Yang *et al. BMC Palliative Care* (2024) 23:248
https://doi.org/10.1186/s12904-024-01575-4

BMC Palliative Care

RESEARCH **Open Access**

Family caregivers' administration of medications at the end-of-life in China: a qualitative study

Fei Yang[1*], Pusheng Wang[1], Yong Tang[2], Min Song[3], Jun Jing[3*], GuiJun Lu[4*] and Bee Wee[5]

Abstract

Background Effective medication management is crucial for ensuring timely pain and symptom control at the end of life. Dying in pain is a major concern for patients, yet some find less effective pain control at home. Family caregivers (FCGs) play a vital role in managing pain and symptom control for dying patients. However, the experience of administering medications at home for terminal-stage patients has not been widely recognized or understood. Our study aimed to explore the experiences of FCGs in administering medications to adult dying patients.

Methods We conducted a directed content analysis of data from 73 semi-structured interviews with FCGs across 19 Chinese provinces from 2021 to 2023. FCGs were recruited through the Voluntary Cooperative Network Research. We asked, "Could you recall the end-of-life care process for the patients?" We aligned the themes with the five issues identified by Wilson et al. (2018): administration, organizational skills, empowerment, relationships, and support.

Results FCGs in China exhibit concerns about over-engagement and empowerment in medication administration, concealing medication information from the patient, and medication accessibility. FCGs faced significant challenges in accurately identifying and addressing pain and symptoms, determining appropriate dosages, accessing effective medications, and managing the emotional stress associated with potential medication errors. Financial burden, medication regulatory restrictions, geographical inequality, and travel restrictions during COVID impeded patients and FCGs from accessing medication. A culturally specific finding is the use of alternative medicine at the end of life.

Conclusion Our findings build upon Wilson et al.'s framework and extend their insights on empowerment, highlighting the need for policies to support home-based palliative care professionals in training FCGs for effective medication administration.

Keywords Family caregiver, Medication administration, End-of-life care, Community care, Directed content analysis

---

*Correspondence:
Fei Yang
yangfei20@mails.tsinghua.edu.cn
Jun Jing
jingjun@tsinghua.edu.cn
GuiJun Lu
luguijun301@163.com
[1]Tsinghua Shenzhen International Graduate School, Tsinghua University, Shenzhen, Guangdong, China
[2]Sociology Department, School of Government, Shenzhen University, Guangdong, China
[3]Department of Sociology and Public Health Research Center, Tsinghua University, Beijing, China
[4]Department of Pain and Symptom Management, Beijing Tsinghua Changgung Hospital, Beijing, China
[5]Harris Manchester College and Nuffield Department of Medicine, Oxford University, Oxford, UK

Introduction

Effective pain and symptom control is critical to support patients to remain at home. Although there has been an increasing trend in professional care for dying patients [1, 2], FCGs continue to serve the predominant role in providing end-of-life care for their loved ones. Evidence shows that FCGs face considerable burdens regarding caring responsibilities, unpaid care, and both physical and emotional distress as individuals approach the end of life [3, 4]. This challenging circumstance frequently leads to feelings of inadequacy and lack of support in their roles. FCGs articulate a pressing need for assistance from healthcare professionals to ensure the provision of high-quality patient care. In particular, they seek access to information, knowledge, and resources that can enhance their caregiving capacities and mitigate some of their stressors [5]. Administering medication to patients is among the various caregiving responsibilities of FCGs. However, there is insufficient understanding of how FCGs cope or could be best supported in medication administration.

Cultural considerations impact palliative care, influencing decision-making and caring styles, communication patterns, responses to symptoms, and emotional expressions related to dying and death [6, 7]. FCGs in various cultures are embracing medication training to empower themselves, thereby enhancing the likelihood of a 'good death,' increasing satisfaction, reducing anxiety and frustration, preventing unnecessary hospital admissions, and alleviating pressure on community palliative care services [8–10]. For example, effective pain and symptom management for palliative care patients at home can be achieved with caregiver-administered subcutaneous medications. In Australia and the United Kingdom (UK), it is legal and practical for FCGs to timely and safely administer injectable medications at home to control pain and distressing symptoms in patients during their final days of life, under the training and support from skilled community and palliative care nurses [9, 11–13]. However, evidence on the level of empowerment among Chinese FCGs and the extent of support they receive from healthcare professionals remains limited.

In China, most patients with life-limiting and terminal illnesses die at home, with previous research indicating a range from 71.5 to 89.8% [14–16]. Regardless of the place of death, dying patients spend more of their final three months of life being cared for at home [5, 17, 18]. Evidence from China indicates a high prevalence of potentially inappropriate medication use among community-dwelling older adults [19, 20]. Older Chinese patients frequently encounter challenges such as medication errors, polypharmacy [21] and decreased adherence to prescribed medication regimens [22], with these issues typically increasing in complexity as death approaches. These challenges complicate the medication management responsibilities of FCGs, with significant implications for the allocation of resources and the organization of professional end-of-life care services. However, evidence specifically addressing FCGs' medication administration for terminally ill patients is lacking. In this study, we aimed to delineate the experiences of FCGs regarding medication administration at the end of life in China.

Materials and methods

Dataset

Our research was derived from a dataset of 73 out of 251 semi-structured interviews with FCGs conducted between 2021 and 2023 as part of a large research project titled "Study of End-of-Life Care Models in China" that involved collecting both quantitative and qualitative data through questionnaires and interviews. In total, we collected over 1,000 quality-of-death questionnaires and almost 500 death narratives. The death narratives were obtained through interviews with healthcare professionals (e.g., doctors, nurses, social workers, hospice volunteers) and bereaved family caregivers or other knowledgeable informants of deceased patients (e.g., relatives, friends, neighbors). We reviewed the texts and found that, out of 251 narratives from bereaved family caregivers, 73 contained information on medication administration. The remaining texts did not address this topic; therefore, we included only the 73 relevant narratives in our analysis. FCGs were eligible for this study if they were the primary knowledgeable informants in a family aware of the diagnosis, prognosis, medical treatment process, and dying and death experiences of the decedents.

The semi-structured interviews covered personal information about both the FCG and the decedent, the circumstances of the decedent's last illness and death, and the FCG's experiences caregiving for the decedent. Although interviewees were not directly questioned about medication administration, in their responses to the questions "Could you recall the end-of-life care process for the patients?" and "How would you assess the quality of medical care the patient received during their illness?" a substantial minority of participants raised the topic.

