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Patient and proxy perspectives in decision-making for geriatric hip fracture management, a qualitative study

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Patient and proxy perspectives in decision-making for geriatric hip fracture management, a qualitative study

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Conflicts of interests

None declared.

Author contributions

DWPML was closely involved in setting up the methodology, data collection and data analysis. TK contributed greatly to processing of the data. AvdB contributed to collecting and analyzing the data. MACdJ and RT were both involved in setting up the methodology, together with DvdV and TMPN who were the initiators of this study. All authors approved the final version of the manuscript to be published.

Data statement section

Data are available upon reasonable request.

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

Keywords:

Qualitative; shared-decision making; hip fracture; geriatric; trauma; palliative, non-operative management; P-NOM

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Abstract

Objective

The objective of this study was to evaluate the perspectives with the decision-making process between surgery and palliative, non-operative management (P-NOM) of geriatric hip fracture patients and their proxies.

Design

A qualitative, retrospective cohort study was performed where patients and proxies were asked to participate in semi-structured interviews. The interviews were analysed according to Braun and Clarke's six-step guide.

Setting and participants

Convenience sampling was used, where hip fracture patients aged 70 years or above admitted to our large regional rural hospital were eligible for inclusion. In hip fracture patients with a pre-existing diagnosis of dementia and/or who were treated with P-NOM, proxies were asked to participate in the semi-structured interview.

Results

A total of 16 patients and 12 proxies were included. Five themes were identified during thematic analysis: 1) Underlying patient values, 2) The provision of information, 3) Reasons to consider either P-NOM or surgery, 4) Involvement in decision and 5) Realization of expectations. Information provided by the physician varies in terms of desired level of detail, but should involve discussing the advantages and disadvantages of surgery and P-NOM. Patients and proxies underscored the importance of achieving optimal quality of life and aligning expectations regarding various outcomes.

Conclusions

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3 In-depth analysis provided a unique insight in the patient and proxy perspectives. Crucial aspects of
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5 SDM were identified and the importance of a patient-centered approach was emphasized, where
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7 physicians should be informative and guiding, using a personalized communication style and
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9 providing opportunities for reflection during the decision-making process.
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Strengths and limitations of this study

- ➔ The first study to explore shared decision-making from the perspectives of both patients and proxies following hip fracture
- ➔ A holistic approach was used, extending beyond mere consideration of the fracture itself
- ➔ Proxies were included to gather the experiences of palliatively treated and/or cognitively impaired patients
- ➔ First-hand experiences were included
- ➔ Data saturation was reached after 16 interviews

Introduction

Geriatric hip fractures are becoming increasingly prevalent.(1–3) Generally, hip fractures are treated with surgery, i.e. operative management (OM).(4) However, depending on the patient goals and preferences, the emergence of palliative, non-operative management (P-NOM) provides an alternative when limited added value of OM is expected.(5–8) With P-NOM, the focus primarily lies on the patients' preferences, comfort and adequate analgesia. In an acute setting, the treating physician can initiate a Shared Decision-Making (SDM) process to determine the course of treatment, based on the patients preferences.(9) Due to its recent emergence, P-NOM plays an increasingly important and frequent role in SDM for geriatric hip fracture patients with a limited life expectancy. The decision between OM and P-NOM for geriatric patients with a limited longevity is complicated due to uncertainty in forecasting a patient-specific prognosis, absence of a pre-existing patient-physician relationship, and time pressure originating in an optimal window of OM of 24-48 hours. (10–17) Additionally, the unforeseen acute hip fracture setting is emotionally demanding for patients and proxies, which entails that not all verbally explained information will be retained.(10,13,18) For hip fracture patients, the patient's goals of care serve as the cornerstone in selecting the most suitable course of action, emphasizing the vital role of the patient's perspective in SDM.(6,9) With the emergence of P-NOM and associated SDM, it has become essential to explore perspectives of this fragile population on SDM in the acute hip fracture setting.(6,19) The objective of this study was to explore the perspectives of geriatric patients and their proxies with SDM in case of a hip fracture regarding OM and P-NOM.

Methods

Design

A qualitative cohort study was performed in a large regional rural hospital between December 1st 2022 and February 1st 2023. To minimize recall bias, patients and proxies were asked to participate in semi-structured interviews within a year after presentation at the emergency department with a hip fracture. The study design was approved by the Medical Ethics Review Committee Utrecht (MEC-U), the Netherlands (W22.233). The "Standards for Reporting Qualitative Research" by O'Brien et al. guided this article.(20)

Participants

Hip fracture patients were retrospectively identified from the electronic patient file and eligible for inclusion if they were 70 years of age or older. Patients were diagnosed with a femoral neck, intertrochanteric or subtrochanteric fracture and were treated with OM or P-NOM. For hip fracture patients with a pre-existing diagnosis of dementia or patients who were treated with P-NOM, proxies were asked to participate in the semi-structured interview. Proxies were eligible for inclusion if they were offspring, partner or caregiver of a patient meeting the inclusion criteria. Patients and proxies were excluded from the study if they lacked fluent Dutch or English proficiency. Patients and proxies were allocated between four cohorts according to the type of treatment (OM or P-NOM) and the presence of a pre-existing dementia diagnosis as illustrated in Figure 1.

Recruitment and consent

Convenience sampling was used to include patients and proxies. Patients and proxies were recruited by calling the patient or their proxy as registered in the electronic patient file. All eligible patients and proxies received an uniform informative introduction by telephone regarding the study. Patients and proxies provided verbal informed consent, after which a interview was scheduled. Patients and proxies had the option to withdraw from the interview at any point.

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Data collection

The semi-structured interviews were conducted via telephone. The interviews were recorded and the audio recordings were anonymously stored in a secured server. DL, AvdB and TN conducted the interviews. TN is a medical doctor and DL is a medical student. Both are experienced with qualitative studies in trauma geriatrics. AvdB is a sociology student researcher at the trauma geriatric research department. In addition to the qualitative data on patient and proxies' perspective, baseline characteristics of patients and proxies were collected from the electronic health records and the interviews. In patients, data were collected on age (in years), sex (male/female), the presence of a pre-existing diagnosis of dementia, Charlson Comorbidity Index (CCI), living situation (independent at home, home with activities of daily living care, institutional care facility), type of management (OM, P-NOM), admittance to our hospital, mortality and time from hospital admission to death (days). In proxies additional data were collected on age (in years), sex (male/female) and relation to the patient (spouse, offspring or acquaintance).

Data analysis

Thematic analysis was done according to Braun and Clarke's six-step guide.⁽²¹⁾ The study adopted a phenomenological approach, acknowledging that the perceptions of both the relative and the patient concerning SDM surrounding the hip fracture exist within a reality beyond their individual experiences.⁽²²⁾ Patient recruitment started with patients who were presented at the emergency department at 24-11-2022 and was continued further into the past, ensuring no omissions. Patient recruitment ended when four patients per cohort were included. After conducting four interviews in each cohort, DL and AvdB transcribed the audio recordings verbatim. Upon transcription, DL and AvdB proceeded to formulate preliminary themes. DL and an independent researcher (TK) thematised half of the transcripts based on these preliminary themes. DL and TK compared the themes and the content of those themes, and after DL and TK reached consensus on thematization, themes were discussed with TN and AvdB. DL, TK, TN and AvdB considered that the data had enough rigour to perform a thorough analysis. Afterwards, DL and TK proceeded with the independent coding process and reached intercoder agreement in the final thematization using ATLAS.ti (version 23.1.1.0).

Results

A total of 16 interviews were conducted, consisting of 4 patient interviews and 12 proxy interviews (Figure 2). The baseline characteristics of all patients and proxies are presented in Table 1. The median age of the patients was 84 (IQR 80-91), ten (63%) patients with female sex and a median CCI of 6 (IQR 5-6). All patients were admitted to the hospital, with a median length of stay of six (IQR 3-10) days. Of the patients who received P-NOM, six (75%) were deceased at the time of the interview, with a median time from hospital admission to death of 14 (IQR 7-48) days. The included proxies had a median age of 62 (IQR 56-69), eight (67%) were female, and eleven (92%) were offspring.

Cohort A, B, C and D had a median age of 88 (IQR 84-90), 83 (IQR 90-91), 94 (IQR 81-101) and 75 (IQR 71-81), respectively. In cohort D, all patients lived at home without needing additional ADL care. Regarding patients in cohort A, B and C, two patients (50%), three patients (75%) and two patients (50%) lived in an institutional care facility, respectively.

During thematic analysis, five themes were identified: 1) Underlying patient values, 2) The provision of information, 3) Reasons to consider either P-NOM or OM, 4) Involvement in decision and 5) Realization of expectations.

