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Original Paper

Caregivers' Care Needs for Advanced Cancer Pain Patients with Intrathecal Morphine Pump: A Mixed Methods Journey Mapping Study

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Abstract

Aim: *This study aimed to explore the dynamic care needs and emotional experiences of caregivers during the perioperative and early post-discharge periods using a mixed-methods approach and patient journey mapping.*

Design: *A mixed-methods design, qualitative in-depth individual interviews and integrating quantitative data analysis.*

Methods: *A total of 17 caregivers of patients undergoing intrathecal morphine pump implantation participated in semi-structured interviews. Interviews were conducted across five key care phases: Pain Clinic (Decision-making Stage); Admission Day (Preoperative Preparation); Surgery Day/Pain Relief Treatment Implementation; One Day Before Discharge (Home Care Preparation); 1-2 Weeks After Discharge. Quantitative data were collected using the Hamilton Anxiety Rating Scale (HAMA) and the Zarit Caregiver Burden Scale. We combined qualitative themes with quantitative data to build a full journey map. This map shows how the care needs, emotional ups and downs, and key contact points change over time for caregivers of advanced cancer pain patients. We also tracked caregivers' anxiety and burden levels across the five phases.*

Result: *Caregivers' needs shift across the treatment trajectory. Anxiety and burden peak during the home care period after intrathecal morphine pump implantation. The main pain points are: fear of handling complications alone at home, and insufficient discharge instructions. On the flip side, caregivers feel relief and safety during hospital stays, largely because they trust the professional care. The journey map also reveals that limited home support and poor follow-up services keep caregivers struggling.*

Conclusion: *Caregivers of these patients have different needs at different stages. Nurses should focus on*

periods with high burden and high anxiety, offering tailored assessments and interventions. That would ease caregiver stress and improve end-of-life care quality.

Patient or Public Contribution: *No patients or public members were involved in designing, conducting, or reporting this study.*

Keywords

Pain, caregivers, Advanced cancer, Care need

1. Introduction

Cancer pain is common and very distressing for advanced cancer patients. It seriously lowers their quality of life. Around 70% of patients with localised cancer have significant pain, and over 90% of those with advanced disease experience severe pain[1]. Intrathecal morphine pumps work well for refractory cancer pain, especially in end-stage cases. But caregivers—who monitor pain and help make decisions—face changing demands, emotional strain, and little guidance throughout the whole process. Even though these pumps are used more and more, few studies have looked closely at caregivers' real-life experiences during the perioperative and home care periods. So, we designed this study to explore caregivers' experiences, emotions, and unmet needs at key stages of the pump intervention, using a journey-mapping approach. We hope the results will help shape more responsive and personalised palliative care strategies.

2. Background

Latest figures show that in 2022, China had about 4.82 million new cancer cases—a rise from previous years, highlighting cancer as a continuing major public health issue[2]. Pain is one of the most frequent complaints, especially in advanced or metastatic cancer, and it is a huge source of suffering at the end of life[3].

The intrathecal morphine pump is now a standard treatment for intractable pain in advanced or metastatic cancer. The procedure is minimally invasive: a catheter tip goes into the lumbar intrathecal space, and the other end connects to a subcutaneous reservoir. It delivers opioid painkillers continuously or on a programmed schedule directly into the cerebrospinal fluid. That way, the drugs act on spinal and brain opioid receptors, giving strong pain relief with fewer systemic side effects[4].

Caregiving needs in cancer pain are not static—they change as the disease progresses and pain gets worse[5]. Caregivers are the main people managing pain, and they have to juggle many stressors: physical exhaustion, psychological distress, family duties, social expectations, and financial pressure. Providing high-intensity care for a long time leads to chronic overload and high anxiety, which in turn can affect the patient's own pain and quality of life. Earlier studies have noted that family caregivers of advanced cancer patients carry a heavy burden[6], but few have dug into exactly what drives that burden and how it builds up over time.

3. Materials and Methods

3.1 Aim

In this study, we used an integrated journey-mapping framework and a convergent mixed-methods design to capture how caregivers' emotions, behaviours, and care needs evolve over time in the context of cancer pain. By systematically analysing touchpoints and pain points at each stage, we want to build an evidence base that helps caregivers deliver better care, improves patient well-being, and reduces caregiver strain and anxiety.

