

## QUALITATIVE PAPER

# Outcomes as experienced by older patients after hospitalisation: satisfaction, acceptance, frustration and hope—a grounded theory study

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## Abstract

**Background:** outcomes of hospitalisation are often described in quantitative terms. It is unknown how older frail patients describe their own outcomes.

**Objective:** to discover how older frail persons describe their own hospitalisation outcomes and the meaning of these outcomes for their daily lives.

**Design:** Constructivist Grounded Theory approach.

**Participants:** frail older people discharged from hospital.

**Methods:** Open interviews in the participant's home. Transcripts were coded inductively according to the Constructivist Grounded Theory approach.

**Results:** Twenty-four interviews were conducted involving 20 unique participants. Although for some participants hospitalisation was just a ripple, for others, it was a turning point. It could have positive or negative impacts on outcomes, including remaining alive, disease, fatigue/condition, complaints, daily functioning, social activities and intimate relationships, hobbies, living situation and mental well-being. Few participants were completely satisfied, but for many, a discrepancy between expectation and reality existed. Some participants could accept this, others remained hopeful and some were frustrated. Factors associated with these categories were research and treatment options, (un)clarity about the situation, setting the bar too high or pushing boundaries, confidence in physicians, character traits and social factors.

**Conclusions:** of the persons whose outcomes did not meet their expectations, some were frustrated, others hopeful and others accepted the situation. The following interventions can help patients to accept: clear communication about options and expectations before, during and after hospitalisation; giving room for emotions; help finding social support, encouragement to engage in pleasant activities and find meaning in small things. For some patients, psychological treatment may be needed.

**Keywords:** posthospitalisation, older people, expectations, coping, qualitative research

## Key Points

- For many older people, hospitalisation is a turning point: the outcomes, or their absence, have a profound impact on their lives, either positively or negatively.
- Outcomes described by participants can be grouped into: remained alive, disease-oriented, fatigue/condition, complaints, daily functioning, social activities and intimate relationships, hobbies, living situation and mental well-being.

- Three categories were constructed describing how participants coped with a discrepancy between expectation and reality, namely acceptance, frustration and staying hopeful.
  - Clear communication about expectations before, during and after hospitalisation and allowing room for emotions are key interventions to promote acceptance.
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## **Background**

Outcomes of hospitalisation are often described in terms of mortality, re-admission, complications, length of stay, discharge destination or functional decline, with worse outcomes for frail persons [1–5]. It is questionable whether these outcomes reflect what patients find important. Goals older persons described during hospitalisation were highly individual and included: wanting to know what the matter is, controlling disease, staying alive, improving condition, alleviating complaints, improving daily functioning, improving/maintaining social functioning, resuming work/hobbies, regaining/maintaining autonomy [6]. There is little knowledge about actual outcomes described in these terms and, moreover, quantitative studies represent values on group level but do not reflect individual cases and the meaning of these numbers for the individual patient.

A qualitative study in the first weeks after hospitalisation revealed that people experienced functional decline, the inability to take up usual leisure or social activities, extreme fatigue, apathy and feelings of uncertainty [7]. How older people describe their outcomes after this period is unknown.

Therefore, the aim of this study is to discover how older frail persons describe their outcomes of hospitalisation and the meaning of these outcomes for their daily lives.

## **Methods**

A Constructivist Grounded Theory approach was used to describe the subjective experiences of participants and underlying processes [8, 9].

### **Participants**

Inclusion criteria were: (i) having been admitted to a hospital for at least 48 hours, 6–15 weeks prior to the interview; (ii) aged 70 years and older; (iii) frail ( $\geq 3$  points) according to the Fried-criteria as operationalised by Avila Funes [10]; (iv) being able to speak and understand Dutch and (v) informed consent to the interview and audio recording. We used the timeframe 6–15 weeks after discharge because we expected that after 6 weeks, the first rehabilitation and recovery weeks were over and people had a clear picture about how far their health and daily functioning was restored. However, we wanted to prevent that the picture was troubled by new (health) events and therefore used the limit of 15 weeks.

Within eligible persons, we aimed for maximum variation in age, frailty score, medical speciality, acute/planned admissions and living at home or in a nursing home. A real theoretical sampling plan was difficult since not all

information was available and we were dependent on availability of participants. We started with patients admitted to a university hospital. Patients were prospectively approached during admission by the first author (M.J.v.d.K.) or were phoned after discharge. We later continued sampling via a home care organisation. After we constructed the categories, we decided to do second interviews later in time with some participants to investigate whether participants moved from one to another category or were static and which factors influenced this. We aimed to continue sampling until saturation was achieved, meaning that the properties of our theoretical categories were saturated with data.

Inclusion criteria were verified with a staff nurse. Potential participants were given oral information by the interviewer (M.J.v.d.K.) about the procedure and received an information letter and informed consent form. When M.J.v.d.K. was not able to see the patient personally in the hospital, the nurse asked the patient permission to be called by M.J.v.d.K. and the patient received the oral information by telephone and the information letter was sent by mail. When the participant agreed to participate, an appointment was made for the interview. Before the start of the interview, the procedure was explained a second time. The participant could ask questions, and then informed consent was signed. In cases where the interview was conducted by telephone, the participant gave verbal consent, which was audio-recorded. The Medical Ethics Research Committee of the UMCG (file number M16.199647) confirmed that the Medical Research Involving Human Subjects Act did not apply to the research project. Official approval by the committee was hence not required.