Theme 1: Underlying patient values

Patients and proxies described the essence of life as a state of happiness, with various individual interpretations encompassing activities such as: "reading, having conversations", "just going his way", but also participating in society and "helping others". Both patients and proxies addressed independence and adequate self-reliance as an essential contributor to the qualitative measure of life. In response to the question about what patients did not want, patients and proxies offered various descriptions of a state characterised by complete dependency on care and devoid of happiness, referring to it as a "vegetative state". Mobility was described as a prerequisite for engaging in activities with a certain degree of independence. All surgically treated patients and proxies expressed a strong desire to return to their pre-fracture level of mobility, as being unable to be as active as before made them feel like "bystanders in life". Even minor improvements in mobility could contribute to the quality

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of their life, such as sitting in a chair or participating in activities. Also, preserving every bit of cognitive function was deemed very valuable in the last phase of life. However, the impact of cognitive impairment had to do with the patient's state of mind: a patient unaware of her Alzheimer's diagnosis still exhibited happiness, while another patient displayed aggressive behaviour devoid of happiness. The absence of pain was deemed of utmost importance for the quality of life, where pain was mentioned as a crucial factor in "letting life go".

"If a phase comes where mom deteriorates significantly, and I will call it vegetating, for lack of a better term, then surgery will no longer be pursued."

"Overall, things are going quite well, and she still enjoys the moments when we are together. She also continues engaging in enjoyable activities in her home, and she generally remains cheerful."

"I do not think she knows anymore, that she has Alzheimer's, but she is still happy. Moreover, that is actually what she indicated recently: 'I am still glad to be here.'"

"If the pain continues like this, I do not want it." She has expressed this to several people in different circumstances." (a proxy of a patient describing the pre-fracture situation and pain experience before P-NOM)

Theme 2: The provision of information

The shape and the amount of information provided by the physician emerged as an important theme. All interviewed patients indicated they had "enormous" trust in the medical staff and consequently relied on the information provided by the medical staff resulting in little need for additional information. For fourteen of the sixteen participants, the conversations with the physician were the most important source of information. For two of the twelve proxies questions remained about the details of P-NOM, such as "how to proceed" and "who ultimately arranges for the patient to be comfortable and how that will happen". These two proxies consulted the internet for additional information. The desired level of details in the provision of information varied. Two of the four patients in cohort D indicated they would have liked information about the specific surgical techniques and prospects regarding the rehabilitation process. In contrast, all four patients in cohort D stated that there was no necessity to discuss complications, since they "wanted surgery anyway" and "would only get nervous about possible complications". Essential questions patients and proxies wanted to express during SDM concerned the treatment options, the added value of OM, timing and logistics of OM, revalidation process and pain management.

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"They could explain that more clearly, this palliative care."

"I was just like, guys, throw me into that operating room, get busy!"

"I was already happy to be there and believed everything I was told."

"How long before I could do anything again?"

Theme 3: Reasons to consider either P-NOM or OM

A considerable part SDM involves the presentation of medical options (either P-NOM or OM) and their implications, i.e. advantages and disadvantages after sustaining a hip fracture. Discussed risks of OM were urinary tract infection, pneumonia, delirium, aggravated dementia and mortality. In five out of eight patients who underwent OM, participants indicated that complications associated with OM had been discussed before OM. Important considerations for choosing OM were: "being able to walk again", "having a better longevity", compared to choosing P-NOM, "being able to return home" and "being relieved of pain". Prior to OM, the option of P-NOM was discussed with three out of eight surgically treated patients. The patients without dementia who received OM declared that there was no need for discussing P-NOM as OM was absolutely preferred, since it was the only curative option. When P-NOM was discussed, proxies indicated that they were told that the doctors would make sure the patient would have "as little pain as possible" to ensure that the patient was as comfortable as possible, concurrently entailing absent mobility and possible swift demise. In terms of prognosis, wide variations were discussed, from mortality within 1 year to mortality within 10 days. Proxies of patients who opted for P-NOM reported that the decision was primarily based on the following considerations: the lack of added value of OM if a patient already had impaired mobility or short longevity, the desire to be pain-free, anaesthesiologic objections for surgical treatment based on medical history, cognitive issues of the patient that would result in a more challenging rehabilitation (i.e. instructability) and a completed life wish of the patient.

"I remember very well that it (discussing P-NOM) overwhelmed me; I thought "Oh dear, what now?"."

"To operate or not to operate means to have mobility or not to have mobility."

"I just wanted surgery; I was not nervous about that."

"The more information you get, I think, the more worried you can get."

Theme 4: Involvement in decision

The central role of the patient's perspective in choice of treatment emerged as a critical element found in all transcripts. Of all patients and proxies, fifteen out of sixteen reported a certain degree of SDM.

One participant indicated with discontentment that the treatment was communicated without presentation of a choice. In five patients and proxies, the course of treatment was evident towards OM, that SDM was merely aimed at the provision of insights in the treatment and rehabilitation process. Patients and proxies highly valued the physician's role, describing it as informative and guiding, originating from professional experience and knowledge. Personal experiences of healthcare professionals with hip fracture treatment were preferred over the presentation of plain statistical data. The identity of the decision-maker differed: ranging from patients making independent decisions or joint decision-making of the patient with a proxy, to proxies deciding on behalf of the patients and ultimately some patients leaving the decision entirely to the physician. Time and space with opportunity for reflection was considered essential for SDM, in particular engagement in multiple SDM dialogues was deemed valuable. Interpersonal interaction and patient centeredness in communication were considered indispensable, where the seating posture of the physician was perceived as positive, while the standing position of the physician was regarded as unfavourable. A similar sentiment was expressed regarding the tone of communication regarding the prospects in life duration, where a direct approach was perceived as highly inappropriate. Considering the treatment option P-NOM was reported as carrying a "substantial emotional burden", arising from the sudden nature of a hip fracture combined with confrontation with an unfamiliar poor prognosis. The decision-making itself added to the emotional load through the time pressure and the final nature of the decision, even reflecting on their decision in the study was perceived as challenging by both patients and proxies. The majority of patients and proxies expressed no regret regarding their treatment decision, as addressed further in the theme *Realization of expectations*.

"During the conversation, we had the space to express that we would prefer her to undergo surgery. (...) We have no experience, so we rely on those people and hold them in high regard."

"We always stood behind that decision afterwards. That sounds contradictory because we did lose our mother because of it."

"Just making contact with the patient's family, telling them how things are going, always being available for questions, is incredibly important."

"I think it is important to have a say in the decision-making process, not just the doctor or the patient deciding everything (...) You listen most to the doctor. I am not an expert, but I can discuss and think about what the doctor says and talk about it."

Theme 5: Realization of expectations

Fourteen out of sixteen participants reported that disparity between expected and actual treatment outcomes was connected to a negative connotation regarding the overall experience, hence this is elaborated further. Overall experiences varied widely among different patients and proxies and concerned rehabilitation process, pain, cognitive decline, longevity and P-NOM. Several findings stand out. Regarding the rehabilitation process, in four of the eight surgically treated patients the rehabilitation process went slower than expected. About pain experience, patients and proxies indicated that they desired to be pain free, regardless of treatment. Therefore, prompt administration of analgesia was pivotal to ensure patient's comfort. A PENG block with the neurolytic agent (phenol 5%) was administered locally to four of the eight patients who opted for P-NOM, where patients assumed it would render them painfree. However, becoming pain free with the PENG block alone was not ensured in three for these patients, requiring additional oral analgesia. The importance of experiencing comfort is stressed further in the theme *Underlying patient values*. Regarding cognitive decline, three operatively treated patients with a pre-existing diagnosis of dementia showed a substantial cognitive decline since the operation. Especially the sudden deterioration of cognitive status was unexpected by patients and proxies. Concerning the experience with longevity, three proxies indicated that the expectation of the patients' passing within a few weeks did not match the reality of the patient surviving for longer than three months. One of these three participants expressed that, in retrospect, the longer lifespan would have led to a different choice of initial treatment. Regarding proxy expectation with P-NOM compared to the reality, proxies indicated the following issues were perceived as pleasant with P-NOM: the patient passing away in their own home or hospice, unburdening of the family members by the hospital, the opportunity for proxies to express their final goodbyes. Issues that were perceived as unpleasant with P-NOM were: the absence of contact with the patient in the last days of life, the development of a death rattle in the dying process and unavailability of palliative care team on weekends.

"That she would deteriorate so incredibly mentally, we did not expect that."

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3 *"We were both worried once we made that decision that day of not operating; how long will this*
4 *process take?"*
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6 *"They did say that recovery can take six months, but even so, it's too slow for me."*
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8 *"I do not walk charmingly, but I do walk."*
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Discussion

This study involved a comprehensive analysis of the perspectives of geriatric hip fracture patients and their proxies regarding SDM for hip fractures. Underlying patient values, the provision of information, reasons to consider either P-NOM or OM, involvement in decision and realization of expectations emerged as crucial themes that come into play during SDM for hip fractures. Within these themes, several vital aspects were identified which come into play during shared decision-making for hip fractures.

