dimension emphasizing affection and gratitude (Yeh & Bedford, 2003)—creates both motivation and psychological strain (Yu, Duan, Zhu, & Deng, 2025), fostering heightened caregiving motivation while intensifying anxiety and fear surrounding parental loss (Shen, Ciobanu, van der Horst, Kliegel, & van Tilburg, 2025). Traditional family ethics that discourage open

discussion of death and emphasize “sweeping one’s own doorstep clean” further isolate caregivers, fostering distrust of external support (Guo, 2023). As a result, many only children bear their emotional and ethical burdens in silence, striving to embody the ideals of the “dutiful child” and the “all-capable caregiver.”

Yet caregiving is not solely a source of depletion. Studies reveal that, despite significant stress and isolation, caregivers often experience emotional growth, strengthened kinship intimacy, and a renewed sense of meaning (Rezaei et al., 2024). These positive transformations suggest that caregiving is an embodied process of learning to “live with vulnerability,” where individual resilience plays a crucial role in mitigating the adverse effects of burden, anxiety, and depression on quality of life (Chen, Qiao, Arber et al., 2023).

2.2 Theoretical Framework

Building on this understanding, the study adopts the Communication Theory of Resilience (CTR) to examine how caregivers rebuild psychological and social functioning through interaction within supportive communities. CTR conceptualizes resilience as a dynamic and constructive process: through communicative practices that help individuals cope with stressors such as trauma or major life transitions, people can re-establish emotional stability and social connection (Buzzanell & Houston, 2018). In this process, self-narratives emerging from personal memory systems enable caregivers to derive positive meaning from their experiences, fostering emotional integration, psychological growth, and the reconstruction of the autobiographical self (Mroz, Monin, Gaugler et al., 2024).

The construction of the autobiographical self involves three interrelated dimensions: witnessing (the articulation of lived facts), interpretation (the attribution of meaning), and stance (the positioning of self toward the world)(Bruner, 1995). The “narrating-transcribing-reading-narrating” model, widely used in therapeutic contexts, has demonstrated the capacity to enhance self-narrative quality, promote well-being, and strengthen self-coherence (Smorti, 2011).

Yet the formation of autobiography is never an isolated process, it depends on the shared narrative frameworks of one’s surrounding miniculture. Communities define collective identity through shared stories, while individuals draw upon these narrative structures—forms, vocabularies, and cultural metaphors—to make sense of personal experience (Bruner & Feldman, 2009). However, only child caregivers in cancer contexts often face social isolation, which limits their capacity to construct the autobiographical self through dialogue alone. Studies suggest that socially isolated caregivers benefit from building support networks(Shen, Ciobanu, van der Horst, Kliegel, & van Tilburg, 2025) and engaging in sustained interaction to share experiences, reframe identity, and cultivate resilience. Such communities facilitate mutual empathy, reflection, and death education through ongoing peer dialogue (Chen, Qiao, Arber et al., 2023). Within this context, the Community of Practice (CoP) framework conceptualizes caregiving as a collaborative endeavor, wherein

sustained dialogue represents a *joint enterprise* and the collective sharing of experiences forms a *shared repertoire* (Wenger, 1998). Through dynamic participation in this communal learning process, caregivers enhance their competencies and construct resilient identities.

Furthermore, self-disclosure is a critical factor shaping the effectiveness of caregiver support groups. In cancer caregiving contexts, Chinese only-child caregivers frequently experience *self-image inconsistency*—a tension between “forced resilience” and “suppressed vulnerability”—as well as *expression inhibition*. These tendencies, compounded by disparities in communication competence and power-structured inequalities within dialogue (Leirvik, 2005), reveal the inherent limitations of traditional group-based conversational models in this particular caregiving scenario.

2.3 Literature Review

2.3.1 Existing caregiver group support

Existing online platforms—such as Caregiver Speaks, a Facebook private group for family caregivers of dementia patients receiving end-of-life care that uses photos to prompt narration(Rolbiecki, Oliver, Teti et al., 2021), and VOICE me OUT, a transformative narrative technology website designed for informal caregivers in Europe(Petrović, 2022)—provide psychological support for specific caregiver groups in Western contexts.