3.2 Study Design and Population

Between October 2024 and April 2025, we applied purposive sampling to enlist caregivers of late-stage cancer pain patients treated at the Pain Department of a high-volume tertiary medical center. Eligible participants met the following inclusion criteria: (1) primary caregiver of a patient with a confirmed diagnosis of advanced cancer who was informed of their diagnosis; and (2) provided written informed consent and voluntarily agreed to participate in both qualitative interviews and quantitative surveys. Participants were excluded if: (1) their care recipient passed away during the course of treatment or follow-up; or (2) they were unable to comprehend study materials or cooperate with data collection procedures. A total of 17 caregivers were ultimately included. The participant selection and data-collection process is depicted in Figure 1.

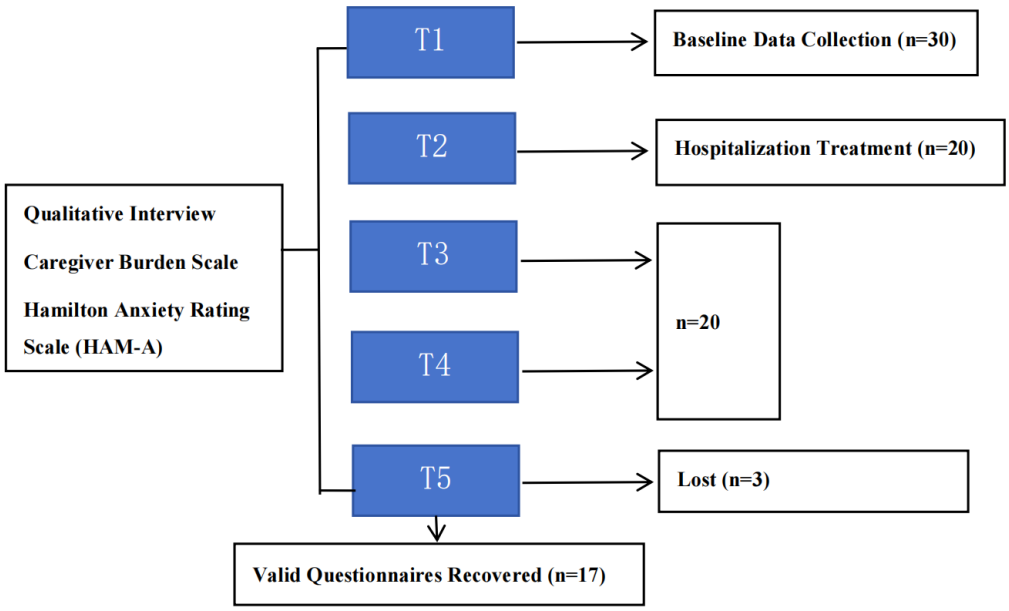

Figure 1. The Participant Selection and Data-collection Process

3.3 Qualitative Study

3.3.1 Interview Methodology

A descriptive qualitative methodology was adopted, with semi-structured interviews as the primary data-collection technique to explore the evolving care needs of caregivers supporting patients with cancer-

related pain.

3.3.2 Development of the Interview Guide

An initial draft of the interview outline was constructed based on the study aims and then pre-tested in three pilot interviews with caregivers of advanced cancer pain patients. Following a debriefing and group discussion, the guide was refined into its final version. Key domains included:

(1) Pain-management plans: Which pharmacologic or non-pharmacologic strategies did clinicians present, and how did you interpret them?

(2) Educational support: Did physicians or nurses provide pain-management education you could understand, and what additional information or resources would you find helpful?

(3) Hospitalization experience: What were your main impressions during the inpatient stay, and were there aspects that confused you?

(4) Caregiving competence: To what extent do you feel capable of caring for the patient, and in which areas would you welcome assistance?

(5) Efficacy of pain control: After surgery or other treatments, how well was the patient's pain managed, and did this meet your expectations?

(6) Help-seeking pathways: If pain control proved unsatisfactory, through which channels did you seek further assistance?

(7) Follow-up support: Did the hospital offer post-discharge follow-up, and would you have preferred more support?

(8) Post-discharge concerns: What worries do you have about caring for the patient at home?

(9) Impact on caregivers: How has caregiving affected your life, and what are your greatest challenges?