The identified reasons to opt for P-NOM were consistent with earlier findings where refraining from OM was not purely driven on comorbidity, but also on severe advanced dementia, poor functional status and patients' wishes.(23–25) Novel findings supporting opting for P-NOM were the desire to reduce pain of the hip fracture and the expected influence of cognitive impairment on future rehabilitation. The desire to reduce pain was not reported in previous studies and could be explained by a recent innovation in hip fracture pain management through a local Pericapsular Nerve Group (PENG) block.(26) This anatomic approach for local pain management of the hip was used in four of eight P-NOM patients and scientifically shows promise in providing long term pain relief in P-NOM.(27–29) The importance of pain management in hip fracture patients is underlined by its emergence in both themes *Realization of expectations* and *Underlying patient values*, which is consistent with previous research that emphasizes the importance of pain management.(6) Patients and proxies indicated that the PENG block provided less pain relief than expected. In previous studies a satisfaction rate of 83% with PENG block was reported, which is higher than this study, were 3 out of 4 patients reported full satisfaction with PENG block.(27) In the theme *Involvement in decision*, a variation of “sharedness” in the decision-making was reported, this aligns with the recommendation to “tailor the sharedness of the decision to the needs of patients and their family”.(13) Patients and proxies reported that time to reflect in between consultations with their treating physician was valuable, this is in line with previous research, where iterative communication is suggested to encourage dialogue and focus on patients' goals and values.(17) Furthermore, proxies reported a significant emotional burden associated with making the decision for treatment, originating in proxies not just dealing with a patient with a hip fracture, but a dear human being for whom a life-changing decision must be made. This is not addressed by previous scholars, although the importance of

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Advanced Care Planning in the geriatric population is stressed.(24,30) The theme *Realization of expectations* is characterized by a great variety between participant expectations and reality, which is in line with previous articles which state that decision-making within the field of trauma geriatrics is accompanied by a great degree of uncertainty.(13) In terms of prognosis regarding longevity, there were wide variations in longevity from 10 days to a year. Previous scholars attribute this variation to the current limitations in predicting the prognosis of patients, although the 1-year survival is reported to be longer after OM when compared to P-NOM.(5,31,32) Discrepancies between expectation and reality of longevity were perceived as unpleasant, with one proxy even expressing regret regarding the decision because of a longer duration of life than expected. Although longevity appears to be longer when patients receive OM, patients and proxies attribute great importance to quality of life, which is reported to be non-inferior in P-NOM.(5)

One of the strengths of the study lies in its exploration of SDM from the perspectives of both patients and proxies following hip fracture, marking the first study in this specific domain. The study design included various patient categories and proxies, providing insight from a unique perspective and comprehensive overview of SDM in hip fracture treatment of frail geriatric patients in acute situations. This overview highlights that the focus in SDM should be on the patient as a human being in all its versatility rather than merely on a person's medical condition (i.e. holistic approach). The study design has several possible limitations. A relative limitation concerns the participation of proxies originating in the nature of the palliative treatment and inclusion of patients with cognitive impairment. This is legitimated as the interviewed proxies were highly involved in the clinical practice, similar to regular situations in this patient category. Another limitation to this study is the relative over-representation of P-NOM in the study sample. The proportional division of the sample did not represent the general hip fracture patient population, as the vast majority of patients undergoes OM. This was accounted for by consulting the coders group to agree on data saturation of the OM group in the study sample complemented by exploratory research methods. This allowed for infrequently mentioned, but important aspects to come up in the results.

Several direct clinical implications can be derived from this study. Through all identified themes this study underscores the important role of the patient's and their caregiver's perspective. In this context, the healthcare provider takes on a facilitating role, encompassing provision of information, guidance and the organization of appropriate logistic conditions. The healthcare provider should tailor their

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approach to the specific individual, while recognizing and addressing the emotional and psychological challenges faced by patients and proxies. In this regard a seated position outweighs a standing one, and professional insights based on experience are favored over bare statistical facts. Advantages and disadvantages of OM and P-NOM should be discussed where deemed relevant by the physician. Physicians should assess each patient's need for extensiveness of information and assess the need for discussing P-NOM. With regards to expectation management, physicians should treat burdensome topics with care and emphasis the uncertainty of topics such as cognitive decline and longevity. Furthermore, physicians should provide the appropriate logistic conditions to provide opportunity for reflection, possible through multiple conversations. Lastly, this study holds the potential not only to enhance patient satisfaction with SDM but, more significantly, to facilitate treatment choices that are personalized for the individual, where the patient takes precedence over the hipfracture itself.

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Conclusion

In-depth analysis provided a unique insight in the patient and proxy perspectives in shared decision-making for geriatric hip fracture management in the acute setting. Crucial aspects of SDM were identified and the importance of a patient-centered approach was emphasized, where physicians should be informative and guiding, using a personalized communication style and providing opportunities for reflection during the decision-making process. Future research should focus on implementing these findings in everyday practice.

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Figure 1: The formation of the cohorts

Please see attached file

OM: operative management

P-NOM: palliative, non-operative management

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Figure 2: Flowchart of the selection process of included patients and proxies

Please see attached file

OM: operative management
P-NOM: palliative, non-operative management
*Patient recruitment started with patients who were presented at the emergency department at 24-11-2022 and was continued further into the past, ensuring no ommisions. Patient recruitment ended when four patients per cohort were included.

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Table 1: Baseline characteristics of included patients and proxies

Patient characteristics	Total N = 16	Cohort A Demented, OM N = 4	Cohort B Demented, P-NOM N = 4	Cohort C No dementia, P-NOM N = 4	Cohort D No dementia, OM N = 4
Age (Y), median (IQR)	84 (80-91)	88 (84-90)	83 (80-91)	94 (86-101)	75 (71-81)
Female sex, n (%)	10 (63)	4 (100)	3 (75)	1 (25)	2 (50)
Dementia, n (%)	8 (50)	4 (100)	4 (100)	-	-
CCI, median (IQR)	6 (5-6)	6 (5-6)	7 (5-7)	5 (4-10)	4 (3-4)
Living situation, n (%)					
Home, independent	5 (31)	-	1 (25)	-	4 (100)
Home, with ADL care	4 (25)	2 (50)	-	2 (50)	-
Institutional care facility	7 (44)	2 (50)	3 (75)	2 (50)	-
Management					
Surgery	8 (50)	4 (100)	-	-	4 (100)
P-NOM	8 (50)	-	4 (100)	4 (100)	-
Admittance in hospital, n (%)	16 (100)	4 (100)	4 (100)	4 (100)	4 (100)
Length of stay (d), median (IQR)	6 (3-10)	10 (4-15)	4 (2-12)	6 (2-10)	54 (50-60)
Deceased at the time of the interview, n (%)	7 (44)	1 (25)	2 (50)	4 (100)	-
Time from hospital admission to death (d), n (%)	14 (7-48)	48 (48-48)	15 (10-15)	10 (3-91)	-
Time to interview (d), median (IQR)	61 (53-141)	59 (50-69)	85 (53-113)	320 (188-342)	5 (3-7)
Proxy characteristics	Total N = 12	Cohort A N = 4	Cohort B N = 4	Cohort C N = 4	
Age (Y), median (IQR)	62 (56-69)	63 (53-66)	59 (55-79)	66 (57-71)	
Female sex, n (%)	8 (67)	3 (75)	3 (75)	2 (50)	
Relationship with patient, n (%)					
Spouse	1 (8)	-	1 (25)	-	
Offspring	11 (92)	4 (100)	3 (75)	4 (100)	

OM: operative management

P-NOM: palliative, non-operative management

Cohort A: Geriatric hip fracture patients with dementia who have chosen OM (interview with proxy)

Cohort B: Geriatric hip fracture patients with dementia who have chosen P-NOM (interview with proxy)

Cohort C: Geriatric hip fracture patients without dementia who have chosen P-NOM (interview with proxy)

Cohort D: Geriatric hip fracture patients without dementia who have chosen OM (interview with patient)

Y: years

IQR: interquartile range

CCI: Charlson Comorbidity Index

P-NOM: palliative, non-operative management

OM: operative management

d: days

Pre-existing diagnosis of dementia?		
Type of treatment	Dementia YES	Dementia NO
	Cohort A OM Dementia YES	Cohort B OM Dementia NO
	Cohort C P-NOM Dementia YES	Cohort D P-NOM Dementia NO