### **Data collection**

Open interviews were conducted between July 2019 and September 2021 by the first author (M.J.v.d.K.) in the participant's home. During the Covid pandemic, we conducted some interviews by telephone. The interviews started with participants being given the opportunity to summarise (the reason for) admission, and then, we moved towards the hospitalisation outcomes. Further development of the interviews was dependent on each participant discussing topics that were relevant to them. Initially, no topic list was used, but as the process of theory forming advanced, themes from earlier interviews were sometimes introduced by the interviewer, for example the participant was asked about the categories acceptance, frustration and staying hopeful and which factors could influence these processes. The interviews took 10–65 (average 29) minutes and were audio-recorded and transcribed verbatim. The quotes were translated from

Dutch into English and, therefore, changed slightly for comprehensibility. All names or other identifiable information was removed or changed into fictional names.

### Data analysis

Since an iterative process and constant comparison is characteristic of grounded theory [8, 9, 11], data collection and analysis occurred simultaneously. Coding was done inductively according to the following steps: initial coding, focused coding, axial coding and theoretical coding [8, 11].

Initial coding took place as soon as possible after the interview and transcription. During initial coding, we remained close to the data and coded open and spontaneously. During focused coding, the most significant initial codes were selected in order to code larger amounts of data, which resulted in more conceptual codes. With axial coding, the various dimensions and characteristics of the identified concepts were described under which conditions, actions/interactions and consequences they occurred. With theoretical coding, the relationships between the categories were described, to be integrated in theory forming.

In all stages, constant comparison was used: new codes, theories and relationships were compared with each other, and with previous data, to identify similarities and differences in data, define and sharpen concepts and categories and to verify the constructed theory. To enhance reflexivity, memos were written during the entire process. Memos to reflect immediately after an interview, after the coding of each interview and how it related to former interviews, codes and categories. Also memos were written about the construction of categories. This was all recorded in an audit trail. The transcripts were coded by the first author. All transcripts were also read by the second author (G.J.D.). Major codes, memos and the audit trail were discussed together. This process continued until we reached saturation [8, 11]. Data analysis and organisation was supported by the use of *Atlast.ti* Version 5.2.18.

### Results

In total, 24 interviews were conducted concerning 20 unique participants. An additional five persons were approached but refused to participate because they had too much on their mind. Participants had a broad variety of reasons for admission; almost half of the participants had an elective admission. Ages varied from 70 to 92 years. Details of the sample are shown in [Table 1](#).

#### Ripple or turning point

For a number of participants, the outcomes of one specific hospitalisation were difficult to distinguish because the admission occurred in a series of hospitalisations and treatments. This meant that for some, admission was a ripple in their medical history: the specific hospitalisation had contributed little to the overall picture, there were no or only minor outcomes, but expectations were not high either. For example, there were complications between chemotherapy treatments that were resolved or new medication was

initiated during a hospitalisation. However, there was also a group of participants for whom the hospitalisation was a turning point. For these participants, the outcomes or their absence had a profound impact on their lives, either positively or negatively. The outcomes described by participants can be grouped into the following categories: remained alive, disease-oriented, fatigue/condition, complaints, daily functioning, social activities and intimate relationships, hobbies, living situation and mental well-being. Each participant described several categories, each in their own unique combination. [Table 2](#) provides descriptions and examples of these categories.

#### Meaning of the outcomes

As [Table 2](#) reveals, hospitalisation outcomes can be either positive or negative. Some participants had fully recovered to their situation before the complaints for which they had been admitted and were completely satisfied. That situation was in all cases with diseases and limitations that coexisted with the disease for which they had been admitted. The comorbid complaints remained, but the participants had not expected otherwise and were therefore completely satisfied. For example, a woman with significant movement limitations due to rheumatism who was hospitalised for valve replacement, her stamina was vastly improved, but the movement impairments and associated walking and self-care disabilities remained.

However, often there was a discrepancy between expectation and reality. Three categories were constructed describing how participants coped with this discrepancy, namely acceptance, frustration and remaining hopeful. These categories were not mutually exclusive; there was sometimes some overlap. For example, a participant could be angry or frustrated but could accept some of the limitations. Or a hopeful participant who also had moments of frustration. All participants could be assigned to the category that was, for them, the most significant. One participant was an exception: she had been diagnosed with cancer during hospitalisation with a very poor prognosis, which was very unexpected. This woman could hardly comprehend this, she was numb: not frustrated, not hopeful, but she was not ready for acceptance either. [Figure 1](#) shows a graphical representation of the results, the different meanings given to them and the factors that influenced them.