(10) Home pain management: How smoothly has pain been managed after discharge, and have any unexpected events occurred?

3.3.3 Data-Collection Procedure

Prior to each interview, researchers introduced the study's objectives, estimated interview duration (15~30 minutes), and confidentiality protocols. Written informed consent was obtained. During the interviews, researchers attentively noted verbal responses as well as nonverbal behaviors—gestures, facial expressions, emotional tone—and employed probing, paraphrasing, and clarification to verify critical information. All interviews were audio-recorded and transcribed verbatim. To safeguard privacy, caregivers were assigned anonymized codes (N1~N17). The overall process is summarized in Table 1.

Table 1. Basic Patient Information

	Age	Gender	Caregiver	Cancer Site	Time of Cancer Diagnosis
N1	61	Male	Spouse	Pancreatic Cancer	1 Years Ago
N2	74	Female	Children	Pancreatic Cancer	1 Years Ago
N3	77	Female	Children	Pancreatic Cancer	10 Month Ago

N4	47	Female	Spouse	Neuroendocrine Tumor	3 Years Ago
N5	74	Female	Spouse	Lung Cancer	1 Years Ago
N6	48	Male	Spouse	Cholangiocarcinoma	2 Years Ago
N7	68	Male	Children	Renal Cell Carcinoma	5 Years Ago
N8	58	Male	Spouse	Lung Cancer	3 Years Ago
N9	37	Female	Parents	Appendiceal Adenocarcinoma	4 Years Ago
N10	55	Male	Spouse	Liver Cancer	2 Month Ago
N11	61	Male	Spouse	Lung Cancer	1 Years Ago
N12	53	Male	Spouse	Pancreatic Cancer	1 Years Ago
N13	60	Male	Spouse	Liver Cancer	4 Month Ago
N14	50	Female	Spouse	Cervical Cancer	4 Month Ago
N15	61	Male	Spouse	Liver Cancer	2 Years Ago
N16	67	Male	Spouse	Lung Cancer	1 Years Ago
N17	64	Male	Children	Liver Cancer	4 Years Ago

3.4 Quantitative Study

3.4.1 Questionnaire Survey Method

Following each semi-structured interview, participants were administered the Hamilton Anxiety Rating Scale (HAMA) to assess their anxiety levels and the Zarit Caregiver Burden Scale to quantify the subjective burden of caregiving.

3.4.1.1 Hamilton Anxiety Rating Scale

The HAM-A[7] has 14 items that cover both psychic anxiety (like tension and fears) and somatic symptoms (such as muscle tightness and sensory issues). Each item uses a 5-point scale, giving a total from 0 to 56. The usual cutoffs are: ≥29 = severe, >21 = marked, >14 = definite, ≥7 = possible, and <6 = no clinical significance. In this study we took a score of 7 or higher to mean clinically relevant anxiety.

3.4.1.2 Zarit Caregiver Burden Interview

The ZBI[8] is a 22-item questionnaire that measures how burdened caregivers feel, regardless of the patient's condition or stage. It breaks down into two subscales—Personal Burden and Role Burden. Each item is scored 0–4, so the total can reach 88. A higher total indicates more burden; we used the standard thresholds: <19 = none, 20–39 = mild, and >39 = severe.

3.5 Analytical Methodology for Study Data

3.5.1 Qualitative Data Analysis

We transcribed every interview verbatim and organised the transcripts within 24 hours of the session. Using conventional content analysis, two researchers independently read through the texts multiple times, highlighted significant statements, and assigned tentative codes. They then compared their codes, discussed disagreements, and iteratively refined a unified coding framework. Finally, they recoded all the material with that framework to produce the final codebook.

3.5.2 Quantitative Data Analysis

For the HAM-A and ZBI scores, we ran descriptive statistics. For each disease stage, we calculated the mean and standard deviation of both anxiety and burden scores.

3.5.3 Journey Map Construction

We merged the qualitative themes with the quantitative results to build a full journey map. This map traces how care needs, emotional states, and key touchpoints change over time for caregivers of advanced cancer pain patients.