Figure 1: The formation of the cohorts

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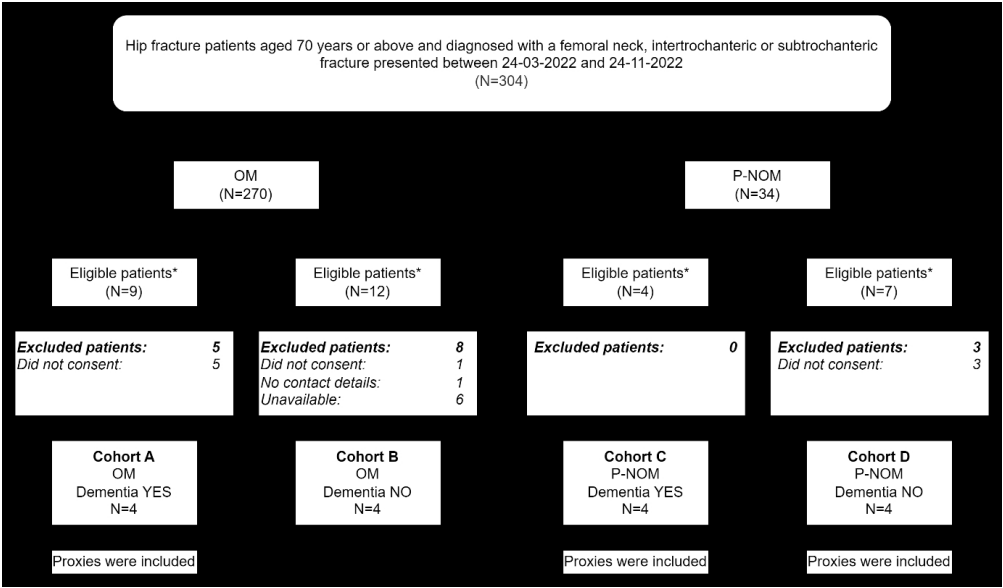


Figure 2: Flowchart of the selection process of included patient and proxies
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No.	Topic	Item
Title and abstract		
S1	Title	Concise description of the nature and topic of the study identifying the study as qualitative or indicating the approach (e.g., ethnography, grounded theory) or data collection methods (e.g., interview, focus group) is recommended
S2	Abstract	Summary of key elements of the study using the abstract format of the intended publication; typically includes background, purpose, methods, results, and conclusions
Introduction		
S3	Problem formulation	Description and significance of the problem/phenomenon studied; review of relevant theory and empirical work; problem statement
S4	Purpose or research question	Purpose of the study and specific objectives or questions
Methods		
S5	Qualitative approach and research paradigm	Qualitative approach (e.g., ethnography, grounded theory, case study, phenomenology, narrative research) and guiding theory if appropriate; identifying the research paradigm (e.g., postpositivist, constructivist/interpretivist) is also recommended; rationale ^a
S6	Researcher characteristics and reflexivity	Researchers' characteristics that may influence the research, including personal attributes, qualifications/experience, relationship with participants, assumptions, and/or presuppositions; potential or actual interaction between researchers' characteristics and the research questions, approach, methods, results, and/or transferability
S7	Context	Setting/site and salient contextual factors; rationale ^b
S8	Sampling strategy	How and why research participants, documents, or events were selected; criteria for deciding when no further sampling was necessary (e.g., sampling saturation); rationale ^b
S9	Ethical issues pertaining to human subjects	Documentation of approval by an appropriate ethics review board and participant consent, or explanation for lack thereof; other confidentiality and data security issues
S10	Data collection methods	Types of data collected; details of data collection procedures including (as appropriate) start and stop dates of data collection and analysis, iterative process, triangulation of sources/methods, and modification of procedures in response to evolving study findings; rationale ^b
S11	Data collection instruments and technologies	Description of instruments (e.g., interview guides, questionnaires) and devices (e.g., audio recorders) used for data collection; if/how the instrument(s) changed over the course of the study
S12	Units of study	Number and relevant characteristics of participants, documents, or events included in the study; level of participation (could be reported in results)
S13	Data processing	Methods for processing data prior to and during analysis, including transcription, data entry, data management and security, verification of data integrity, data coding, and anonymization/deidentification of excerpts
S14	Data analysis	Process by which inferences, themes, etc., were identified and developed, including the researchers involved in data analysis; usually references a specific paradigm or approach; rationale ^b
S15	Techniques to enhance trustworthiness	Techniques to enhance trustworthiness and credibility of data analysis (e.g., member checking, audit trail, triangulation); rationale ^b
Results/findings		
S16	Synthesis and interpretation	Main findings (e.g., interpretations, inferences, and themes); might include development of a theory or model, or integration with prior research or theory
S17	Links to empirical data	Evidence (e.g., quotes, field notes, text excerpts, photographs) to substantiate analytic findings
Discussion		
S18	Integration with prior work, implications, transferability, and contribution(s) to the field	Short summary of main findings; explanation of how findings and conclusions connect to, support, elaborate on, or challenge conclusions of earlier scholarship; discussion of scope of application/generalizability; identification of unique contribution(s) to scholarship in a discipline or field
S19	Limitations	Trustworthiness and limitations of findings
Other		
S20	Conflicts of interest	Potential sources of influence or perceived influence on study conduct and conclusions; how these were managed
S21	Funding	Sources of funding and other support; role of funders in data collection, interpretation, and reporting

^aThe authors created the SRQR by searching the literature to identify guidelines, reporting standards, and critical appraisal criteria for qualitative research; reviewing the reference lists of retrieved sources; and contacting experts to gain feedback. The SRQR aims to improve the transparency of all aspects of qualitative research by providing clear standards for reporting qualitative research.

^bThe rationale should briefly discuss the justification for choosing that theory, approach, method, or technique rather than other options available, the assumptions and limitations implicit in those choices, and how those choices influence study conclusions and transferability. As appropriate, the rationale for several items might be discussed together.

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Patient and proxy perspectives in decision-making for geriatric hip fracture management in the Netherlands, a qualitative study

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Patient and proxy perspectives in decision-making for geriatric hip fracture management in the Netherlands, a qualitative study

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Keywords:

Qualitative; shared-decision making; hip fracture; geriatric; trauma; palliative, non-operative management; P-NOM

Word count: 3999

Abstract

Objective

The objective of this study was to explore the perspectives with the decision-making process between surgery and palliative, non-operative management of geriatric hip fracture patients and their proxies.

Design

A qualitative interview study was performed. Patients and proxies were asked to participate in semi-structured interviews. Data were analysed using reflexive thematic analysis according to Braun and Clarke's six-step guide.

Setting and participants

Hip fracture patients in the Netherlands were eligible for inclusion. For hip fracture patients with a pre-existing diagnosis of dementia and for patients who opted for palliative, non-operative management, proxies were included.

Results

A total of 16 interviews were conducted, consisting of 4 patient interviews and 12 proxy interviews. Five themes were identified during thematic analysis: 1) Underlying patient values, 2) The provision of information, 3) Reasons to consider either palliative, non-operative management or surgery, 4) Involvement in decision and 5) Realisation of expectations. Information provided by the physician varied in terms of desired level of detail but involved discussing the advantages and disadvantages of surgery and palliative, non-operative management. Patients and proxies underscored the importance of achieving optimal quality of life, and the disparity between expected and actual treatment outcomes was unpleasant and negatively influenced the overall experience.

Conclusions

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In-depth analysis provided a unique insight into the patient and proxy perspectives in shared decision-making for geriatric hip fracture management in the acute setting. Overall, there were differences between reported experiences and preferences of participants. This heterogeneity stresses the importance of keeping a person-centred approach during shared decision-making. Other key considerations during shared decision-making include physicians informing patients from professional experience and communicating sensitively about both treatment options and prognosis. Physicians should aim to provide realistic, sensitive and timely information to both patients and proxies during the choice between curative and palliative care for their hip fracture.

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Strengths and Limitations of this study

- ⇒ A holistic approach was used, extending beyond mere consideration of the fracture itself.
- ⇒ Besides interviewing patients, experiences were also obtained by interviewing proxies.
- ⇒ Although geriatric hip fracture care is an international phenomenon, it was conducted in Dutch trauma geriatric care.
- ⇒ Face-to-face interviews might have enriched the data for thematic reflexive analysis.
- ⇒ More homogeneity in time to interview could have provided a clearer view on experiences at a certain moment after treatment.

Introduction

Geriatric hip fractures are becoming increasingly prevalent and are generally treated with surgery, i.e. operative management (OM).(1–4) OM provides quick analgesia and allows patients to start rehabilitation but is associated with high morbidity and mortality. Common post-operative complications include urinary tract infections, pneumonia, and delirium, and the 1-year mortality following OM is ~25-35%.(5–9) Depending on the patient’s Goals of Care (GOC), the emergence of palliative, non-operative management (P-NOM) provides an alternative when limited added value of OM is expected.(10–13) With P-NOM, the focus primarily lies on the patient’s GOC, comfort and adequate analgesia.

