Ideas, concerns and expectations of frail older adults regarding the transition from hospital to home: a qualitative study using semi-structured interviews in two primary care practices.

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Abstract (EN)

Background: Frail older people are particularly vulnerable during the transition from the hospital to home. This period is often characterized by poor communication, complex care needs, and an increased risk of adverse outcomes, such as functional decline, reduced quality of life, and rehospitalisation. Although primary care plays a central role in ensuring continuity of care, little is known about how frail older adults themselves experience this transition and what they expect from post-discharge care.

Aim: The aim of this study was to understand how frail older adults experience their transition from hospital to home setting, with a particular focus on their ideas, concerns and expectations regarding follow-up care and care coordination in primary care. This is essential for identifying and addressing challenges in healthcare in the transition from hospital to home, and may help reduce hospital readmissions while improving the overall quality and satisfaction of healthcare delivery.

Method: A qualitative study was conducted using semi-structured interviews with frail older adults aged 65 years and older who had been discharged from hospital within the preceding six months. Participants were recruited from two general practices in Belgium. Interviews were conducted at participants' homes and analysed using reflexive thematic analysis according to Braun and Clarke. Data collection continued until data saturation was reached. Thirteen participants were interviewed.

Results: The analysis identified seven interrelated themes: (1) communication as a key element in the transition from hospital to home; (2) professional care coordination; (3) vulnerability; (4) social networks and the role of family members; (5) self-reliance; (6) structural and organisational barriers; and (7) resilience. Participants frequently reported late or unclear discharge communication, inconsistent interprofessional information transfer, and variation in follow-up by general practitioners. Expectations regarding proactive versus reactive follow-up differed widely and were shaped by personal vulnerability, coping strategies, and the availability of informal support.

Conclusion: The transition from hospital to home remains a vulnerable and complex period for frail older adults. The continuity of care is strongly influenced by the quality and timing of communication, effective coordination between hospital and primary care, and explicit attention to individual preferences, frailty, and the social context. Personalised, patient-centred strategies that take these factors into account may improve patient experiences and potentially reduce the number of adverse outcomes following hospital discharge.

Abstract (NL)

Achtergrond: Kwetsbare ouderen zijn bijzonder vatbaar tijdens de overgang van het ziekenhuis naar de thuissetting. Deze periode wordt vaak gekenmerkt door gebrekkige communicatie, complexe zorgbehoeften en een verhoogd risico op ongewenste uitkomsten, zoals functionele achteruitgang, verminderde kwaliteit van leven en heropname. Hoewel de eerstelijnszorg een centrale rol speelt bij het waarborgen van de continuïteit van de zorg, is er weinig bekend over hoe kwetsbare ouderen deze overgang zelf ervaren en wat zij verwachten van de zorg na ontslag.

Doel: Het doel van deze studie was te begrijpen hoe kwetsbare ouderen de overgang van het ziekenhuis naar de thuisomgeving ervaren, met bijzondere aandacht voor hun ideeën, zorgen en verwachtingen ten aanzien van nazorg en zorgcoördinatie in de eerstelijnszorg. Dit is essentieel voor het identificeren en aanpakken van uitdagingen in de gezondheidszorg bij de overgang van het ziekenhuis naar huis, en kan helpen heropnames te verminderen en tegelijkertijd de algehele kwaliteit en tevredenheid over de zorgverlening te verbeteren.

Methode: Er werd een kwalitatief onderzoek uitgevoerd aan de hand van semi-gestructureerde interviews met kwetsbare ouderen van 65 jaar en ouder die in de voorgaande zes maanden uit het ziekenhuis waren ontslagen. De deelnemers werden gerekruteerd bij twee huisartsenpraktijken in België. De interviews werden afgenomen bij de deelnemers thuis en geanalyseerd aan de hand van reflexieve thematische analyses volgens Braun en Clarke. De gegevensverzameling werd voortgezet totdat data verzadiging was bereikt. Er werden dertien deelnemers geïnterviewd.

Resultaten: Uit de analyse kwamen zeven onderling samenhangende thema's naar voren: (1) communicatie als sleutelelement in de overgang van ziekenhuis naar thuis; (2) professionele zorgcoördinatie; (3) kwetsbaarheid; (4) sociale netwerken en de rol van familieleden; (5) zelfredzaamheid; (6) structurele en organisatorische belemmeringen; en (7) veerkracht. Deelnemers meldden vaak late of onduidelijke communicatie bij ontslag, inconsistente interprofessionele informatieoverdracht en variatie in de nazorg door huisartsen. De verwachtingen ten aanzien van pro-actieve versus reactieve nazorg liepen sterk uiteen en werden bepaald door persoonlijke kwetsbaarheid, copingstrategieën en de beschikbaarheid van informele ondersteuning.

Conclusie: De overgang van het ziekenhuis naar huis blijft een kwetsbare en complexe periode voor kwetsbare ouderen. De continuïteit van de zorg wordt sterk beïnvloed door de kwaliteit en timing van de communicatie, effectieve coördinatie tussen het ziekenhuis en de eerstelijnszorg, en expliciete aandacht voor individuele voorkeuren, kwetsbaarheid en de sociale context. Gepersonaliseerde, patiëntgerichte strategieën die rekening houden met deze factoren kunnen de ervaringen van patiënten verbeteren en mogelijk het aantal ongewenste uitkomsten na ontslag uit het ziekenhuis verminderen.

Introduction

People aged 65 and over make up a large proportion of the world's population and are also among the most vulnerable groups in healthcare. They often have complex medical conditions and are more likely to be admitted to hospital (again) (1). We see that older people are more likely to end up in residential care centers with the aim of providing continuous care and support, yet a significant proportion of older people in need of care remain in their own homes (e.g., for financial reasons, waiting lists, etc.) (2, 3). This makes it important to map out the continuity of care in the home setting in order to continue to optimize it.

Given that there are large interindividual differences among older people, it is important to select those who are particularly vulnerable, meaning that even minor ailments can easily cause significant health problems, the so-called 'frail' elderly. Sciensano defines frailty as "a state of increasing vulnerability in older people." (4). The need for greater insight is further reinforced when focusing specifically on frail older adults. Frailty is commonly conceptualized through two complementary theoretical models. The phenotypic model proposed by Fried et al. uses five observable characteristics (reduced grip strength, slower walking speed, low physical activity, exhaustion, and unintentional weight loss) to define frailty as a biological syndrome characterized by diminished physiological reserve and increased vulnerability to stressors (5). Individuals meeting three or more criteria are classified as frail, one or two as 'pre-frail'. In contrast, the Rockwood et al. deficit accumulation model (or their 'Frailty Index') conceptualizes frailty as the cumulative burden of physical, cognitive, psychological, and social deficits (6). It is then calculated as the proportion of present deficits relative to a list of age-related symptoms, signs, diseases, disabilities, or laboratory abnormalities. This then produces a score ranging from zero to one, with higher values reflecting greater vulnerability. Together, these frameworks highlight that frailty reflects multidimensional vulnerability rather than merely chronological age (5, 6).

Research indicates that for older people, hospitalisation can lead to a decline in physical functioning, increased dependency, and a reduction in health-related quality of life (HRQoL) (7). Notably, HRQoL often continues to deteriorate during the post-discharge period (8). An important question that arises here is how home care can be adapted to counteract this deterioration in quality of life. Research shows, in fact, that older people want to stay in their own homes for as long as possible (9, 10). However, after returning home, many older adults struggle to adapt and cope with the consequences of their illness or hospitalisation (11). It is therefore important that primary care responds to the needs of this vulnerable group of patients and serves as a kind of bridge between the hospital and the patient in a home setting.

Primary care, including the general practitioner (GP) and other caregivers, plays a crucial role in both the hospital discharge process and the period that follows (12). As the foundation of continuity and person-centered care, primary care is essential to ensuring a smooth transition from hospital to home (12, 13). Research shows that effective communication and personalised follow-up plans not only improve patient satisfaction but also lead to better health outcomes, potentially reducing hospital (re)admissions (14). In contrast, when there is a delay between discharge and the first contact with primary care, the risk of readmission increases significantly (15, 16). Additionally, whether or not patients are contacted promptly after discharge has been shown to impact the number of medication errors, further emphasizing the importance of early follow-up (17). Facilitating a smooth transition and offering support not only improves quality of life but also reduces healthcare costs and therefore has a positive economic impact (18).

The outcome of hospitalisation is usually described in terms of mortality or morbidity in both literature and practice. It virtually always follows that there are worse outcomes for the most vulnerable individuals (19, 20). Nevertheless, the sparse existing literature shows that patients accept outcomes more readily when expectations and possible options are clearly communicated both before, during, but also, importantly for our study, after hospitalisation (19). This serves as sufficient evidence that deeper, more comprehensive studies are needed. Understanding the perspective of older people is crucial to achieving person-centered continuity.

Topics such as perceived quality of follow-up care, the sense of feeling heard, trust in healthcare providers, and integration of personal preferences into care plans are still misunderstood (21-23). This lack of focus on patient-reported outcomes and experiences can impact decision-making in primary care, particularly regarding recovery and rehabilitation. Older patients present unique challenges in care continuity due to multimorbidity, cognitive changes, and differing priorities compared to younger populations (1). This complexity underscores the importance of exploring their expectations of primary care follow-up.

Previous studies clearly demonstrate the importance of this personalised care, along with the fact that, according to the WHO, “person-centred care” is one of the defining characteristics of quality care (24, 25). In recent years, we have therefore seen a shift toward a greater emphasis on the importance of this person-centred care. One example is the study by Leithaus et al. in which the authors themselves indicate that patient-reported outcomes and experiences are crucial for the development of models for transition care (26). The systematic review and meta-synthesis by Van Grootel et al. also shows that tailored care, information, and support are essential for both patients and their family members to ensure a smooth transition and optimal recovery process after discharge from hospital (27). Despite this growing recognition of the value of person-centered, experience-based insights, there remains limited understanding of how frail older adults themselves perceive their care needs, concerns and expectations during the transition from hospital to home in primary care contexts (28). Existing studies often focus on clinical, organisational, or caregiver perspectives, leaving the subjective experience of the elderly un(der)explored. This lack of insight represents a critical knowledge gap, as understanding how older adults experience this transition is essential for identifying problems and obstacles in the continuity of care following discharge and, consequently, for reducing the number of hospital readmissions (29).

The aim of this study is to understand how frail older adults experience their own care in relation to hospital discharge, as this is essential for identifying and addressing challenges in healthcare in the transition from hospital to home, and may help reduce hospital readmissions while improving the overall quality and satisfaction of healthcare delivery.

Understanding these expectations will help the primary caregivers, as well as geriatricians and hospitals, to create a more person-centered approach in primary care settings, ultimately optimizing continuity care and enhancing both recovery experiences and health outcomes. The main question that arises is: “How do frail older adults experience the transition from hospital to home, and what ideas, concerns, and expectations do they have regarding follow-up and care coordination in primary care?”. In addition, one may also ask how older adults experience the role of the family physician in the period following discharge from the hospital, and what their expectations are with regard to proactive versus on-demand follow-up. Or how physical, cognitive, and contextual vulnerabilities influence their experience of the transition from hospital to home. And what role do family members and informal caregivers play in organising and supporting post-discharge care, and how is this involvement perceived by the patients.

Methods

Study Design and Reflexivity

This qualitative study was conducted in two general practices located in Genk (Medi-Mine) and Beersel (Medisch Huis Beersel). These are the practices where Elisabeth Lemmens (E.L.) and Sophie Jansen (S.J.) were respectively appointed as General Practitioners in Training (HAIOs). The study focused on the subjective experience of patients and was conducted between January 2025 and December 2026. We received ethical approval from the Ethics Committee for Research at UZ/KU Leuven. Consolidated Criteria for Reporting Qualitative Research (COREQ) were followed as guidelines to ensure the accuracy of the research (see supplementary file 1) (30). This study was conducted by S.J. and E.L., both general practitioners in training, who conducted 6 and 7 interviews respectively in the practices where they were employed. Because the researchers shared a professional background and clinical role within these practices, reflexivity was considered essential throughout the project. Their position as clinicians-in-training may have influenced how participants perceived them, introducing possible social desirability or authority-related bias. To minimize this influence, the interviews were always with colleagues' patients, so there was no pre-existing relationship between the interviewer and the interviewee. As a result, the interviewed patients only knew the interviewers' profession and their master's degree. After each interview both researchers actively integrated reflexive practice. During these telephone calls both researchers reflected on assumptions, emotional reactions, new insights and potential sources of bias. An overview about the research team and about reflexivity can be found in supplementary file 2.

