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Discharge Resistance and Unpreparedness Experiences of Caregivers of Patients With Prolonged Hospitalization in a Palliative Care Unit: A Qualitative Study

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Abstract

Background

Moving from hospital to home in palliative care changes caregivers' daily responsibilities and access to support. Being unprepared for discharge may have different meanings for family and paid caregivers. This study aimed to explore experiences of discharge resistance and unpreparedness among caregivers of patients with prolonged hospitalisation in a palliative care unit in Türkiye.

Methods

Nineteen caregivers (nine family members and ten paid caregivers) were purposively recruited from the palliative care unit at Konya Meram State Hospital. They cared for patients who had been hospitalised for more than 30 days and whose discharge had been recommended by the multidisciplinary team. Semi-structured interviews were conducted in Turkish in June 2026 and examined using reflexive thematic analysis, also undertaken in Turkish.

Results

Four themes were developed: perceived medical insecurity and caregiving anxiety at home; the palliative care unit as a safe haven; caregivers' socioeconomic vulnerabilities and structural constraints; and psychosocial aspects of discharge unpreparedness and limited participation in decisions. Concern about losing access to professional support was prominent in both groups. Some family members associated discharge with abandoning the patient to death, whereas some paid caregivers described concerns about their livelihoods and limited influence over decisions. Participants who viewed discharge positively emphasised family support, previous caregiving experience and continuity of the caregiving relationship.

Conclusions

Discharge unpreparedness was closely intertwined with caregivers' concerns about patient safety, moral responsibility and material circumstances. Considering the feasibility of home care, access to equipment and the differing support needs of the two caregiver groups during discharge planning may help clarify what the transition from hospital to home means for caregivers.

Background

Palliative care aims to improve the quality of life of patients with life-threatening illnesses and their caregivers through holistic symptom management [1]. Discharge is a critical clinical and psychosocial transition during which care must be continued at home [2]. Prolonged hospital stays, however, arise not

only from medical needs but also from social factors, such as insufficient caregiving capacity and unsuitable home conditions [3]. The literature has generally considered discharge readiness in relation to patients' clinical status, while caregivers' experiences of unpreparedness have received less attention [4]. Griffin and colleagues' study (2025) showed that patient-related variables did not fully explain caregiver readiness, highlighting the need to investigate subjective experiences and social support mechanisms [5].

Although delayed discharge, inadequate planning and communication problems directly influence discharge decisions [6, 7, 8], the experiences underlying caregivers' resistance remain insufficiently understood. Gonella and colleagues (2019) examined families' experiences of institutional end-of-life care but did not explain how discharge can become a source of crisis and resistance in societies such as Türkiye, where family involvement in care and expectations of symptom management are high [9]. In Muslim-majority societies, end-of-life care decisions are shaped by family responsibility, religious values and moral obligations, making discharge a deeply felt moral burden as well as a change in the location of care [10, 11]. Family and paid caregivers may also occupy different economic positions and have different opportunities to participate in decisions, even when they perform similar daily tasks. Studying both groups is therefore important for understanding how concerns about patient safety intersect with moral responsibility, employment and access to support when a move from hospital to home is proposed. The question extends beyond whether caregivers experience difficulties to how these circumstances shape what they perceive to be at stake when discharge is recommended.

Qualitative evidence on experiences of unpreparedness or resistance to discharge among caregivers of patients with prolonged stays in palliative care units remains limited. This study aimed to explore experiences of discharge resistance and unpreparedness among caregivers of patients hospitalised for more than 30 days in the palliative care unit at Konya Meram State Hospital, and the underlying patterns of meaning. Following analysis, the findings were interpreted and discussed in relation to Meleis's Transitions Theory [12], Pearlin's Stress Process Model of Caregiving [13] and Boss's Theory of Ambiguous Loss [14].

Methods

Study design

This qualitative study was designed to understand family and paid caregivers' experiences of discharge during prolonged palliative care hospitalisation. Braun and Clarke's thematic analysis approach was adopted to interpret shared patterns of meaning in the data [15], and the analysis was conducted reflexively.