#### Category: acceptance

Although participants in this category had not entirely reached the outcomes as expected, they had a positive opinion about what they had achieved. These participants accepted the outcomes they had not achieved and were able to look at the positive side, such as focusing on what is still possible or enjoying the small things and social contacts. For example:

*But you adapt . . . you do learn to adapt. That's very strange, you know. I have sometimes wondered about that myself. One moment you can't do anything, and the next moment you think, oh, it's not too bad. Yes, then you just think differently at once, like, well, this way is also possible. You have to . . . And people who then*

**Table 1.** Participant characteristics

Participant	Gender	Age	Living situation at moment of interview	Admission type	Admission reason <sup>a</sup>	Length of hospital stay (days)	Timing interview since discharge (weeks)	Partner or family member present during interview?	Number of interviews	Interview mode
1	Female	71	Independent	Elective	Appendectomy	4	5	Partner	1	Face to face
2	Female	74	Independent	Elective	Mitraclip	4	6/65 <sup>b</sup>	No	2	Face to face/telephone
3	Male	71	Independent	Elective	Mitral repair	3	7/60	Partner	2	Face to face (2×)
4	Female	85	Independent	Acute	Myocard infarct	4	7/62	No	2	Face to face (2×)
5	Female	70	Independent	Acute	Chest pain	3	6/58	No	2	Face to face (2×)
6	Female	72	Nursing home	Acute	Abscess after tumour removal	2	6	No	1	Face to face
7	Male	73	Sheltered accommodation	Acute	Diarrhoea/dehydration/-congestive heart failure	12	9	No	1	Face to face
8	Male	72	Independent	Elective	Liver cancer	3	16	Partner	1	Face to face
9	Male	72	Independent	Elective	Pulmonal hypertension	5	12	Partner	1	Telephone
10	Female	70	Independent	Acute	Paracentesis	4	18	Partner	1	Telephone
11	Male	78	Independent	Acute	Absences	10	15	Partner	1	Telephone
12	Male	86	Independent	Elective	Mitraclip	4	13	No	1	Telephone
13	Female	78	Independent	Acute	Side effects chemotherapy	13	11	No	1	Telephone
14	Male	92	Independent	Acute	Femur fracture after fall	10	12	Partner	1	Telephone
15	Female	72	Independent	Acute	Obstruction stomach/bowel	47	11	No	1	Telephone
16	Female	76	Independent	Acute	Congestive heart failure	9	13	No	1	Telephone
17	Female	87	Independent	Elective	Hip replacement	4	11	No	1	Face to face
18	Female	88	Sheltered accommodation	Acute	Vomiting	10	9	Son	1	Face to face
19	Female	76	Independent	Acute	Delirium, pneumonia	'Few days', exact length unknown	7	Partner, daughter	1	Face to face
20	Female	85	Independent	Elective	Transcatheter aortic valve implantation (TAVI)	11	6	No	1	Face to face

<sup>a</sup>Reason according to the participant. <sup>b</sup>First interview/second interview.

*start whining, I can't stand that at all. Then I think, man, come on! (...) Yes, I can really enjoy it. And my children take turns every day. Well, I really enjoy that! We wouldn't have that otherwise. They didn't come every day. (laughs) No. So this is just extra, I keep saying. This is a bonus. [Participant 6].*

**Category: frustration**

For these participants, there was a large discrepancy between expectations and outcomes. This led to negative emotions such as anger, sadness, disappointment, self-blame, powerlessness, uncertainty, fear and a feeling of being misunderstood. Participants often tried to accept their situation, but often without success. For example:

*For me it is very, way, way, way below expectations. I uh, I had imagined getting a new hip and maybe a month and a half or so and then I can just get back on the bike, so to speak. And get in the car and drive away. [Participant 17].*

Almost all participants in this category were able to mention also positive points that were worth fighting for, such as the

presence of children and grandchildren or a great-grandchild on the way. Or they were grateful to be still alive. For example:

*And if I didn't have the kids, I wouldn't care at all anymore. I have four lovely grandchildren walking around. (...) Yes, I more or less still live for them. Yes, especially for both of them, those two boys over there [points to pictures of grandchildren]. Well. That one is at grandpa's again on Saturday. I'm just grandpa to them. Yes, that keeps you, that keeps you alive. [Participant 11].*

**Category: hopeful**

In these cases, there was also a discrepancy between expectations and outcomes. Participants did not accept the situation but remained positive; they remained hopeful that results would still turn out all right. For example:

*P: I'm pretty optimistic again. Maybe too.  
I: Yes. And in what sense are you more optimistic now?  
P: That something will still be found. Because in the hospital, for example, they wanted to repeat the gastroscopy and colonoscopy that had been done a year ago,*