4. Results

4.1 Journey Map Construction

A patient journey map has two axes: time on the horizontal and tasks on the vertical. We split the caregiver journey into five phases: (1) Pain Clinic (decision-making); (2) Admission Day (pre-op preparation); (3) Surgery Day (pain treatment delivery); (4) One Day Before Discharge (home-care planning); and (5) 1–2 Weeks After Discharge. For each phase, we plotted four elements: (1) care tasks – what the caregiver had to do; (2) touchpoints – key interactions or moments; (3) emotions – how the caregiver felt; and (4) pain points – the main obstacles or frustrations they encountered.

Using this framework, we went back through our interview notes to pull out, for each stage, what caregivers were doing, thinking, and feeling—and where they got stuck or felt stressed. By laying those stories side by side across the five stages and four dimensions, we created a complete "storyline" of the caregiver experience. The final map is shown in Figure 2.

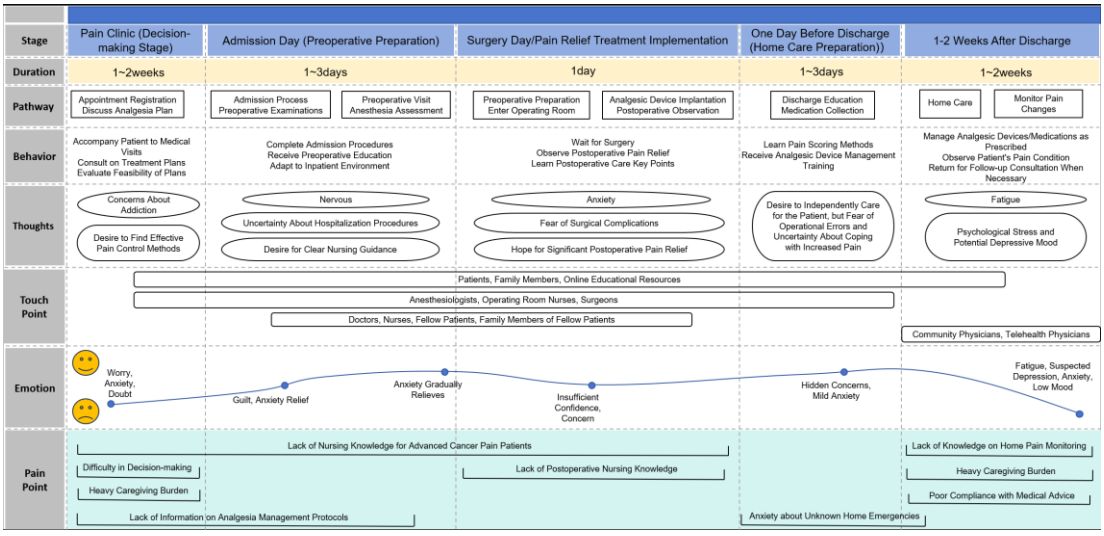

Figure 2. Journey Map of Caregiving Needs for Caregivers of Advanced Cancer Patients

4.2 Caregiving Experiences of Caregivers at Different Stages

4.2.1 Pain Clinic (Decision-making Stage)

4.2.1.1 Behavior

Caregivers accompany the patient to each visit and proactively ask about pain-relief options.

N6: “I didn’t know what pain relief methods were available. I heard there’s a pain clinic, so I came.”

N7: “If my dad is admitted, what treatments will he receive?”

N8: “I don’t really understand the nerve blocks and intrathecal injections you mentioned—do they actually work? I also don’t know where to find information about pain relief methods.”

4.2.1.2 Thought

Caregivers express worries about addiction and a strong desire to ease the patient’s suffering.

N6: “Doctor, will these methods make him addicted?”

N10: “Doctor, please make sure he isn’t in so much pain. It breaks my heart to see him like this.”

4.2.1.3 Emotions

Caregivers experience intense worry and anxiety about the patient’s pain:

Worry.N9: “She was moaning all night at home—I’m so worried about her, but I feel helpless.”

Anxiety.N10: “What can I do, doctor? His pain has kept me awake for nights.”

4.2.1.4 Pain Points

Unfamiliar with pain-relief options, difficulty deciding.

N8: “I don’t really understand the nerve blocks and intrathecal injections you mentioned—do they actually work? I also don’t know where to find information about pain relief methods.”

N12: “I’m not sure exactly which pain-relief method will be used, only that it’s supposed to work—I just want to give it a try.”

Insufficient caregiving knowledge, heavy burden.