Researcher characteristics and reflexivity

Ö.A.İ. is the hospital's chief physician and H.S.Y. its deputy chief physician. To reduce the risk that these positions would influence the interviews, neither physician participated in data collection. The interviews were conducted by Ş.S.Ö., a gerontologist who was not involved in patients' clinical treatment or discharge decisions. Participants were invited by the ward's head nurse, who was not a member of the research team. The two physicians contributed to the analysis as critical friends, discussing the gerontologist's interpretations and the developing themes. They did not have access to raw audio recordings or transcripts containing personal information and worked only with anonymised coding structures. These arrangements sought to reduce the potential influence of institutional power relationships; they were not assumed to eliminate it.

Study setting

The study took place in the ward of the Palliative Care Centre at Konya Meram State Hospital, which has 99 beds: 75 ward beds and 24 intensive care beds. Patients at the centre are reviewed every 30 days by a committee comprising 13 disciplines, using a six-stage palliative care algorithm and daily monitoring forms. The institutional protocol sets a target stay of 7–14 days; stays exceeding 30 days for reasons other than medical necessity require further justification. Study preparation, data collection and analysis took place between April and August 2026, with interviews conducted in June 2026.

Sampling and participants

Purposive sampling was used to recruit 19 primary caregivers of patients whose hospital stay exceeded 30 days and whose discharge had been recommended by the multidisciplinary team. Nine were family members and ten were paid caregivers. Eligibility required being the primary caregiver of such a patient, having encountered at least one discharge recommendation, being older than 18 years and being able to communicate in Turkish. Exclusion criteria concerned caregivers whose patients were in the final 72-hour terminal phase, caregivers experiencing a psychiatric crisis, and those who did not consent. Sample adequacy was considered using Malterud and colleagues' information power approach [16]. Nineteen interviews were judged sufficient in view of the focused study aim, participants' directly relevant experiences and the content of the interviews. All 19 people invited to the main study participated, and none withdrew during an interview. Two pilot interviews used to develop the interview guide were excluded from the analysis.

Ethical considerations

Ethical approval was obtained from the Non-Drug and Non-Medical Device Research Ethics Committee of the Faculty of Medicine, Konya Chamber of Commerce Karatay University (KTO Karatay University) (30 April 2026; decision no. 2026/065), and institutional permission was obtained from the Konya Provincial Health Directorate (5 May 2026; no. 136989). Participants were informed that participation was voluntary, that they could withdraw without penalty, and that their decisions would not affect their

patients' care. Written consent was obtained for participation, audio recording and the use of anonymised data. Consent was also obtained for the use of anonymised data and direct quotations in scientific publications. Family members were assigned codes A-1–A-9 and paid caregivers B-1–B-10. This study was conducted in accordance with the ethical principles of the Declaration of Helsinki and its subsequent amendments.

Data collection and processing

Ş.S.Ö. conducted and audio-recorded the interviews in Turkish in a quiet room on the ward in June 2026. The interviewer had no previous relationship with participants. The semi-structured interview guide was developed specifically for this study, informed by the literature and clinical observations, and revised following two pilot interviews. The sociodemographic data form and an English translation of the Turkish interview guide are provided in Additional file 1. Interviews lasted an average of 35 minutes (range: 25–55). Caregiver fatigue and difficulty leaving the patient's bedside limited the time available for interviews. Field notes were taken, and audio recordings were transcribed verbatim in Turkish, including pauses and emotional expressions. Transcripts were checked against the recordings, and identifying details were removed. Minor grammatical changes were made to quotations to improve readability without altering their meaning. Coding and theme development were undertaken using the Turkish texts, with codes and analysis records stored in MAXQDA. Once the analysis was complete, the manuscript, themes and quotations selected for publication were translated into English. Member checking was not conducted.

Data analysis

Data were examined in MAXQDA using Braun and colleagues' six-stage thematic analysis framework: familiarisation with the data, generating codes, developing candidate themes, reviewing themes, defining themes and reporting [17]. Ş.S.Ö., who conducted the interviews, developed the initial codes and candidate themes from the Turkish transcripts. Critical-friend meetings with Ö.A.İ. and H.S.Y. explored how interpretations were grounded in the data and how the accounts might be read differently. These meetings were not used to calculate inter-coder agreement coefficients. The final themes were developed through this reflexive analytical process, conducted in Turkish.