However, support communities for Chinese only-child caregivers of parents with cancer are mostly grassroots-led, lacking ethical guidance and in-depth companionship. Data shows that caregivers participating in social media support report significantly higher burdens than non-participants, as frequently transmitted negative information further exacerbates their psychological stress (Chen, Qiao, Arber et al., 2023).

2.3.2 Existing digital technology support in the caregiving

Digital technologies have emerged as effective tools for enhancing health literacy, emotional empowerment, and social connectedness among informal caregivers (Soares, Hoffmeister, Fernandes et al., 2024). AI-based emotional companionship systems—such as *Replika*, *Wysa*, and *Woebot*—leverage natural language processing to deliver empathetic responses and are increasingly applied in healthcare and mental health counseling contexts (pa-2).

Recent advances in large language models (LLMs), including frameworks such as LangChain and Ollama, have enhanced dialogue comprehension and affective responsiveness (Gupta, Swami, Shukla, & Krishnan, 2024). Multimodal systems further integrate diverse data inputs for nuanced emotional support (McStay, 2025), while AI-assisted online cognitive behavioral therapy (CBT) interventions have demonstrated efficacy in home-based care (Biliunaite et al., 2021; Carter, Mikan, & Simpson, 2009). For example, *Woebot* users reported a 41% reduction in depressive symptoms within two weeks through CBT-guided self-expression (Kislev, 2022). As “cognitive

assistants,” AI systems can support decision-making, filter negative information, and reshape caregivers’ perceptions of time and uncertainty (Olson, 2011).

Most studies suggest that users tend to disclose more to conversational AI than to human interlocutors (Papneja & Yadav, 2024), with chatbots eliciting approximately 30% deeper levels of self-disclosure (Lee *et al.*, 2020). However, in healthcare contexts, individuals remain more willing to confide in humans due to perceived limitations in AI’s expertise (Kemp, Bui, Tangari, & Zhang, 2025). Moreover, current AI applications predominantly target disease management and diagnosis, leaving a significant research gap in AI-companionship group narratives within caregiving contexts.

2.3.3 Practice-based research in caregiving

Participatory journaling and dialogue have been employed as narrative approaches in informal caregiving research. In one study, four participants documented their care experiences in multiple formats, complemented by regular telephone interviews that fostered reflective dialogue between researchers and participants (Breheny, Horrell & Stephens, 2020). However, this one-on-one design remained researcher-led and limited to interview-based data collection.

Arts-based methods have also been utilized as participatory co-design tools. In another study, nine female caregivers engaged in a half-day co-design workshop integrating multiple artistic techniques to share care experiences and collaboratively design a caregiver-specific app (Miller & Zelenko, 2022). Although conducted in a group setting, the single-session format constrained longitudinal insight and failed to capture evolving changes in caregivers’ perspectives throughout the care process.

To address these gaps, the research questions are as follows:

1. How can participatory and autobiographical narratives support dialogue within Chinese only-child caregiving communities facing cancer?
2. In what ways can AI act as a material and dialogic medium to hold narrative space among these caregivers?
3. How can the frameworks and modes of AI intervention be co-created through iterative dialogue among caregivers, AI, and the researcher, and what insights emerge from this process?

4. Research Methods

4.1 Research Design

This study integrates practice-based research and participatory methodology to explore how to co-generate an ethical framework of AI intervention through dialogue with participants and AI.

This participatory orientation stems from an ethical concern to avoid researcher-led interpretation and the influence of personal caregiving experience on participants' narratives. Rather than observing caregivers from a distance, the research re-enters the community as both participant and reflective mediator, tracking and interpreting caregivers' psychological states and role transitions while engaging in shared narrative dialogues with caregivers and AI to co-examine the roles and ethical boundaries of digital intervention.

Within this process, caregivers negotiate autobiographical identity through community narrative practices, and dialogue functions both as data and as a form of care, where each exchange becomes part of an unfolding death pedagogy.