Epistemological Positioning

In this study, it is important to focus on gathering patients' subjective interpretations and experiences rather than objective facts. Such an approach aligns with Braun and Clarke's reflexive thematic analysis, which emphasizes the researcher's active, interpretive role in generating themes (31). Semi-structured interviews are methodologically appropriate because they allow participants to express their lived experiences in their own words, while offering the interviewer enough flexibility to explore emerging meanings in depth. This balance between structure and flexibility supports a nuanced understanding of the experiences of frail older adults following hospital discharge, in line with the interpretive aims of the study.

Study Population and Recruitment

The study group was recruited from two general practices located in Genk (Medi-Mine) and Beersel (Medisch Huis Beersel). Eligible patients were actively selected by their own primary care physician, meaning they were colleagues of the interviewers, who applied the predefined inclusion and exclusion criteria during routine consultations, home visits, or telephone contacts. This approach was chosen because these GPs were most familiar with their patients' medical and social history, allowing them to efficiently identify those who met the criteria. Additionally, to reduce the risk of conflicts of interest and role-related bias, participant selection was conducted by colleagues instead of the interviewers themselves. The downside of this is that it may have resulted in the sample consisting mainly of people who were more accessible or whom the selecting general practitioner knew better, in other words, selection bias may have occurred. For logistical reasons, participants were recruited from the practices where the researchers were employed as GP trainees.

The inclusion criteria consisted of patients aged 65 years or older who were considered physically, socially, and/or psychologically frail and/or patients with multimorbidity, who were recently (<6 months) discharged after hospitalisation for any reason. Frailty of the patients was determined solely through the clinical assessment of the patient's primary care physician, with no standardized frailty instrument used (meaning 'Frailty Index' or 'Frailty Phenotype' as explained earlier, were not applied as measurement tools in this study). This choice aligns with the broader conceptual understanding of frailty as a state of reduced resilience in older individuals, resulting from age-related deterioration across multiple biological and functional systems, which decreases their capacity to handle everyday or acute stressors. Multimorbidity is defined in this context as the simultaneous presence of two (or more) conditions that have a significant impact on the patient's health and/or functioning.

The exclusion criteria for this study were patients with a (known) Minimal Mental State score of less than 21 or patients with severe psychiatric comorbidities. The reason for this was that the reliability of their responses could be questioned. In addition, we did not focus on patients in palliative care settings, nor on patients living in residential care centers, as their environment makes them less suitable for our research question. To avoid language bias, we only included Dutch-speaking patients in our study. An overview of patients' characteristics can be found in Table 1.

Sixteen patients were ultimately identified by colleagues, who informed them, during home visits, consultations, or telephone calls, about the opportunity to participate in our study. For patients who expressed interest, their telephone numbers were provided to the research team, allowing us to contact them directly to explain the study procedures in detail and arrange a time to review the informed consent form. Patients were subsequently given sufficient time to examine the consent document, with the option to do so together with a family member if desired. An interview appointment was then scheduled at a location of the patient's choosing. During this recruitment process, one patient immediately declined participation, and the other two initially agreed but later withdrew on the day of the scheduled interview. The reasons were not specified. The remaining thirteen patients consented to proceed with the interview.

Table 1. Demographic data of participants (n = 13)

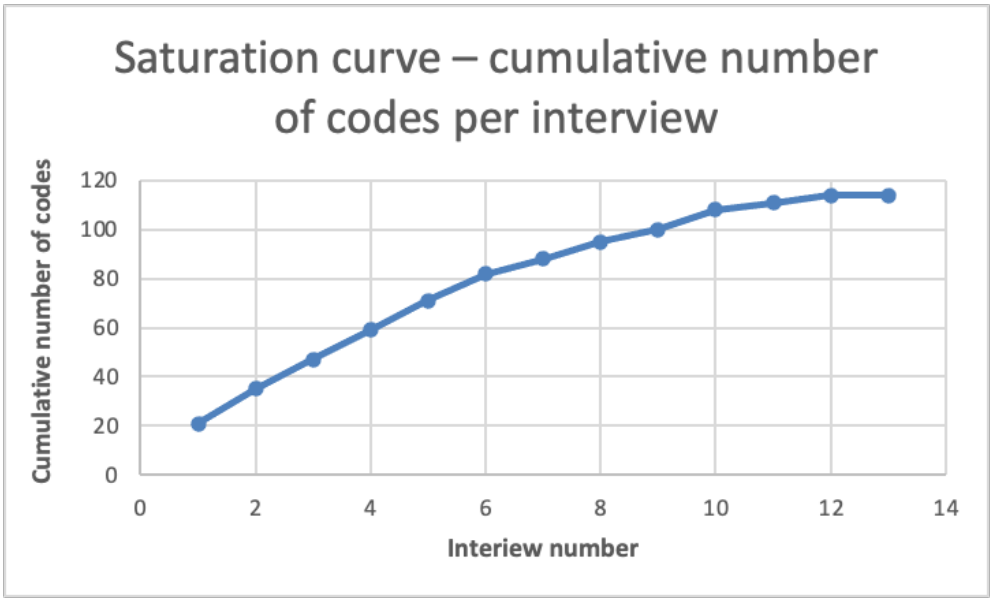
	Medical practice	Gender	Age	Living Situation	Use of Home Care Services
Participant 1	Genk	Male	74	With partner	No
Participant 2	Genk	Female	85	Alone	Yes
Participant 3	Beersel	Female	83	Alone	No
Participant 4	Beersel	Male	86	Alone	Yes
Participant 5	Genk	Female	72	With partner	Yes
Participant 6	Genk	Male	73	With partner	Yes
Participant 7	Beersel	Female	67	Alone	No

Participant 8	Beersel	Male	84	With partner	No
Participant 9	Genk	Female	71	Alone	Yes
Participant 10	Beersel	Male	86	With partner	Yes
Participant 11	Beersel	Male	92	With partner	No
Participant 12	Genk	Female	69	Alone	Yes
Participant 13	Genk	Male	78	Alone	Yes

Data Collection

During our semi-structured interviews, we used a pre-drafted interview guide based on literature identified through PubMed, Sciensano and other major databases, focusing on hospital-to-home transitions, frailty, multimorbidity and continuity of care. While reviewing this literature, we identified several gaps and underexplored themes. The first version of the interview guide was therefore constructed by explicitly targeting the gaps and underrepresented aspects found in the literature. This preliminary version was reviewed together with our supervisor to determine which topics were essential for answering our research questions and which were less relevant. Subsequently, the guide was pilot-tested on a patient. This pilot allowed us to critically assess which questions generated meaningful, research-relevant information and which led to an overload of data without contributing to the study objectives. Based on this evaluation, certain questions were removed, refined or reformulated to improve clarity and focus. These pilot transcripts were ultimately included in the study but simultaneously served as a basis for optimizing the interview guide. The final version thus reflected a more targeted set of themes, aligned with both the identified literature gaps and the practical insights gained during the pilot phase. The final interview guide is provided in Supplementary File 3. Participants could choose the interview location to ensure maximum comfort. All opted for an interview at home. Although family members were sometimes present in the household, all interviews were conducted privately with the participant in a separate room. Interviews lasted between 20 and 30 minutes. The interviews were audio-recorded using a voice recorder. No video recordings were made. All recordings were used for transcription only by the researchers and were destroyed immediately afterward, along with personal interviewer notes. As interviewers, we contacted each other by telephone after each interview to discuss our findings and make any necessary adjustments. The interviews were analysed in chronological order, and the number of new codes identified in each interview was recorded. These data were subsequently processed in Excel and presented in a saturation curve, illustrating the cumulative increase in codes across interviews. Data saturation was considered achieved when no substantial new codes emerged in two consecutive interviews. As shown in Graphic 1, the curve flattened out after interview 13, indicating that no relevant new codes were identified beyond this point. Finally, we would like to add that the participants did not derive any benefit from the research and were therefore not compensated in any way for their participation.

Graphic 1: Saturation curve of cumulative number of codes per interview



Data Management

All interviews were transcribed into text files, which were subsequently transferred to the supervisor (corresponding author) and stored on a secure server. Anonymized versions of the transcripts can be made available to interested researchers upon request.

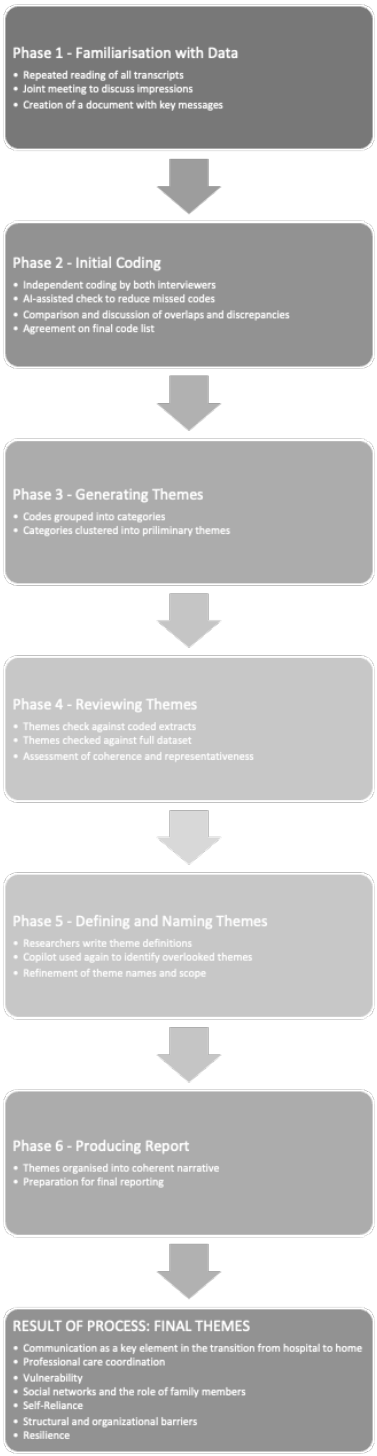
Data Analysis

Reflexive thematic analysis according to Braun and Clarke was used as a reference after the interviews were manually transcribed and anonymized in a separate document (31). This thematic analysis consists of six phases. Phase 1 is the familiarization of data. In the study, this began with repeated readings of their own transcripts and the ones by the fellow interviewer. Next, a meeting was scheduled to discuss everyone's findings and to begin the analysis. A document was then drawn up highlighting the most important key messages, so that codes could then be created. Which brings us to phase 2, the initial coding. A preliminary coding system was developed by both interviewers reviewing all the interviews and individually compiling a list of codes. In addition, the AI-tool CoPilot (paid pro version provided by KU Leuven) was used to reduce the risk of missing codes. The codes found were then compared, both by the researchers themselves and by AI, to discuss similarities and discrepancies. This ultimately led to the final codes. The codes were then classified into categories based on differences and similarities and finally grouped into themes (Phase 3 “Generating Themes”). The developing themes were then reviewed against the coded extracts and the full dataset to check coherence and representativeness (Phase 4 “Validity and Reliability of Themes”). That brings us to phase 5, where themes were defined and named. Here, the themes were first obtained in writing by both researchers, with Copilot being used again in a second stage to bring any forgotten themes to light. Finally, the themes were organised into a coherent narrative and prepared for reporting (Phase 6).

The analysis was predominantly inductive, as codes and themes were primarily generated from the data through iterative reading of the transcripts. At the same time, the semi-structured interview guide

was developed based on prior research on hospital-to-home transitions, frailty, and continuity of care, which informed the analytic process. Therefore, the analysis can be characterised as hybrid, combining inductive data-driven coding with a theoretically informed, deductive orientation. A visual overview of the analytic process and resulting themes can be found in Image 1.