Trustworthiness

Practices supporting trustworthiness are summarised in Table 1. Lincoln and Guba's criteria of credibility, transferability, dependability and confirmability were used to report the research process transparently [18]. Consistent with Braun and Clarke's approach to quality in reflexive thematic analysis, emphasis was placed on the researcher's interpretive role and the reasons for analytical decisions rather than numerical measures of coding agreement [19]. Field notes, checks of transcripts against recordings, MAXQDA records and reflexive team discussions supported this process. Reporting was guided by the 32-item Consolidated Criteria for Reporting Qualitative Research (COREQ) checklist [20].

Table 1
Measures undertaken in the study to ensure trustworthiness

Criterion	How it was addressed in the study
Credibility	In-depth interviews, reflexive analysis, critical friend
Transferability	Detailed description of the context, participant characteristics
Dependability	Analysis memos, MAXQDA records
Confirmability	Reflexivity, field notes, analytical discussions

Results

Caregivers had a median age of 53.0 years (range: 23–73), and 13 were women. Fourteen participants had primary education or less. Seven reported that their income matched their expenses, and 11 reported receiving no support with caregiving. The youngest patient receiving care was 68.0 years old and the oldest was 96.0. These patients had a median stay of 161 days in the palliative care unit (range: 35–310). Other clinical and demographic characteristics of the patients are presented in Table 2.

Table 2
Clinical and demographic characteristics of the patients

Criterion	How it was addressed in the study
Credibility	In-depth interviews, reflexive analysis, critical friend
Transferability	Detailed description of the context, participant characteristics
Dependability	Analysis memos, MAXQDA records
Confirmability	Reflexivity, field notes, analytical discussions

The 135 codes developed in the analysis were organised into four main themes. Themes, subcategories and illustrative codes are presented in Table 3.

Table 3
Themes, categories and representative codes

Criterion	How it was addressed in the study
Credibility	In-depth interviews, reflexive analysis, critical friend
Transferability	Detailed description of the context, participant characteristics
Dependability	Analysis memos, MAXQDA records
Confirmability	Reflexivity, field notes, analytical discussions

Theme 1. Perceived medical insecurity and caregiving anxiety at home

Participants worried that the professional help readily available in hospital would be difficult to obtain at home. Swallowing difficulties, aspiration and sudden breathing problems made the prospect of providing care alone particularly concerning. Some family members described other caregiving responsibilities at home and uncertainty about waiting for help in an emergency. Paid caregivers also reported a lack of equipment and feeling insufficiently prepared to respond to emergencies. These accounts reflect participants' assessments of safety; they do not independently establish that patients were clinically unsuitable for home care.

[Participant A-2, family member] "Discharge means a complete nightmare and chaos for us. There is another person at home who needs care. What will we do if something goes wrong? My mother is also 75–76 years old and needs care herself. Will we wake up in the middle of the night and call the emergency service? How will we manage? Going home with this uncertainty really is a nightmare."

[Participant A-3, family member] "I am alone at home. My son comes from time to time, but he has his own work and responsibilities. What will I do if my spouse suddenly cannot breathe or something gets stuck in their throat? Here I call the nurse and she comes immediately. At home I will not find anyone. How can I sleep peacefully at home with this fear?"

[Participant B-6, paid caregiver] "Patients in this condition definitely need to be under a doctor's supervision. The patient cannot eat or drink by mouth and cannot swallow. If they are taken home, even if someone looking after them gives them water without realising, it could enter their airway. This is a very big risk. Looking after this patient at home is very difficult."

[Participant B-4, paid caregiver] "The patient is 96 years old and has completely lost the ability to swallow. If the feed goes into their lungs while I am giving it at home, there is neither a suction device there for immediate intervention nor do I have that knowledge. It is safest for them to be under a doctor's supervision in hospital. The home does not seem able to cope with these risks."

Theme 2. The palliative care unit as a safe haven

Alongside access to medical help, remaining in hospital gave participants a sense that they were not alone. Relationships developed over time with nurses, physicians and other staff were described as support that made daily caregiving responsibilities easier to share. A-6 contrasted the closeness experienced in hospital with the isolation anticipated at home, while B-3 described the ward as a home. Discharge therefore also meant leaving a familiar circle of support. Positive accounts of the institution should be interpreted in light of the interviews having taken place in the same hospital.

