


# BMJ Open Proxy-reported experiences of palliative, non-operative management of geriatric patients after a hip fracture: a qualitative study

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## ABSTRACT

**Objective** The objective of this study was to explore the experiences from the period after the choice was made for palliative, non-operative management for geriatric patients with a hip fracture, to the most important factors in the process, as reported by a proxy.

**Design** Semistructured interviews were conducted between 1 August 2020 and 1 April 2021 to investigate by-proxy reported patient experiences of non-operative management after hip fracture. Interviews followed a topic guide, recorded and transcribed per word. Thematic analysis was used to identify themes in the data.

**Setting and participants** Patients were retrospectively identified from the electronic patient record. Relatives (proxies) of the patients who underwent palliative, non-operative management were contacted and were asked to participate in a semistructured interview and were named participants. The participants were proxies of the patients since patients were expected to be deceased during the timing of the interview.

**Results** A total of 26 patients were considered eligible for inclusion in this study. The median age of the patients was 88 years (IQR 83–94). The 90-day mortality rate was 92.3%, with a median palliative care period of 11 days (IQR 4–26). A total of 19 participants were subjected to the interview. After thematic analysis, four recurring themes were identified: (1) the decision-making process, (2) pain experience, (3) patient–relative interaction and (4) the active dying.

**Conclusions** With the introduction of shared decision-making in an acute setting for geriatric patients with hip fracture, proxies reported palliative, non-operative management as an acceptable and adequate option for patients with high risk of adverse outcomes after surgery. The emerged themes in palliative care for patients with hip fracture show great similarity with severe end-stage disease palliative care, with pain identified as the most important factor influencing comfort of the patient and their environment after hip fracture. Future research should focus on further improving targeted analgesia for these patients focusing on acute pain caused by the fracture.

## STRENGTHS AND LIMITATIONS OF THIS STUDY

- ⇒ The qualitative approach of this study is supported with quantitative data to gain more insight in the patients' palliative care process.
- ⇒ Several doctors participated in drafting the topic list, and during the interviews, many open probes were used to obtain possible additional information.
- ⇒ Participants were recruited from a small existing population of P-NOM patients since it is a relatively new option for geriatric hip fracture patients.
- ⇒ Data saturation was reached in our relatively small group of P-NOM patients.
- ⇒ First-hand patient experiences of the P-NOM are missing since more than 70 percent of the patients were already diagnosed with dementia, and most of the patients deceased shortly after hip fracture.

## INTRODUCTION

The 1-year mortality rate following hip fracture surgery is 22%–33%.<sup>1 2</sup> Due to an ageing population, the absolute number of hip fractures is expected to rise globally to 4.5 million by 2050.<sup>3 4</sup> Surgery is the cornerstone of hip fracture treatment and is performed in almost all cases (98%).<sup>5</sup> Operative management stabilises the fracture, allowing for early mobilisation and direct start of rehabilitation.<sup>6</sup> However, the postoperative period after this curative treatment is associated with a substantial risk of severe complications such as pneumonia, delirium and in-hospital mortality.<sup>7 8</sup> Several risk factors are identified with higher mortality risk after a hip fracture. These include older age, American Society of Anesthesiologists (ASA) physical status classification, male sex and decreased body mass index.<sup>9</sup> In addition, multiple comorbidities further increase the mortality after hip fracture surgery.<sup>10</sup> For these patients with various risk factors, palliative, non-operative management (P-NOM) could provide a more

peaceful last period of one's life. Currently, P-NOM is increasingly presented as an option for these patients with a high risk of adverse outcomes.<sup>11–14</sup> Early experiences after P-NOM were described in recent literature but little is known about the palliative care process of P-NOM for geriatric trauma patients.<sup>15 16</sup> The integration of palliative care for geriatric trauma patients represents a paradigm shift in hip fracture care from disease-oriented to patient goal-oriented management. The choice for palliative care is an emotion-charged subject and has a major impact on the patient and those around him.<sup>17</sup> An important objective in palliative care is to address supportive care needs early in the process to improve patients' experiences.<sup>18</sup> Physicians build on general palliative guidelines from experiences in other patient populations with chronic and oncological diseases.<sup>19–21</sup> The palliative care principles need translation and adaption into acute traumatic clinical practice since the patient with hip fracture is usually unknown at presentation for the physician. Therefore, exploring key components, the impact of P-NOM on patients and relatives, is critical. The objective of this study was to explore the experiences from the period after the choice was made for P-NOM for geriatric patients with a hip fracture, to the most important factors in the process, as reported by a proxy.