Image 1: A Visual Overview of the Analytic Process



Transparency statement on the use of generative artificial intelligence

During the preparation and writing of this master's thesis, generative artificial intelligence (AI) tools were used in a limited and critical manner, in accordance with the guidelines of KU Leuven and the Interuniversity Center for General Practice Education. Microsoft Copilot (Pro version provided by KU Leuven) was used as a tool during the qualitative data analysis process, specifically to identify potential (overlooked) codes and themes and to reduce the likelihood of relevant analytical elements being overlooked. All substantive decisions regarding coding, theme formation, and interpretation were made exclusively by the researchers. Since it was not initially clear to the researchers that AI could be used, the majority of the thesis was written without the use of AI. However, AI was subsequently used to search for literature to support the discussion section and to finetune the literature of the introduction. AI was also used to proofread the methods section for spelling and to enhance the academic quality of the text. The purpose of these applications was to increase efficiency, refine linguistic quality, and strengthen the overall coherence of the research report. No AI tools were used to generate original research results, interpretations, or conclusions. All content has been critically evaluated by the authors, who retain full responsibility for the final manuscript. No personal data or non-anonymized research material was entered into the publicly accessible AI system.

Ethical Approval

The study was approved by the Ethics Committee for Research at UZ/KU Leuven (MP035368 on 27/03/2025). All participants have given their written consent.

Results

Participants' characteristics

Thirteen interviews were conducted with both male and female participants. All participants provided informed consent. Interviews lasted between 20 and 30 minutes. An overview of patients' characteristics can be found in Table 1. Supplementary File 4 contains an overview table of themes, subthemes, codes, and illustrative quotes.

Theme 1: Communication as a key element in the transition from hospital to home

Participants frequently referred to communication when describing their experiences of the hospital discharge process. Participants reported barriers related to the discharge process itself and to communication between healthcare professionals across care settings.

Subtheme 1.1: Communication surrounding hospital discharge

Participants described differences in the timing, content, and mode of discharge communication, as well as in the information provided about medication and their involvement in discharge decision-making.

First, many participants reported that discharge was announced late, often only one day in advance or even on the day of discharge itself. As a result, patients experienced limited time to prepare or ask questions.

> *"I wasn't sure when I was allowed to go home."* (Participant 3)
>
> > *"Ik wist niet goed wanneer ik juist naar huis mocht."*
>
> *"In the evening, I was told that I could go home the next day. I would have liked to have known this two to three days in advance.*" (Participant 9)
>
> > *"Ik werd 's avonds ingelicht dat ik 's anderendaags naar huis mocht gaan. Ik had dit graag twee tot drie dagen op voorhand geweten."*

In addition, respondents indicated that discharge information was often limited or difficult to understand. While written discharge documents were commonly provided, participants reported that these were not always explained, were only briefly discussed, or contained medical jargon. In some cases, patients reported not having received a discharge letter but having been told to access it online.

> "*You'll receive a report, but as a non-expert, you won't understand it."* (Participant 3)
>
> > *"Je krijgt een verslag mee, maar als leek snap je dat niet."*
>
> *"It all happened so fast, there was no time to ask questions."* (Participant 7)
>
> > *"Het ging allemaal zo snel, er was geen tijd om vragen te stellen."*

"And then I asked, I called, I said: 'What about the paperwork?' [nurse:] *'Oh, it's all sent online to the doctor, you won't get anything.' I thought that was strange. That I wasn't involved myself, actually."* (Participant 9)

> *"En toen heb ik gevraagd, heb ik gebeld, ik heb gezegd: 'En de papieren?'* [verpleegkundige:] *'Ah, dat gaat allemaal online naar de huisarts. Jij krijgt niks mee.' Dat vond ik raar. Dat ik er zelf niet bij betrokken werd eigenlijk."*

Medication-related information was another aspect described by participants in relation to discharge. Some reported that explanations about medication changes and potential side effects were limited or not provided. In several cases, patients reported becoming aware of differences in their medication only after returning home.

"I was in a lot of pain and confused by the medication, but no one had explained that to me." (Participant 1)

> *"Ik had veel pijn en was verward door de medicatie, maar niemand had dat uitgelegd."*

Finally, participants reported varying levels of involvement in the discharge decision-making process. Some described receiving discharge information primarily from nursing staff without direct contact with a physician, while others reported being satisfied with limited information and expressed trust in healthcare professionals. In contrast, several participants indicated a preference for more direct involvement or communication with a physician.

"The nurse said I could go home, not the doctor." (Participant 1)

> *"De verpleegster zei dat ik naar huis mocht, niet de arts."*

"I didn't get much of an explanation, but that was enough for me." (Participant 11)

> *"Ik kreeg niet veel uitleg, maar voor mij was dat voldoende."*

"I shouldn't have to hear that from the nurse, but from the specialist himself. He's the one who treated me, after all." (Participant 6)

> *"Ik moet dat niet horen van de verpleger maar van de specialist zelf. Die heeft mij behandeld, hé."*

Subtheme 1.2: Interprofessional communication

In addition to communication with patients themselves, participants referred to communication between hospital specialists and the GP, and between other first-line professionals.

Several interviewees reported that their GP had not been informed of the hospital admission or discharge, and that they themselves communicated this information to their GP.

"Then we called the doctor, and she didn't know anything either. Nothing had been forwarded to her. I think it's really scandalous. That you're not informed, that the GP doesn't know anything either, and neither do we. That wasn't okay." (Participant 6)

> *"Dan hebben we naar de dokteres gebeld, en die wist ook van niks. Er was niks doorgestuurd. Ik vind het echt schandalig. Dat ge niet op de hoogte zijt, dat de huisarts dan ook helemaal van niks weet en wij dan ook niet, hé. Dat was niet oké."*

> *"Two days later, I called my doctor to ask about the paperwork. He even had to call me back to access it online. It still wasn't there. I thought that was a bit of a shame."* (Participant 9)

> *"Ik heb toen twee dagen later naar de huisarts gebeld voor iets te vragen in verband met de papieren. En die heeft zelf nog moeten terugbellen voor het online te kunnen krijgen. Het was er nog altijd niet. Dat vond ik een beetje erg."*

In addition, in some cases, participants reported that no instructions for home nursing care were provided, and that the GP contacted the hospital to obtain the necessary information.

> *"Then the GP also had to request the paperwork, so there were no written instructions for home nursing or similar provisions from the hospital."* (Participant 9)

> *"Dan heeft de huisarts ook de papieren moeten vragen, dus er waren ook geen papieren instructies voor de thuisverpleging of dergelijke voorzien vanuit het ziekenhuis."*

Theme 2: Professional care coordination

Interviewees described varying degrees of coordination across healthcare professionals, with particular emphasis on the roles of social workers, general practitioners, home nursing services, and other health care professionals. Participants reported different experiences of care coordination, ranging from well-organised arrangements to situations in which care was organised by themself or their families.

Subtheme 2.1: Social workers

Participants described social workers as important figures in the coordination between hospital and home. When involved early, social workers ensured continuity of care by arranging home nursing services or post-discharge support prior to hospital discharge.

> *"The social worker first discussed everything with me and then arranged everything with my son. I didn't have to worry about anything."* (Participant 2)

> *"De sociaal assistente had eerst alles met mij besproken en heeft dan alles verder geregeld met mijn zoon. Ik moest me van niets aantrekken."*

> *"At the rehabilitation center, the social worker arranged for them* [home nurses] *to come by."* (Participant 13)

> *"In het revalidatiecentrum heeft de sociaal assistente alles geregeld, dat die* [thuisverpleging] *langskwamen."*

In contrast, when social work support was absent or limited, participants described organising care themselves, in some cases within a short timeframe.

"We were given two days to arrange everything, which was really very short." (Participant 6)

> *"We kregen twee dagen om alles te regelen, dat was echt heel kort."*

Subtheme 2.2: General practitioners

Participants described considerable variation in the timing and nature of general practitioners' involvement following hospital discharge, including differences in the extent to which GPs assumed an active or reactive role.

Participants often consulted their GP for additional explanation and valued GP involvement in explaining the hospital admission and treatment, managing and clarifying medication changes, and coordinating post-discharge care such as the continuation of home nursing.

Experiences ranged from proactive follow-up and regular contact to situations in which contact occurred only when initiated by the patient.

Overall, participants differed in their expectations regarding GP follow-up, and these expectations were not always aligned with the care received.

2.2.1. (Pro)active and routine follow-up

Some participants described their GP as a central and proactive coordinator, particularly valuing follow-up contact shortly after discharge. Proactive phone calls or home visits were experienced as reassuring and contributed to a sense of being monitored during a vulnerable period.

"My family doctor called me himself to ask how I was doing, and since then he has been visiting me regularly." (*Participant* 13)

> *"Mijn huisdokter heeft mij zelf opgebeld om te vragen hoe het ging en sindsdien komt hij geregeld langs."*

Others took the initiative to schedule a follow-up appointment themselves, particularly to clarify hospital information they found difficult to understand.

"I decided to schedule an appointment myself, because you don't understand those reports anyway." (Participant 10)

> *"Ik heb op eigen initiatief dan toch een afspraak voorzien, omdat je die verslagen toch niet verstaat."*

Participants also indicated that periodic routine follow-up, such as a monthly consultation after hospitalisation, was sufficient to feel supported. In some cases, this approach was already in place and was experienced as reassuring, particularly when no immediate problems were present and patients felt confident in contacting the GP when needed.

"After such an admission, I might want to see my GP once a month. If I'm not feeling well, it's nice to have someone keep an eye on me." (Participant 2)

"Ik zou misschien toch wel na zo'n opname de huisarts één keer per maand willen zien. Als ik mij niet goed voel, dan is dat wel fijn als iemand mij toch wat in de gaten houdt."

Interviewer: "*So, in summary, it is not systematically necessary for you that, for example, when you are discharged from the hospital, the doctor visits you within the same week? For you, it is sufficient that they visit routinely or come when you call?"*

Participant: *"Yes, that's right. I call myself. I don't have a problem with that."* (Participant 1)

Interviewer: *"Samengevat is het voor u dus niet systematisch nodig dat, als u bijvoorbeeld uit het ziekenhuis komt, de dokter in diezelfde week nog langskomt. Voor u is het genoeg dat ze gewoon routinematig komen of komen als u belt?"*

Participant: *"Ja, dat klopt. Ik bel zelf, dat vind ik geen probleem."*

2.2.2. Limited follow-up and unmet expectations

Other participants, however, reported a limited follow-up and expressed a desire for more proactive GP contact after hospital discharge. Several expected at least a phone call or brief check-in, but reported that no such contact occurred unless they initiated it themselves.

"I still think they should have called; just to ask if everything was okay." (Participant 3)

"Ik vind toch dat ze eens hadden mogen bellen; gewoon om te checken of alles goed ging."

In these cases, participants reported the absence of proactive follow-up and described this as disappointing, particularly in the context of long-standing relationships with the GP practice.

2.2.3. Acceptance of limited follow-up and emphasis on accessibility

Despite these unmet expectations, many participants demonstrated understanding for the workload pressures faced by GPs. Rather than insisting on proactive follow-up, for several participants, being able to contact the GP directly in case of a problem was considered sufficient, provided that timely access was ensured.

Interviewer: *"And would you like us to call you to check how things are going and whether we need to come by?"*

Participant: *"I don't think it's necessary either, you all have enough work to do. You'll receive a letter anyway, so you'll know what you need to do, right?"* (Participant 1)

Interviewer*: "En zou u het bijvoorbeeld fijn vinden als wij zouden bellen om te polsen hoe het gaat en of we moeten langskomen?"*

Participant: *"Voor mij ook niet nodig, jullie hebben allemaal al werk genoeg. Jullie krijgen toch een brief en dan weten jullie toch wat jullie moeten doen, hé."*

"No, no follow-up. But if necessary, we'll call, and then we'll surely get a place." (Participant 11)

"Nee, geen opvolging. Maar als het nodig is bellen we, en dan krijgen we wel een plaats."