We utilized our own designed method, named Voluntary Cooperative Network Research (VCNR), to recruit our participants [23, 24]. Voluntary cooperation in this context involves collaborative research where individuals both within and outside the research group share academic goals, gather data, engage in analysis, and share findings, all on a pro bono basis, receiving only travel expenses. Research group leaders recruit and train volunteers through their social networks to expand the research network. For example, during the second round of research conducted in 2021, the principal investigator recruited five other voluntary researchers to lead six sub-groups by presenting the research aims and plan. These sub-group leaders recruited 70 volunteers from disciplines like sociology, anthropology, health economics, etc., to eventually recruit 209 voluntary researchers to conduct interviews. (Fig. 1) These volunteers used their social networks to recruit participants for in-depth interviews on end-of-life care, encompassing diverse demographics.

The inclusion criteria for volunteer researchers were: (1) A minimum of a bachelor's degree and completion of coursework in qualitative research methods; (2) An interest in death and end-of-life issues and comfort discussing these topics; (3) Completion of three training sessions totaling six hours, which included understanding death narratives, conducting interviews, and writing death narrative reports. After report submission, the team leader reviews the quality of the reports and excludes those that do not meet the standards.

After completing the training, the volunteer researchers began identifying participants and scheduling times and locations for face-to-face interviews. All interviews analyzed for this article were conducted in Mandarin Chinese. The interview lasted an average of about 30 min, with the shortest being 20 min and the longest lasting several hours.

Ethical consideration

Ethics approval was provided by the Internal Review Board at Tsinghua University's Public Health Research Center, encompassing the research proposal and interview guides (Ethical Approval number: THZWJC27). The interview guide was developed in consultation with an expert panel led by the Principal Investigator (PI) of the project. (Supplementary 1) The consent procedure consisted of three parts: (1) Informed consent, before conducting interviews, we provided the participants with an introduction and explanation of the project and obtained and recorded the verbal informed consent. (2) The purpose of the interview, where we sought to understand the impact of palliative care and hospice on alleviating the psychological, physical, spiritual, and social suffering of patients, the medical decisions made by the deceased in their final stages of life, and the caregiving burden on the family; (3) Confidentiality principles, ensuring that the interview materials would be kept confidential, with no real names disclosed, and inviting the interviewees to express any concerns they might have about the interview. After confirming that the interviewees understood the purpose of the interview and the privacy and confidentiality commitments, the interviewer formally sought their consent to begin the interview. Interviews were recorded and later transcribed, ensuring anonymity using pseudonyms, removal of identifying information, and secure data storage measures. Given the sensitivity of discussing death, our training emphasized respectful questioning techniques that consider the interviewee's emotional state. No time limits were imposed, and interviewees were not required to answer all questions; instead, the interview was conducted according to the interviewee's wishes.

Analysis

Our directed content analysis explored how FCGs in mainland China administer medicine at the end of life [25]. We applied an established framework developed by Wilson et al. [26] This framework was based on a literature review of studies carried out in various Western countries exploring FCGs' experiences with managing medications for patients dying at home. This framework outlines five key aspects of medication management by FCGs: administration, organizational skills, empowerment, relationships, and support. [26] This framework helps illuminate FCGs' experiences in medication

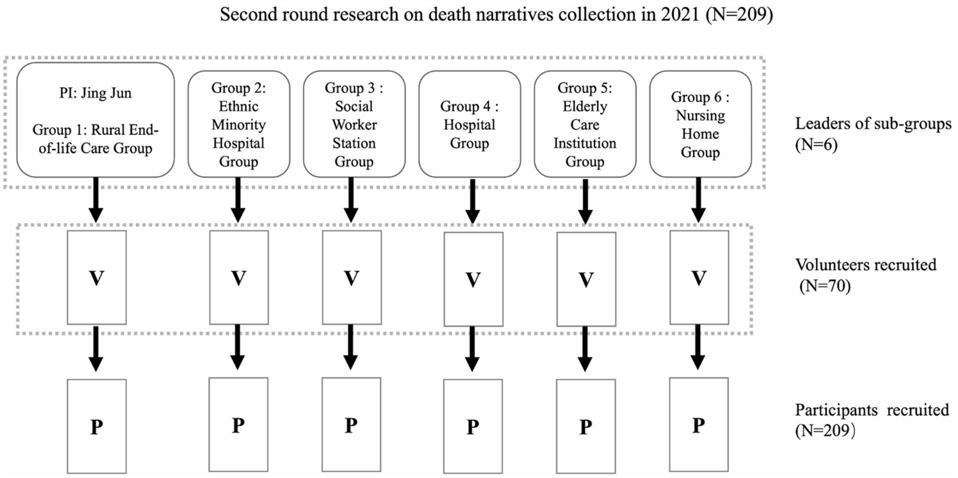

Fig. 1 Flowchart of the research method for the voluntary cooperative network

management for terminally ill patients at home, as well as the support and training needs of FCGs. In our study, we aligned identified barriers and facilitators from our qualitative work with each relevant domain, enabling the research team to evaluate their impact on FCGs' experiences as observed and described in the interviews. We used this framework to make the medication management experiences of Chinese FCGs comparable to those in other Western countries, helping readers worldwide understand the topic within a familiar conceptual framework.

We conducted the analysis in several stages [25]. First, we developed operational definitions for the five themes identified in Wilson's framework [26]. The first author (FY) then carefully reviewed all death narratives, highlighting any text related to medication administration. We coded the highlighted text using the predetermined categories whenever applicable. Text that did not fit these categories was assigned new labels that captured the essence of the medication administration process (e.g., concealment of medication information from the patient). To enhance credibility and minimize bias, a second researcher (MS) cross-coded the first 20 cases (27.4%).

Next, the first author reviewed the data within each category to determine if subcategories were necessary (e.g., relationships with physicians, other stakeholders, or within family caregiver groups). Data that could not be coded into one of the five predetermined themes were re-examined to account for variations in the medication administration experience. The first author then compared the data's alignment with Wilson's framework to identify any divergent experiences. Discrepancies in coding and categorization were resolved through team discussions, followed by a re-review of the data to enhance thematic concordance, confirmability, and dependability.

Finally, we reported the study findings by comparing the frequency of codes representing medication administration experiences consistent with Wilson's framework to those reflecting different experiences. In the discussion, we summarized how the study validated Wilson's framework and highlighted the new perspectives that emerged.