## MATERIAL AND METHODS

### Design

Semistructured interviews were conducted to gain insight into the experience of P-NOM of patients who sustained a hip fracture through the experience of first-degree or second-degree relatives. The qualitative approach of this study was thematic content analysis.<sup>22</sup> A phenomenological approach was used, recognising the fact that the experiences of the relative and patient regarding the patient's injury exist in a reality outside of their own perception(s).<sup>23</sup> The interviews were conducted with proxies of patients who had been admitted with a hip fracture in a level 2 trauma centre in an urban setting between 1 August 2020 and 1 April 2021, with a minimum of 2 months and maximum of 8 months after injury. The 'Standards for Reporting Qualitative Research' by O'Brien *et al* was used to guide this article.<sup>24</sup>

### Participant identification

This study is part of a clinical audit of hip fracture treatment. Study participants were first-degree or second-degree relatives of the patients who underwent P-NOM, since patients were expected to have died during the time of the interview. Participants were eligible for inclusion if they were able to give informed consent, were aged 18 years or above, had a relative in the first or second degree who underwent P-NOM, and the eligible participant was the main caregiver. Participants were excluded if they did not speak Dutch or English fluently.

### Sampling

Convenience sampling was used for this study. All patients who met inclusion criteria with P-NOM after hip fracture

were eligible for inclusion. Participants were approached between 2 and 8 months after presentation at the emergency department (ED). The interview was not conducted in the acute phase of the grieving process, and also in our opinion an acceptable time frame for complete memory of details related to the P-NOM experience. The sampling strategy allowed for a diverse range of participants and patients with regard to age, sex, dementia, discharge destination, survival, time to death, and family connection between participant and patient.