Interviewer: *"Would you have preferred the GP to have visited earlier than the routine check-up?"*

Participant: *"No, that doesn't matter to me. If there's anything wrong, we'll call the practice and they're always there for us. We waited until she came by, because there weren't any problems for us either."* (Participant 1)

> Interviewer*: "Had u dat liever anders gezien, dat de huisarts wel al eerder was langsgekomen dan de routinecontrole?"*
>
> Participant: *"Nee, dat maakt voor mij niet uit. Als er iets is dan bellen wij toch naar de praktijk en dan staan ze altijd klaar. We hebben nu gewacht totdat ze gewoon langskwam omdat er voor ons ook geen problemen waren."*

Subtheme 2.3: Home nursing

Participants described variation in the organisation, scope, providers, and experiences of home nursing care after discharge.

First, differences were reported in how home nursing care was organised. Home nursing services were organised by the hospital social worker or by family members prior to discharge, and were initiated shortly after hospital discharge.

Second, participants described variation in the types of tasks involved, which were generally nursing-related and including assistance with personal hygiene, medication preparation, and the application of compression stockings.

Third, differences were noted in who performed these tasks. While many participants received care from professional home nurses, others reported that certain aspects of care were taken on by family members.

Interviewer: *"And how was home care organised? Did a nurse come by?"*

Participant: *"No, that wasn't necessary. My wife took care of everything. She helped me with my personal hygiene and with getting my medication ready."* (Participant 1)

> Interviewer: *"En hoe werd de thuiszorg georganiseerd? Is er een verpleegster gekomen?"*
>
> Participant: *"Nee, dit was niet nodig. Mijn vrouw deed alles. Zij hielp me bij het wassen en bij het klaarleggen van de medicatie."*

Finally, participants described differing experiences with home nursing care. Some reported positive experiences, describing the care as well-organised.

"The home care went very well. Everything was taken care of down to the last detail." (Participant 6)

> "*De thuiszorg is goed verlopen. Tot in de puntjes."*

In contrast, others experienced care as rushed and task-oriented, with limited time for personal interaction, and indicated that they needed to express their needs explicitly to receive specific support.

"I'll be honest, the nurses are very sweet, but they never have any time. We know them quite well because they've been coming here for years. Sometimes they haven't even finished coming in yet, they want my ID card right away, but they don't make time to wash me. You have to explicitly ask for what you want. I sometimes tell them too: 'You're so kind and lovely, but you're always in such a rush'." (Participant 5)

"Ik ga eerlijk zijn: de verpleegsters zijn heel lief, maar ze hebben nooit geen tijd. We kennen ze redelijk goed *want die komen hier al jaren. Ze zijn soms nog niet eens binnen, moeten ze direct mijn pas hebben, maar maken ze wel geen tijd om mij te wassen. Je moet al expliciet vragen wat je wilt. Ik zeg het hun soms ook: 'Jullie zijn zo lief en goed maar jullie zijn echt vliegensvlug'.''*

Despite these differences, home nursing care was frequently described as supportive, particularly when nurses collaborated closely with the GP and acted as a link to primary care.

"And I can also tell her about my medical complaints. In that case she will call the doctor to see if it is necessary for the doctor to come by. I really appreciate that." (Participant 9)

"En daar kan ik ook mijn medische klachten tegen zeggen. Dan belt zij de arts op om te zien of het nodig is dat de arts langskomt. Dat vind ik heel fijn."

Subtheme 2.4: Other (healthcare) services

Participants also referred to the involvement of other healthcare and support services, most notably physiotherapy and family assistance. The coordination of these services was largely described as patient- or family-initiated.

2.4.1. Physiotherapy

Several participants arranged physiotherapy after discharge on their own initiative or through family members, sometimes by contacting a previously consulted physiotherapist. Proactive organisation of physiotherapy by the hospital was reported only rarely.

"The physical therapist, who comes twice a week, was arranged through my daughter-in-law." (*Participant* 4)

"De kiné, die twee keer per week komt, werd via mijn schoondochter geregeld."

2.4.2. Family assistance

With regard to family assistance and home help services, several participants indicated that they were not well informed about the scope or content of these services. Knowledge about available support was often limited, and services had to be actively requested by patients or their relatives.

Interviewer: *"And will there be family support?"*

Participant: *"No, I don't have that at the moment, but they say I could use it. What can I actually ask for?"* (Participant 2)

Interviewer: *"En komt er ook familiehulp?"*

Participant: *"Nee, dat heb ik op dit moment niet, maar ze zeggen dat ik dat wel zou kunnen gebruiken. Wat kan ik daar eigenlijk allemaal aan vragen?"*

Theme 3: Vulnerability

Participants referred to different aspects of vulnerability when describing their experiences of hospital discharge. These may be subdivided in personal vulnerability on the one hand and external vulnerability on the other.

Subtheme 3.1: Personal vulnerability

Participants described personal vulnerability after discharge in relation to their physical condition, cognitive functioning, and emotional coping.

A first type of personal vulnerability may be linked to the physical condition of the participants. Many participants described physical vulnerability following hospitalisation, including reduced mobility, pain, fatigue, and limited functional capacity.

"I had just gotten out of bed once to go to the bathroom, so I actually thought it was much too short, much too fast. Especially since I'm single." (Participant 9)

"Toen was ik net één keer uit bed geweest om naar de WC te gaan, dus ik vond het eigenlijk veel te kort, veel te snel. Zeker omdat ik alleenstaande ben."

"I'm not going to lie, I need that [home nursing]. *I really can't do anything with my left hand at the moment. And then there's my husband, who is right-handed and can't do anything with his left hand anymore because of his stroke. So we're two of a kind* [laughs]*."* (Participant 5)

"Ik ga niet liegen, ik heb die [thuisverpleging] *nodig. Ik kan momenteel echt niks linkshandig. En dan, mijn man, die is rechtshandig en door zijn infarct kan die niks meer linkshandig. Dus we zijn twee figuren* [lacht]*."*

"The ambulance had to take me home because it really wasn't going to work with the car; it hurt too much." (Participant 6)

"De ambulance heeft me naar huis moeten brengen want met de auto ging het echt niet, dat deed me te veel pijn."

Interviewer: *"And was home nursing care arranged?"*

Participant: *"No, that wasn't really necessary. The only problem was actually my blister pack, my Zaldiar, where I couldn't get the pills out with one hand and needed help to get them out and put them in a jar.*" (Participant 7)

Interviewer: *"En was er iets van thuisverpleging opgestart?"*

Participant: *"Nee, dat was eigenlijk niet nodig. Het enige probleem was dus eigenlijk mijn blister, mijn Zaldiar, waar ik de pilletjes niet uit kreeg met één hand en dan heb ik hulp nodig om die eruit te krijgen en in een potje te doen."*

In addition to physical limitations, participants frequently reported confusion, memory problems, or difficulty processing information, particularly in the context of acute illness, medication effects, or fatigue.

> *"The night before, I had hallucinations and crawled across the floor. I was uneasy."* (Participant 9)
>
> > *"De nacht voordien had ik hallucinaties gehad en heb ik over de vloer gekropen. Ik was er niet gerust in."*
>
> *"Then they came twice, because I slept a lot from the pills. Apparently, I was quite irritable and confused* [laughs]*."* (Participant 6)
>
> > *"Dan zijn ze daarna 2 keer gekomen, omdat ik veel sliep van de pillen. Het schijnt dat ik nogal ambetant en verward was* [lacht]*."*

This mental overload limited their ability to understand discharge information and to actively participate in decision-making. As a result, some participants reported relying on others to interpret information or make decisions on their behalf.

> Interviewer: *"Do you think the discharge should have been handled differently?"*
>
> Participant: *"He* [the specialist] *should have come by himself, and my wife should have been there. If I seemed confused, they should have waited until she was there. I couldn't explain it to her."* (Participant 1)
>
> > Interviewer: *"Had het ontslag volgens jou op een andere manier moeten gebeuren?"*
> >
> > Participant: *"Dat hij* [de specialist] *zelf was langsgekomen en dat mijn vrouw erbij was. Als ik verward overkom, dan hadden ze moeten wachten totdat zij erbij was. Ik kon het haar niet terugzeggen."*

Participants also varied in how they described coping with their situation after discharge, ranging from stress and insecurity to acceptance and optimism.

> *"Things were actually going really well when I was still in Hasselt, in a short-stay accommodation. But since I've been home, I can't cope with the stress."* (Participant 2)
>
> > "*Het ging eigenlijk heel goed toen ik nog in Hasselt zat in een Kortverblijf. Maar sinds ik thuis ben, kan ik het niet meer aan van de stress."*
>
> *"You have to stay positive, otherwise you won't get through it."* (Participant 11)
>
> > *"Je moet positief blijven, anders geraak je er niet door."*

Subtheme 3.2: External (and contextual) vulnerability factors

In addition to individual factors, participants also referred to external circumstances in relation to hospital discharge.

Some participants described returning to homes that were not adapted to their physical needs, increasing their reliance on others for support and heightening vulnerability, especially when living

alone during the immediate post-discharge period. In some cases, however, these risks were anticipated and mitigated through additional support.

> *"I live in a small apartment, so there are stairs. It's not ideal. If help needs to come, whether it's an ambulance, a doctor, or whatever, I have to use those stairs to let them in. So, from a practical standpoint, that's already a problem. Here* [other apartment] *there are stairs too, but here, my girlfriend is there to let them in. So that was one of the issues, the practical aspect."* (Participant 10)

> > *"Ik woon op een klein appartement, dus er zijn trappen. Het is niet ideaal. Als er hulp moet komen, zoals een ziekenwagen, een arts, weet ik veel, moet ik die trappen doen om open te maken. Dus op het praktische gebied is dat al een probleem. Hier* [ander appartement] *zijn ook trappen, maar hier is mijn vriendin erbij om open te doen. Dus dat was één van de zaken, het praktische oogpunt."*

Others described situations of mutual dependency within couples, where both partners had health limitations.

> "*And yes, I'll be honest, my husband was at home, lost and alone, because he had suffered a stroke in the past. So, I felt so sorry for him, thinking he would be so lost without me, that I just left. In a different situation, I might have stayed."* (Participant 5)

> > *"En ja, ik ga eerlijk zijn, mijn man was thuis, verloren en alleen, want die heeft een herseninfarct gehad in het verleden. Dus ik vond dat zo erg voor hem dat hij zo verloren zou lopen zonder mij, dat ik zomaar vertrokken ben. In een andere situatie was ik misschien wel gebleven."*

Uncertainty around the timing of discharge and the absence of family members during discharge conversations further heightened vulnerability.

> Interviewer: *"Do you think the discharge should have been handled differently?"*
>
> Participant: *"He* [the specialist] *should have come by himself, and my wife should have been there. If I seemed confused, they should have waited until she was there. I couldn't explain it to her.* (Participant 1)

> > Interviewer: *"Had het ontslag volgens jou op een andere manier moeten gebeuren?"*
> >
> > Participant: *"Dat hij* [de specialist] *zelf was langsgekomen en dat mijn vrouw erbij was. Als ik verward overkom, dan hadden ze moeten wachten totdat zij erbij was. Ik kon het haar niet terugzeggen."*

Theme 4: Social networks and the role of family members

Participants referred to the involvement of social networks in relation to care after hospital discharge. They described how both professional caregivers (e.g. home nursing and family assistance) and non-professional caregivers (e.g. family members, friends, neighbours) helped compensate for gaps in formal care provision, particularly during the early post-discharge phase. Given the prominence of family involvement in participants' accounts, the following section focuses specifically on support provided by family members, who assumed both logistical and emotional roles.

Subtheme 4.1: Logistical support

Family members frequently took responsibility for the practical organisation of post-discharge care, including transport, home preparation, medication management, and coordination of follow-up services.