**Table 2.** Descriptions and citations of outcomes

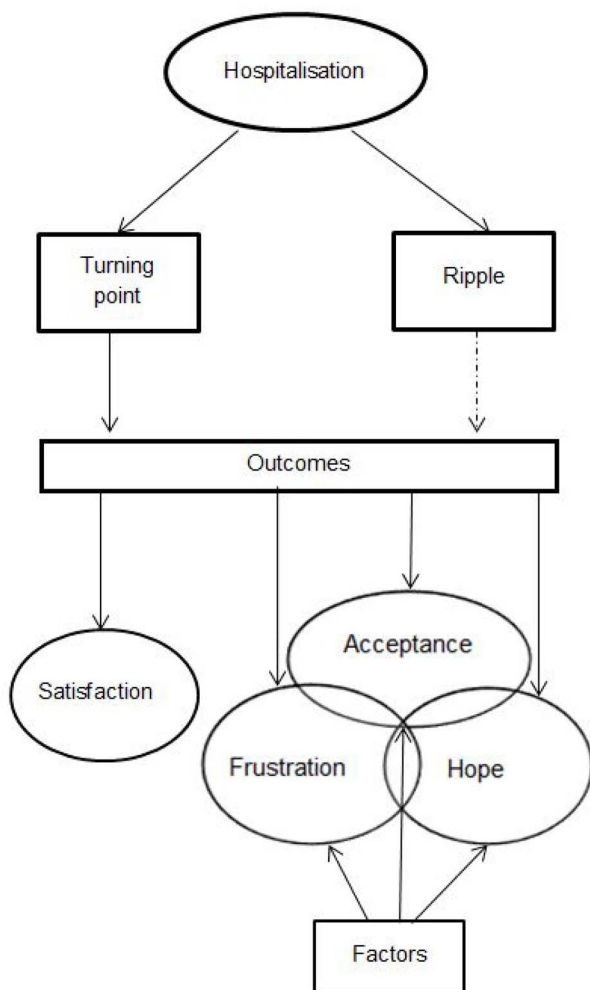
Category	Description	Citation(s) of positive outcome	Citation(s) of negative outcome
Remained alive	Participant indicates, directly or indirectly, that the hospitalisation has kept him alive or that the risk of death has been reduced.	Yes, and the danger is over, eh. At least that's what I was told: If the fluid couldn't get out, I'd eh, I'd die. [Participant 10] Otherwise I would have gone. So uh. No, because I was so far gone. I was 95%, it was completely clogged. He says, you hadn't had much longer. [Participant 4] So I'm in, in this sense very glad that the heart valve is closed. He said, the heart valve is now leaking in two small spots. It will never close completely. Because you got two staples in it. They could go to three, no further. So I was just lucky. [Participant 2] Yes, I think I'm a little fitter. [Participant 3] It's going perfectly. And I'm feeling so good! Really, I feel great. [Participant 8]	Then they took me back to the cardiac ward. And checking again. And yes, he says, yes, you are really sick, but we'll send you off again, there's nothing we can do for you here. And that's a powerless feeling. [Participant 5] I'm so, so tired! I just can't describe how tired I am. [Participant 4] Yes, before I... I just did everything myself. Just like I said to you. I was OK. I was always busy. And suddenly I got hit hard and then it was over. (...) I didn't have any more energy. There was nothing left in my body. I was just empty. [Participant 7] P: Nothing at all. It just got worse! Worse? And what got worse? P: Yes, the shortness of breath! I was short of breath. So when we left, we went to the market, for example. Then I could walk in the market for a while, but then I stopped. Then I had to gasp for air again. And, well, then move on. And that's how you went across the market. But when I came back home. Well, that was all. It started right away with walking. It was very strange, this. Then it was much worse. [Participant 2] Yes, I did have a headache. But now it really is that I think, eh, yes, eh, bah, huh. And last night too, but I couldn't sleep. And then your ear feels very strange. And all those things more. And I actually didn't have that before I ended up in hospital. So I find that a bit strange. [Participant 5] Well, then I could er... yes I could still cycle, you name it and... yes, I didn't do everything in the household, because I do get help (...). But, there are always things. Yes, I'm still a homey type who has to tidy everything up, so then I see things again that I think I can just do that myself. But I can't do that at all, at the moment. I: And the cycling? P: Yes, that, I don't think that will work at all. No. [Participant 5] But hey, there's more on my wife now. Because I, I didn't do much at home, but I did, well, I did go grocery shopping now and then. And set the table, I often did. And that's a bit difficult now. So She does... I didn't do much, but what I did in the house, it almost all comes down to my wife now. She's busier because of that, I must say. [Participant 14]
Disease-oriented	Description of outcomes in disease specific measures and numbers. For example: heart valve no longer leaks, or leaks again, oxygen level increased, Hb that continues to fall. Or: the participant receives a diagnosis or the cause of the complaints is not found.		
Fatigue/condition	Changes in general condition, described in subjective terms like 'fatigue' and 'condition', sometimes in more objective terms like 'muscle strength' and 'weight gain'	Well, that shortness of breath, when I exert myself I still have it. I mean, it's not like it's completely over. But it has become a lot easier. [Participant 12] And just being able to do your things without screaming pain all day long. [Participant 17]	
Complaints	Changes or lack of change in a wide variety of complaints, such as diarrhoea, appetite, headache, itching, shortness of breath, nausea, pain, sleep.		
Daily functioning	Daily activities such as washing and dressing, showering, walking, climbing stairs, house-keeping, cooking, shopping, driving and cycling.	I couldn't climb the stairs anymore. So that has improved a lot. I can walk a reasonable distance again. I'm not going to take hours of walking, but I can walk to the shops around here. Well, yeah, that's not that far away. I can walk to a friend, which is 300 m, I can easily get there. I went to town once. We took the bus and then we walked around a bit. That's fine. And I'm able to climb the stairs again. Unless I walk with a heavy bag of groceries, then I can't make it. But that's why I have a stairlift. [Participant 12] Well, shopping. I didn't do that anymore. And now it was like, oh, I still have some shopping to do. And now I just do that. And now I succeeded. Yes. [Participant 20]	