### Recruitment and consent

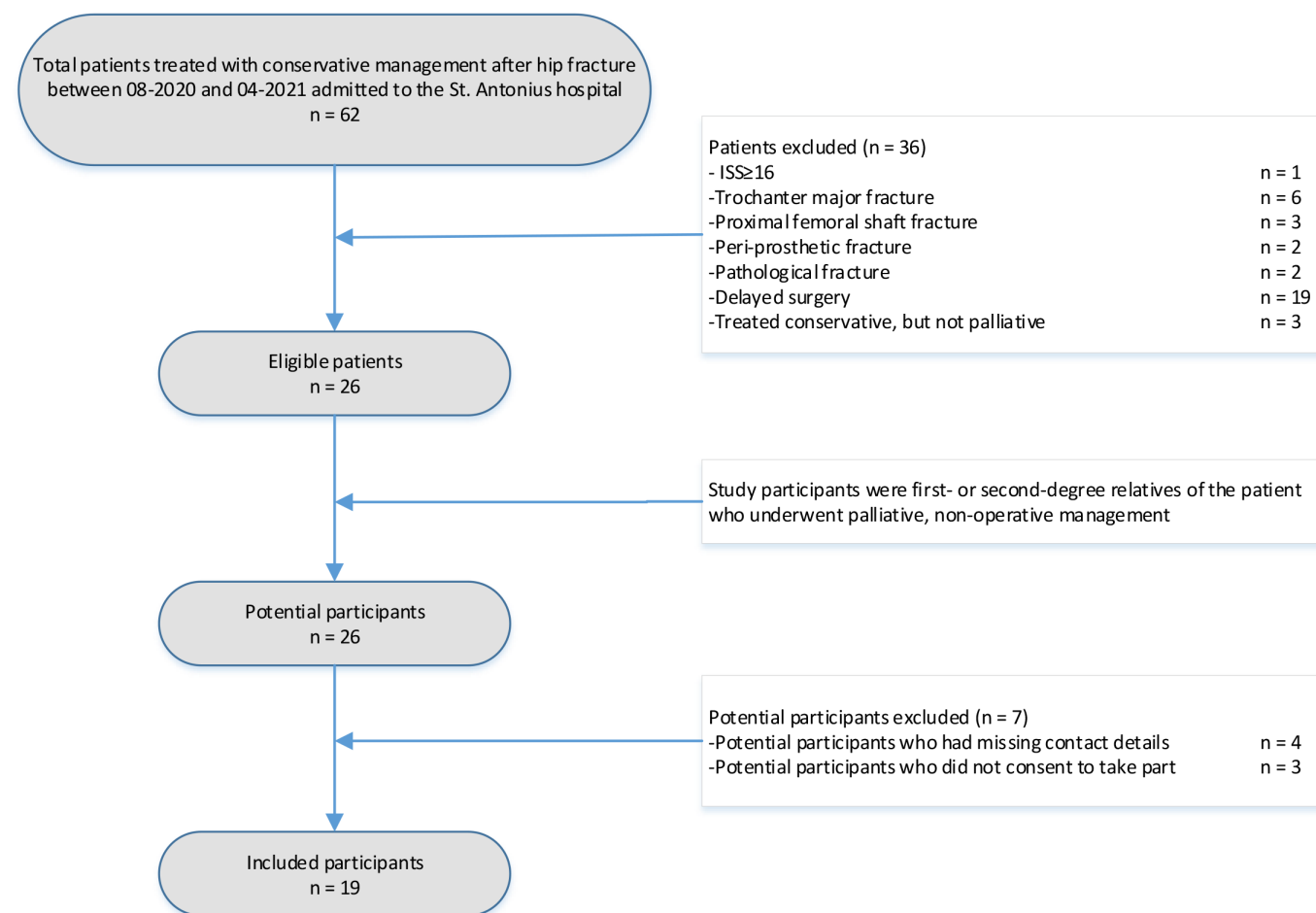
Patients were retrospectively identified from the electronic patient record (EPR). Patients were considered suitable for inclusion when they received P-NOM, were 70 years of age or older and had a hip fracture. Contact details from proxies of patients who underwent P-NOM were collected from the EPR. These proxies were screened by sampling attributes: age, sex and relationship to the patient, and were named the participants. Potential participants were contacted by phone and asked to participate in the study. Participants gave verbal informed consent for partaking in a semistructured interview. Participants could withdraw from the study at any given time. After data collection, authors TMPN and DWPML considered that the data had enough rigour to perform a thorough analysis.

### Data collection

The lead author (TMPN) conducted the interview from 1 January 2021 to 30 June 2021. TMPN is currently working as a medical doctor and PhD candidate. He had no prior relationship with the patients or participants. A topic guide was produced to guide the similar semistructured interviews (online supplemental appendix A). Field notes regarding details of non-verbal communication or latent codes were taken during the interview.

### Data analysis

The interviews were recorded with an encrypted digital audio device, only accessible to authors TMPN and DWPML. Recordings were extracted, transcribed per word, and uploaded to a secure server with a code only accessible to TMPN and DWPML. The transcripts were coded with a unique study number. Thematic analysis, according to Braun and Clarke, was used to analyse the data.<sup>25</sup> After coding all transcripts, differences in the codes were discussed among both authors until agreement was reached. Data analysis was performed concurrently with data collection until no new themes emerged from a new semistructured interview. In addition to the qualitative data, quantitative data were extracted from the EPR for several patient characteristics. The patient characteristics included age (in years), sex, living situation (independent at home, home with activities of daily living care, institutional care facility), diagnosis of dementia, Charlson Comorbidity Index (CCI), admittance to the geriatric trauma ward of our hospital, discharge destination (home, nursing home or died in hospital), 90-day



**Figure 1** Flow chart of palliative management. ISS, Injury Severity Score.

mortality and time from hospital admittance to death (in days). The municipal basic administration was consulted for data on mortality. Information from participants, including sex, relation to the patient and country of birth, was extracted from the interviews. Participants rated the decision-making process on a scale from 1 (very poor) to 10 (outstanding).