> *"Then the nurse said to the son: 'Your father can go home, so you can start making arrangements'."* (Participant 6)
>
> "*Toen had de verpleger gezegd tegen de zoon: 'Uw vader mag naar huis dus ge kunt beginnen regelen'."*

> *"I had all my children who took good care of me, so they came to get me."* (Participant 3)
>
> *"Ik had al mijn kinderen die goed voor mij zorgden, die zijn me dan ook komen halen."*

> *"My wife was at home and could therefore prepare dinner."* (Participant 8)
>
> *"Mijn vrouw was thuis en kon dus eten klaarmaken."*

> *"My children had arranged everything: nursing care, new family doctor, service apartment, etc."* (Participant 4)
>
> *"Mijn kinderen hadden alles geregeld: verpleging, nieuwe huisarts, service flat, etc."*

> *"My wife arranged for a hospital bed, contacted the White-Yellow Cross, and then we had to buy all sorts of things."* (Participant 6)
>
> *"Mijn vrouw heeft dan een ziekenhuisbed geregeld, het Wit-Gele Kruis aangesproken en dan hebben we vanalles moeten kopen."*

Several participants indicated that the involvement of family members in post-discharge care was expected rather than explicitly discussed or arranged by the hospital.

> Participant: *"My son-in-law came to pick me up that day."*
>
> Interviewer: *"Did you arrange that yourselves or did the hospital arrange it?"*
>
> Participant: *"I arranged it myself. Actually, I don't think they even ask at the hospital. I think they just expect you to arrange it yourself."* (Participant 5)
>
> Participant: *"Mijn schoonzoon is me komen halen die dag."*
>
> Interviewer: *"Hebben jullie dat zelf geregeld of vanuit het ziekenhuis?"*
>
> Participant: *"Dat heb ik zelf geregeld. In feite denk ik dat ze dat niet eens vragen in het ziekenhuis; ik denk dat ze dat verwachten."*

Subtheme 4.2: Emotional support

In addition to practical assistance, social networks provided emotional reassurance during a period marked by vulnerability and uncertainty. The presence of family members was described as calming and supportive, particularly in the first days following discharge.

> *"My children all live nearby, so if anything happens, I just need to call them and they'll be here in no time. That's why I wanted to live here."* (Participant 4)
>
> > *"Mijn kinderen wonen hier allemaal dichtbij, als er iets is, moet ik maar bellen, en dan staan ze hier. 't Is daarmee dat ik hier graag wilde wonen."*

Family involvement during discharge conversations was also experienced as beneficial, as relatives could help patients understand and remember information provided by healthcare professionals.

> *"My son was always there. He was the one who arranged everything with the doctor."* (Participant 4)
>
> > *"Mijn zoon was er altijd bij. 't Is hij ook die het allemaal met de dokter had geregeld."*

In contrast, participants who were alone during discharge or who had limited social support reported increased feelings of insecurity and stress.

> *"I was alone at the dismissal meeting.*" (Participant 3)
>
> > *"Ik was alleen bij het ontslaggesprek."*

At the same time, some participants expressed ambivalence about depending on family members, balancing gratitude for the support received with concerns about burdening others or losing independence.

> *"My son works in Antwerp. He's not likely to be here anytime soon. And you don't want to rely entirely on the children either."* (Participant 2)
>
> > *"Mijn zoon werkt in Antwerpen. Die is niet snel hier. En je wilt ook niet volledig afhankelijk zijn van je kinderen."*

Theme 5: Self-reliance

Many frail older adults described taking an active role in organising their care, managing daily activities and seeking support when needed. Self-reliance was reflected in initiative-taking, a strong sense of autonomy, and contextual enablers.

Subtheme 5.1: Active coping

Several participants reported actively arranging aspects of their post-discharge care, such as contacting healthcare providers and organising follow-up appointments.

> *"I called myself to arrange that."* (Participant 9)
>
> > *"Ik heb zelf gebeld om dat te regelen."*

Participants also highlighted the importance of being assertive in expressing needs and asking questions. Some noted that patients who were less vocal or less likely to take initiative, might receive less support.

> Interviewer: *"For example, did they ask you if you could use some extra help at home?"*
>
> Participant: *"No, they didn't ask that, and it wasn't necessary. If I need to know something, I'll ask myself. But I can imagine that there are other people who might need that question to be asked."* (Participant 7)
>
> > Interviewer: *"Hebben ze u bijvoorbeeld gevraagd of u graag wat extra hulp kunt gebruiken in de thuissetting?"*
> >
> > Participant: *"Nee, dat hebben ze niet gevraagd en dat was niet nodig. Als ik iets moet* weten*, dan zal ik het wel vragen. Maar ik kan mij voorstellen dat er andere mensen zijn die dat misschien wel nodig hebben, dat die vraag wordt gesteld."*

Subtheme 5.2: Autonomy and involvement

Maintaining autonomy and independence in daily functioning was frequently emphasised. Participants expressed pride in being able to manage on their own and in limiting reliance on formal or informal care. One participant indicated a lack of involvement in her care, which she perceived negatively.

> *"And then I think, if I need help, I'll just call my neighbour. Yeah, I'm a bit of a self-reliant person."* (Participant 7)
>
> > *"En dan denk ik, als ik hulp nodig heb, dan zal ik de buurvrouw wel opbellen. Ja, ik ben een beetje een plantrekker."*
>
> *"I thought that was strange. That I was''t involved myself, actually."* (Participant 9)
>
> > *"Dat vond ik raar. Dat ik er zelf niet bij betrokken werd eigenlijk."*

Subtheme 5.3: Contextual enablers of self-reliance

Contextual factors, such as adapted housing and a supportive living environment, were described as facilitating independence after discharge.

> *"I arrived here* [in the service flat] *and I have always been able to get around here with my walker.*" (Participant 4)
>
> > *"Ik ben hier toegekomen* [in de serviceflat] *en ik heb hier altijd mijn plan kunnen trekken met de rollator."*

Theme 6: Structural and organisational barriers

Participants described structural and organisational barriers related to financial constraints and limited availability of formal care services after discharge.

Subtheme 6.1: Financial barriers

Financial considerations limited post-discharge options for some participants, particularly regarding residential care.

> *"We thought about it and talked about it together, and then our son said: 'A retirement home* [for our father] *won't work, because then our mom would have to come with us, and that is not affordable for the two people'."* (Participant 6)

> > *"Dan hebben we daarover nagedacht en daar samen over gesproken en dan zei onze zoon: 'Een rusthuis* [voor onze vader] *zal niet gaan, want dan moet ons mama mee en dat is voor twee niet te betalen'."*

Subtheme 6.2: Overburdened services

Participants reported long waiting lists for home help and residential care facilities, increasing reliance on informal networks.

> *"First of all, it's crazy to start looking for a place in a nursing home, which isn't easy."* (Participant 10)

> > *"Het is te gek om ten eerste te gaan zoeken voor een plek in een rusthuis, dat is niet gemakkelijk."*

Theme 7: Resilience

Many participants demonstrated resilience in adapting to their situation after discharge. Resilience was reflected in appreciation for the care received, understanding of healthcare system constraints, and efforts to maintain a positive and proactive attitude during recovery.

Despite experiencing challenges during and after discharge, participants often expressed gratitude for the support they received. Several also showed understanding of time pressure and workload within the healthcare system, particularly in primary care.

> *"I sometimes tell them, 'You're all so kind and wonderful, but you're really quick.' And I get it, in a way it's normal, they're so busy. I'm not alone in this. But they also want to get home quickly for their children and so on."* (Participant 5)

> > *"Ik zeg het hun soms ook, jullie zijn zo lief en goed maar jullie zijn echt vliegensvlug. En ik snap het hoor, ergens is het normaal, die hebben het zo druk. Ik ben niet de enige. Maar ze willen ook snel thuis zijn voor hun kinderen enzo."*

In addition, several respondents described maintaining optimism and taking personal responsibility as important ways of coping with illness and recovery.

> *"But I admit, it will also differ from person to person. I have been confronted with this so often that I eventually got to know the ins and outs. It will be different for someone else who is being admitted for the first time; they will probably have different questions than I did, I think.*" (Participant 7)

"Maar ik geef toe, het zal ook wel verschillen van persoon tot persoon. Ik ben daar al zo dikwijls mee geconfronteerd geweest dat ik op den duur het reilen en zeilen wel ken. Dat zal anders zijn voor iemand anders die voor de eerste keer opgenomen wordt; die zal waarschijnlijk andere vragen hebben dan ik, denk ik toch."

"You sometimes say, we can't handle this, but humans can handle a lot." (Participant 11)

"Je zegt soms, we kunnen dit niet aan, maar de mens kan veel aan."

Discussion

This qualitative study explored how frail older adults experience the transition from hospital to home and how they perceive continuity of care in primary care. Four interrelated dimensions were identified: (1) communication as the foundation of continuity; (2) coordination of care and the role of the general practitioner; (3) multidimensional vulnerability influencing patients' capacity to navigate discharge; and (4) the presence or absence of informal networks supporting resilience.

Building on earlier findings, participants noted that discharge communication often felt hurried, generic, and poorly coordinated between care providers. Comparable issues emerged in Parker et al.'s TRANSFER-I study (2025), in which older patients highlighted the need for earlier discharge planning and clearer explanations about their medications (32). Van Grootel et al. (2025) also found that disjointed communication during handovers was a major obstacle to ensuring safe care transitions (27).

Our results contribute to this research by illustrating how factors such as cognitive overload, medication side effects, and fatigue can hinder patients' ability to absorb discharge instructions. The communication problems identified therefore arise not only from a lack of information or unclear information, but also from a discrepancy between standard discharge procedures and the changing cognitive abilities of vulnerable older adults. This interpretation is consistent with research indicating that effective transitional care depends on repeated, individualized communication rather than a one-time exchange of information (33, 34). This underscores that the quality of communication is determined not only by what is said, but also by when and how it is conveyed, and by the patient's ability to process information at that moment.

Interprofessional communication also proved to be crucial to the discharge process. When discharge reports were delayed or important information was missing, participants felt less confident about the quality of their ongoing care. This is consistent with previous findings that poor information flow between hospitals and primary care disrupts continuity (27). Within this broader context, coordination after discharge was described very differently in the various reports. Some individuals experienced timely, proactive follow-up by their general practitioner, which gave them a sense of support, while others described a more passive system in which they had to make contact themselves. Expectations also varied: certain participants appreciated early outreach, while others placed greater value on being able to reach their GP when concerns arose. Despite these differences, the GP consistently stood out as someone who could interpret and clarify hospital information and offer stability during an uncertain transition. However, this coordinating role was limited when discharge reports were late or incomplete, leaving GPs without the necessary information to confidently supervise aftercare.

These results are consistent with broader transitional care research, which highlights the central role of primary care in maintaining continuity once patients leave the hospital. Evidence shows that structured GP follow-up and coordinated transition programs can support better patient outcomes, while persistent gaps in communication between hospital teams and primary care continue to be noted as key obstacles in systematic reviews (33, 34). Qualitative research also describes GPs as crucial coordinators who bridge the gap between specialists' recommendations and ongoing, long-term care in the community (35). Our study shows that the effectiveness of this coordinating role depends not only on the system but also on expectations: patients have widely varying views on what constitutes "good follow-up care," and these expectations determine how they evaluate the support they receive.

Our results contribute further nuance to existing evidence. First, they show that patients vary widely in what they expect from proactive follow-up, indicating that standardized post-discharge outreach

may not suit everyone's preferences. Secondly, our findings show that the ability of general practitioners to coordinate care is fundamentally dependent on receiving accurate and timely information from hospital services. This makes continuity of care a function of how well the system is integrated, rather than something that can be achieved solely through individual clinical efforts. Finally, interviews with participants show that patients often adjust their expectations to the perceived workload in primary care, which can conceal ongoing or unmet support needs.

Taken together, these findings indicate that reinforcing the GP's contribution to transitional care requires more than structured follow-up plans. It also depends on reliable communication between professionals and an approach that accommodates the individual expectations of each patient.

The participants' stories describe vulnerability as a multifaceted concept shaped by multiple interacting factors at both the personal and environmental levels. On a personal level, participants pointed to issues such as declining physical health, cognitive fatigue, emotional stress, and a reduced ability to perform daily activities. Contextual influences included living conditions, the availability and reliability of informal support networks, health literacy, and the way in which services were organised after discharge. This layered perspective is consistent with well-known frailty models, such as Rockwood's approach to deficit accumulation and Fried's phenotypic model, which view vulnerability as the result of the combined effects of biological, psychological, and social deficits (5, 6). It also reflects qualitative research on transitional care, which shows that frailty is dynamically shaped by both an individual's capacities and the broader social environment (27).