*Continued*

**Table 2. Continued**

Category	Description	Citation(s) of positive outcome	Citation(s) of negative outcome
Social activities and intimate relationships	Going on a visit, to a coffee meeting, on trips, on vacation. Influence of admission on the relationship with loved ones.	Because I always said to my husband, no, I'm staying home, you know. I'm not going. Just go alone. I didn't feel like it anymore. Because I always had pain, look and now I have, uh, no, now I say myself sometimes, shall we, let's get out, pay a visit to my daughter or this or that. [Participant 1] Yes, I can really enjoy it. And my children take turns every day. Well, I really enjoy that! We wouldn't have that otherwise. They didn't come every day. (laughs) No. So this is just extra, I keep saying. This is a bonus. (...) Yes, but that people can be so nice. That people all care about you so... so much and things like that, you get so much in return. That's so beautiful... I: Just the love and attention you get. P: The love and attention you get. That's so important! Before it was also important, you know. But you did not realise it, I always say. [Participant 6]	You can't eh... I say to him (husband) every time, I would like to visit her sometime. Just drink a coffee. Every time there is, yes, you are tired. And uh. Yes, it doesn't happen. And it just can't. It just doesn't work. And uh. It's disappointing every time. [Participant 19] Well, then you come home, and then um... the problem child came home again. Because before that, eh, I was always busy. I was (deep sigh) busy in the garden, I liked cycling. And my girlfriend, who receives mental healthcare treatment, and she couldn't cope with the situation at home. That I, where I was sitting. There I was just sitting. And I got no further. And she was put under too much of a strain. (...) Yes, look, I could have stayed at home, if only my girlfriend had been a little better. But she herself was on the sick-list. And you shouldn't bother her with that. So that's all there is to it. She just couldn't handle it. I've lived with her for 4 years. And uh... she turned 65 too. Well, I've lived with her for 4 years and we've always enjoyed vacations together and whatnot. Well. That just doesn't work. Because she is mentally ill. [Participant 7] The drive to do it again. That's it, you know. And you've been away from it ( <i>sewing machine</i> ) for too long. [Participant 19] Well. Look, if I have to go back to singing again, it's restarting soon, but I couldn't do that yet. No, no, no. Because I sing quite high, then I get very weird. Yes. So on Saturday evenings I always watch eh, that's the Netherlands sings, that's for the Christian eh ( <i>points to the TV</i> )... and those are songs I know, well, I normally just sing along, but I don't have to, I don't do it now, because then I'll get very weird in my head. Then I actually have to, yes you have to take a deep breath to sing and then sing along, and that doesn't work now. [Participant 5] I sounded the alarm myself. I called my son. I said, Frank, that's the way it is, dude. This just can't go on any longer. I said Caroline will break down or I will break down. I said, intervention is needed here. There is a place for me. (...) I won't go back to my former address again, because then, in no time, it will be wrong again. I don't need that anymore. [Participant 7] I'm a bit restless now. Yes. Yes. I am not feeling well. And they don't know. I think, yes, and now? How does it go on then? Like this. That's my restless feeling. (...) Yes. Those are things uh... yes, which I didn't have before. Well, yeah, before I um... that attack, let me put it that way. Really a bit of a feeling of fear. Let me just say it very honestly. Yes that is it. Yes. That is it. Yes. Because that uncertainty of eh... (...) Yes, uncertainty. It overwhelms me. It just overwhelms me. It's very odd. Then I think, um... it's all going well, and then all of a sudden I get those very restless feelings in my body, and then um... yes, then you all start to worry. (...) Well, that eh... that I think, yes... eh... will it get worse soon? Is it really getting worse? Is it going the wrong way? That's what I think. That's what I think then. [Participant 5] Yes, then I sometimes think, yes, you're just sitting at home. You depend on, my husband, that he eh, that we can go to the city centre together. You just can't go alone there. I can't walk it with my walker yet. (...) And he does, if I ask, shall we just go to the city centre. He does that with all his love. That's not the point. Yes but. It's just, you are dependent. You're uh, just uh. [Participant 19]
Hobbies	Hobbies, sports and exercise	We have an exercise bicycle and I've cycled on it again. Three times one minute, with a one minute break, but now I do that for five minutes and then a minute break. So three times five minutes. So I'm going to build that up slowly. [Participant 10] I've been working somewhat in the garden again. [Participant 16]	
Living situation	Two participants moved from home to a nursing home or care center after hospitalisation.	And uh... Then I ended up here ( <i>nursing home</i> ). Well, here the care is really good. They are really lovely people. I feel very much at home here. (...) So... that's what I mean by the feeling of being at home. You can do whatever you want. Only, they have to help you. But beyond that, for the rest, I can decide for myself. And... Well, that's great. [Participant 6] P: No, the pain and, and, well you constantly have that appendix again. I: You were constantly thinking about it. P: Yes (...) So and now I'm done with that. Wonderful. (...) Yes, this one really got me, eh, it shouldn't have lasted any longer, then I would have become over, eh, overstrained. [Participant 1] Before, if I had to do something, it was like, oh, I am dreading it, forget it. And now I saw, and oh, I'll tackle it right away! [Participant 20]	
Mental well-being	Mental consequences of hospitalisation such as happiness, reassurance, freedom, fear, powerlessness, restlessness and dependence. Residual symptoms of delirium such as confused, difficulty with words, amnesia.		