### Patient and public involvement

Patients or participants were not involved in the design, intervention, research question or outcome measures of the current study.

## RESULTS

A total of 62 patients presented with a hip fracture met the inclusion criteria in this study, as can be seen in the flow chart (figure 1). From these patients, 36 were excluded, which resulted in 26 patients eligible for inclusion. As can be seen in the baseline table (table 1), the median age of the total group was 88 years (IQR 83–94), with a median CCI of 6 (IQR 5–6). In this study, 19 (74%) of all patients had been diagnosed with dementia. After the hip fracture was diagnosed, 50% of patients were admitted to the geriatric ward with a median length of stay of 2 days (IQR 1–4). The 90-day mortality was 24 (92.3%), with a

median palliative care period (from admission to death) of 11 days (IQR 4–26). Four patients could not participate in this study due to missing emergency contact details. Three potential participants did not consent to take part in this study with unclear reasons. In total, 19 out of 26 participants were recruited and interviewed as part of this study.

During thematic analysis, four themes were identified: (1) the decision-making process, (2) pain experience, (3) patient–relative interaction and (4) the active dying.

### The decision-making process

In the acute setting, the goals of care for the patient were assessed, including prognosis, patient goals, likelihood of recovery and pain. The physician, the patient, and their relatives discussed the burdens and benefits of the treatment strategies with non-operative management as the preferred option. In 14 (74%) cases, the participant outlined that shared decision-making (SDM) was used. In those cases, the physician clearly discussed the advantages and disadvantages of surgery and left the final decision to the patients and their relatives. These participants emphasised the value of being a part of the decision-making process. Few participants pointed out that they were fond of the approach the physician took with understandable

**Table 1** Patient and participant characteristics

Patient characteristics (n=26)	
Female sex, n (%)	18 (69)
Age, years (IQR)	88 (83–94)
Living situation before fracture, n (%)	
Home, independent	2 (8)
Home, with ADL care	6 (23)
Institutional care facility	18 (69)
Charlson Comorbidity Index, median (IQR)	6 (5–6)
Dementia, n (%)	19 (73)
Discharge destination, n (%)	
Home, independent	1 (4)
Nursing home	23 (89)
Died in hospital	2 (8)
Admission in hospital, n (%)	13 (50)
90-day mortality, n (%)	24 (92)
Time from hospital admission to death (days), median (IQR)	11 (4–26)
Participant characteristics (n=19)	
Relation to the patient, n (%)	
Partner	3 (16)
Offspring	12 (63)
In-law	3 (16)
Legal representative	1 (5)
Female sex, n (%)	12 (63)
Country of birth	
The Netherlands	19 (100)
All variables are in total amount (percentage) or median (IQR). ADL, activities of daily living.	

language and a clear translation of medical terminology. In addition, the relatives were satisfied with the time they received to think about the treatment options. In one of those cases, the patient had already indicated that he no longer wanted to receive any surgery, before the families could participate in the decision-making process. In three cases, the physician directed firmly towards non-operative management based on medical grounds. However, the families felt like the official final judgement was with them, which was pleasant, according to the participants. In two other cases, the treating physician assessed the patient as unfit to undergo hip surgery, and therefore SDM was not applicable. Multiple participants addressed the fact that the potential for worse outcomes after surgery was unexpected and a lot to process in the acute setting. The relatives assumed that fixing a fractured hip was child's play for the surgeon without knowing the consequences of the surgical intervention for a geriatric patient. Two participants pointed out the lack of written information about the palliative process after leaving the ED. This was experienced as unpleasant, where it felt like lots of questions remained unanswered after the physician left due to the

unexpected possible adverse outcomes after hip fracture. Overall, the communication between the physicians and the families was rewarded with an average grade of 8 out of 10.

Pt.16: It was not a difficult choice; we were all at peace with it.

Pt.20: There was clear advice not to operate, and we supported that advice.