N13: “He’s so frail and can’t eat much; I don’t know how to help him feel more comfortable.”

4.2.2. Admission Day (Preoperative Preparation)

4.2.2.1 Behavior

Caregivers complete admission procedures, attend preoperative education sessions, and adapt to the hospital environment:

N7: “Do I need to do anything before the surgery? Do I need to buy anything?”

N3: “Could you give me some materials about the surgery to look over?”

4.2.2.2 Thought

Unclear about hospitalization process, hoping for clear caregiving guidance.

N8: “The doctor explained everything very professionally, but I forget it right after hearing it. Terms like ‘epidural’ and ‘intrathecal’ are too technical.”

N2: “Doctor, now that I’ve brought my mother to the hospital, is there any immediate pain relief option available to ease her suffering?”

N13: “He’s eating very little and is so thin. Is there a way to help improve his condition?”

4.2.2.3 Emotions

Guilt.

N15: “I should have brought him here earlier. Maybe then he wouldn’t have suffered so much.”

N16: “I don’t know what to do to make him feel better.”

Relieved anxiety.

N17: “Now that there are many medical staff helping to manage my father’s pain, I feel much more at ease.”

N2: “Now that we’re in the hospital, at least I’m not as worried.”

4.2.2.4 Pain Points

Lack of caregiving knowledge for late-stage cancer patients.

N8: “When we were at home, I couldn’t do anything to help him. I really want to learn from the medical staff how to care for him and make him feel more comfortable.”

Insufficient information about pain management methods.

N9: “The surgery is coming soon, but I still don’t understand how the medication inside the implanted pump is delivered, how long it will last, or whether it could lead to addiction.”

4.2.3 Sugrgery Day/Pain Relief Treatment Implementation

4.2.3.1 Behavior

Waiting during surgery, monitoring patient’s response to pain relief.

N12: “He’s not crying anymore, but he seems dazed. He doesn’t respond to us.”

N15: “He still looks like he’s in pain.”

Trying to learn postoperative care basics

N7: “Now that the surgery is done, what else can I do to help?”

4.2.3.2 Thought

Fear of complications, hope for better pain relief.

N5: “This pain pump doesn’t seem effective. He still appears to be in pain.”

N12: “He had the surgery, but he still can’t even open his eyes to talk to us.

Lack of wound care knowledge.

N7: “I really don’t know how to take care of the wound. Should I touch it? Will it get infected? There’s no information for me to read.”

4.2.3.3 Emotions

Anxiety temporarily relieved, but uncertain about postoperative care.

N17: “He doesn’t look like he’s in as much pain now, but is that just temporary?”

N5: “Is there anesthetic in that device? How long before it wears off?”

4.2.3.4 Pain Points

Lack of caregiving knowledge for late-stage cancer and post-surgery care.

N7: “I really don’t know how to take care of the wound. Should I touch it? Will it get infected? There’s nothing for me to read about it.”

N13: “It would be so helpful if you could just walk me through how I should care for him at home.”

4.2.4 One Day Before Discharge (Home Care preparation)

4.2.4.1 Behavior

Learning to assess pain and manage pain-relief equipment.

N12: “Today the doctor taught me how to tell if he’s in pain by watching his facial expressions.”

N6: “The doctor said just keep the wound dry at home and go to the local clinic for dressing changes regularly.”

4.2.4.2 Thought

Hopes to care independently, but worries about making mistakes.

N1: “He’s much better now than when we first came. I think he’ll be more comfortable at home.”

N2: “In the hospital, at least I could ask someone. Now that we’re home, I’m responsible for everything, and the pressure is mounting.”

N3: “The doctor says he’s ready to go home, but honestly, I don’t feel ready. Who’s going to guide us with meds and nursing after discharge?”

Uncertain how to deal with illness or side effects after discharge.

N4: “She’s sleeping too much now. I’m afraid the medication is too strong, that she won’t be able to eat, and that it may slow down her recovery.”

4.2.4.3 Emotions

Worry, mild anxiety.

N16: “I’ve learned a lot at the hospital. The nurses and doctors explained many things, so I no longer feel as lost as I did in the beginning.”

N12: “I’m afraid that once we get home, if the pain flares up again or side effects like sudden breathing pauses occur, I won’t know how to handle it.”