In line with existing evidence that frail older adults are particularly vulnerable during the discharge process, our findings show that these determinants have a significant impact on patients' autonomy and their ability to participate in decision-making during care transitions (27, 32). Current discharge procedures appear to assume a stable level of cognitive functioning, health literacy, and organisational skills. Similar assumptions have been made in assessments of transitional care, where expectations regarding self-management often exceed patients' varying capacities (33). Participants who experienced cognitive overload or limited health literacy reported difficulties in understanding discharge information. This is consistent with broader research showing that lower health literacy is associated with poorer outcomes after hospital discharge.

Self-reliance proved to be an important coping strategy. Many participants emphasized their desire to remain independent and not be a burden on others, which is consistent with previous research showing that maintaining autonomy is a core value in later life (35). For some individuals, this attitude strengthened their resilience and supported their active involvement in their care, while for others it masked underlying frailty, especially in the absence of strong social support. This duality reinforces the argument that patient reports can reveal risks that are not apparent from clinical assessments alone (26).

Informal caregivers acted as both contextual factors and moderators within the transition process. When they were available and actively involved, they helped compensate for patients' cognitive limitations, supported joint decision-making, and strengthened continuity of care. This is consistent with previous research in which caregivers are seen as important factors in guiding care transitions (27, 35) In contrast, when informal support was limited, strained, or absent, patients' vulnerability increased and their capacity for autonomous action became more restricted. Our findings also show that healthcare providers often implicitly assumed that family members would take on these tasks, even when the participants themselves expressed doubts about the availability or capacity of their informal support network. This implicit reliance on family support can lead to blind spots in discharge planning.

Overall, these results indicate that safety during the transition arises from the interplay between underlying determinants (such as health status, cognitive abilities, and social circumstances), adaptive responses (including self-reliance and other coping mechanisms), and moderating influences (particularly informal support and the organisation of care systems).

Informal caregivers proved to play a crucial role in ensuring continuity. They coordinated care, explained changes in medication prescriptions, and monitored patients' recovery, often compensating for structural shortcomings in the transition process. These observations are consistent with the findings of Kolade et al. (2025), who identified informal caregivers as key figures in facilitating the transition from hospital to home (34). Similarly, van Grootel et al. (2025) emphasize that individual support for both patients and family members is essential for optimal recovery (27). Our study adds that the degree of caregiver involvement was highly variable and often depended on informal negotiations within families.

However, in our study, the involvement of healthcare providers was largely informal and was not routinely evaluated or included in discharge planning. Participants with limited or stressful social networks reported feeling particularly uncertain, which is consistent with broader findings that social isolation is a significant risk factor for negative outcomes after discharge. These findings underscore the importance of integrating structured assessments of patients' social networks and the capacity of healthcare providers into transition care pathways, particularly for vulnerable older adults.

Future research should aim to refine transitional care models to ensure they are better aligned with the complex and heterogeneous needs of frail older adults. Co-designed interventions, actively involving patients, informal caregivers, and primary care professionals, hold particular promise for developing transitional pathways that more accurately reflect individuals' capacities, preferences, and social contexts. The variability in expectations regarding post-discharge contact observed in this study further highlights the importance of systematically comparing proactive follow-up strategies with preference-sensitive models. Such comparative evaluations may help determine which approaches most effectively promote continuity of care. Moreover, additional research is warranted to explore how structured frailty screening can be integrated into discharge planning to identify patients who may require enhanced communication, coordination, or social support during the transition from hospital to home.

Strengths and Limitations

This qualitative study offers important insights on the transition from hospital to home by gathering detailed, experience-based interviews from patients shortly after their discharge. The use of semi-structured interviews made it possible to explore subtle, emotionally layered aspects of their experiences. Holding the interviews within six months of the hospital stay helped balance the need to reduce recall deterioration with the opportunity for participants to reflect meaningfully on their recovery. The fact that all the interviews took place in an environment chosen by the participants (in this case, their own homes) probably contributed to a sense of ease and honesty which is more difficult to achieve in a clinical setting.

Having physicians conduct the interviews added clinical depth, as they were able to pursue medically relevant topics with appropriate sensitivity. Importantly, these interviewers were not the patients' own GPs, which reduced the likelihood that participants would tailor their responses to protect an ongoing care relationship. Recruitment from two primary care practices, ongoing evaluation of data saturation, and adherence to established qualitative reporting frameworks (COREQ and SRQR)

strengthened the study's methodological foundation. (30) The use of only two interviewers ensured a stable interviewing style and contributed to consistency across the dataset.

Nonetheless, several limitations need to be considered. Frailty was identified through clinical judgement rather than by means of a standardised assessment instrument, which may have introduced heterogeneity in participant selection. Recruitment was further restricted to two Dutch-speaking general practices, limiting the transferability of the findings and creating potential contextual bias related to differences in practice organisation and patient populations. Selection bias cannot be excluded, as individuals who attend less frequently, engage less readily, or hold more neutral views may have been underrepresented. Interviewer and social desirability biases also remain plausible, given the professional background of the interviewers. Although the timing of the interviews may have mitigated recall bias to some extent, retrospective accounts may still have been influenced by memory-related distortions. Additional risks include reporting and confirmation bias during transcription, coding, and interpretation, despite the use of structured thematic analysis and AI-assisted verification to minimise such effects. Finally, the absence of data triangulation with caregivers or healthcare professionals constrains the depth and broader applicability of the findings, as complementary perspectives that could have enriched or challenged patient narratives were not incorporated.

Overall, the study delivers clinically useful and implementation-ready insights into a critical phase of healthcare transitions, while acknowledging the methodological constraints that shape interpretation.

Implications for Practice and Organisation

The findings of this study point to a number of practical and organisational implications that may be helpful in improving transitional care for vulnerable older adults. First and foremost, the results underscore the potential need for risk-based post-discharge care. Patients with higher vulnerability might profit from more intensive follow-up after hospital discharge. Healthcare providers must also actively verify whether patients understand the discharge information: by using clear language, checking to see if they understand, etc., to prevent confusion and adverse events. Furthermore, the study indicates that explicitly involving family members or other informal caregivers in discharge communication could support patients, particularly those experiencing cognitive overload or emotional stress. A more systematic assessment of the patient's social network may therefore be worth considering, as informal support appeared to play an important role in continuity of care, though it varied considerably among participants. At the organisational level, the findings point to the potential value of stronger integration of care across healthcare settings, including more consistent information exchange between hospitals and primary care providers. Improved collaboration between sectors may help general practitioners coordinate post-discharge care more effectively, for instance through the timely delivery of discharge summaries. This includes, among other things, the timely delivery of discharge summaries. Finally, incorporating standardized risk-stratification tools into discharge procedures could be explored as a way to tailor the intensity of transitional care to the individual needs of patients.

Conclusion

This study demonstrates that the transition from hospital to home remains a clinically vulnerable period for frail older adults, determined by the quality of communication, physical frailty, and the availability of both formal and informal support. Communication that is rushed, poorly timed, or fragmented across different care settings limits patients' ability to understand medical

recommendations, participate in decisions/treatments, and regain a sense of control and autonomy. When discharge information is personalised, repeated, and presented in a manner tailored to patients' knowledge of health and cognitive status, older adults report greater confidence and security. This underscores once again that communication is a crucial clinical determinant of continuity of care.

The role of the primary care physician emerges as central, although it is interpreted in various ways. Participants consistently describe the GP as the healthcare provider who translates complex hospital information into "plain language," explains changes in medication, and stabilizes the care process after discharge. However, expectations regarding the timing and nature of follow-up care varies widely: some prefer early and/or proactive contact, while others prefer an accessible, on-demand model that respects their autonomy. These findings underscore the need for aftercare strategies that are not uniformly prescribed but are tailored to the patient's preferences, vulnerabilities, and the severity of their health condition. The general practitioner's ability to provide coordinated follow-up care is often limited by delayed or incomplete discharge reports, illustrating that effective follow-up care after hospitalisation depends on timely and accurate information transfer, as individual clinical responsiveness cannot compensate for structural communication gaps.

Physical, cognitive, and contextual vulnerabilities shape how patients cope with returning home. Functional limitations, confusion, and an unsuitable living environment increase dependence, while coping strategies such as self-reliance sometimes mask unexpressed needs. Family members often play a central role in organising care and providing emotional support, although this support is often taken for granted rather than being systematically evaluated.

In summary, safe transitional care requires clear and timely communication, follow-up care that aligns with the patient's preferences and needs, early identification of vulnerability, and explicit attention to the patient's social network. By integrating these elements into daily practice, the continuity of care can be strengthened and recovery can be supported during this crucial phase.

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Supplementary Material

Supplementary File 1. The filled in checklist of the 'Consolidated Criteria for Reporting Qualitative Research'

Consolidated criteria for reporting qualitative studies (COREQ): 32-item checklist

Developed from:
Tong A, Sainsbury P, Craig J. Consolidated criteria for reporting qualitative research (COREQ): a 32-item checklist for interviews and focus groups. *International Journal for Quality in Health Care*. 2007. Volume 19, Number 6: pp. 349 – 357

YOU MUST PROVIDE A RESPONSE FOR ALL ITEMS. ENTER N/A IF NOT APPLICABLE

No. Item	Guide questions/description	Reported on Page #
Domain 1: Research team and reflexivity		
Personal Characteristics		
1. Inter viewer/facilitator	Which author/s conducted the interview or focus group?	8
2. Credentials	What were the researcher's credentials? E.g. PhD, MD	8
3. Occupation	What was their occupation at the time of the study?	8
4. Gender	Was the researcher male or female?	8
5. Experience and training	What experience or training did the researcher have?	N/A
Relationship with participants		
6. Relationship established	Was a relationship established prior to study commencement?	8
7. Participant knowledge of the interviewer	What did the participants know about the researcher? e.g. personal goals, reasons for doing the research	8
8. Interviewer characteristics	What characteristics were reported about the inter viewer/facilitator? e.g. Bias, assumptions, reasons and interests in the research topic	8, 9, 32
Domain 2: study design		
Theoretical framework		
9. Methodological orientation and Theory	What methodological orientation was stated to underpin the study? e.g. grounded theory, discourse analysis, ethnography, phenomenology, content analysis	6,7,8
Participant selection		

10. Sampling	How were participants selected? e.g. purposive, convenience, consecutive, snowball	8,9
11. Method of approach	How were participants approached? e.g. face-to-face, telephone, mail, email	8,9
12. Sample size	How many participants were in the study?	8,9,14
13. Non-participation	How many people refused to participate or dropped out? Reasons?	9
Setting		
14. Setting of data collection	Where was the data collected? e.g. home, clinic, workplace	9
15. Presence of non-participants	Was anyone else present besides the participants and researchers?	10
16. Description of sample	What are the important characteristics of the sample? e.g. demographic data, date	8,9
Data collection		
17. Interview guide	Were questions, prompts, guides provided by the authors? Was it pilot tested?	10
18. Repeat interviews	Were repeat interviews carried out? If yes, how many?	N/A
19. Audio/visual recording	Did the research use audio or visual recording to collect the data?	10
20. Field notes	Were field notes made during and/or after the interview or focus group?	10
21. Duration	What was the duration of the interviews or focus group?	10,14
22. Data saturation	Was data saturation discussed?	10,11
23. Transcripts returned	Were transcripts returned to participants for comment and/or correction?	N/A
Domain 3: analysis and findings		
Data analysis		
24. Number of data coders	How many data coders coded the data?	8
25. Description of the coding tree	Did authors provide a description of the coding tree?	14
26. Derivation of themes	Were themes identified in advance or derived from the data?	11
27. Software	What software, if applicable, was used to manage the data?	11
28. Participant checking	Did participants provide feedback on the findings?	N/A

Reporting		
29. Quotations presented	Were participant quotations presented to illustrate the themes/findings? Was each quotation identified? e.g. participant number	14-28
30. Data and findings consistent	Was there consistency between the data presented and the findings?	14-28
31. Clarity of major themes	Were major themes clearly presented in the findings?	14-28
32. Clarity of minor themes	Is there a description of diverse cases or discussion of minor themes?	14-28

Supplementary File 2. Research team and reflexivity

Individual Characteristics		
	Sophie Jansen (SJ)	Elisabeth Lemmens (EL)
Interviewer	Conducted 6 interviews Coded 7 interviews	Conducted 7 interviews Coded 6 interviews
Credentials	MD	
Occupation	General Practitioner in Training	General Practitioner in Training
Sex	Female	
The relationship to participants		
Relationship	General practitioner in training at the practice where the interviews were conducted, but no direct therapeutic relationship with the patients (patients of colleagues)	
Participant's knowledge about the interviewer	Their occupation and masters degree	

Supplementary File 3. Interview guide

Interview guide voor semi-gestructureerde interviews:
Ervaring van zorg van kwetsbare ouderen met
betrekking tot de overgang van het ziekenhuis naar huis

Naam interviewer:

Naam participant:

Leeftijd participant:

Datum interview:

Introductie van het onderzoek

Samen overlopen van de informatiebrief/ informed consent.