Pt.29: No other relatives were present during the decision-making. It is favorable to involve the family in the decision to forgo surgery.

Pt.37: We all thought fixing the hip would be child's play for the surgeon.

Pt.38: Actually, these kinds of talks should be done beforehand, especially for people who fall frequently.

### The experience of pain

The pain was experienced in different degrees by patients during P-NOM. In nine (47%) cases, patients seemed comfortable with morphine, experiencing little to no pain lying peacefully in bed. As a result, these patients seemed comfortable. Six patients initially used almost no painkillers. Pain increased over time, and their morphine was adjusted, with the downside of decreased consciousness. Two other patients appeared uncomfortable after bed transfers because of their facial expressions of pain. The relatives expressed lack of clarity regarding treatment between physicians after the transfer to the nursing home. While hospital physicians gave high doses of analgesic drugs for comfort, nursing home staff seemed reluctant to give higher doses of painkillers. This was confusing for patients and families. These issues were discussed with the nursing home staff, their analgesic regimen was adjusted and patients were comfortable. Participants reported analgesia to be key to comfort caregivers, patients and families in hospice care. As relatives described, increasing levels of pain for the patient, a domino effect in restlessness for the patient, panic for family and uncontrolled situations for health suppliers emerged.

Pt.12: The pain relief in the hospital was good, but in the nursing home, the pain was not under control.

Pt.18: She laid there quietly and comfortably.

Pt.20: The morphine was useful for the pain but also induced drowsiness for mother.

Pt.21: Is everybody on the same page when they say "palliative nonoperative management?"

Pt.36: The pain was well under control with the prescribed painkillers.

### Patient-relative interaction

This interaction described the communication and interaction with the patient and their relatives between hip fracture and death. Cognitive impairment was mentioned by 11 participants as a pre-existing barrier to interaction between family and patient. Several participants described the interaction during this period of time as inconsistent. Some days, communication and interaction were better than other days without an apparent reason.



Almost all participants described consciousness as best in the first days after trauma and decreasing over time. The last moments with the patient were described as 'precious' physical contact without any verbal communication. Many thought the increasing dosage of morphine over time was the reason for the declining possibility to communicate with their passing loved ones.

Pt.12: In the beginning communication was pretty good, in the hospice, the morphine was taking over, and her consciousness was fading.

Pt.17: Her mind was clear for short periods of time when she was awake, most of the time she spent sleeping and resting.

Pt.21: Due to dementia, adequate interaction has already been a problem for a long time.

Pt.26: The most valuable memory in the last moment was to be there and hold hands before she passed away.

Pt.33: Over time morphine dosage was increased, and communication seemed more and more difficult.

### The active dying

Almost all participants described the patients' active dying process as calm and peaceful. The last clear moments together were already shared, and in the last period of time, the patient seemed comfortably asleep or less conscious, as observed by participants. Several mentioned adequate pain relief as the critical factor of comfort in this final stage. In addition, family members cherished the particular moment of passing that could be with all relatives and in a comfortable (home) setting. For three participants, the last moments related to the dying process were uncomfortable to witness. This was not related to discomfort after hip fracture. One of the participants reported that the family experienced the process as unpleasant, mainly because she felt her mother was dying while her skin colour turned grey and interaction was fading. The second patient developed Kussmaul breathing in the last hours before passing away. In these two cases, the participants emphasised that the patient's discomfort was not noticeable for the witnessing relatives. The last patient had a death rattle, and the family indicated that they felt that the patient suffered excessively.

Pt.11: She passed away in peace after the morphine dosage was increased.

Pt.15: She slipped away in a state of sedation.

Pt.21: It is unbearable to see your parent choking on their saliva as they pass away.

Pt.29: She had always hoped she would pass away peacefully in her sleep, and luckily that was exactly what happened.

Pt.36: The last few hours mother was still breathing, but it was clear she was dying, that was unpleasant to witness, but luckily mother (patient) did not seem to suffer.