[Participant A-8, family member] "I am afraid that if my father suddenly becomes unwell, I will not get him to hospital in time and will lose him. Here, when there is a crisis, I can immediately run to the nurses

and they come and intervene straight away."

[Participant A-6, family member] "This place has become warmer than our own home. Our doctors and nurses do everything we ask. If we were at home, the neighbours would not open the door; they would keep away for fear of catching an illness. Here we are not alone. When we have a problem, there are people we can turn to."

[Participant B-8, paid caregiver] "There is no problem with staying in hospital for us; the environment here is very good. The nurses, the doctor and all the staff take a close interest in us and our patient. But if we are discharged, I would really be upset about the patient's condition."

[Participant B-3, paid caregiver] "We have been on this ward for nine months. We have become like family with the nurses. Whenever there is a problem, they are right beside us. It is impossible to find this comfort and security outside, at home. This no longer feels like a hospital to us, but like a home."

Theme 3. Caregivers' socioeconomic vulnerabilities and structural constraints

The cost of medical beds, incontinence products and other care supplies featured prominently in family members' accounts. A-5 also anticipated that obtaining public assistance would take time. These are participants' experiences and expectations; the scope of assistance and reimbursement processes were not independently examined. For some paid caregivers, caregiving work was central to their own livelihood. B-1 described receiving food and accommodation in hospital and worrying about losing the job and daily pay after discharge. B-8's account combined affection for the patient with the need for paid work. These accounts show how the sustainability of patient care can be closely linked to caregivers' own living conditions.

[Participant A-1, family member] "A special medical bed is needed for use at home, but the prices are very high. It is impossible for me to buy one. I receive only 7,500 lira a month from the shop; I cannot meet these costs."

[Participant A-5, family member] "My spouse has only a pension. I have seven grandchildren and children. We can barely afford the patient's incontinence pads, and now they have told us to buy an air mattress as well. Ten to fifteen thousand lira. How can I buy it? They said the state provides it, but apparently that takes a long time too. If we are discharged, we will not be able to afford these medical supplies."

[Participant B-8, paid caregiver] "I do whatever the patient's relatives think is appropriate. There is nothing I can do financially. If I were well off, I would even care for this patient in my home for free, because I love them very much. But I need this job and the daily pay to cover my own rent and bills."

[Participant B-1, paid caregiver] "I do not own a home; I rent. When I stay here, I look after the patient and my food and accommodation are free. When the patient is discharged, my job will end and my daily pay

will stop. I keep worrying about how I will pay the rent and what I will eat and drink."

Theme 4. Psychosocial aspects of discharge unpreparedness and limited participation in decisions

For some family members, discharge carried a meaning more troubling than a change in the location of care. A-2 and A-7 associated taking the patient home with abandoning them to death and described the moral burden this would create. Paid caregivers B-2 and B-10, meanwhile, said they were not consulted about discharge despite taking responsibility for daily care. These statements indicate limited participation in decisions; they do not, by themselves, demonstrate covert resistance or deliberate obstruction of discharge.

[Participant A-2, family member] "I do not even want to think about discharge. Because if we are discharged, it will be as though we have knowingly accepted their death. It is not possible for us to provide care at home; either we abandon them to death or we stay here."

[Participant A-7, family member] "Discharging my father is like pulling the plug on him. We know that we cannot care for him at home. It means knowingly sending him to his death. How could my conscience accept that? That is why I do not even want to hear the word discharge."

[Participant B-2, paid caregiver] "I do not have the right to say anything or make a decision about discharge. We are only workers. Family members and doctors make the decision."

[Participant B-10, paid caregiver] "The family and doctor make the decision. We are only workers here. If they tell us, 'We are leaving tomorrow', we leave; if they say, 'We are staying', we stay. Nobody asks our opinion, so we withdraw."

Divergent experiences

A-4 expressed a wish to return home, drawing on family support and previous experience of home care: "There are many of us at home; I have daughters and daughters-in-law. Staying in hospital wears us down, and my father is very bored here too. It would be better for him to be in his own room at home, among the people he loves."