4.2 Fieldwork Sites

The researcher's caregiving background provides practical familiarity with cancer consultation processes and sustained connections with oncology specialists. Academic and internship experience at Beijing University of Chinese Medicine offer access to medical networks across major tertiary hospitals, while volunteer work in palliative care supports continued collaboration with clinical staff.

These resources enable engagement with participants in institutions such as the Cancer Hospital of the Chinese Academy of Medical Sciences, China-Japan Friendship Hospital, Beijing Hospital of Traditional Chinese Medicine, and Beijing Songtang Hospice.

Local hospitals will also serve as comparative sites to capture variations in cancer care practices and user needs across regions.

4.3 Fieldwork Procedures

4.3.1 Offline Clinical Setting:

Acting as an accompanying caregiver, the researcher will observe family caregivers in oncology clinics and utilize family waiting areas outside chemotherapy rooms as natural community spaces.

4.3.2 Online AI-Enhanced Setting:

Caregivers identified offline and additional recruitment via social media will be invited to join online communities, where they can narrate experiences and engage in art-based co-creation.

4.3.3 Preliminary Findings:

A pilot participatory art-based workshop was conducted at Beijing Songtang Hospice to examine the feasibility of employing “doodling and handicrafts as entry points for narrative externalization.” Twelve frontline caregivers were recruited and divided into two subgroups—professional caregivers and family caregivers—to ensure diversity of care experiences and emotional perspectives.

Guided by the CoP framework, the workshop was designed to facilitate a transition from “individual task orientation” to “collective emotional resonance” among participants. Randomized prompts (Table 1) derived from the Caregiver Support Needs Assessment Tool (CSNAT) (Ewing, Brundle, Payne & Grande, 2013) were used to elicit personal reflection and spontaneous narration. Participants first engaged in free-form doodling as a medium for individual narrative expression, followed by collaborative collage-making to foster group communication and shared meaning construction.

This preliminary pilot conducted by the researcher employed art-based co-creation to test the feasibility of participatory engagement. The findings (Figure 1) suggested that artistic expression could serve simultaneously as data and intervention, providing a safe medium for emotional externalization and shared reflection. However, the pilot also revealed the need for more accessible and interactive tools to engage participants without an artistic background (Liu, Yang, Luo et al., 2024), as well as the importance of further examining dialogic methods in participatory research. Future work will pay particular attention to issues such as differences in linguistic competence, group dynamics, power asymmetries, and the researcher’s positional limitations (Leirvik, 2005)—and how these dynamics might be reconfigured or mitigated within an AI-mediated participatory space.

Building upon the researcher’s prior experience as the core designer of the “Hongen Little Artist” APP, existing AI modules—such as image recognition and real-time voice feedback—were adapted and migrated into this study’s research environment to prototype AI-supported online art therapy workshops. Collaborating with AI experts from Hongen Education, the project team constructed an AI-augmented group communication platform that integrates an interactive art-creation section, ensuring the technical implementation, usability testing, and iterative optimization of AI functionalities in a caregiving context.

4.4 Participants

Participants will be adult only children who have cared for or are currently caring for parents with cancer. Comparative studies will consider regional, educational, and gender differences in caregiving experiences.

An interdisciplinary focus group comprising psychologists, Traditional Chinese Medicine practitioners, and hospice professionals will provide expert oversight.

4.5 Data Collection and Analysis

Data will include field notes, audio-visual recordings, narratives, artworks, and AI-assisted reflections. Thematic and narrative coding, visual analysis, and reflective writing will be used to explore the dynamic formation of identity, resilience, and meaning.

4.6 Ethical Considerations

The study adheres to university ethics committee requirements, with clear explanations of tasks and objectives in plain language to obtain informed consent. Confidentiality agreements are signed for privacy-related topics, and data is anonymized.

AI technology application is transparent, with participants explicitly informed of AI-supported components (Battisti, 2025). The AI prototype framework integrates emotional, ethical, and spiritual dimensions; interdisciplinary collaboration optimizes clinical applicability, and cultural adaptation enhances equity across diverse contexts (Rai, 2025).