### DISCUSSION

The results of this qualitative study show that participants have had a generally positive experience related to P-NOM for patients who sustained a hip fracture. Four recurring themes were identified in the interviews that were deemed most important to the proxies in the palliative process. The decision-making process was awarded with an 8 out of 10 on average, and SDM was present in most cases. Also, communication with the patients was most frequently hampered due to pre-existing dementia and was best in the first days after the trauma. Most participants described the final moments as calm and peaceful, and the presence of relatives was considered very valuable.

The participants reported that adequate pain medication was the most important aspect to keep the patient comfortable. However, they also indicated that increasing the morphine was often accompanied by adverse effects such as a decreasing level of consciousness which increasingly impeded the communication with the patient in the last days before passing away. This is in line with current literature for palliative care in severe end-stage disease where optimal pain management is stated as the most important element in the palliative care process.<sup>15</sup> To optimise pain relief, different anaesthetic techniques are studied for patients with hip fracture with long-term and sometimes even irreversible effects.<sup>25</sup> These techniques include nerve blocks, ultrasound-guided pericapsular nerve group hip joint phenol neurolysis and phenol neurolysis of L4.<sup>26-28</sup> Future studies must determine the applicability of these novel analgesic techniques for patients with hip fracture receiving palliative care in order to identify long-term outcomes. Further, our data showed a need for written information, confirming that short written materials can be a preferred method of information delivery for palliative patients since memory for verbal medical information, especially in older patients, can be very poor and inaccurate.<sup>29,30</sup> A brochure with information about P-NOM could be distributed at the ED to support verbal communication with additional information in a written brochure. Our data also revealed the importance of good communication between healthcare workers from the hospital and nursing homes. These results reflect Romoren *et al.*<sup>31</sup> who also outlined the importance of good communication and improving information exchange between the nursing home staff and hospital doctors to optimise treatment and care for each individual patient.<sup>31</sup> To enable proper communication between healthcare providers, the term P-NOM could be used instead of conservative management, in order to be clear about the nature of the policy. Finally, our participants indicated that the choice between surgery and P-NOM came very unexpected in the hospital. The confrontation with the acute end-of-life choice came as a shock and was very unpleasant for patients and families. Perhaps ideally, SDM between geriatric patients and physicians should take place in a non-acute setting. Advance care planning ensures greater satisfaction with medical care for patients and their relatives.<sup>32,33</sup> We would

like to endorse the importance of advance care planning. We advise patients and physicians to discuss together what is important to them and how far they are willing to go for a certain outcome, including potential consequences of high-risk interventions such as hip fracture surgery.

One of the strengths of our study is that, to our knowledge, a qualitative approach to gather the experiences of the P-NOM process for patients with hip fracture is not yet performed in literature since the questionnaire-based experience in the FRAIL hip study by Loggers *et al.*<sup>14</sup> Another strength is the reflection on the acute introduction of the palliative care process for geriatric patients at the ED. Since patients are relatively unknown to the physician in this situation, identification of the patients' needs in the short term seems critical. In addition, qualitative research provides concrete directions for improvement of palliative care in geriatric hip fracture management. In an acute setting, SDM for geriatric patients with hip fracture also shows good feasibility and acceptability when advance care planning is not yet performed. Also, all included patients were retrospectively identified in a single hospital, and little information was lost searching for data. Lastly, several doctors participated in drafting the topic list, and during the interviews, many open probes were used to obtain possible additional information. In general, it is essential to consider that thematic analysis has limited interpretative power when it is used outside of an existing theoretical framework.<sup>22</sup> Nevertheless, our results can provide the fundamental for future prospective studies with yet promising and valuable insights in the P-NOM process. One of the limitations of our study is that our study was based on the experience of the relatives of the patient. First-hand patient experiences of the P-NOM are missing since more than 70% of the patients were already diagnosed with dementia, and most of the patients died shortly after hip fracture; this was the most viable method to gather the experience. The lead and second researchers are medical doctors (in training) and perform medical research. During the study, they aimed to be reflexive and minimise bias. However, the personal experiences and professional background of both researchers may have introduced bias throughout data collection, analysis and interpretation. Lastly, seven potential participants were lost to follow-up. It could be possible that additional participants would reveal new insights in the experience of P-NOM.