4.2.4.4 Pain Points

Lack of confidence in caregiving skills; insufficient information and practical know-how.

N1: “Even though the nurses and doctors told me what to watch out for at home, I still don’t feel confident about dealing with anything if something actually happens.”

N5: “The patient previously had lung surgery. If the pain medication suppresses her breathing, I wouldn’t know how to deal with it.”

4.2.5 1~2 Weeks After Discharge

4.2.5.1 Behavior

Managing pain pump/medication as instructed.

N1: “So far, there’s no indication that the medication in the pump has run out, and we’ve been careful to protect the site around the incision as instructed.”

Monitoring the patient’s pain and returning to the hospital if needed.

N5: “Her pain is much better than before we went to the hospital, but she still seems groggy.”

N4: “I’m still unclear about what symptoms would actually require us to come back for a follow-up.”

4.2.5.2 Thought

Fatigue.

N5: “It worked well in the beginning, but now she’s in pain again. I don’t know if the medication has

worn off. Should I take her back to the hospital?"

N11: "I thought this method would last a while, but after just a few weeks the pain came back. It's really wearing me down."

High emotional stress; risk of depression.

N15: "She sleeps more and more. I have to monitor her reactions to the medication constantly. I'm afraid she might 'pass away' suddenly."

4.2.5.3 Emotions

Fatigue, anxiety, low mood, possible depression.

N8: "Watching him sleep all day and eat so little, I'm increasingly worried the illness is getting worse."

N9: "I thought this method would work for a while, but now the pain is back after only a few weeks. It's really draining."

N6: "I haven't been eating or sleeping well lately. I'm afraid of complications from the pump—he's unconscious more and more."

4.2.5.4 Pain Points

Lack of home pain–monitoring knowledge; heavy caregiving burden.

N13: "He sleeps so much, I don't know when he's actually in pain. The doctor told me to watch his facial expressions, but it's not that simple in real life."

Poor adherence to follow-up advice.

N14: "I thought this method would work for a while, but now the pain is back after only a few weeks. It's really draining."

4.3 Trends in Caregiver Burden and Anxiety Throughout the Care Trajectory of Caregivers of Patients with Advanced Cancer Pain

In caregivers of patients with advanced cancer pain, Caregiver Burden (ZBI) Scores: (1)Pain Clinic (Decision-making Stage): 27.94 ± 8.13; (2)Admission Day (Preoperative Preparation): 14.53 ± 6.24; (3)Surgery Day/Pain Relief Treatment Implementation: 15.18 ± 6.14; (4) One Day Before Discharge (Home Care Preparation): 14.47 ± 4.16; (5) 1~2 Weeks After Discharge: 26.76 ± 9.57.Anxiety (HAM-A) Scores: (1)Pain Clinic: 8.82 ± 5.50; (2)Admission Day: 5.00 ± 4.06; (3)Surgery/Treatment Day: 4.94 ± 4.39; (4)Day Before Discharge: 6.06 ± 3.31; (5)1~2 weeks After Discharge: 9.47 ± 8.50.

Caregiver burden and anxiety scores were relatively low during the inpatient period; following discharge, anxiety scores reached their peak, whereas caregiver burden remained lower than that recorded in the pre-admission phase (Figure 3).