Hartelijk dank om tijd vrij te maken voor dit interview. Wij zijn Elisabeth Lemmens en Sophie Jansen, twee huisartsen-in-opleiding aan respectievelijk de KU Leuven en VUB. Wij voeren dit onderzoek uit in het kader van onze masterproef binnen onze vervolgopleiding: Master in de Huisartsgeneeskunde. Met dit onderzoek willen wij nagaan hoe u het ontslag uit het ziekenhuis heeft ervaren. Daarnaast willen we graag weten hoe u de voortzetting van de nodige zorg in de thuisomgeving heeft ervaren. De vragen zullen gaan over uw persoonlijke ervaringen, wat u ervan vindt, wat u er goed of niet goed aan vindt en wat u zou willen verbeteren.

Het interview zal ongeveer 45 minuten in beslag nemen. We zouden dit graag opnemen via ‘voicerecorder’ zodat we het interview achteraf volledig kunnen uitschrijven en verwerken zonder informatie te missen. Dit gebeurt uiteraard zonder uw naam te vermelden. Daarnaast zullen al uw gegevens verwerkt en bewaard worden volgens de GDPR wetgeving waarbij anonimiteit wordt gegarandeerd. Tussendoor zullen we ook notities nemen. We starten het interview met het tekenen van een document waarmee u verklaard akkoord te zijn om deel te nemen aan onze interviewstudie. Als u nog verdere vragen hebt, mag u deze steeds stellen.

Inleidende vragen

- Hoe gaat het nu met u?
- Waarom werd u opgenomen?
    - Was het voor u voldoende duidelijk waarom u werd opgenomen?
- Hoelang werd u opgenomen?
- Via welke weg bent u binnengekomen in het ziekenhuis?
    - Bijvoorbeeld: via verwijzing (huisarts, specialist…), via spoed

Notities:

(Voorbereidend) ontslag in het ziekenhuis

- Hoe heeft men u voorbereid op uw ontslag?
    - Herinnert u zich nog hoeveel dagen dit was voor uw ontslag?
    - Wat werd er voor u geregeld?
        - Hoe hebben ze u hierover geïnformeerd?
        - Was u hier tevreden over?
            - Zo nee, hoe had u het graag anders gezien?
- Hoe verliep (de communicatie van) uw ontslaggesprek?
    - Was er toen iemand, zoals een familielid, die met u mee luisterde?
    - Welke informatie kreeg u bij dit gesprek?
        - Bijvoorbeeld: informatie over uw opname zelf, over uw medicatielijst, over thuiszorg, over uw vervolgafspraken…
    - Hoe werd u en/of uw familielid betrokken bij dit gesprek?
    - Had u nog vragen bij dit ontslaggesprek?
        - Zo ja, zijn die beantwoord?
- Hoe tevreden bent u over uw ontslag, met andere woorden: wat liep er goed en wat liep er minder goed?
- Welke zaken zou u veranderen om (de voorbereiding op) het ontslag aangenamer te maken?

Notities:

Verloop ontslag uit ziekenhuis en aankomst thuis

- Hoe verliep de dag van uw ontslag?
- Hoe bent u thuis geraakt?
    - bv. met welk vervoermiddel?
    - bv. was er iemand bij u?
    - bv. wie had er de huissleutels bij?
    - Was er eten voorzien? Stond de verwarming aan?
- Wie heeft u opgevangen bij thuiskomst?
    - Was er direct hulp of heeft u even moeten wachten?
    - Zo onmiddellijk, welke hulp was er?
        - Werd dit op voorhand al meegedeeld?
    - Zo nee, had u het graag anders gezien? (En hoe?)
- Hoe tevreden bent u over de dag van uw ontslag, met andere woorden: wat liep er goed en wat liep er minder goed tijdens die dag?
- Welke zaken zou u veranderen om de overgang aangenamer te maken?

Notities:

Thuiszorg

Praktisch

- Hoe werd de zorg georganiseerd na uw opname?
    - Welke bijkomende hulp werd er voorzien? (Bijvoorbeeld: thuisverpleging, poetshulp, familiehulp, kinesiste …)
    - Wie regelde de hulp voor u of van wie kreeg u hulp om de zorgverleners te contacteren?
- Welke thuishulp kreeg u reeds voor uw opname?
    - Waren de zorgverleners op de hoogte van uw thuiskomst?
        - Had u instructies/papieren van het ziekenhuis voor hen meegekregen?
    - Hoe veranderde de thuishulp na uw opname?
        - Bijvoorbeeld: verandering in de dagelijkse/wekelijkse routine?
- Hoe tevreden bent u van de thuiszorg na uw opname, met andere woorden: wat liep er goed en wat liep er minder goed bij de organisatie van de thuiszorg?
- Welke zaken zou u veranderen om de thuiszorg aangenamer te maken?

Verpleging

- Had u voor uw opname reeds verpleging?
    - Zo ja: was dit na uw opname dezelfde persoon?
    - Zo neen: wie regelde dat er verpleging aan huis kwam of van wie kreeg u hulp?
- Wanneer zag u voor het eerst de verpleging?
- Waar helpt de verpleging u vooral bij?
        - Is dit voor u voldoende of zijn er zaken die u nog extra zou willen?
- Hoe tevreden bent u van de verpleging in de thuissetting, met andere woorden: wat liep er goed en wat liep er minder goed bij de organisatie?

Huisarts

- Wanneer zag u voor het eerst uw huisarts?
- Hoe werd dit eerste contact georganiseerd?
    - Nam de huisarts zelf contact met u op?
        - Zo nee: wie nam contact op met de huisarts?
- Wat werd er met u besproken tijdens deze eerste afspraak?
    - Heeft dit geholpen om uw weg te vinden? Zo ja: hoe? Zo nee: wat had u dan verwacht?
- Was het voor u duidelijk wanneer uw volgende afspraak met hem/haar zou zijn?
- Hoe tevreden bent u over de opvolging van uw huisarts na uw ontslag uit het ziekenhuis, met andere woorden: wat liep er goed en wat liep er minder goed?

Notities:

Afronding

- Vragen of de patiënt nog vragen heeft of nog iets wil toevoegen aan het interview.
- Vragen aan patiënt of we hem/ haar in een later stadium opnieuw mogen contacteren om bijkomende input te geven voor het project, eventueel via een andere manier van werken.
- Afspraken rond de terugkoppeling van de resultaten.
- Dankwoord ter afsluiting van het gesprek

Supplementary file 4. Overview table of semi-structured interviews

Theme	Subtheme	Code	Quotes[1]
1. **Communication as a key element in the transition from hospital to home**	**Communication surrounding hospital discharge**	• Late or last-minute discharge • Insufficient time to prepare • Unclear discharge timing • Information overload / rushed communication • Use of medical jargon (lack of comprehensibility) • Lack of explanation of discharge documents • Absence of discharge documents for patients • Insufficient medication counselling • Lack of explanation about side effects or changes • Limited patient involvement in discharge decision-making • Communication by nurses instead of physicians • Variation in patients' information needs	• *"In the evening, I was told that I could go home the next day. I would have liked to have known this two to three days in advance."* (Participant 9) • *"And then I asked, I called, I said: 'What about the paperwork?'* [nurse:] *'Oh, it's all sent online to the doctor, you won't get anything.' I thought that was strange. That I wasn't involved myself, actually."* (Participant 9) • *"It all happened so fast, there was no time to ask questions."* (Participant 7)
	Interprofessional communication	• Poor information transfer between hospital and general practitioner (GP) • GP not informed about admission/discharge • Delayed or missing discharge documents • Lack of instructions for home care services • Patient as intermediary of information transfer	• *"Then we called the doctor, and she didn't know anything either. Nothing had been forwarded to her. I think it's really scandalous. That you're not informed, that the GP doesn't know anything either, and neither do we. That wasn't okay."* (Participant 6) • *"Then the GP also had to request the paperwork, so there were no written instructions for home nursing or similar provisions from the hospital."* (Participant 9)
2. **Professional care coordination**	**Social workers**	• Early involvement of social worker • Proactive organisation of home care • Reduced burden for patients/families • Improved sense of preparedness • Time pressure in arranging care	• *"The social worker first discussed everything with me and then arranged everything with my son. I didn't have to worry about anything."* (Participant 2) • *"At the rehabilitation center, the social worker arranged for them* [home nurses] *to come by."* (Participant 13)
	General practitioners	• GP as a clarifier of explanations • Translation of medical information into understandable language • Clarification of medication changes and medication management support • Trust in the GP	

[1]Subsequent list provides an illustrative overview of quotes made by the participants. A comprehensive overview can be found in the main text.

Theme	Subtheme	Code	Quotes[1]
	(Pro)active and routine follow-up	• GP-initiated contact (phone/home visit) • Routine follow-up perceived as sufficient	• *"My family doctor called me himself to ask how I was doing, and since then he has been visiting me regularly."* (Participant 13)
	Limited follow-up and unmet expectations	• Perceived lack of follow-up as inadequate or disappointing • Expectation of proactive contact	• *"I still think they should have called; just to ask if everything was okay."* (Participant 3)
	Acceptance of limited follow-up and emphasis on accessibility	• Patient-initiated follow-up • Understanding of GP workload • Preference for timely access to care rather than proactive follow-up	• Interviewer*: "So, in summary, it is not systematically necessary for you that, for example, when you are discharged from the hospital, the doctor visits you within the same week? For you, it is sufficient that they visit routinely or come when you call?"* Participant: *"Yes, that's right. I call myself. I don't have a problem with that."* (Participant 1)
	Home nursing	• Organisation by family or social worker • Focus on basic tasks (hygiene, medication, stockings) • Task-oriented and time-pressured care • Limited personal interaction • Need for patient assertiveness • Positive collaboration with GP • Nursing as intermediary between patient and GP	• *"I'll be honest, the nurses are very sweet, but they never have any time. We know them quite well because they've been coming here for years. Sometimes they haven't even finished coming in yet, they want my ID card right away, but they don't make time to wash me. You have to explicitly ask for what you want. I sometimes tell them too: 'You're so kind and lovely, but you're always in such a rush'."* (Participant 5) • *"And I can also tell her about my medical complaints. In that case she will call the doctor to see if it is necessary for the doctor to come by. I really appreciate that."* (Participant 9)
	Other (healthcare) services		
	Physiotherapy	• Mostly self- or family-organised • Rarely arranged by hospital	• *"The physical therapist, who comes twice a week, was arranged through my daughter-in-law."* (Participant 4)
	Family assistance	• Limited awareness of available services • Lack of information about possibilities • Need for patient/family initiative	• Interviewer: "*And will there be family support?"* Participant*: "No, I don't have that at the moment, but they say I could use it. What can I actually ask for?"* (Participant 2)