## Outcomes as experienced by older patients after hospitalisation



**Figure 1.** Graphical representation of the results. Hospitalisation led for some participants to a turning point, while for others, just a ripple. In both cases, there is a diversity of outcomes, but when hospitalisation was a ripple, outcomes were of minor importance, as depicted by the dashed line. When fully recovered as expected, participants were satisfied. With a discrepancy between expectation and outcome was coped with in different manners: acceptance, frustration or hope, which sometimes had some overlap. The lowest text block depicts the different factors associated with these categories.

*probably. So, that's where I have to be. Then we'll do it again. So they aren't satisfied either that they haven't found my blood loss. Well, guys, fight for it! Search! And then I say: nice! Because I used to think: oh, if you're that old, I'm 71, then it's not important, then they don't do that anymore. But they continue for quite a long time these days. (...) But uh, as long as there is tinkering there is hope.*

*I: And what is your hope?*

*P: Well, that I can get back in reasonable condition. [Participant 3].*

### Transition between categories

After 1 year, the first five participants in the categories frustration and hopeful were recontacted for a second interview to investigate whether there had been a transition between the categories. One participant in the category

'frustration' had died, but two participants from the category 'frustration' and two participants from the category 'hopeful' were reinterviewed. The situation of the two participants from category 'frustration' had not changed much. One was in the same condition but still could not accept it and was in a process for a possible new surgery. The other had slightly recovered and now accepted the (bad) condition she was in. Of the participants in the category 'hopeful', one had an accumulation of partly new ailments. She had now somewhat accepted her fatigue, and in addition, she alternated between hope, acceptance and frustration. The other participant had significantly improved since the previous interview and could accept the limitations that no longer improved. The factors that led to a transition, or its absence, are described together with the other factors associated with the different categories.

### Factors associated with acceptance, frustration and hopeful

#### Research and treatment options

Research and treatment options could, on the one hand, give hope. On the other hand, it meant that participants could not accept their situation as it was and, therefore, could also cause negative emotions as described in the category 'frustration', as with this participant:

*Well (sigh), then you think, then you really can't do much more. And if so? And there's nothing you can do about it, then you'll have to put up with it. And then you have to make of it what can be made of it, hey? That's how I'm in it. But I don't think that yet... I can't accept that, yet. Because there are still operations that are possible. [Participant 2].*

As long as research and treatment options were offered, participants did not know where they stood.

#### (Un)clarity about the situation

When participants did not know whether to accept the situation as it was at that moment or whether it would change, they became restless, insecure or anxious. For example:

*I'm a bit restless now. Yes. Yes. I am not feeling well. And they don't know. I think, yes, and now? How does it go on then? Like this. That's my restless feeling. (...) Really a bit of a feeling of fear. Let me just say it very honestly. Yes that is it. Yes. That is it. Yes. Because that uncertainty of eh... (...) I'm 70, but I still want to live a little, so. (...) Yes, uncertainty. It overwhelms me. It just overwhelms me. It's very odd. Then I think, um... it's all going well, and then all of a sudden I get those very restless feelings in my body, and then um... yes, then you all start to worry. (...) Well, that eh... that I think, yes... eh... will it get worse soon? Is it really getting worse? Is it going the wrong way? That's what I'm thinking. That's what I'm thinking, then. [Participant 5].*

For some participants in the category 'frustration', reality was (yet) beyond comprehension. The 'blow' was too hard for them. On the other hand, certainty about the situation could help with acceptance. For example:

*So maybe it remains this way. Then I have to learn to live with that. Then I hope that I can still live a little longer. Yes. Yes. I do. The feeling of eh... that I'm*

*really getting better, I don't have that feeling anymore. No. No, I'll have to assume it will stay this way. And it's no different. [Participant 5, second interview].*

One participant in the category 'frustration' had had an intake just before the interview with a new physiotherapist who gave her clarity and she hoped this could help her to accept her situation:

*And she [physiotherapist] then said to me: if you ask me what this should have been like, now, you would have been in a wheelchair and you were trying to get on your feet. At your age and with your history and sitting on your bottom with your leg up for more than two months. When you're 30, she says, and you're going to do that, you won't have any muscles left. Then you'll be back on your feet a little faster, but still. And, yes, I hope that gets me out of the slump a bit. I have a lot of trouble with that (crying). (. . .) Yes I mean, she put me like that, so back to reality, actually. And get.., tried to help me to get rid of that feeling of guilt, because it's not gone, but anyway. I can now work with it and work on it and do something with it. [Participant, 17].*