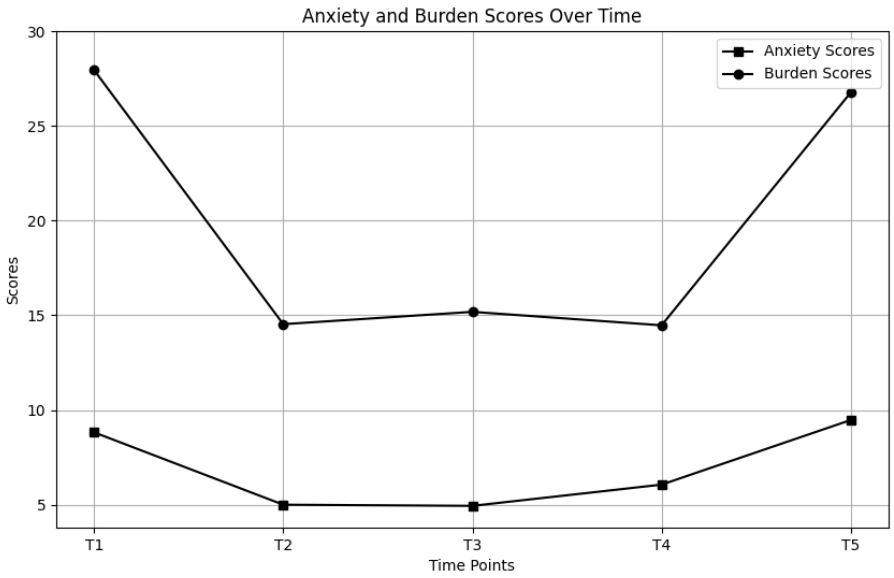

Figure 3. Trajectories of Anxiety and Caregiving Burden Among Caregivers of Advanced Cancer Patients

5. Discussion

5.1 Pain Clinic (Decision-making Stage)

At this point, caregivers mainly accompany patients to outpatient appointments, gather information about pain relief options, and weigh the pros and cons of each approach[9]. They want to find the best pain management strategy, but their limited medical knowledge often makes the decision difficult. Many feel anxious about the heavy care work ahead, and some worry that painkillers might cause addiction. Their main needs in this decision phase are: picking a suitable treatment, understanding how the intrathecal pump works, and figuring out how to cope with the caregiving load.

Patients and caregivers often have trouble grasping treatment plans because medical terms are unfamiliar—they can't easily compare effectiveness or costs across options. So they urgently need clear, practical information about the pump's mechanism, benefits, how it's operated, post-op care, and expenses. Earlier studies have shown that most caregivers feel anxious during the care process[10]. In our study, all caregivers were family members. Looking after a patient with cancer pain is a long-term, ongoing job. When the caregiver is an adult child who also has their own family, or is the main breadwinner, this role naturally takes a toll on their mental health and daily life.

To support caregivers at this stage, clinicians should avoid medical jargon during consultations. Plain, straightforward language works much better[11]. They should explain the intrathecal analgesia procedure in detail—its principles, expected results, and practical nuts and bolts. Staff should also encourage caregivers to voice their worries, offer supportive solutions, and point them to reliable educational materials.

5.2 Admission Day (Preoperative Preparation)

By this stage, caregivers' anxiety and burden have eased somewhat—probably because the hospital

environment feels safer and more professional, which takes some weight off their shoulders. Their main needs now include: understanding admission procedures, getting used to the new setting, learning about perioperative care, and dealing with the uncertainties that come with inpatient treatment. Since admission is often decided on short notice, caregivers may feel unprepared, and not knowing how the hospital works adds extra stress. At the same time, they feel hopeful about the treatment's potential benefits, but also worry about side effects. With surgery approaching, their limited knowledge of pre-op preparation and nursing care makes them hungry for more guidance from the medical team[12].

During this phase, patients and caregivers are in a professional environment where they can get timely help from staff—which helps lower stress and anxiety. Our journey map shows that it's important for healthcare professionals to actively guide caregivers through the hospital system when they first arrive. Caregivers are eager to learn and need clear, straightforward communication. Staff should explain the step-by-step pain management plan, give detailed information about inpatient care requirements, and answer any questions or concerns as they come up.

5.3 Surgery Day/Pain Relief Treatment Implementation

Pain is still the single biggest factor that ruins quality of life for advanced cancer patients[13]. Among all available treatments, intrathecal or intraspinal analgesic pump implantation is now seen as one of the most effective ways to manage severe pain in this group. That said, in current practice, most hospitals still rely on intramuscular injections, oral meds, or sublingual opioids—morphine pump use is relatively uncommon.

Our findings suggest that during the perioperative period, caregivers interact a lot with healthcare professionals—surgeons, nurses, and even other patients' families—which helps them sort out problems as they arise. However, since this is usually the patient's first pump implantation, caregivers often lack confidence in post-op care. Their burden tends to rise shortly after admission, possibly because the patient has to stay in a fixed position for several hours after the procedure.

Plenty of studies have confirmed that intrathecal analgesic pumps work well for post-operative pain—pain scores often drop from 10 to about 3.5 after surgery[14],[15]. At this stage, both the patient and caregiver can see the pain relief firsthand, which lowers their anxiety and burden. Still, it's worth noting that the pump doesn't remove pain completely. If patients or families expect total relief, they may end up disappointed.