Table 1 Sociodemographic of the decedents

	Residential Zone	
	Rural (*n* = 53)	**Urban (*n* = 20)**
Age		
18–34	1	0
35–59	10	5
60 and above	42	15
Gender		
Male	40	12
Female	13	8
Cause of death		
Advanced cancer	32	16
COVID	3	0
Other [a]	18	4
Occupation		
Farmer	43	2
Other [b]	10	18
Area [c]		
First class	36	12
Second class	13	4
Third class	4	4
Relationship to decedents		
Spouse	10	4
Children and grandchildren	32	13
Other [d]	11	3
Place of death		
Home	47	9
Hospital	5	6
Hospice	1	4
Nursing Home	0	1

[a] Other causes of death include cardiovascular disease, cerebral hemorrhage, dementia, diabetes, fall, liver cirrhosis, stock, suicide and natural death

[b] Other occupations include captain, journalist, manager, healthcare professional, sales, scientist, self/un-employed, businessman, carpenter, carpenter, civil servant, and housewife

[c] The class of the area was grouped according to the minimum wage standard in 2024 of the province where the patients lived. The first-class area includes Shandong, Fujian, Heibei, Guangdong, Beijing, Shanghai, Gansu, and Xizang; the second-class includes Shanxi, Yunnan, Henan, Shanxi, Hubei, Xinjiang, and Inner Mongolia; and the third class includes Hainan, Liaoning, Jilin, Hei Longjiang, and Guangxi

[d] Other participants who were caregivers of the descent include bother, nephew, daughter in law

Results

We included 73 FCGs of deceased patients, with 61.6% being the patients' next of kin. The majority of the deceased individuals were aged 60 and above (78·0%), male (71·2%), residing in rural areas (72·6%), engaged in farming occupations (61·6%), and died at home (76·7%). The prevailing diagnosis among the deceased was advanced cancer, accounting for 65·8% of cases. (Table 1) We found that FCGs exhibited a high level of engagement in both medication administration and decision-making, feeling empowered in their capability to care for patients. Patients sought assistance from FCGs while preserving their independence. However, FCGs encountered challenges in recognizing and responding to pain and symptoms, determining appropriate dosages, accessing effective medications, and coping with the emotional stress of perceived medication mismanagement. Geographic disparities in end-of-life care resources and limited professional palliative care and hospice support were also evident, particularly in remote areas. We provide definitions and specific exemplars for all domains described in Wilson et al.'s conceptual framework identified from the review of FCGs' experiences in managing medicines for patients dying at home (Table 2).

Table 2 Patient characteristics of the exemplars

Patient No.	Age	Gender	Cause of death	Residential zone	Living arrangement	FCGs' relationship to patient [a]	Theme	Subtheme	Quotation
143	77	Male	Advanced cancer	Rural	With spouse, daughter	Daughter	Administration	Concerns in determining the correct dose: Overmedication	Q1
								Consideration of cost-effectiveness of the medication	Q9
							Organizational skills	Cancelation information from the patients	Q15
							Empowerment	Feeling powerlessness in medication	Q25
							Relationships	Relationships with other stakeholders: pharmacies	Q32
209	79	Male	Stroke	Rural	With spouse, son, daughter	Granddaughter	Administration	Concerns in determining the correct dose: Undermedication	Q2
217	59	Male	Advanced cancer Retroperitoneal liposarcoma	Urban	With spouse	Spouse	Administration	Concerns in determining the correct dose	Q3
								Concerns in side effects	Q6
							Support	Palliative care and hospice utilization	Q35
174	72	Male	Pancreatic cancer	Rural	With spouse, son, daughter	Son	Administration	Lacking knowledge of recognizing and addressing symptom	Q4
							Empowerment	Decision-making proxy	Q21
							Support	Palliative care and hospice utilization	Q38
							Culturally specific finding	Alternative medications utilization	Q42
146	77	Male	Prostate cancer	Rural	With spouse, son	Granddaughter	Administration	Concerns in side effects	Q5
104	68	Male	Cardiovascular and cerebrovascular diseases	Urban	With spouse	Nephew	Administration	Concerns in side effects	Q7
							Empowerment	Negotiation with healthcare professionals	Q19
011	41	Female	Rare disease	Urban	Not mentioned	Patient self [b]	Administration	Accessibility of medication: Facing financial burden in finding the most effective medication	Q8
							Relationships	Relationships between FCGs and HCPs	Q27
204	79	Male	Renal cancer	Rural	With son	Son	Administration	Accessibility of medication: Medication regulatory restriction	Q10
							Empowerment	Conflicts among FCGs on medication	Q22
167	86	Female	Advanced cancer	Urban	With spouse	Son, daughter-in-law	Administration	Accessibility of medication: Medication regulatory restriction	Q11
193	63	Male	Lung cancer	Rural	With spouse, son, daughter	Daughter-in-law	Administration	Accessibility of medication: Medication regulatory restriction	Q12
							Relationships	Relationships with other stakeholders: third-party payers	Q31
							Culturally specific finding	Folk remedies utilization	Q43

Table 2 (continued)

Patient No.	Age	Gender	Cause of death	Residential zone	Living arrangement	FCGs' relationship to patient [a]	Theme	Subtheme	Quotation
221	67	Male	Liver cancer	Rural	With son, daughter	Daughter	Administration	Accessibility of medication: Medication regulatory restriction	Q13
005	85	Male	Malignant tumor	Urban	With spouse	Daughter	Organizational skills	Cancelation information from the patients	Q14
148	66	Female	Advanced cancer	Urban	With spouse, daughter	Daughter	Organizational skills	Cancelation information from the patients	Q16
							Support	Palliative care and hospice utilization	Q36
099	78	Male	Diabetes, stroke	Rural	With spouse	Granddaughter	Empowerment	Negotiation with healthcare professionals	Q17
							Support	Geographic disparities in healthcare resources	Q33
035	62	Female	Pancreatic cancer	Urban	With spouse, daughter	Daughter	Support	Palliative care and hospice utilization	Q34
018	44	Female	Malignant tumor	Urban	With spouse	Spouse	Empowerment	Negotiation with healthcare professionals	Q18
177	47	Male	Liver cancer	Rural	With spouse	Spouse	Empowerment	Decision-making proxy	Q20
176	58	Male	Brain tumor	Rural	With spouse	Spouse, daughter	Empowerment	Conflicts among FCGs on medication	Q23
006	75	Male	Advanced gastric cancer	Urban	With spouse	Granddaughter	Empowerment	Feeling powerlessness in medication	Q24
189	64	Male	Unknown	Rural	With spouse, son	Son	Relationships	Relationships between FCGs and HCPs	Q26
237	78	Male	Dementia	Urban	With spouse, son	Daughter	Relationships	Relationships among FCGs	Q28
001	77	Male	Respiratory failure	Urban	With daughter	Brother	Relationships	Relationships among FCGs	Q29
161	107	Female	Natural death	Rural	With son and daughter	Son	Relationships	Relationships among FCGs	Q30
212	78	Female	Colonic tumor	Urban	With spouse, son, daughter	Daughter	Support	Palliative care and hospice utilization	Q37
220	68	Female	Gastric cancer	Rural	With son, daughter, granddaughter	Granddaughter	Support	Lack of home-based palliative care	Q39
098	47	Male	Malignant tumor	Urban	With spouse	Spouse	Support	Lack of home-based palliative care	Q40
169	53	Female	Dementia	Rural	With spouse, daughter, son	Daughter	Culturally specific finding	Alternative medications utilization	Q41

[a] FCG: Family Caregiver

[b] Carer 011 was the only dying patient we interviewed

Theme 1: administration

The administration of medications encompasses the development of FCGs in both symptom and medication knowledge and skills, as well as their endeavor in medication accessibility. FCGs are concerned about their ability to recognize and respond to pain at the end of life, which raises challenges in determining the correct dosage and can lead to both over-medication and under-medication. Both patients and FCGs may be distressed when the intended outcome of reducing the patient's pain or discomfort is not achieved, despite escalating treatment options.