### Setting the bar too high or pushing boundaries

Some participants had higher expectations for the outcome, for example by setting high(er) demands on themselves or comparing themselves with others. For example:

*Yes, like I said, I had set my expectations, my bar, much higher. And then you ignore everything that happened before.*

*I: Yes, so you actually had expectations for yourself that were too high.*

*P: Yes. Well, for the situation. I thought that's peanuts. Yes and then I will go on the slide again because I heard from my friend who was here on Saturday, that her mother-in-law, she is a lot younger than me and right as rain, she has had a new hip two weeks before I did. And she has now signed up for the other hip. And then I think again: Yes, that's also possible, but I do not even want to think about that, because I haven't even rehabilitated on one side yet. (. . .) But then again that's something I think, yes. Damn, that's also possible and why? And am I doing it wrong? Am I not doing enough? Am I not working hard enough on it? Or so. Yes, a kind of inner guilt. You're not good at it and that could have been better, but I don't know how (laughter). No, not at all. No, not at all. [Participant 17].*

Other participants pushed their boundaries and were, as a consequence, able to accept what they could no longer do or what they had to adjust. For example, a bedridden participant:

*Well. You can live with that, too. I've always said: I don't want to think about being in bed all day. I've always said that: that seemed like the worst thing that could happen to me. Now, and now. The children sometimes say: And? I say: my story hasn't finished yet at all. (laughs) I'm still going strong. Then you can also see that you are pushing your boundaries again, can't you? Yes, because I always thought, if I lay in bed, I'll go crazy. [Participant 6].*

### Confidence in physicians

The participants in the category 'hope' all had great confidence in physicians and their ability to improve their situation. For example:

*P: I have no idea how it would be, but it will be okay. I have no idea what to do for it, but I'll be told.*

*I: Yes. You put that in the hands of the physicians.*

*P: Yes, of course. Uh . . . I absolutely can't do that myself. [Participant 3].*

In contrast, a number of participants in the category 'frustration' had sometimes lost confidence in physicians.

### Character traits

Some character traits were related to particular categories. Participants in the category 'acceptance' all said they were able to think positively. For example:

*I: You just said, you're very optimistic.*

*P: Yes.*

*I: And what causes that optimism?*

*P: The nature of the beast.*

*I: It's just in your character.*

*P: That's it. Yes. I think so. If you see what I've had over the years. If I hadn't been an optimist, then I would have been... well, either dead or very depressed or impossible to be around, I think. And uh. Now, I think I'm still eh... bearable. [Participant 3].*

Others were able to transform into more positive thinking after consulting a psychologist.

### Social factors

The social environment, in particular immediate family, can be supportive to accept or provide an incentive to carry on. For two participants in the category 'frustration', social support was partially lost due to a divorce or a partner with dementia, which made life even more difficult for the participant.

### Discussion

This study showed that hospitalisation has an impact on many areas of life for frail older persons. This impact can be positive as well as negative. Most participants had experienced decline in one or more areas. Some participants accepted this; others remained hopeful or were frustrated.

The negative outcomes described in previous quantitative studies, such as complications, functional decline and nursing home admission [1–3, 12], were also seen in this study. But instead of numbers, meaning was assigned in the qualitative interviews by the participants. Many participants could accept these outcomes and some even gave it a positive meaning, whereas there were also participants for whom these outcomes led to frustration. Nevertheless, in almost all cases, a silver lining was found: gratitude for being still alive and being able to enjoy the presence of close family.

In a former qualitative study into the first 2–3 weeks after discharge, fatigue, apathy, insecurity and dependence were most prominent [7]. Our study took place later in time, yet these themes also recurred frequently among our participants. New is the meaning given to these themes: where in the former study frustration dominated [7], we also saw hope and acceptance.

In the last decades, there has been a hospital avoidance policy for frail older people in order to reduce costs and



pressure on healthcare [13–15] and to reduce poor outcomes such as complications and functional decline [15–17]. This study could be a counter against this policy, since many participants experienced positive outcomes, and when outcomes were negative, participants were often able to accept these. However, the decision to hospitalise was never called into question. Former literature also demonstrated that the decision to hospitalise is often not discussed and seen as a default [18–20]. Therefore, it is unknown whether participants would opt to forgo hospitalisation if they were given an informed choice.

When comparing the outcomes described in this study with goals mentioned in the first days of hospitalisation [6], we noticed much similarity, but two remarkable differences: First, while during hospitalisation many disease-related goals were mentioned [6, 21, 22], this was quite rare during the interviews after discharge, where the focus was much more on daily functioning and social activities. A possible explanation could be that, during hospitalisation, participants were in a medical environment, whereas the interviews for this study were at home. In the medical environment, participants were probably more focussed on medical outcomes, while at home, they focus more on daily life. The second difference is more focus on the mental consequences of living with a disease, or being released from that disease. Apparently, this also comes more to mind in the home situation.