In an acute setting, the treating physician can initiate a Shared Decision-Making (SDM) process to determine the course of treatment based on the patient’s GOC.(14) For hip fracture patients, these GOC serve as the cornerstone in selecting the most suitable course of action, emphasizing the vital role of the patient's perspective in SDM.(11,14) Recent work into the most important GOC for geriatric patients in the case of hip fracture has shown heterogeneity between patients’ and proxies most important GOC.(14)

GOC-based SDM between OM and P-NOM for geriatric patients with limited longevity is complicated due to uncertainty in forecasting a patient-specific prognosis, the absence of a pre-existing patient-physician relationship, and time pressure originating in an optimal window of OM of 24-48 hours. (15–22) Additionally, the unforeseen acute hip fracture setting is emotionally demanding for patients and proxies, which makes it difficult for patients and proxies to retain information.(15,18,23)

With the emergence of P-NOM and associated SDM, it has become essential to explore the perspectives of this fragile population on SDM in the acute hip fracture setting.(11,24) To the authors’ knowledge, these perspectives have not been documented in scientific literature before. Therefore, the objective of this study was to explore the perspectives of geriatric patients and their proxies with SDM in case of a hip fracture regarding OM and P-NOM.

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Methods

Design

A qualitative interview study was performed in a large regional rural hospital in the Netherlands between December 1st 2022 and February 1st 2023. To minimize recall bias, patients and proxies were asked to participate within a year after presentation at the Emergency Department (ED) with a hip fracture. The "Standards for Reporting Qualitative Research" by O'Brien et al. guided this article and are attached in Appendix 1.(25)

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.

Participants

Hip fracture patients were retrospectively identified from the electronic patient file and eligible for inclusion if they were aged 70 years or above and diagnosed with a femoral neck, intertrochanteric or subtrochanteric fracture. Patients were allocated between four cohorts according to the type of treatment (OM or P-NOM) and the presence of a pre-existing dementia diagnosis. Cohort A contained patients with dementia who opted for OM, cohort B contained patients without dementia who opted for OM, cohort C contained patients with dementia who opted for P-NOM, and cohort D contained patients without dementia who opted for P-NOM (Figure 1). The study adopted a phenomenological perspective, acknowledging perceptions of individuals exist within a reality beyond their individual experiences.(26) Therefore both patients and proxies were eligible to participate in the study. For hip fracture patients with a pre-existing diagnosis of dementia (cohorts A and C) or patients who opted for P-NOM (cohorts C and D), proxies were asked to participate in the semi-structured interview. Proxies were eligible for inclusion if they were offspring, partners or caregivers of a patient meeting the

inclusion criteria. Patients and proxies were excluded from the study if they lacked fluent Dutch or English proficiency.

Recruitment and consent

Convenience sampling was used to include patients and proxies. Patients and proxies were recruited by calling the patient or their proxy as registered in the electronic patient file. All eligible patients and proxies received a uniform informative introduction by telephone regarding the study. Patients and proxies provided verbal informed consent, after which an interview was scheduled. Patients and proxies could withdraw from the interview at any point. Patient recruitment started with patients who were presented at the ED on 24-11-2022 and was continued further into the past, ensuring no omissions. Four patients or proxies per cohort were initially included.

Data collection

An interview guide was used during the semi-structured interviews, which were conducted via telephone. The semi-structured interview guide for patients and proxies is attached in Appendix 2. The interviews were recorded, and the audio recordings were anonymously stored in a secured server. DL, AvdB and TN conducted the interviews. TN is a medical doctor, and DL is a medical student. Both are experienced with qualitative studies in trauma geriatrics. AvdB is a sociology student researcher at the trauma geriatric research department. In addition to the qualitative data on the patient and proxies' perspectives, baseline characteristics of patients and proxies were collected from the electronic health records and the interviews. In patients, data were collected on age (in years), sex (male/female), the presence of a pre-existing diagnosis of dementia, Charlson Comorbidity Index (CCI), living situation (independent at home, home with activities of daily living care, institutional care facility), type of management (OM, P-NOM), admittance to our hospital, mortality, and time from hospital admission to death (days). In proxies, additional data were collected on age (in years), sex (male/female) and relation to the patient (spouse, offspring, or acquaintance).

Qualitative analysis

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3 A reflexive thematic analysis was performed following Braun and Clarke's six-step guide.⁽²⁷⁾ The
4 interview recordings were transcribed ad verbatim by DL and AvdB. DL and AvdB familiarised with the
5 data during both transcription and repetitive reading of the transcripts. Hereafter, DL and AvdB
6 established data saturation and proceeded to formulate preliminary themes. The transcripts were then
7 coded by DL and an independent researcher (TK) using ATLAS.ti (version 23.1.1.0). In the analytic
8 process several theoretical assumptions were made.⁽²⁸⁾ A constructionist epistemology was chosen
9 to acknowledge the significance of recurrence while prioritising meaning and meaningfulness as
10 central criteria. An experiential orientation was chosen to acknowledge the subjective reproduction of
11 thoughts, feelings, and experiences. A combination of inductive and deductive analysis was
12 employed, inductive to generate themes based on the data and deductive based on the
13 predetermined topics as provided in the interview guide. Semantic and latent coding was used,
14 switching between techniques based on the properties of the data analysed.

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17 Based on assigned codes, the themes were repeatedly compared and redefined as needed in
18 intercoder meetings between DL and TK, with approval of AvdB and TN. When comparing codes and
19 thematic analysis, a collaborative and reflexive approach was used to enrich the themes rather than
20 achieve consensus. Themes were connected logically and meaningfully and placed in the appropriate
21 context, as reported in the Results section of this article.

Results

A total of 16 interviews were conducted, lasting between 30 and 60 minutes and consisting of 4 patient interviews and 12 proxy interviews (Figure 2). The baseline characteristics of all patients and proxies are presented in Table 1. The median age of the patients was 84 (IQR 80-91), ten (63%) patients with female sex and a median CCI of 6 (IQR 5-6). All patients were admitted to the hospital, with a median length of stay of six (IQR 3-10) days. Of the patients who received P-NOM, six (75%) were deceased at the time of the interview, with a median time from hospital admission to death of 14 (IQR 7-48) days. One patient (13%) who received OM was deceased at the time of the interview. The included proxies had a median age of 62 (IQR 56-69), eight (67%) were female, and eleven (92%) were offspring. The most recent patient that was included was diagnosed with a hip fracture on 19-11-2024, and the patient included furthest back in history was diagnosed with a hip fracture on 02-02-2022.

Cohort A, B, C and D had a median age of 88 (IQR 84-90), 83 (IQR 90-91), 94 (IQR 81-101) and 75 (IQR 71-81), respectively. In cohort D, all patients lived at home without needing additional ADL care. Regarding patients in cohorts A, B and C, two patients (50%), three patients (75%) and two patients (50%) lived in an institutional care facility, respectively.

During thematic analysis, five themes were identified: 1) Underlying patient values, 2) The provision of information, 3) Reasons to consider either P-NOM or OM, 4) Involvement in decision and 5) Realisation of expectations.

Theme 1: Underlying patient values

This theme uncovers the values guiding treatment decisions, shedding light on patients' desires for independence, mobility, cognitive function, and pain relief, directly informing the decision-making process between surgery and palliative care. Patients and proxies described the essence of life as a state of happiness, with various individual interpretations encompassing activities such as: "reading, having conversations", "just going his way", but also participating in society and "helping others". Both patients and proxies addressed independence and adequate self-reliance as essential contributors to

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the qualitative measure of life. In response to the question about what patients did not want, patients and proxies offered various descriptions of a state characterised by complete dependency on care and devoid of happiness, referring to it as a "vegetative state".

"If a phase comes where mom deteriorates significantly, and I will call it vegetating, for lack of a better term, then surgery will no longer be pursued." Proxy 1: Proxy of patient with dementia who chose OM.

Mobility was described as a prerequisite for engaging in activities with a certain degree of independence. Even minor improvements in mobility could contribute to the quality of one's life. Also, preserving every bit of cognitive function was deemed very valuable in the last phase of life. However, the impact of cognitive impairment had to do with the patient's state of mind: a patient unaware of her Alzheimer's diagnosis still exhibited happiness. In contrast, another patient displayed aggressive behaviour devoid of happiness.

"Overall, things are going quite well, and she still enjoys the moments we are together. She also continues engaging in enjoyable activities in her home and generally remains cheerful." Proxy 2: Proxy of patient with dementia who chose OM.

"I do not think she knows anymore that she has Alzheimer's, but she is still happy. Moreover, she indicated recently: 'I am still glad to be here.'" Proxy 4: Proxy of patient with dementia who chose OM.

The absence of pain was deemed of utmost importance for the quality of life, where pain was mentioned as a crucial factor in "letting life go". In essence, in treatment decision-making, individuals strive for optimal quality of life characterized by happiness, which is a subjective experience.

"If the pain continues like this, I do not want it." She has expressed this to several people in different circumstances." (a proxy of a patient describing the pre-fracture situation and pain experience before P-NOM) Proxy 11: Proxy of patient without dementia who chose P-NOM.