> *"My father needed around 10 different medications pre-day to treat cancer, given his slow reaction and mental fogginess, we supervise him occasionally in case he retook the medication." (Q1, Carer 143).*

> *"He took painkillers in small doses since we were afraid that he couldn't bear too many." (Q2, Carer 209).*

> *"The medication has been increased to the maximum limit, and there's no room for further escalation. Pain relievers have no effect on him anymore." (Q3, Carer 217).*

The lack of knowledge among FCGs in recognizing and addressing symptoms also placed additional stress on them.

> *"My father experienced delirium after using the fentanyl patch and expressed feelings of neglect, accusing me of not caring for him, which I initially didn't recognize as hallucinations." (Q4, Carer 174).*

Worries about medication side effects further complicated matters. The patient's belief that "medication is three parts poison (Carer 104)" also resisted medication taking.

> *"We were concerned that feeding medication might cause choking, so we rarely gave him any." (Q5, Carer 146).*

> *"After trying various medications to alleviate his pain, not only did it not help, but it also, affected his mental clarity, and intensified the pain." (Q6, Carer 217).*

> *"Like most people from Northeast China, my uncle believes in the saying 'medicine is three parts poison.' He personally resists taking medication, even though he has been diagnosed with high blood pressure." (Q7,Carer 104).*

FCGs' reported their struggles with the accessibility of medication for dying patients. Problems in finding the most effective medication might be affected by financial burden, e.g., the cost of the medication was expensive (Carer 011); cost-effectiveness evaluation, e.g., weighing the cost of genetic testing and the effectiveness of targeting the medication for cancer treatment (Carer 143); medication regulatory restriction, e.g., FCGs can't directly obtain opioid drugs from the hospital without providing prescription and packaging of the used drugs (Carer 204), and anesthesia medications are barely available at home (Carer 167); geographical inequality, e.g., patients in remote rural area reluctantly traveled between village medical institutions and home for pain control (Carer 193); and travel restriction during COVID impeded patients to outpatient visit for medication (Carer 221).

> *"A doctor told her that there is currently no particularly effective medicine available domestically. So, she had to search online and found several upcoming medicines. She wrote down the names and asked the doctor which one could be used. The doctor recommended one and advised her to quickly start saving money because this medicine is very expensive." (Q8, Carer 011).*

> *"Apart from that, it's also possible to use genetic testing to search for targeted medicine. However, the chances are like finding a needle in a haystack, and it costs over ten thousand yuan. The doctor emphasized that genetic testing might likely yield no results, essentially wasting money. He suggested that we go back and reconsider. However, my father never agreed. Despite my attempts to persuade him several times, he still insisted on not putting money into such a slim hope." (Q9, Carer 143).*

> *"During the time at home, the pain reactions were quite evident, and she basically took painkillers every day. However, due to strict control, it was very troublesome for terminally ill elderly people at home to obtain painkillers. Family members cannot directly obtain painkillers from the hospital; they need to get a prescription from the doctor and provide the hospital pharmacy with the original packaging of the previously used painkillers. If the hospital doesn't see the doctor's proof and the original packaging of the used medication, they won't prescribe such painkillers to the family." (Q10, Carer 204).*

> *"Because we were concerned about her pain in the late stage, once we returned home, there was no way to alleviate it. If she were only dealing with a typical paralysis stroke, we could take her home, but her cancer-related pain was something we couldn't address. The strict control of anesthesia medications in the country meant it was impossible for anyone to guarantee that we could get the necessary treatment for her pain. We couldn't manage that." (Q11, Carer 167).*

> *"When my father-in-law couldn't bear the pain, he would go to the clinic to get pain relief injections and sedatives. However, he stopped going later on because staying in the clinic meant an extended stay, and the pain relief involved intravenous drips. When my husband was at home, if my father-in-law couldn't endure the pain, he would sometimes have to rush to the clinic in the middle of the night; other-*

> *wise, the pain was unbearable for him." (Q12, Carer 193).*

> *"It wasn't very convenient to treat my father's illness. Every time I went to get medicine, I had to report to the village and township. In situations where they wouldn't allow him to go out, we had to go and fetch the medicine ourselves. After getting the medicine, we had to administer the injections to my father and make sure he took the medication." (Q13, Carer 221).*

Theme 2: organizational skills

The organization skills and techniques that were applied by FCGs are defined as the administering, tracking, and monitoring of the medication effects. FCGs reported they regularly brought medications home and tracked and monitored the effects such as "improving blood circulation in the brain and preventing strokes (Carer 152)". FCGs developed the skills for medication administration by "labeling the medication for each meal, especially those with English generic, brand names and introduction, scissoring the tablet packing, and sharping parts of the edges into a round shape to avoid cutting the patients (Carer 205)."

We found that FCGs were likely to conceal medication information from the patient. This striking finding, that FCGs may conceal information about medication from patients by employing organizational skills, extends Wilson's framework. In some cases, patients were kept unaware of their medication treatment (Carer 143), or disease diagnosis and prognosis. (Carer 148)

> *"I removed the packaging of the medication (for cancer treatment) and placed the pills in a small vitamin C bottle, deceiving the patient by claiming it to be a medication for inflammation and nutritional supplement." (Q14, Carer 005).*

> *"My father began medication treatment without knowing that he had malignant tumors." (Q15, Carer 143).*

> *"To keep it a secret from her, I downloaded a template of a lab report from the internet. Every time we received the results of a CT scan, I would give her that modified report." (Q16, Carer 148).*

Theme 3: empowerment

FCGs' empowerment is defined as being able to engage in timely and appropriate medication administration. FCGs might negotiate with healthcare professionals regarding prescribing more medication or reducing the dosage and making unremitting efforts to rescue their loved ones.

> *"Uncle made multiple appeals to the doctor for additional medication for grandfather, even though its effectiveness had waned." (Q17, Carer 099).*

> *"Mr. Zhou had the doctor reduce the dosage since he though his wife couldn't absorb so much." (Q18, Carer 018).*

> *"Aunt requested the paramedics to use all the medications they had brought in their emergency kit to save her husband." (Q19, Carer 104).*

FCGs played an active role in making medication or treatment decisions on behalf of the patients. FCGs also reported feeling disempowered when pain and symptoms were out of control. Notably, FCGs predominantly used the first-person singular pronoun "I" to describe their decision-making on behalf of patients' medication, emphasizing their roles in determining what they perceived as the "best for the patient".