Four key themes could be of relevance in clinical practice for the geriatric trauma patient receiving palliative care after hip fracture. First, as the experience of pain was the most important theme, future research should focus on the application of novel analgesic techniques for P-NOM. Second, additional information in a brochure during the decision process was suggested to support verbal communication at the ED. Third, we would like to endorse the importance of advance care planning prior to life-changing trauma events in geriatric patients to minimise the emotional impact of the potential choice for a palliative trajectory after hip fracture; if not yet

performed, the acute phase should be the designated time and place for this discussion when carried out appropriately by SDM with patient and family. Lastly, since themes in our study are in line with the key elements in previous studies of palliative care in end-stage disease, we believe the cause of death may be irrelevant once a patient has transitioned to palliative care. Even though the build-up to palliative care process might be different, expertise in the palliative care management could be directly applied to the patient with P-NOM after hip fracture.

## CONCLUSION

With the introduction of SDM in an acute setting for geriatric patients with hip fracture, proxies reported pP-NOM as an acceptable and adequate option for patients with high risk of adverse outcomes after surgery. The emerged themes in P-NOM show great similarity with severe end-stage disease palliative care, with pain identified as the most important factor influencing comfort of the patient and their environment after hip fracture. Future research should focus on further improving targeted analgesia for these patients focusing on acute pain caused by the fracture. The participants clearly underlined the impact of the end-of-life choice in an acute setting. Therefore, we should include advance care planning as a routine feature of general healthcare for geriatric patients to protect patients and families from these unanticipated situations.

**Contributors** DvdV was the guarantor of this study and made substantial contributions to the concept and design together with HJS and DPJS. JFS was accountable for the elaboration of the qualitative methodology. TMPN and DWPMML contributed equally to the data acquisition and thematic analysis of the interviews. All authors worked on the interpretation of the data, made contributions to intellectual content and approved the final version of the manuscript to be published.

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**Competing interests** None declared.

**Patient and public involvement** Patients and/or the public were not involved in the design, or conduct, or reporting, or dissemination plans of this research.

**Patient consent for publication** Next of kin consent obtained.

**Ethics approval** The study was conducted in accordance with the Declaration of Helsinki, and the study design was approved by the Medical Ethics Committee, Utrecht (MEC-U), The Netherlands (W21.099). Participants gave informed consent to participate in the study before taking part.

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**Data availability statement** Data are available upon reasonable request.

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**Appendix A: Topic guide of the semi-structured questionnaire with the proxy****Overarching questions**

Q: What was the impact of the trauma on the patient?

Q: What was the impact of the trauma on you, as a proxy?

Q: How was the communication with the treating physician (scale 0-10, 0 = very poor and 10 = outstanding)?

Q: Did you feel the decision for nonoperative management was 'shared decision-making'?

Q: Were you (the proxy) present/involved in the doctor-patient meetings

Q: What kind of doctor led the doctor-patient meetings?

**In-depth questions***Health status*

Q: Please describe the palliative, non-surgical trajectory in terms of pain?

Q: How was the analgesia arranged?

Q: Did you feel that the patient was in pain?

Q: Do you think the patient was comfortable?

Q: How was the patients appetite?

Q: How was the patients night's sleep?

*Health Related Quality Of Life*

Q: Please describe the palliative, non-surgical trajectory in terms of mental health/sanity?

Q: Has the patient experienced delirium during the palliative trajectory?



Q: How was the patients consciousness during the palliative trajectory?

Q: What do you think was the most important to the patient during the palliative, non-surgical trajectory?

Q: Do you think that the patient would choose the palliative, non-surgical management again if he/she would have to make the decision a second time?

Q: How was the communication between the patient and their loved ones?

### **Concluding questions**

Q: Has the palliative care option ever been discussed with the patient, prior to the event?

Q: Were there any post-traumatic complications during the palliative, non-surgical trajectory?

Q: What is the cause of death of the patient?

Q: Did the dying occur in an acceptable manner according to you?

Q: Was the patient comfortable during the death?

Q: Is there anything you would like to add?