Theme 2: The provision of information

This theme reveals how patients and proxies seek and receive information, influencing their understanding of treatment options and their involvement in decision-making, thus impacting

perspectives on OM versus P-NOM. For fourteen of the sixteen participants, the conversations with the physician were the most important source of information. All interviewed patients indicated they had “enormous” trust in the medical staff and consequently relied on the information provided, resulting in little need for additional information. For two proxies, questions remained about the details of P-NOM, such as “how to proceed” and “who ultimately arranges for the patient to be comfortable and how that will happen”. These two proxies consulted the internet for additional information.

"They could explain that more clearly, this palliative care." Proxy 5: Proxy of patient with dementia who chose P-NOM.

Essential questions patients and proxies wanted to express during SDM concerned the treatment options, the added value of OM, the timing and logistics of OM, the revalidation process, and pain management. The desired level of detail in the provision of information varied. Regarding the patients in cohort D, two of the four patients indicated they would have liked information about the specific surgical techniques and prospects regarding the rehabilitation process. In contrast, all four patients in cohort D stated that there was no necessity to discuss complications since they “wanted surgery anyway” and “would only get nervous about possible complications”. This discrepancy reflects variability in desired shape and amount of information, where the provider of the information, i.e. the physician, plays a major role.

"I was just like, guys, throw me into that operating room, get busy!" Patient 1: Patient without dementia who chose OM.

"I was already happy to be there and believed everything I was told." Patient 2: Patient without dementia who chose OM.

"How long before I could do anything again?" Patient 3: Patient without dementia who chose OM.

Theme 3: Reasons to consider either P-NOM or OM

This themes involves the specific reasons to opt for P-NOM or OM. Important considerations for choosing OM were: “being able to walk again”, “having better longevity” (compared to choosing P-NOM), “being able to return home”, and “being relieved of pain”.

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"To operate or not to operate means to have mobility or not to have mobility." Proxy 4: Proxy of patient with dementia who chose OM.

Proxies of patients who opted for P-NOM reported that the decision was primarily based on the following considerations: the lack of added value of OM if a patient already had impaired mobility or short longevity, the desire to be pain-free, anaesthesiologic objections for surgical treatment based on medical history, cognitive issues of the patient that would result in a more challenging rehabilitation (i.e. instructability) and a completed life wish of the patient. It is remarkable that alleviating pain was mentioned as a reason to opt for both OM and P-NOM, reflecting that decision-making may be based on subjective judgement. Instead of objective measures, patients choose a management which fits their idea of a happy life, grounded in underlying patient values as described in theme 1.

In five out of eight surgically treated patients, the option of P-NOM was not brought during SDM. When a curative management was absolutely preferred, patients reported no need to discuss P-NOM. When P-NOM was discussed, proxies reported being informed that pain management would be prioritised, and involved absent mobility and possible swift demise. In terms of prognosis, wide variations were discussed, from mortality within 1 year to mortality within 10 days.

"I just wanted surgery; I was not nervous about that." Patient 1: Patient without dementia who chose OM.

"The more information you get, I think, the more worried you can get." Patient 4: Patient without dementia who chose OM.

Theme 4: Involvement in decision

This theme outlines the relevance of patient- and proxy involvement in treatment decision-making, with time and space to reflect during this process and an important role reserved for the physician. These components are surrounded by the emotional burden that participants reported was associated with considering PNOM.

A varying degree of SDM was reported, where the identity of the decision-maker differed. This ranged from patients making independent decisions or joint decision-making of the patient with a proxy, to proxies deciding on behalf of the patients and some patients leaving the decision entirely to the physician. When the course of treatment was evident towards OM, SDM was merely aimed at

providing insights into the treatment and rehabilitation process. Despite this variation, collaboration with the physician in SDM was widely appreciated and a lack of opportunity to participate in treatment choice was perceived negatively.

"I think having a say in the decision-making process is important, not just the doctor or the patient deciding everything (...) You listen most to the doctor. I am not an expert, but I can discuss and think about what the doctor says and talk about it." Patient 3: Patient without dementia who chose OM.

Time and space for reflection in SDM were also positively valued. The first SDM dialogue was performed at the ED where the GOC were evaluated and both options (OM and P-NOM) presented. In some cases, patients and families opted for a particular treatment in the acute setting. However, a time-out was preferred, followed by a second or sometimes even a third SDM dialogue. This allowed patients and proxies to reflect if the provided information was comprehensible and if they had any remaining questions.

"Just making contact with the patient's family, telling them how things are going, always being available for questions, is incredibly important." Proxy 11: Proxy of patient without dementia who chose P-NOM.

Patients and proxies highly valued the physician's role, describing it as informative and guiding. Healthcare professionals' professional experiences with hip fracture treatment were preferred as information source over sole presentation of statistical data or information brochures. Communication and information tailored to both patient characteristics and care situation were considered indispensable, where a seating posture of the physician was perceived as positive and a standing position as unfavourable. In communication regarding the prospects in life duration, a direct approach was perceived as highly inappropriate.

"During the conversation, we had the space to express that we would prefer her to undergo surgery. (...) We have no experience, so we rely on those people and hold them in high regard." Proxy 5: Proxy of patient with dementia who chose P-NOM.

Considering the treatment option P-NOM was reported as carrying a "substantial emotional burden", arising from the sudden nature of a hip fracture combined with the confrontation with an unfamiliar

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poor prognosis. The decision-making itself added to the emotional load through the time pressure and the final nature of the decision. Even reflecting on their decision in the study was perceived as challenging by both patients and proxies, which underscores the emotional load.

"We always stood behind that decision afterwards. That sounds contradictory because we did lose our mother because of it." Proxy 8: Proxy of patient with dementia who chose P-NOM.

"I remember very well that it (discussing P-NOM) overwhelmed me; I thought "Oh dear, what now?"." Proxy 2: Proxy of patient with dementia who chose OM.

Theme 5: Realisation of expectations

In this theme the importance of alignment between anticipated and actual treatment outcomes is addressed. A disparity between expected and actual treatment outcomes was reported as unpleasant and negatively influenced the overall experience. This concerned outcomes such as pain management, rehabilitation and P-NOM, which are elaborated further.

Patients and proxies in both P-NOM and OM indicated they desired to be fully pain-free, for which prompt administration of analgesia was essential. When a PENG block was performed, patients and proxies expected that this treatment would provide complete pain reduction. This was disappointing, because achieving comfort generally required additional oral analgesia.

The post-operative rehabilitation process performing below expectations regarded both physical and cognitive terms. Physical rehabilitation went slower than expected in four of the eight surgically treated patients, which was perceived negatively. Three operatively treated patients with a pre-existing diagnosis of dementia showed a substantial cognitive decline since the operation, which also impeded physical rehabilitation. Especially the sudden nature of cognitive decline was unexpected and not pleasant.

"That she would deteriorate so incredibly mentally, we did not expect that." Proxy 3: Proxy of patient with dementia who chose OM.

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3 *"They did say that recovery can take six months, but even so, it is too slow for me." Patient 1:*
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5 *Patient without dementia who chose OM.*
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8 *"I do not walk charmingly, but I do walk." Patient 2: Patient without dementia who chose OM.*
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10 Relevant in P-NOM were adequate care, presence of loved ones and dying in the desired way on a
11 location as desired, on an expected moment. Adequate care entailed unburdening of the family
12 members by the hospital with availability of a palliative care team on weekends as prerequisite. The
13 presence of loved ones concerned the opportunity for proxies to express their final goodbyes, where
14 the absence of contact with the patient in the last days of life was unpleasant. And lastly the patient
15 peaceful passing away in their own home or hospice, without development of a death rattle in the
16 dying process. Concerning the experience with longevity, three proxies indicated that the expectation
17 of the patients' passing within a few weeks did not match the reality of the patient surviving for longer
18 than three months. One of these three participants expressed that, in retrospect, the longer lifespan
19 would even have led to a different choice of initial treatment.
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30 *"We were both worried once we decided not to operate that day; how long will this process*
31 *take?" Proxy 8: Proxy of patient with dementia who chose P-NOM.*
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Discussion

Red line

This study involved a comprehensive analysis of the perspectives of geriatric hip fracture patients and their proxies regarding SDM regarding P-NOM or OM in hip fractures. Underlying patient values, the provision of information, reasons to consider either P-NOM or OM, involvement in decision and realisation of expectations emerged as central themes.

Comparing with previous literature

~Reasons to opt for P-NOM~

Identified reasons for opting for P-NOM were consistent with earlier findings, where abstaining from OM was not purely driven by physical comorbidity but also by severe advanced dementia, poor functional status, and patient's wishes.(29–31) Novel findings supporting opting for P-NOM were the desire to reduce hip fracture pain and expected negative influence of cognitive impairment on future rehabilitation chances.