> *"I was the one who decided to buy medication for my husband." (Q20, Carer 177).*

> *"I felt conflicted and torn because I didn't want him to be unconscious by using the stabilizing injection and the sedative." (Q21, Carer 174).*

Conflicts arise among FCGs and between FCGs and the patients regarding medication usage, resulting in a waning empowerment of FCGs. In most cases, FCGs respected patients' authority in taking medication (Carer 174).

> *"Mr. Xie's second son believed that opioids had side effects, so his first son tried to avoid giving his father medication when the second son was around. This led the first son to experience inner turmoil, feeling helpless and heartbroken to see his father suffering." (Q22, Carer 204).*

> *"He refused my suggestion to take the medication because he thought too many medications were harmful to his body." (Q23, Carer 176).*

FCGs reported a sense of powerlessness witnessing the patient's suffering and being unable to alleviate the pain, especially when they perceived ineffective assistance from the HCPs (Carer 006 & 143).

> *"We all speculated that the doctor might not have prescribed a sufficient dosage or effective painkillers. In the last month of his life, Grandpa Li was constantly accompanied by pain day and night, and his symptoms worsened. Taking medication seemed more like a psychological suggestion than a real relief… As a family member, I often felt powerless seeing Grandpa suffer, knowing there was little I could do to alleviate his pain. " (Q24, Care 006).*

> *"Father was in intense and unbearable pain, his face contorted. He sat in a chair, unable to move, emitting weak and mournful moans, and even shouting, 'Just let me die! Death would be better!' I felt helpless and extremely sad, to the point of considering death as a possible relief for my father. I called for an ambulance. Father couldn't walk; he was supported and carefully moved onto a stretcher near the door, then wheeled into the ambulance. It was my first time riding in an ambulance. There was no one on the road, and inside the vehicle, it felt really cold… Seeking medical help and obtaining medication involves various challenges, but the more profound difficulty lies in the internal pain, which no one can truly understand or share." (Q25, Care 143).*

Theme 4: relationships

Medication administration was influenced by relationships between FCGs and HCPs, and within families. The supportive and collaborative relationship between FCGs and HCPs significantly influences access to pain and symptom management information. FCGs in rural areas reported efforts to maintain communication with physicians, despite facing challenges related to limited literacy. (Carer 189) FCGs reported non-adherence to medical guidance regarding prescription and medication treatment if they questioned the expertise of HCPs. (Carer 011)

> *"We, the family members, are all farmers. We don't understand and haven't discussed the details of the illness, but we have always been in communication with the doctor. The doctor keeps explaining complex medical principles that we don't understand. We just listen to what they say about how to treat it, as there's no other option for us." (Q26, Carer 189).*

> *"The doctor explained to Mrs. Huang's parents about the medications they used, how they finally gained control, and helped her overcome several challenges. However, Mrs. Huang felt that the doctor never really understood what was happening." (Q27, Carer 011).*

Within the theme of relationships in Wilson's framework, the concept of 'teamwork' was examined to highlight the coordination among multiple family caregivers (FCGs) involved in medication administration. This coordination can lead to tensions among FCGs and may increase the risk of medication errors. However, a notable aspect of coordination within FCGs in our study is their collective teamwork to find effective medications from various sources for the patients. FCGs reported utilizing multiple channels, including searching the Internet and purchasing medications online (Carer 237), seeking and acquiring medications through social networks (Carer 001), and obtaining them through connections with HCPs (Carer 161).

> *"We would go back to the pharmacy or a small clinic to get his medication. Additionally, I bought some medicines online, spending roughly another 4,000 yuan." (Q28, Carer 237).*

> *"Mr. Huang still had a cough. His nephew Mr. Chen found out that his aunt's daughter worked at the Yangtze River Pharmaceutical Factory. One of the medicines produced there is called "Huangqi Jing," which can help the body recover and strengthen. This medicine, when purchased through regular channels, costs over 300 yuan, but when obtained through internal connections, it's only 100 yuan. So, Mr. Chen bought a good amount of Huangqi Jing and Lung Nourishing Pills through acquaintances. He had Mr. Huang take one piece in the morning and one in the evening. After taking them, Mr. Huang condition improved slightly." (Q29, Carer 001).*

> *"The 30,000 yuan included human albumin, and albumin is not reimbursable. Every time I bought it, I purchased 10 bottles through the doctor. I trusted the doctor because I was afraid of buying the wrong thing. After the doctor bought it, I paid him back. I would get the injection every three to four days, hoping it would help the skin on the back heal faster. However, the effect was not significant. In the end, we discussed having the elderly person discharged from the hospital." (Q30, Carer 161).*

FCGs also encountered difficulties with third-party payers and pharmacies when prescribed medications were inaccessible or unaffordable (Carer 193 & 143).

> *"The reimbursement percentage under the New Rural Cooperative Medical System is quite high, but if a medication is not listed in the medical insurance reimbursement catalog, the cost can be significant. Pain relievers may still be reimbursed, but for medications like human albumin prescribed outside, the reimbursement is minimal." (Q31, Carer 193).*

> *"They mentioned that due to my father's advanced age, he couldn't undergo another surgery. As there was no specific treatment available, the only option was to try a more universally applicable targeted drug. This medication cost over two thousand yuan per box, and he needed to take two boxes every three weeks for one treatment cycle. Unfortunately, it wasn't reimbursable, but after completing ten treatment cycles, they could apply for free medication." (Q32, Carer 143).*

Theme 5: support

Professional support played a pivotal role for FCGs. FCGs mentioned receiving more effective knowledge about symptom control from HCPs in higher-level hospitals, indicating geographic disparities in healthcare resources (Carer 099).

> *"During the hospital stay in the county, a small bedsore appeared on my grandfather's back. The county hospital disinfected it with iodine and applied medication, but the treatment was not effective. Later, a nurse at a hospital in Baoji City told us that iodine prevents skin growth and the correct approach is to disinfect with saline solution before applying medication. It turned out that what the nurse said was correct." (Q33, Carer 099).*

FCGs reported receiving effective pain and symptom management (Carer 035 & 217), humane environment and care (Carer 148), attentive caring by health aides (Carer 212) and advance care planning (Carer 174) in palliative care and hospice centers.