5. Expected Contributions

1. Developing a participatory, practice-based methodology for ethically exploring AI's involvement in human care practices, demonstrating how frameworks and meanings can be co-generated through dialogue.
2. Establishing a culturally informed framework of relational care that integrates autobiographical narrative, reciprocal filial piety, and embodied death education, revealing how caregivers reconstruct identity and resilience through shared storytelling in Chinese only-child cancer caregiving contexts.
3. Co-defining the ethical and practical boundaries of AI participation in caregiving narrative communities, offering a foundation for future culturally sensitive and ethically sustainable AI-assisted care systems.

Table 1: Example prompts for professional and informal caregiver art-based sessions.**Professional Caregiver Group Painting Prompts**

| Card & Title | Prompt Content |
|--|--|
| Card 1: Draw the voice of your body at this moment | Close your eyes and recall how your body has accompanied you in recent work. Has it felt tense, tired, or heavy—or perhaps relaxed and light at times? What color might those aches take? If exhaustion had a shape, what would it look like? As your brush gently moves across the paper, might your physical discomfort find a moment of relief? |
| Card 2: Draw the ripples reflected in your heart | When you accompany patients with severe illness, what emotions arise within you? Recall one patient who left a deep impression. Was the caregiving experience one of tender closeness, or did it stir feelings of sorrow or helplessness from deep within? If this emotion became a painting, what colors or lines would appear? |
| Card 3: Draw the support you have felt | In your collaboration with colleagues, can you recall a moment of being supported—perhaps a glance, a few words, or seamless teamwork? If you could visualize this sense of support, what image would it become? |
| Card 4: Draw your moment of self-healing | Imagine finishing a work shift—how do you rest and restore yourself? A cup of hot tea, a deep sleep, a walk, or simply sitting quietly? If this “moment of recovery” became a painting, what tone or color would it have? What shapes might compose it? |
| Card 5: Draw your feelings toward the end of life | When you accompany a patient at the end of life, what is the deepest feeling in your heart? Is there a patient you still remember vividly? Is that feeling heavy, tender, reverent, or complexly intertwined? If these emotions became a visual form, would they appear as overlapping colors, intersecting shapes, or a single symbolic image? |
| Card 6: Draw the stress you most often feel | How has your work been lately? As a caregiver, stress may come from complex patient conditions, long shifts, or high self-expectations. Pause for a moment and think about the kind of stress you most often experience. If it became an image, what shape or color would it take? |

Informal Caregiver Group Painting Prompts

| Card & Title | Prompt Content |
|---|---|
| Card 1: Draw the sensations of your body | During the process of caring for a loved one, your body often endures quietly. Which parts often feel fatigue or pain? Are these discomforts sharp and fleeting, or dull and lingering? If such sensations became a color or shape, what would they look like? |
| Card 2: Draw your moment of loneliness | Have there been times when you felt alone on the caregiving journey? Perhaps during the quiet of a night vigil, the powerless wait for a test result, or the sorrow of being misunderstood. If this loneliness were a painting, what imagery would it show—scattered dots, or tangled lines? |
| Card 3: Draw the image of support in your heart | Think back—have you ever received support from family, friends, healthcare workers, or even strangers? Perhaps it was a few comforting words, a cup of warm water, or a reassuring glance. If you could paint this sense of support, what would it look like? |
| Card 4: Draw the worry in your heart | When you think about your loved one's illness, what form does your concern take? Is it fear of the unknown, or the ache of witnessing their suffering? Do these feelings feel like a stone pressing on your chest, or a string pulling you forward? If you could express them visually, what shapes and colors would they have? |
| Card 5: Draw your own moment | Beyond the busy caregiving routine, do you allow yourself moments that belong only to you? Perhaps a quiet walk, a short nap, or simply a brief mental pause. Do you enjoy spending time alone like this? How does taking a break from caregiving make you feel? If this moment were a painting, what would it look like? |
| Card 6: Draw the pressure in your heart | In caregiving, you may face financial strain, time pressure, family disagreements, or constant waves of worry. Pause and imagine all these stresses gathered together—what kind of image would they form? Entangled threads, or overlapping geometric shapes of varying sizes? |

Figure 1: Preliminary findings from the hospice art-based co-creation workshop.