B-5 described caring for the same patient at home and in hospital for several years and expected the work to continue because of the relationship with the family: "Because I have been caring for him for four or five years, because they love and respect me, because I am a meticulous... person. So they would not let me go, in terms of the price, the cleanliness, or how I care for their father." B-5 also described feeling able to continue providing care at home: "I do not have a fear of losing the patient; I do not know whether the other caregivers do... When we go home, we will keep doing what we have seen here... Even if this patient died, I would still want to stay in care work; I would continue caregiving." These accounts suggest that family support and continuity of the caregiving relationship can hold different meanings within experiences of discharge.

Discussion

For participants, the most difficult aspect of leaving hospital was the prospect of losing ready access to help when they needed it. On the ward, they could turn to a nurse or physician when a problem arose; at home, they were unsure who would share that responsibility. Some family members worried that they would be unable to prevent the patient from deteriorating at home and would have to bear the resulting moral burden. Some paid caregivers considered the same transition in terms of whether their work, income and basic support would continue. Thus, although concerns about discharge overlapped between the two groups, the circumstances underlying those concerns differed.

Everall and colleagues reported experiences of uncertainty and limited participation in decisions among patients and caregivers facing delayed discharge [6]. Anderson and colleagues' review likewise showed variation in family involvement in end-of-life communication and highlighted the importance of sharing information clearly and in ways suited to the individual [8]. In our study, these issues appeared together in the accounts of family and paid caregivers who had spent an extended period on the same ward. The study contributes by examining familiar discharge difficulties within the everyday circumstances of these two caregiving relationships. Understanding what a person who feels unprepared believes they cannot manage, which support they fear losing and how much say they have in the decision may help identify their needs more clearly.

Weetman and colleagues showed that discharge from specialist palliative care to community settings can have different meanings and highlighted the importance of written and verbal information, follow-up plans and contact details [21]. Ewing and colleagues found that discharge preparation often remained focused on the patient's needs, while caregivers' support needs required a separate conversation [22]. The accounts in our study suggest that these conversations should also address the material circumstances of care. If a family does not know which bed or equipment they can obtain, or whether paid care will continue at home, receiving care instructions alone may not be enough to feel prepared.

Family members' moral concerns can be understood in the tension between wanting to protect the patient and having the means to sustain care at home. Tripodoro and colleagues discussed the difficulties of treating the family as an unlimited source of care in relation to social expectations, care burden and participation in decisions [23]. In our study, too, willingness to provide care did not always coincide with having the necessary resources. Paid caregivers' accounts combined closeness to the patient with the need to earn a living. B-8's expression of affection for the patient alongside a need for daily pay shows why both aspects of the caregiving relationship should be considered together. Explaining these experiences solely through religious values or financial self-interest could overlook part of what participants described.

Türkiye is classified by the World Bank as an upper-middle-income country [24]. Nevertheless, participants on this ward described the cost of supplies for home use, difficulty finding help and uncertainty about the continuity of caregiving work. In the transition from hospital to home, the resources available to households and caregivers matter alongside national income classification. For

some paid caregivers, the food and accommodation provided on the ward formed part of their working arrangements. Discharge planning should therefore also consider what the loss of that support would mean. The study contributes to understanding palliative care in low- and middle-income countries by showing that everyday living conditions need to be considered if care is to move home. How these needs are met in other centres should be examined in relation to local service and financing arrangements.

The accounts of A-4 and B-5 show that prolonged hospitalisation did not have the same meaning for every caregiver. A-4 relied on family support at home, while B-5 expected a longstanding caregiving relationship to continue after discharge. Both viewed returning home more positively than some other participants. These differences are a reminder to understand caregivers' attitudes through their own accounts rather than infer them from the length of hospitalisation. Family support and continuity of the caregiving relationship are circumstances that warrant closer examination in relation to feeling prepared for discharge.

Meleis's Transitions Theory offers a useful framework for understanding how discharge changes roles, relationships and access to support [12]. Pearlin's Stress Process Model of Caregiving allows caregiving demands to be considered alongside a person's material and social resources [13]. Together, these approaches help to interpret the tension between participants' responsibilities for care at home and the resources available to them. Boss's Theory of Ambiguous Loss may offer an additional perspective on family caregiving relationships, particularly where advanced cognitive impairment is involved [14]. However, because the interviews did not specifically explore ambiguous loss, guilt associated with discharge cannot be explained by this concept alone. The theories informed interpretation of the findings and were not tested in the study.