> *"In hospice wards, they mainly use strong anesthetic and sedatives. At that point, they don't even consider the side effects anymore. Without them, it would be unbearable. The doctors in the hospice ward are very good. I hope to volunteer in hospice care to express my gratitude through practical actions and also to help more people." (Q34, Carer 035).*

> *"The sedative has already been increased to the maximum limit and cannot be increased further. Anesthetics have no effect on him. Just think, if my husband hadn't been admitted to hospice center, he would have been truly miserable in the later stages. If my husband's final moments weren't in the calm and comfortable state provided by hospice, but rather in excruciating pain, tortured to death, it would be a nightmare for me. So, I am very grateful to palliative care and hospcie, especially to the hospice care team. This gratitude comes from the bottom of my heart." (Q35, Care 217).*

> *"When I sent my mom in, I felt that hospice center was really great. First, its environment has a kind of humanistic care that you can't feel in other hospitals; second, the professionalism of the nurses is excellent, with a very meticulous attitude. I asked the doctor the most important thing, I said, "Do you have uncontrolled pain here?" He said no, and I really breathed a sigh of relief at that time." (Q36, Carer 148).*

> *"Mom's stable condition is the greatest comfort for our family and having Mrs. Guo (health aide at hospice center) proficiently and patiently provide daily care is a blessing for everyone. She washes and combs Mom's hair, washes her face, assists with bathing, gives her water, and administers nasal feeding after blending meals. She also helps with measuring temperature, administering medication, toileting, pays attention to the color and volume, and immediately reports any issues to the doctors or nurses. Changing clothes and bedsheets are promptly done as needed. Due to Mom's prolonged hemiplegia, her biggest discomfort is the pain in her bones all over her body. Apart from frequently changing positions to relieve pressure, Mrs. Guo occasionally applies herbal ointment to major joints to ease the pain, and she always responds promptly to Mom's requests." (Q37, Carer 212).*

> *"During the final days of Mr. Lao Hai, his three children even meticulously drafted plans for posthumous arrangements and related ceremonies. By being prepared for their father's departure, the entire family, including their elderly mother, calmly followed the established plan in subsequent posthumous activities. Mr. Hai quickly passed through the period of grief. Although there was reluctance for their father's passing, there was inner peace. Mr. Hai also spoke highly of the hospice care and medical staff. Clearly, hospice care services were integrated*

> *into the caregiving arrangement for Mr. Hai by his children and played a significant supportive role." (Q38, Carer 174).*

FCCs also reported difficulties in pain and symptom control at home. (Carer 220 & 098)

> *"We used the local hospital's 'maka' (Anesthetic Drug-Specific Card) to get painkillers for Grandma. However, without the guidance of a doctor and proper pain management measures, many symptoms couldn't be controlled or relieved at home." (Q39, Carer 220).*
>
> *"It's really hard when he came back home since here's no anesthesia available, and we didn't have a pain relief pump at home either." (Q40, Carer 098).*

Theme 6: Culturally specific finding

Alternative medications were found to be used extensively. FCGs explored alternative medicines such as Traditional Chinese Medicine. (Carer 169 & 174) However, FCGs have differing opinions on the efficacy of Traditional Chinese Medicine. This theme did not align well with the Wilson framework; therefore, it is presented separately as a culturally specific finding, distinct from the Western context.

> *"After taking all the traditional Chinese medicine, she has been persevering. My mom drinks a bunch of bitter concoctions every day, but it seems to have no effect. However, if she stops taking the medicine, her condition worsens. It's a situation where the medicine doesn't seem to be working, but not taking it makes things worse." (Q41, Care 169)*
> *"We started seeing a TCM doctor in May. We've consumed over 100 doses of Chinese herbal medicine. Western medicine never acknowledges the significant role traditional Chinese medicine plays. Our Chinese heritage is truly profound; we often can't comprehend the selected herbs, and even Western medicine can't fully understand them. From a Western medical perspective, it might seem like poisonous substances, and they can't grasp it. However, it works effectively." (Q42, Care 174)*

Folk remedies like cactus (Carer 160), bitter melon (Carer 161), snake bile (Carer 193), and herbal remedies (Carer 191 & 244) were also used in addition to contemporary Western medication.

> *"During the period of conservative treatment at home, we tried many traditional Chinese medicines. We experimented with medicinal diets, snake bile, black-bone chicken, and various folk remedies; we tried all sorts of medicines." (Q43, Carer 193)*

Discussion

Our study presents a comprehensive investigation into the medication administration by FCGs at the end of life in China. Our findings indicate that family caregivers (FCGs) in both Western countries and China share several similarities, including concerns regarding the development of knowledge and skills to effectively respond to symptoms and manage medications, organizational abilities to track and monitor medication effects, feelings of disempowerment when symptoms are not adequately controlled or when hospital admissions become necessary, the influence of relationship dynamics on FCGs' capacity to optimize medication administration, a perceived lack of professional support for home-based care.

However, notable differences exist between FCGs in China and their Western counterparts. Chinese FCGs exhibit specific concerns regarding medication accessibility for dying patients, demonstrate heightened involvement and empowerment in medication administration, and a tendency to conceal medication information from patients by employing organizational strategies, such as removing medication packaging. They also engage in collaborative efforts to source effective treatments, drawing on social networks to access a range of medications, with a notable finding of the use of alternative medicine at the end of life. Additionally, FCGs in China face pronounced geographic disparities in the availability of end-of-life care resources. To our knowledge, our study is the first attempt to describe FCGs' medication administration in Chinese end-of-life care settings.

Our findings were consistent with prior studies, indicating FCGs often struggle with medication knowledge and skills, including recognizing and responding to pain and symptoms, determining the correct dose, and concerns about the side effects. However, unlike Kazanowski's study on FCGs in the UK concerning over-medication related to perceptions of duty to keep patients at home [27], we found that FCGs reported their consideration to under-medicate their loved ones. The latter difference is probably explained by limited access to readily available analgesics and sedatives, FCGs' prejudice and misinformation about drug resistance and addiction, stock-outs of drugs, and single route of administration such as oral or injection, which leads to the use of low-level analgesics to manage severe pain. Limited access to readily available analgesics and sedatives, especially in rural areas, potentially due to stringent regulations.

Our study reveals that FCGs in China exhibited significant subjectivity and agency in decision-making and medication management, as evidenced by their frequent use of the first-person singular pronoun "I." For instance, one caregiver stated, "I was the one who decided to buy medication for my husband" (Carer 177). Communication patterns affect the interaction among patients, FCGs, and healthcare professionals [7]. Pollock's research on a British patient demonstrated that the patient and his caregiver (his wife) used the first-person plural, "we," to describe their support from professionals, highlighting the relational nature of managing medicines and care at home [28]. Previous research has suggested that these communication patterns may be influenced by paternalistic values [29], potentially shaping the narratives surrounding caregiving dynamics.

The observation regarding the concealment of medication information related to advanced cancer treatment, as well as the withholding of diagnostic and prognostic information from patients in our study, aligns with findings from prior research conducted within the Chinese population [29–31], which led to the question of whether FCGs empowerment weakens the patient's autonomy [10, 32]. One of our previous studies indicated that approximately 30% of patients made their own end-of-life care decisions, while the remaining deferred this responsibility to FCGs [33]. In the current research, we found that patients are more likely to demonstrate a desire to maintain autonomy after experiencing medication side effects. However, the dynamic of the patient and FCGs empowerment remains under further investigation.