So, before surgery, healthcare providers should give caregivers clear, easy-to-understand education about how the pump works, what therapeutic effects to expect, and possible side effects. Setting up dedicated support groups for caregivers of advanced cancer patients with analgesic pumps could also help. These groups would let caregivers share practical post-op care tips, ensure continuity after discharge, and get prompt help for complications under the unified guidance of professionals.

5.4 One Day Before Discharge (Home Care Preparation)

After a hospital stay and starting pump therapy, patients experience noticeable pain relief, which in turn lightens the caregivers' load. But on the day before discharge, caregivers often grow more anxious about

the uncertainties of home care. Patients, too, worry about what to do if pain flares up, and their anxiety scores go up compared to the previous phase. Even though patients are clinically stable and ready for discharge, the shift from having hospital support to being the sole caregiver at home creates extra psychological strain for both sides.

We recommend that psychological preparedness for family caregivers be built into routine inpatient care. Many caregivers told us they found discharge education hard to follow—too much jargon, too dense—and not nearly enough to handle complex situations after discharge, like pain recurrence, the device coming loose, or side effects. Following internationally used chronic disease discharge case management models could help[16]. There's also a clear need to set up individualised home-based care systems for advanced cancer pain patients.

Given that palliative care infrastructure in China is still underdeveloped and unevenly spread, we suggest creating specialised palliative and supportive care teams. These teams wouldn't just improve patients' quality of life—they'd also give essential support to caregivers and reduce their overall burden.

5.5 1~2 Weeks After Discharge

In this phase, caregivers often feel helpless without healthcare professionals around at home, which leads to a major caregiving burden. Their anxiety hits its peak—probably because pump doses need adjusting from time to time, and drug tolerance can develop, making painkillers less effective. A qualitative study of families receiving home-based palliative care stressed that general practitioners and community nurses need to be clinically competent, available when needed, and person-centred[17]—and our findings support that.

One big challenge we identified was caregivers' limited knowledge about monitoring pain at home. Many said they struggled to spot and interpret side effects or assess pain intensity. In China, because of economic and policy constraints, home visits by on-call doctors are rare. Evidence suggests that patients on intrathecal morphine pumps visit community hospitals more often than those on general medical management[18]. But since these patients are in the advanced stages and have major mobility issues, caregivers often can't easily follow medical advice—which is a huge barrier to effective home care.

Earlier studies have found that patients who die at home tend to have a higher quality of death[19]. In line with Chinese traditions and family structure, families often prefer the patient to pass away at home, which means they use community hospitals or local hospice facilities less. For most caregivers of advanced cancer pain patients, getting pain relief becomes their last hope for giving their loved one a dignified, comfortable end-of-life experience.

Right now, China's home-based clinical nursing services are still inadequate. Patients often face unrelieved physical symptoms, psychological distress, weak social support, and a lack of accessible information—all of which make home care extremely tough for caregivers. These are key obstacles to improving end-of-life quality of life[19].

Many countries have already set up palliative home care services[20]. This points to a clear need: countries with underdeveloped community healthcare systems and limited access to private physicians should

make post-op follow-up for pain procedures a priority. When patients come to hospital for pain interventions, healthcare professionals should take that chance to teach broader cancer care knowledge. For those using intrathecal morphine pumps, regular follow-up should be done to check medication use and help caregivers with ongoing pain assessment and symptom management.

5.6 Limitation

Because intrathecal morphine pump implantation is expensive, relatively few patients choose it, which meant our sample size was small. In the future, if more terminally ill patients receive this treatment, we'll be able to collect a larger sample and analyse what factors influence caregivers' care needs and sources of anxiety.

6. Conclusion

This study used a journey mapping framework to highlight the complex emotional and caregiving experiences of family caregivers supporting patients with advanced cancer pain who received intrathecal morphine pump implantation. The findings underscore the urgent need for continuous, structured support, particularly in the transition from hospital to home care. Enhancing caregiver training, simplifying communication about analgesic devices, and promoting accessible community-based palliative services are vital to reducing caregiver stress and ensuring high-quality end-of-life care. Future efforts should focus on integrating home-care case management models tailored to late-stage cancer pain patients into routine clinical practice.

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