Data Collected from the Artworks

Draw your feelings toward the end of life:



Verbal Expression: "Medical workers dedicate their entire lives to helping others, shining like torches to illuminate the way for people around them. Yet at the same time, they also long to be a safe harbor for their families and loved ones."

Behavior: In the creation of mixed media art, the participant have been exploring the integration of oil pastels and watercolors.

Draw your moment of self-healing:



Verbal Expression: "Green symbolizes vitality—with a vibrant hand clutching the sun, we move toward the light."

Behavior: The painting process flows smoothly, with bold and decisive brushstrokes.

Draw the ripples reflected in your heart:



Verbal Expression: "When patients feel anxious or depressed, we stand behind them like a big tree for support, offer a sunny smile. Creating such a scene with flowers, grass, trees and sunshine is our daily work."

Behavior: Though hesitant before starting to create, the participant can work independently without help.

Draw the support you have felt:



Verbal Expression: "During a patient consultation, the family whispered not to tell the patient the real condition. Due to urgency, I gave a look to my colleague beside me to signal confidentiality, and she understood immediately. Our tacit understanding deeply touched me."

Behavior: At first, the participant showed reluctance to paint and needed a leader's help, but the subsequent creation became smooth gradually.

Draw your feelings toward the end of life:



Verbal Expression: "We all come from nothing, grow and live in order, and finally return to nothing."

Behavior: Creation flows smoothly—no prior composition, painting as thoughts come, with gentle fluidity.

Draw your moment of loneliness



Verbal Expression: "I always feel lonely while caring for patients—anxious as fire by day, but lonely in the quiet night. White dots are the hope in my heart."

Behavior: Mixed media creation: The main composition is completed by rubbing, with decisive creation.

Draw your own moment:



Verbal Expression: "This question reminds me of my childhood—ants represent childhood. The picture has flowers and grass, and I hope I can stay vibrant forever. Behind are the sea and sunset, with seagulls in the sky, and finally the sun. It's that simple."

Behavior: Hesitant at first, but quick in later creation.

Draw the sensations of your body:



Verbal Expression: "This painting represents youth and the growth of all things. Thank you all for caring for the elderly at Songtang. Wish volunteers a happy Mid-Autumn Festival."

Behavior: Has a painting habit; started creating before the event, which has little to do with the theme, but loves painting itself.

Data Collected through Observations



Participants, unfamiliar with the expressive form of painting, appeared awkward when facing blank paper and hesitated to start drawing. Despite prior instruction on painting techniques, they still struggled to begin, fearing mistakes. Future considerations should include: a) adopting expressive forms more familiar to participants; or b) reducing the difficulty of participation.



The professional caregiver group, composed of colleagues, engaged in easier mutual communication during creation. In contrast, the family caregiver group, with members unfamiliar to one another, mostly created individually. Throughout the activity, there was limited interaction between the two groups. Future arrangements should consider having each group complete their creation separately to foster a more focused state and reduce interference from the other group.



Given that some patients required care, Songtang Hospital arranged for those in suitable physical condition to be seated on the other side of the activity venue, where their activity was coloring. On-site observations revealed that participants near the patients were more likely to start creating. It remains unclear whether this was influenced by the patients' coloring behavior, which may have implicitly lowered the threshold for initiating creation, or if the coloring templates provided inspiration for caregivers. Future designs should consider blank coloring templates, allowing participants to focus solely on color matching without hesitating over composition.



Lantern assembly evolved into casual private interactions among interviewees, generating a relaxed atmosphere. Given the collaborative nature of lantern pasting, volunteers and patients often joined in, enabling the formation of a creative community during this segment. Nevertheless, the simultaneous lantern-making by the two participant groups hindered the on-site team from fully and deeply engaging with all conversations. For data collection, only photographic materials were acquired, with a lack of specific conversation recordings.

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