~Pain management~

Previous qualitative research also identified pain management as an essential factor for geriatric hip fracture patients who opted for P-NOM.(11) A Pericapsular Nerve Group (PENG) block for local hip pain management was used in four of eight P-NOM patients and has shown promise for long-term pain relief in P-NOM.(32–34) Patients and proxies indicated that mono treatment with PENG block provided less pain relief than expected. This stresses the importance of optimizing provision of realistic information during SDM. The importance of pain management in hip fracture patients is underlined by its emergence in both themes *Realisation of expectations* and *Underlying patient values*.

~Shared decision-making~

In the theme *Involvement in decision*, a variation of “sharedness” in the decision-making was reported; this aligns with an earlier recommendation to “tailor the sharedness of the decision to the needs of patients and their family”.(18) Patients and proxies reported that time to reflect in between

consultations with their treating physician was valuable, this is in line with previous research, where iterative communication is suggested to encourage dialogue and focus on patients' goals and values.(22) Furthermore, proxies reported a significant emotional burden associated with deciding for treatment, originating in proxies not just dealing with a patient with a hip fracture but a dear human being for whom a life-changing decision must be made. Previous scholars have not yet addressed this emotional weight, although the importance of Advanced Care Planning in the geriatric population is stressed.(30,35)

~Uncertainty with decision-making~

The theme *Realisation of expectations* is characterized by a great variety between participant expectations and reality, which is in line with previous articles which state that decision-making in trauma geriatrics is accompanied by a great degree of uncertainty.(18) In terms of prognosis regarding longevity, there were wide variations in life duration from 10 days to a year. Previous scholars attribute this variation to the current limitations in predicting the prognosis of patients, although the 1-year survival is consistently reported to be longer after OM when compared to P-NOM.(10,36,37) Discrepancies between expectation and reality of longevity were perceived as unpleasant, with one proxy even expressing regret regarding the decision because of a longer than expected duration of life. Although longevity appears to be longer when patients receive OM, Although patients and proxies attribute greater importance to quality of life, longevity might still be a factor to take into account in SDM.(10,14)

Strengths & Limitations

One of the study's strengths lies in its exploration of SDM from the perspectives of patients and proxies following hip fracture, marking the first study in this specific domain. The study design included various patient categories and proxies, providing insight from a unique perspective and comprehensive overview of SDM in hip fracture treatment of frail geriatric patients in acute situations. This overview highlights that the focus in SDM should be on the patient as a human being in all its versatility rather than merely on a person's medical condition (i.e., holistic approach or person centred care). The study design has several possible limitations. One relative limitation arises from the involvement of proxies due to the nature of palliative treatment and the inclusion of patients with cognitive impairment. Justification for this limitation comes from the fact that the interviewed proxies

were heavily engaged in clinical practice, reflecting typical scenarios within this patient category. The constructive epistemology of the study provides a theoretical fundament for proxy inclusion. A third limitation stems from conducting interviews via telephone. While telephone interviews offer convenience and accessibility, there is a lack of visual cues like facial expressions and body language, which can enrich participants' responses for reflexive thematic purposes. Furthermore, differences in the time to conduct interviews across cohorts present another limitation. This discrepancy is attributed to variations in the prevalence of certain demographics among hip fracture patients, elucidating why it took longer to recruit four participants in certain cohorts. Lastly, the study's context within Dutch trauma geriatric care presents a limitation. Physicians intending to apply the results in a different cultural setting may need to scrutinize whether the norms and values of their geriatric hip fracture patients align with those observed in the Dutch context.

Clinical implications

Several direct clinical implications can be derived from this study. Through all identified themes, this study underscores the critical role of the patient's and caregiver's perspectives. In this context, the healthcare provider takes on a facilitating role, encompassing the provision of information, guidance, and the organization of appropriate logistic conditions. The healthcare provider should tailor their approach to the specific individual while recognizing and addressing the emotional and psychological challenges patients and proxies face. In this regard, a seated position outweighs a standing one, and professional insights based on experience are favoured over bare statistical facts. The physician should discuss the advantages and disadvantages of OM and P-NOM where deemed relevant. In which physicians should assess each patient's need for extensiveness of information and the need for discussing P-NOM. With regard to expectation management, physicians should treat burdensome topics with care and emphasise the uncertainty of topics such as cognitive decline and longevity. Furthermore, physicians should separate information provision and actual decision making to answer to a need for reflection of patients and proxies. This could be done, for example, through multiple conversations with a moment of reflection in between. Lastly, this study holds the potential not only to enhance patient satisfaction with SDM but, more significantly, to facilitate personalised treatment choices for the individual, where the patient takes precedence over the hip fracture itself. Future research should focus on optimising the provision of information during shared decision-making, not

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only for patients opting for palliative and non-operative management but also for patients receiving operative management.

For peer review only

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Conclusion

In-depth analysis provided a unique insight into the patient and proxy perspectives in shared decision-making for geriatric hip fracture management in the acute setting. Overall, there were differences between reported experiences and preferences of participants. This heterogeneity stresses the importance of keeping a person-centred approach during shared decision-making. Other key considerations during shared decision-making include physicians informing patients from professional experience and communicating sensitively about both treatment options and prognosis. Physicians should aim to provide realistic, sensitive and timely information to both patients and proxies during the choice between curative and palliative care for their hip fracture.

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Statements

Author contributions

DWPML was closely involved in setting up the methodology, data collection and data analysis. TK contributed greatly to data analysis. AvdB contributed to collecting and analysing the data. MACdJ and RT were both involved in setting up the methodology, together with DvdV and TMPN who were the initiators of this study. All authors approved the final version of the manuscript to be published.

Conflicts of interests

None declared.

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Data statement section

Data are available upon reasonable request.

Ethics approval

The study design was approved by the Medical Ethics Review Committee Utrecht (MEC-U), the Netherlands (W22.233).

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Figure 1: The formation of the cohorts

Please see attached file

OM: operative management

P-NOM: palliative, non-operative management

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Figure 2: Flowchart of the selection process of included patients and proxies

Please see attached file

OM: operative management
P-NOM: palliative, non-operative management
*Patient recruitment started with patients who were presented at the emergency department at 24-11-2022 and was continued further into the past, ensuring no omissions. Patient recruitment ended when four patients per cohort were included.

Table 1: Baseline characteristics of included patients and proxies

Patient characteristics	Total N = 16	Cohort A Demented, OM N = 4	Cohort B Demented, P-NOM N = 4	Cohort C No dementia, P-NOM N = 4	Cohort D No dementia, OM N = 4
Age (Y), median (IQR)	84 (80-91)	88 (84-90)	83 (80-91)	94 (86-101)	75 (71-81)
Female sex, n (%)	10 (63)	4 (100)	3 (75)	1 (25)	2 (50)
Dementia, n (%)	8 (50)	4 (100)	4 (100)	-	-
CCI, median (IQR)	6 (5-6)	6 (5-6)	7 (5-7)	5 (4-10)	4 (3-4)
Living situation, n (%)					
Home, independent	5 (31)	-	1 (25)	-	4 (100)
Home, with ADL care	4 (25)	2 (50)	-	2 (50)	-
Institutional care facility	7 (44)	2 (50)	3 (75)	2 (50)	-
Management					
Surgery	8 (50)	4 (100)	-	-	4 (100)
P-NOM	8 (50)	-	4 (100)	4 (100)	-
Admittance in hospital, n (%)	16 (100)	4 (100)	4 (100)	4 (100)	4 (100)
Length of stay (d), median (IQR)	6 (3-10)	10 (4-15)	4 (2-12)	6 (2-10)	5 (3-7)

Deceased at the time of the interview, n (%)	7 (44)	1 (25)	2 (50)	4 (100)	-
Time from hospital admission to death (d), n (%)	14 (7-48)	48 (48-48)	15 (10-15)	10 (3-91)	-
Time to interview (d), median (IQR)	61 (53-141)	59 (50-69)	85 (53-113)	320 (188-342)	54 (50-60)
Proxy characteristics	Total N = 12	Cohort A N = 4	Cohort B N = 4	Cohort C N = 4	
Age (Y), median (IQR)	62 (56-69)	63 (53-66)	59 (55-79)	66 (57-71)	
Female sex, n (%)	8 (67)	3 (75)	3 (75)	2 (50)	
Relationship with patient, n (%)					
Spouse	1 (8)	-	1 (25)	-	
Offspring	11 (92)	4 (100)	3 (75)	4 (100)	

OM: operative management

P-NOM: palliative, non-operative management

Cohort A: Geriatric hip fracture patients with dementia who have chosen OM (interview with proxy)

Cohort B: Geriatric hip fracture patients with dementia who have chosen P-NOM (interview with proxy)

Cohort C: Geriatric hip fracture patients without dementia who have chosen P-NOM (interview with proxy)

Cohort D: Geriatric hip fracture patients without dementia who have chosen OM (interview with patient)