The relationship between fulfilment of expectations and satisfaction is supported by literature [23–26]. When the discrepancy between expectation and outcome is only small, it could be within the zone of tolerance, and therefore, acceptance may come more easily [25]. But some participants in our study had large discrepancies between expectations and outcomes, and therefore, it is questionable whether expectations should be tempered. In addition to our study, at least one other qualitative study revealed that patients often have realistic expectations and understand that there are limitations of what healthcare can do for them, especially when having chronic conditions [27]. Noble *et al.* [26] showed that surgeons in general had more optimistic expectations than patients; nevertheless, they stated that many patients have overly sanguine expectations. Having high expectations can be beneficial, since positive correlations are seen between expectations, outcomes [23, 28, 29] and satisfaction [24]. Several explanations are given, such as self-efficacy, response expectancy theory, previous experience, social support, triggering of a physiologic response and changing the understanding of the disease [25, 28, 30].

Nevertheless, several authors advise patient education about expectations before surgery [26, 31, 32], which has been shown to be an effective way to modify expectations [32] and can have positive effects on outcomes [33]. Apart from formal education sessions, expectations could also have a place in goal-based shared decision-making [34]. As many admissions are acute, advance care planning could be an alternative [35]. Some of our participants also suggested that clear information about their condition and what to expect

is very important for them in the process of acceptance. Not only before hospitalisation, but also afterwards during their recovery, as some participants were uncertain about their future and what to expect. This argues for ongoing communication between patients and healthcare professionals, such as physicians, nurses and physiotherapists about expectations and satisfaction. Giving patients information on what to expect, and reflecting on the emotions of the experience, enables patients to perceive control [36].

A small group of participants not meeting their expectations remained hopeful of better outcomes. While hope involves ‘thoughts about one’s perceived ability to achieve future goals through successful planning and goal-directed energy’ [37], optimism is a relatively stable, generalised expectation that positive outcomes will occur, without specifying how goals might be achieved, but an optimistic person believes that somehow his future will be successful [37–39]. As the persons in the category ‘hope’ in our study put their faith completely into the hands of others, such as physicians, the term optimism may have been more appropriate.

The category ‘acceptance’ may also be related to the characteristic of optimism, as these participants all described themselves as optimistic, and according to the literature, optimistic persons are better able to see what they can instead of what they cannot do anymore [37, 40]; some participants referred to this as ‘the button’ which makes them see things positively. Therefore, participants in the categories ‘hope’ and ‘acceptance’ are both optimistic; only the difference is that participants in the category ‘acceptance’ accept the situation as it is, while the hopeful participants do not accept but stay optimistic that their condition will ameliorate, which appeared to be realistic in some cases. This might mean that the category ‘frustration’ contains more pessimistic persons. This could also be caused by different coping styles between optimistic and pessimistic persons. Optimistic persons seem to have more flexible coping strategies depending on whether the stressor is controllable, which leads to less frustration [39, 41]. Another cause may be negative events. Although optimism and pessimism are quite stable traits, optimism can fade by negative events [39]; therefore, the amount of adversity can make it more difficult to stay optimistic.

Although this is quite a new area, there are some interventions suggested to enhance optimism such as cognitive behavioural therapy, ‘Best possible self-intervention’ and coping skill training [39, 40, 42–44]. Although positive results are described from ‘Best possible self’, these are all in laboratory settings and with young people, so, as far as we know, no experience, or evidence, exists using this intervention with older persons in clinical practice [44].

Acceptance can also be seen as a form of adjustment to chronic illness [45, 46] with the hospitalisation as a key critical event [46]. In a proposed model of adjustment to chronic illness, many factors mentioned in our study are described as personality, illness-specific factors and social support [46]. Proposed interventions to stimulate adjustment are interventions we just discussed, or which were also recommended by our participants: healthcare professionals should

acknowledge the emotions patients have about the disease, encourage to engage in pleasant activities and find meaning in small things. For the small proportion of patients who have serious psychological problems, professional psychological help should be considered [45]. Some of our participants perhaps just needed more time to adapt to their new situation.

### Strengths and limitations

Although this qualitative method gave a rich insight into the outcomes of hospitalisation and their meanings from the patient's perspective, there are some limitations. First, the quality of recovery may be influenced by the timing of the interviews. Some participants who were interviewed within 10 weeks may have recovered further after the interviews, while some participants interviewed later already had had a new event when they were interviewed. Second, although the presence of a partner or child could be helpful and supportive for the patient, in some cases, the patient was somewhat overruled by them. We also noticed a variety of abilities to express themselves between participants and to provide a clear distinction in their situation before and after admission. Finally, due to the Corona pandemic, we conducted some interviews by telephone and noticed that the telephonic interviews were significantly shorter and less rich.

### Conclusions and recommendations

Hospitalisation can have both positive and negative impacts on many aspects of life of frail older persons. Of the persons whose outcomes did not meet their expectations, some were frustrated, others hopeful or accepted their situation. The following interventions can help patients to accept: clear communication about options and expectations before, during and after hospitalisation; giving room for emotions; help finding social support, encourage engaging in pleasant activities and finding meaning in small things. For some patients with more serious psychological problems, psychological treatment may be needed in the form of cognitive behavioural therapy, 'Best possible self-intervention' and coping skill training.

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