In our study, FCGs took the initiative to administer medication to patients without reporting having received any training. Dying patients are commonly unable to take oral medication, as-needed medication is most often given as a subcutaneous injection by a health-care professional. FCGs are trained to give subcutaneous anticipatory medications in community palliative care at the end of life in Western countries [10, 12, 13, 34, 35], which is rarely found in China. Educating patients and families about pain and symptom management necessitates fostering teamwork with home-based palliative care and hospice [28], which can further empower them in their caring role [36]. However, cares also have their own needs. In our study, FCGs reported satisfaction in the hospice institution, while reported feeling powerless when they saw the patient suffering and couldn't ease the pain, especially if they thought the healthcare providers weren't helping.

Our finding that pain control at home is insufficient highlights the importance of having a key health professional to support and guide patients and FCGs through the system for a positive care experience. One innovative approach to providing this support is through the use of healthcare technologies [37]. A UK-based practice has been initiated to train FCGs in administering as-needed subcutaneous injections for breakthrough symptoms at home without waiting for a nurse to arrive [8, 12], complemented by the development of a digital app to offer enhanced guidance, facilitate remote monitoring, and support caregivers [38, 39]. Currently, China is actively promoting home-based medication management, as evidenced by the Chinese Association of Anesthesiologists Secretariat's proposal of the establishment of the Palliative Care Committee and the Digital Intelligence Committee on December 14, 2023 [40]. Further evidence is needed to assess the feasibility of implementing healthcare technologies in palliative care settings in China.

Our study has limitations. Firstly, 65·8% of the patients described in the bereaved FCGs interviews had a primary diagnosis of cancer, with four patients dying from dementia. Considering that patients with severe mental disorders might experience inequalities in end-of-life care, further studies should pay attention to this subgroup. Second, our investigation predominantly focuses on the barriers to medication administration by FCGs, with less emphasis on the facilitators. Future research can explore the positive factors that facilitate home medication management by FCGs. Third, the 73 death narrative interviews used in this study were part of a larger project. While our participants mentioned medication administration, which piqued our interest, future research could focus specifically on interviewing and observing dying patients themselves and their family caregivers regarding medication management at home. Fourth, building on Wilson et al.'s thematic framework, we aim to compare and contrast the characteristics of family caregivers' medication administration experiences in China with those in the Western world. However, further research should consider introducing a theoretical framework to address cultural and legal differences that may impact its applicability. Despite the above limitations, one notable strength of our study is that it provides a comprehensive understanding of medication administration experiences in end-of-life care among under-researched and hard-to-reach demographics, with 72.6% of our patients being from rural areas, despite the rural population constituting only 36.1% of China's total population in 2020 [41].

In conclusion, our findings build upon Wilson et al.'s framework and extend their insights on empowerment, highlighting the need for policies to support home-based palliative care professionals in training FCGs for effective medication administration. Also, a well-integrated system of palliative care into the mainstream healthcare system is imperative for China. This support can enhance end-of-life care and promote a balance between patient and FCG empowerment in China.

Supplementary Information

The online version contains supplementary material available at https://doi.org/10.1186/s12904-024-01575-4.

Supplementary Material 1

Acknowledgements
We thank Zhimeng Jia from the Department of Family and Community Medicine, University of Toronto, for his insightful suggestions on framing this paper within the context of methodology, specifically in medication administration in palliative care and hospice.

Author contributions

FY and BW designed the study. FY and MS analyzed and interpreted the data. FY drafted the manuscript. PSW, YT, JJ, GJL and BW revised the manuscript.

Funding
This research is funded by the first batch of Independent Projects from the Tsinghua Institute for Governance Studies (IGS202004); A research grant from the Center for Social Governance and Innovation at Tsinghua University, a major research center for Shenzhen Humanities & Social Sciences Key Research Bases; and the Social Technology for Global Aging Research Initiative at Harvard.

Data availability

Data used in this study were made available under a contract with Tsinghua University, China. Prof. Jing Jun should be contacted if data is requested.

Declarations

Ethics approval and consent to participate

We provided the participants with an introduction and explanation of the project and obtained verbal informed consent. The Internal Review Board at Tsinghua University's Public Health Research Center approved the research plan, encompassing the interview guides (Ethical Approval number: THZWJC27).

Consent for publication

Not Applicable.

Competing interests

The authors declare no competing interests.