Y: years

IQR: interquartile range

CCI: Charlson Comorbidity Index

P-NOM: palliative, non-operative management

OM: operative management

d: days

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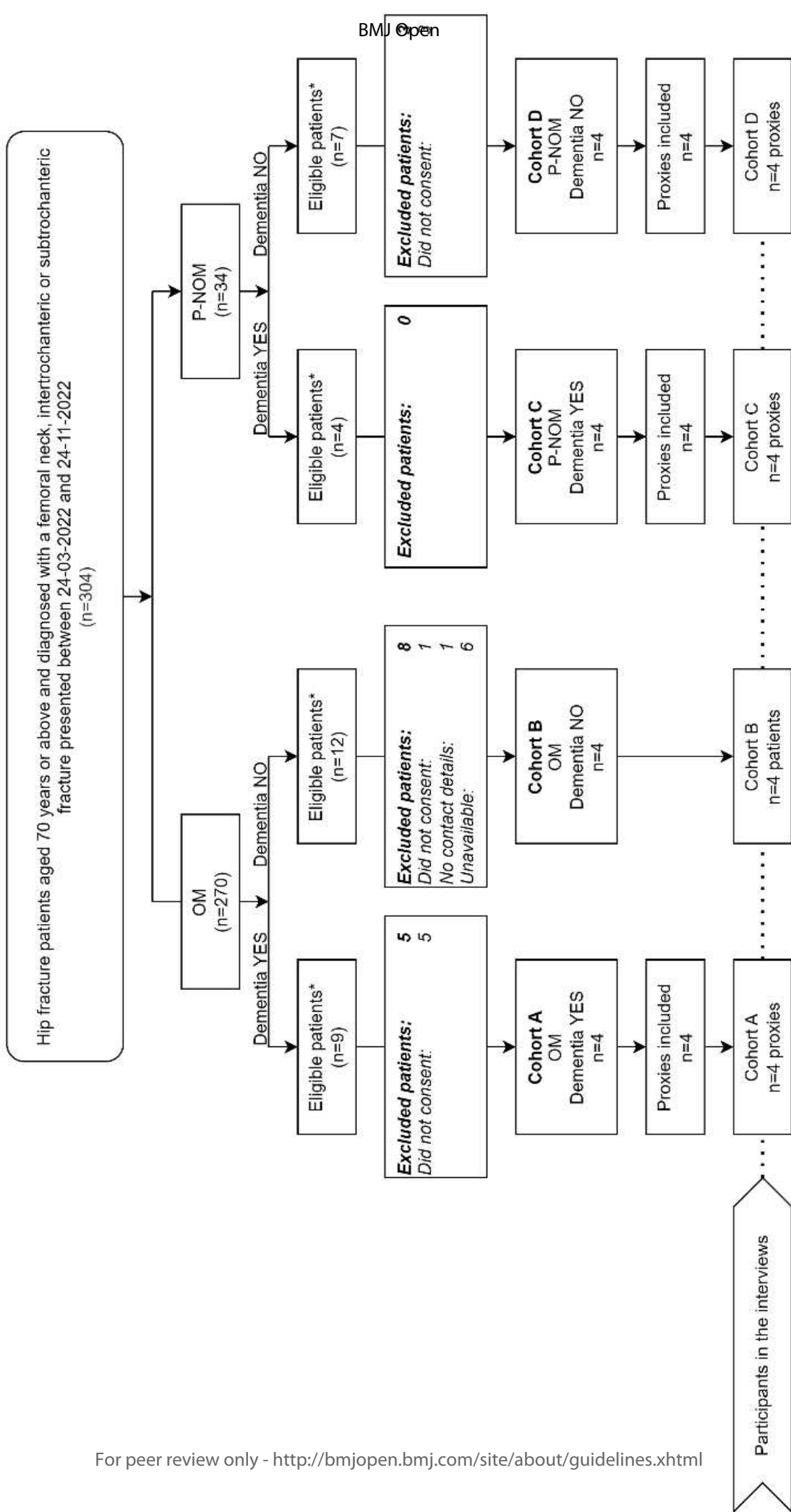
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Pre-existing diagnosis of dementia?

	Dementia YES	Dementia NO
OM	Cohort A OM Dementia YES	Cohort B OM Dementia NO
P-NOM	Cohort C P-NOM Dementia YES	Cohort D P-NOM Dementia NO

Type of treatment



Appendix 1: Standards for Reporting Qualitative Research (SRQR)

No.	Topic	Item	Where to find?
	Title and abstract		
S1	Title	Concise description of the nature and topic of the study identifying the study as qualitative or indicating the approach (e.g., ethnography, grounded theory) or data collection methods (e.g., interview, focus group) is recommended	P 1
S2	Abstract	Summary of key elements of the study using the abstract format of the intended publication; typically includes objective, methods, results, and conclusions	P 3-4
	Introduction		
S3	Problem formulation	Description and significance of the problem/phenomenon studied; review of relevant theory and empirical work; problem statement	P 6
S4	Purpose or research question	Purpose of the study and specific objectives or questions	P 6
	Methods		
S5	Qualitative approach and research paradigm	Qualitative approach (e.g., ethnography, grounded theory, case study, phenomenology, narrative research) and guiding theory if appropriate; identifying the research paradigm (e.g., positivist, constructivist/interpretivist) is also recommended	P 8-9
S6	Researcher characteristics and reflexivity	Researchers' characteristics that may influence the research, including personal attributes, qualifications/experience, relationship with participants, assumptions, or presuppositions; potential or actual interaction between researchers' characteristics and the research questions, approach, methods, results, or transferability	Page 8
S7	Context	Setting/site and salient contextual factors; rationale ^a	P 7
S8	Sampling strategy	How and why research participants, documents, or events were selected; criteria for deciding when no further sampling was necessary (e.g., sampling saturation); rationale ^a	P 8
S9	Ethical issues pertaining to human subjects	Documentation of approval by an appropriate ethics review board and participant consent, or	P 8

	explanation for lack thereof; other confidentiality and data security issues	
S10 Data collection methods	Types of data collected; details of data collection procedures including (as appropriate) start and stop dates of data collection and analysis, iterative process, triangulation of sources/methods, and modification of procedures in response to evolving study findings; rationale ^a	P 8
S11 Data collection instruments and technologies	Description of instruments (e.g., interview guides, questionnaires) and devices (e.g., audio recorders) used for data collection; if/how the instrument(s) changed over the course of the study	P 8
S12 Units of study	Number and relevant characteristics of participants, documents, or events included in the study; level of participation (could be reported in results)	P 7
S13 Data processing	Methods for processing data prior to and during analysis, including transcription, data entry, data management and security, verification of data integrity, data coding, and anonymization/deidentification of excerpts	P 8
S14 Data analysis	Process by which inferences, themes, etc., were identified and developed, including researchers involved in data analysis; usually references a specific paradigm or approach; rationale ^a	P 8-9
S15 Techniques to enhance trustworthiness	Techniques to enhance trustworthiness and credibility of data analysis (e.g., member checking, audit trail, triangulation); rationale ^a	P 8-9
Results/Findings		
S16 Synthesis and interpretation	Main findings (e.g., interpretations, inferences, and themes); might include development of a theory or model, or integration with prior research or theory	P 10-16
S17 Links to empirical data	Evidence (e.g., quotes, field notes, text excerpts, photographs) to substantiate analytic findings	P 10-16
Discussion		
S18 Integration with prior work, implications, transferability, and contribution(s) to the field	Short summary of main findings; explanation of how findings and conclusions connect to, support, elaborate on, or challenge conclusions of earlier scholarship; discussion of scope of application/generalizability; identification of unique contribution(s) to scholarship in a discipline or field	P 17-18
S19 Limitations	Trustworthiness and limitations of findings	P 19-20

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Other		
S20 Conflicts of interest	Potential sources of influence or perceived influence on study conduct and conclusions; how these were managed	P 2
S21 Funding	Sources of funding and other support; role of funders in data collection, interpretation, and reporting	P 2

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Appendix 2: Semi-structured interview guide

When you reflect on the moment you arrived at the hospital after you/your father/your mother broke your/his/her hip,

- Can you briefly outline the admission process to the hospital?
- Do you remember what they told you about the diagnosis?
- What were the main questions you had at the emergency department?

Treatment options and decision-making process

- What was explained about the different treatment options?
- How did you experience the decision-making process? Did you feel like you had a choice and could (co-)decide whether to opt for surgery or not?
- Had you/your father/your mother already thought about what they would want if they became seriously ill before being admitted to the hospital?
- What was important for the quality of life of you/your father/your mother?

Treatment & current functioning

- How did the chosen treatment proceed?
- What was the goal of the chosen treatment?
- Does the course of treatment align with what you had expected beforehand?
- How do you view the choice/decision now?
- What insight would you like to impart to other patients and their loved ones facing the decision of whether to undergo surgery?