In practice, a priority is to work with caregivers to make the proposed home-care plan concrete. This can include clarifying who will provide daily care, whether the necessary equipment is available and how help will be obtained if a problem arises. Evidence on the benefits of individualised discharge plans in general hospital populations [7] supports the importance of this preparation. Recommendations for communication and follow-up in palliative care [21], research addressing interdisciplinary coordination and assistive equipment needs [25], and the Carer Support Needs Assessment Tool (CSNAT) approach [22] provide a basis for discussing caregivers' needs. The potential value of CSNAT in this context should not be interpreted as evidence that it reduces discharge delays.

Conversations with family members could explore why taking the patient home feels like abandonment. Discussing together how care will continue at home and how professional support can be accessed may help bring these concerns into the open. For paid caregivers, expected tasks, willingness to continue caregiving and working conditions could be discussed while respecting the patient's preferences, consent and privacy. This study did not evaluate the effects of equipment support or employment protections. Their contribution to caregiver experiences and the discharge process should be examined in future research.

Future research would benefit from bringing together the experiences of patients, family decision-makers, paid caregivers and clinicians. Studies following the transition from hospital to home could show which concerns raised before discharge are realised and which forms of support prove helpful. Comparisons across centres could also help identify the circumstances in which the difficulties described here recur.

Limitations

Including family and paid caregivers allowed different caregiving relationships to be examined in the same setting. However, the single-centre design and small purposive sample limit transferability. Participants cared only for patients whose hospital stay exceeded 30 days and whose discharge had been recommended. Completed discharges were not followed, and the reasons for prolonged hospitalisation were not independently examined. The inclusion of participants who supported discharge further indicates that continuing hospitalisation and individual reluctance are not equivalent.

The managerial positions of two authors and the hospital interview setting may have influenced participants' willingness to criticise the institution, even though these authors did not collect data. A single interviewer provided continuity, but the accounts were produced within a particular researcher–participant relationship. Fatigue and time constraints may have limited detailed exploration of some topics. Patient and clinician perspectives were not collected, and member checking was not undertaken. Although interviews and coding were conducted in Turkish, the subsequent translation of quotations into English may affect nuances of expression. The findings should be considered in light of the study setting and the interpretive process.

Conclusions

Discharge following prolonged palliative care hospitalisation is a transition that involves caregivers' safety concerns, responsibilities and livelihoods. Although some concerns overlap between family and paid caregivers, their positions in decision-making and the consequences they anticipate differ. Considering these differences when assessing how care will continue at home may support discharge plans that are more responsive to caregivers' needs. The study does not establish that caregivers' attitudes caused prolonged hospitalisation or that the proposed forms of support would reduce discharge delays.

Abbreviations

COPD: chronic obstructive pulmonary disease; COREQ: Consolidated Criteria for Reporting Qualitative Research; CSNAT: Carer Support Needs Assessment Tool; PEG: percutaneous endoscopic gastrostomy; NG: nasogastric.

Declarations

Ethics approval and consent to participate

Ethical approval was obtained from the Non-Drug and Non-Medical Device Research Ethics Committee of the Faculty of Medicine, Konya Chamber of Commerce Karatay University (KTO Karatay University) (30 April 2026; decision no. 2026/065). Institutional permission was obtained from the Konya Provincial Health Directorate (5 May 2026; no. 136989). Written consent was obtained for participation, audio recording and the use of anonymised data. Participants were informed that participation was voluntary and that withdrawal would not affect their patients' care. This study was conducted in accordance with the ethical principles of the Declaration of Helsinki and its subsequent amendments.

Consent for publication

Consent was obtained from participants for the use of their anonymised data and direct quotations in scientific publications. Quotations are presented using participant codes that do not disclose their identities.

Availability of data and materials

The data used and analysed in this study are available from the corresponding author on reasonable request, subject to participant confidentiality, the scope of consent and ethical permissions.

Competing interests

The authors declare that they have no competing interests.

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Authors' contributions

Ö.A.İ.: conceptualisation, analysis, review and editing. H.S.Y.: translation of the manuscript, analysis, review and editing. Ş.S.Ö.: conceptualisation, data collection and analysis, manuscript writing. All authors approved submission of the manuscript.

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