Received: 19 July 2024 / Accepted: 11 October 2024

References

1. Cheng Y, Cui C. Research on the Professional advantages of Medical Social Work in the construction of Inclusive Hospice Care System from the whole person care. Social Work Manage. 2024;24(03):1–11.
2. Zhang Y, Li J, Zhang Y, Chen C, Guan C, Zhou L, Zhang S, Chen X, Hu X. Mediating effect of social support between caregiver burden and quality of life among family caregivers of cancer patients in palliative care units. Eur J Oncol Nurs. 2024;68:102509.
3. McCarthy B, Timmins F, Eustace-Cook J, Connolly M. Informal caregivers' experiences of transitioning during end-of-life care—A scoping review. J Adv Nurs. 2024;80(5):1719–31.
4. Motamedi M, Brandenburg C, Bakhit M, Michaleff ZA, Albarqouni L, Clark J, Ooi M, Bahudin D, Chróinín DN, Cardona M. Concerns and potential improvements in end-of-life care from the perspectives of older patients and informal caregivers: a scoping review. BMC Geriatr. 2021;21:1–12.
5. Cheng G, Chen C. End-Of-Life needs of dying patients and their families in mainland China: a systematic review. OMEGA-Journal Death Dying. 2023;86(3):1019–45.
6. Bosma H, Apland L, Kazanjian A. Cultural conceptualizations of hospice palliative care: more similarities than differences. Palliat Med. 2010;24(5):510–22.
7. Cain CL, Surbone A, Elk R, Kagawa-Singer M. Culture and palliative care: preferences, communication, meaning, and mutual decision making. J Pain Symptom Manage. 2018;55(5):1408–19.
8. Poolman M, Roberts J, Byrne A, Perkins P, Hoare Z, Nelson A, Hiscock J, Hughes D, Foster B, O'Connor J. CARer-ADministration of as-needed subcutaneous medication for breakthrough symptoms in homebased dying patients (CARiAD): study protocol for a UK-based open randomised pilot trial. Trials. 2019;20(1):1–16.
9. O'Hara L, Evans CJ, Bowers B. Family carers' administration of injectable medications at the end of life: a service evaluation of a novel intervention. Br J Community Nurs. 2023;28(6):284–92.
10. Lee L, Howard K, Wilkinson L, Kern C, Hall S. Developing a policy to empower informal carers to administer subcutaneous medication in community palliative care; a feasibility project. Int J Palliat Nurs. 2016;22(8):369–78.
11. Chi N-C, Barani E, Fu Y-K, Nakad L, Gilbertson-White S, Herr K, Saeidzadeh S. Interventions to support family caregivers in pain management: a systematic review. J Pain Symptom Manage. 2020;60(3):630–56. e631.
12. Poolman M, Roberts J, Wright S, Hendry A, Goulden N, Holmes EA, Byrne A, Perkins P, Hoare Z, Nelson A. Carer administration of as-needed subcutaneous medication for breakthrough symptoms in people dying at home: the CARiAD feasibility RCT. Health Technol Assess (Winchester Eng). 2020;24(25):1.
13. Pitts J, Geller G, Muller A. Caregiver experiences in administering subcutaneous medications to community palliative care patients: integrative review. Home Health Care Serv Q. 2023;42(2):154–72.
14. Weng L, Hu Y, Sun Z, Yu C, Guo Y, Pei P, Yang L, Chen Y, Du H, Pang Y. Place of death and phenomenon of going home to die in Chinese adults: a prospective cohort study. Lancet Reg Health-Western Pac. 2022;18:100301.
15. Yang F, Leng A, Jing J, Miller M, Wee B. Ecology of End-of-life Medical Care for Advanced Cancer patients in China. Am J Hospice Palliat Medicine® 2023:10499091231219254.
16. Li Tu MY. The effects of Community Medical resources and their utilization on the end-of-life location of the older people in China from an inter-provincial perspective: an empirical analysis of CLHLS Mortality samples. South China Popul. 2024;39(01):33–45.
17. Leng A, Jing J, Nicholas S, Wang J. Geographical disparities in treatment and health care costs for end-of-life cancer patients in China: a retrospective study. BMC Cancer. 2019;19(1):1–14.
18. Zhu S, Zhu H, Zhang X, Liu K, Chen Z, Yang X, Sun C, Xie W, Xu Q, Li W. Care needs of dying patients and their family caregivers in hospice and palliative care in mainland China: a meta-synthesis of qualitative and quantitative studies. BMJ open. 2021;11(11):e051717.
19. Huang Y, Zhang L, Huang X, Liu K, Yu Y, Xiao J. Potentially inappropriate medications in Chinese community-dwelling older adults. Int J Clin Pharm. 2020;42:598–603.
20. Li Y, Hu J, Gao Y-Z, Zhou F, Zhu Z-H, Zhang B-F, Zhu K, Zhu J-G, Zhang J-J. Prevalence and determinants of potentially inappropriate medications prescribing in elderly patients in Chinese communities. Ann Palliat Med. 2021;10(2):2072–9.
21. Lai X, Zhu H, Huo X, Li Z. Polypharmacy in the oldest old (≥ 80 years of age) patients in China: a cross-sectional study. BMC Geriatr. 2018;18(1):1–8.
22. Chen Y, Gao J, Lu M. Medication adherence trajectory of patients with chronic diseases and its influencing factors: a systematic review. J Adv Nurs. 2024;80(1):11–41.
23. Fa C, Yang F, Wu J, Zeng J, Wang L, Lu X, Song M, Zhang R, Jing J. Design a Voluntary Cooperative Network Research in End-of-Life Care. Asia Pacific Viewpoint [Under review]; 2024.
24. Jing J, Fa C. Explaining a limitation of the theory of Downward Familism from the perspective of Palliative Care. Qinghai J Ethnology. 2024;35(01):35–44. https://doi.org/10.15899/j.cnki.11005-15681.12024.15801.15024.
25. Hsieh H-F, Shannon SE. Three approaches to qualitative content analysis. Qual Health Res. 2005;15(9):1277–88.
26. Wilson E, Caswell G, Turner N, Pollock K. Managing medicines for patients dying at home: a review of family caregivers' experiences. J Pain Symptom Manage. 2018;56(6):962–74.
27. Kazanowski M. Family caregivers' medication management of symptoms in patients with cancer near death. J Hosp Palliat Nurs. 2005;7(3):174–81.
28. Pollock K, Wilson E, Caswell G, Latif A, Caswell A, Avery A, Anderson C, Crosby V, Faul C. Family and health-care professionals managing medicines for patients with serious and terminal illness at home: a qualitative study. Health Serv Delivery Res 2021, 9(14).
29. Mei X, Tu J. Values, skills, and decision-making: a cultural sociological approach to explaining diagnostic disclosure. Soc Sci Med. 2021;279:114034.

30. Jeon ED, Jing J. A study of end-of-life care communication and decision-making in China by exploring filial piety and medical information concealment. Asian J Med Humanit. 2023;2(1):20230006.
31. Xu T, Qin Y, Ou X, Zhao X, Wang P, Wang M, Yue P. End-of-life communication experiences within families of people with advanced cancer in China: a qualitative study. Int J Nurs Stud. 2022;132:104261.
32. Wakefield D, Bayly J, Selman LE, Firth AM, Higginson IJ, Murtagh FE. Patient empowerment, what does it mean for adults in the advanced stages of a life-limiting illness: a systematic review using critical interpretive synthesis. Palliat Med. 2018;32(8):1288–304.
33. Yang F, Leng A, Wang J, Jing J, Leiter RE, Sharma RK, Krakauer EL, Jia Z. Association between primary decision-maker and care intensity among patients with Advanced Cancer in Mainland China. Am J Hospice Palliat Medicine® 2023:10499091221150768.
34. Sheehy-Skeffington B, McLean S, Bramwell M, O'Leary N, O'Gorman A. Caregivers experiences of managing medications for palliative care patients at the end of life: a qualitative study. Am J Hospice Palliat Medicine®. 2014;31(2):148–54.
35. Healy S, Israel F, Charles M, Reymond L. Laycarers can confidently prepare and administer subcutaneous injections for palliative care patients at home: a randomized controlled trial. Palliat Med. 2018;32(7):1208–15.
36. Payne S, Turner M, Seamark D, Thomas C, Brearley S, Wang X, Blake S, Milligan C. Managing end of life medications at home—accounts of bereaved family carers: a qualitative interview study. BMJ Supportive Palliat care. 2015;5(2):181–8.
37. Healy S, Israel F, Charles MA, Reymond L. An educational package that supports laycarers to safely manage breakthrough subcutaneous injections for home-based palliative care patients: development and evaluation of a service quality improvement. Palliat Med. 2013;27(6):562–70.
38. Hopkins C, Eastwood I, Poolman M, Williams I, Hoskin L, Kilkenny C, Gregory J. P-222 Designing a mobile app which supports unpaid carers to administer subcutaneous injections. BMJ Supportive Palliat Care. 2021;11(Suppl 2):A89–89.
39. London, HCIoGHIIC. Palliate.
40. Anesthesiologists TCAo. The Fourth Seventh Council of the Chinese Association of Anesthesiologists. 2023.
41. Statistics NBo. Urban and Rural Population and migrant Population Situation. China Popul Census Yearbook 2020, Seventh National Census Bulletin (7).

Publisher's note