Theme	Subtheme	Code	Quotes[1]
3. **Vulnerability**	**Personal vulnerability**	• Reduced mobility • Pain and fatigue • Functional limitations • Early discharge despite limitations • Need for assistance in daily activities • Dependence on others for basic tasks • Confusion and disorientation • Memory problems • Medication-related cognitive effects • Reduced ability to process information • Difficulty participating in decision-making • Reliance on family or caregivers	• *"I had just gotten out of bed once to go to the bathroom, so I actually thought it was much too short, much too fast. Especially since I'm single."* (Participant 9) • *"The night before, I had hallucinations and crawled across the floor. I was uneasy."* (Participant 9)
	External (and contextual) vulnerability factors	• Living alone • Limited support network • Increased dependency after discharge • Need for external support systems	• *"And yes, I'll be honest, my husband was at home, lost and alone, because he had suffered a stroke in the past. So, I felt so sorry for him, thinking he would be so lost without me, that I just left. In a different situation, I might have stayed."* (Participant 5)
4. **Social networks and the role of family members**	**Logistical support**	• Family arranging transport from hospital to home • Practical arrangements at home (food, heating, keys) • Organisation of home care services by family • Family contacting healthcare providers • Assistance with medication management • Help with activities of daily living (washing, dressing, mobility) • Support in coordinating follow-up care	• *"My wife was at home and could therefore prepare dinner."* (Participant 8) • *"My children had arranged everything: nursing care, new family doctor, service apartment, etc."* (Participant 4)
	Emotional support	• Feeling reassured by presence of family • Relatives helping understand discharge information • Limited social support increases stress • Ambivalence about dependence on family	• *"My children all live nearby, so if anything happens, I just need to call them and they'll be here in no time. That's why I wanted to live here."* (Participant 4)
5. **Self-reliance**	**Active coping**	• Contacting healthcare providers and organising follow-up appointments	• *"I called myself to arrange that."* (Participant 9)
	Autonomy and involvement	• Desire to remain independent • Active participation in care and recovery • Involvement in discharge decisions • Individual preferences regarding level of involvement	• *"And then I think, if I need help, I'll just call my neighbour. Yeah, I'm a bit of a self-reliant person."* (Participant 7)

Theme	Subtheme	Code	Quotes[1]
	Contextual enablers of self-reliance	• Environmental factors enabling independence (home setting, resources)	• *"I arrived here* [in the service flat] *and I have always been able to get around here with my walker."* (Participant 4)
6. **Structural and organisational barriers**	**Financial barriers**	• Cost of residential care	• *"We thought about it and talked about it together, and then our son said: 'A retirement home won't work because then our mom would have to come with us, and that is not affordable for the two of them."* (Participant 6)
	Overburdened services	• Waiting lists for residential care	• *"First of all, it's crazy to start looking for a place in a nursing home, which isn't easy."* (Participant 10)
7. **Resilience**		• Gratitude towards healthcare professionals • Acceptance of healthcare system constraints • Positive attitude	• *"I sometimes tell them, 'You're all so kind and wonderful, but you're really quick.' And I get it, in a way it's normal, they're so busy. I'm not alone in this. But they also want to get home quickly to their children and so on."* (Participant 5)

Supplementary file 5. Ethics Committee Approval

KU LEUVEN

UZ LEUVEN

GROEP BIOMEDISCHE WETENSCHAPPEN
HERESTRAAT 49, O&N II – BUS 700
BE-3000 LEUVEN

English version below.

Ons kenmerk: MP035368
Uw kenmerk: Masterproef studie: Ideeën, bezorgdheden en verwachtingen van ouderen met betrekking tot de overgang van ziekenhuis naar thuissituatie.
Leuven, 27-03-2025

GEEN BEZWAAR BRIEF

Geachte Professor Professor Geert Goderis
Geachte Sophie Jansen, Elisabeth Lemmens

De Ethische Commissie Onderzoek UZ/KU Leuven bevestigt hierbij dat er geen bezwaren zijn tegen het uitvoeren van de voorgestelde studie, zoals ze werd beschreven in het protocol. De Commissie is van oordeel dat er vanuit ethisch standpunt geen bezwaren zijn bij de voorgestelde studie. De studie werd goedgekeurd op 27-03-2025

De Onderwijs-Begeleidings-Commissie voor Medische Ethiek (OBC) heeft in delegatie van het EC Onderzoek UZ/KU Leuven het vermeld protocol onderzocht en besproken op haar vergadering.

Het doel van deze studie is om ideeën, bezorgdheden en verwachtingen van ouderen met betrekking tot de overgang van ziekenhuis naar thuissituatie te analyseren. Semigestructureerde interviews (COREQ-methode) zullen worden afgenomen, rekrutering vindt plaats in twee praktijken (n = 10-15). Interviews vinden thuis bij de patiënten of in de praktijk plaats. Interviews van 30-45 minuten, audio-opnames en NVivo voor transcriptie. Het protocol is goed uitgewerkt, ICF is in orde. Het ICF wordt op voorhand met de patiënt gedeeld zodat deze de tijd heeft om het ICF te bespreken met een familielid of partner. Er zijn geen bezwaren.

EC Onderzoek heeft geen bezwaar tegen het project mits vertrouwelijke behandeling van de gegevens en naleving van de Belgische wetgeving omtrent privacy. EC wenst de hoofdonderzoeker/promotor van de studie te wijzen op zijn/haar verantwoordelijkheid betreft de privacy van de persoons-/patiëntgegevens bij contact met levende personen, patiënten en/of inzage in het elektronisch medisch dossier, inclusief de correcte implementatie hiervan door medewerkers en studenten.

Deze geen bezwaar brief betreft de indiening van 26-03-2025 en wordt gegeven voor de duur van de Masterproef van de betrokken student(en). Elke wijziging aan het protocol doet dit advies vervallen. U dient in dat geval tijdig een amendement voor advies voor te leggen aan de Onderwijs-Begeleidings-Commissie (OBC) die de initiële studie heeft geëvalueerd.

EC bevestigt dat ze werkt in overeenstemming met de ICH-GCP principes (International Conference on Harmonization Guidelines on Good Clinical Practice), met de meest recente versie van de Verklaring van Helsinki en met de van toepassing zijnde wetten en regelgeving.

EC bevestigt dat in geval van belangenconflict, de betrokken leden niet deelnemen aan de besluitvorming omtrent de studie.

Met vriendelijke groet,

Prof. dr. Minne Casteels
Voorzitter
Ethische Commissie Onderzoek UZ/KU Leuven

Prof. dr. Pascal Borry
Voorzitter
Onderwijs-BegeleidingsCommissie voor Medische Ethiek KU Leuvenv

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Aandachtspunten (indien van toepassing)

EC benadrukt dat een GCP-opleiding van elke hoofdonderzoeker verwacht wordt. EC benadrukt tevens dat de hoofdonderzoeker/promotor verantwoordelijk is voor de uitvoering van het projectvoorstel in overeenstemming met de van toepassing zijnde wetten en voorschriften, waaronder, maar niet beperkt tot, de EU-verordening 2016/679 (Algemene Verordening Gegevensbescherming), de Belgische wet betreffende de rechten van patiënten van 22/8/2002, en het beleid van de instelling waar het onderzoek zal worden uitgevoerd.

Bij gebruik van elektronisch medische gegevens is een formeel akkoord van de dienstraad vereist. De opdrachtgever is verantwoordelijk voor de conformiteit van de anderstalige documenten met de Nederlandstalige documenten.

Dit advies van EC houdt niet in dat zij de verantwoordelijkheid voor de geplande studie op zich neemt. U blijft hiervoor zelf verantwoordelijk.

Bovendien dient u als hoofdonderzoeker erover te waken dat de resultaten van dit onderzoek, correct worden weergegeven in publicaties, rapporten voor de overheid enz.

U wordt eraan herinnerd dat bij klinische studies iedere door u waargenomen ernstige verwikkeling onmiddellijk zaan EC moet worden gemeld, ook al is het oorzakelijke verband met de studie onduidelijk.

Our reference: MP035368
Your reference: Master's thesis study: Ideeën, bezorgdheden en verwachtingen van ouderen met betrekking tot de overgang van ziekenhuis naar thuissituatie.
Leuven, 27-03-2025

DEFINITIVE FAVOURABLE ADVICE

Dear Professor Professor Geert Goderis
Dear Sophie Jansen, Elisabeth Lemmens

The Research Ethics Committee UZ/KU Leuven hereby confirms that there are no objections to conducting the proposed study, as it was described in the protocol. After a thorough ethical review, the Commission found no concerns regarding the study. The study was approved on 27-03-2025

De Onderwijs-Begeleidings-Commissie voor Medische Ethiek (OBC) heeft in delegatie van het EC

Onderzoek UZ/KU Leuven het vermeld protocol onderzocht en besproken op haar vergadering.

Het doel van deze studie is om ideeën, bezorgdheden en verwachtingen van ouderen met betrekking tot de overgang van ziekenhuis naar thuissituatie te analyseren. Semigestructureerde interviews (COREQ-methode) zullen worden afgenomen, rekrutering vindt plaats in twee praktijken (n = 10-15). Interviews vinden thuis bij de patiënten of in de praktijk plaats. Interviews van 30-45 minuten, audio-opnames en NVivo voor transcriptie. Het protocol is goed uitgewerkt, ICF is in orde. Het ICF wordt op voorhand met de patiënt gedeeld zodat deze de tijd heeft om het ICF te bespreken met een familielid of partner. Er zijn geen bezwaren.

The Committee has no objection to the project provided that the data are handled confidentially and there is compliance with the Belgian legislation concerning privacy. The Research Ethics Committee UZ/KU Leuven reminds the principal investigator/promotor of the study of their responsibilities with regard to the privacy of personal / patient details, when in contact with living persons, patients, and / or contained within electronic medical records, including the correct implementation by employees and students.

This letter of no objection concerns the submission of 26-03-2025v and is given for the duration of the Master's thesis of the student(s) concerned. Any amendment to the protocol will invalidate this advice. In that case, you must submit an amendment for advice to the committee that previously approved your file must be submitted.

The Committee confirms that they work in accordance with the ICH-GCP principles (International Conference on Harmonisation Guidelines on Good Clinical Practice), with the most recent version of the Helsinki Declaration, and with applicable laws and regulations.

The Committee confirms that in case of a conflict of interest, the members concerned have not participated in decision regarding the study.

Yours sincerely,

Prof. dr. Minne Casteels
President / Chairperson
Research Ethics Committee UZ/KU Leuven

Prof. dr. Pascal Borry
President / Chairperson
Education-Support Committee for Medical Ethics KU Leuven

Points of Interests (if applicable)

EC Research emphasizes that GCP-training is expected from every principal investigator. EC Research refers also to the Belgian legislation (Law from 8/12/1992 for the protection of personal privacy and Law from 22/8/2002 regarding the rights of the patient), and the General Data Protection Regulation (which comes into effect on May 25th 2018).

For use of electronic medical data, a formal agreement from the clinical departmental board is required. The study promotor is responsible for the conformity of foreign language documents with the Dutch language version.

This opinion from EC Research does not imply that it takes responsibility for the planned study. You

remain responsible for this yourself. In addition, as the principal investigator, you must ensure that the results of this research are correctly displayed in publications, reports for the government, etc.

You are reminded that any serious complication you observe must be reported immediately to the Ethics Committee, even if the causal link with the study is unclear.

Supplementary file 6. Protocol

MASTERPAPER PROTOCOL: PROSPECTIVE STUDY USING A SEMI-STRUCTURED INTERVIEW

Belangrijke informatie met betrekking tot het invullen van deze template

Hoewel het formulier in het Engels is, kan de aanvraag zowel in het **Nederlands** als in het **Engels** worden voorbereid. De blauwe tekstvakken die uitleg bieden bij elk onderdeel mogen verwijderd worden bij het indienen van de aanvraag.

Hou het toelichtingendocument bij de hand terwijl je deze template invult. Alle nodige **informatie, voorbeelden en tekstsuggesties** bij de verschillende onderdelen staan in dat document (https://gbiomed.kuleuven.be/nl/obc/documenten).
Bij het indienen van dit protocol bij de OBC worden de **vereisten** met betrekking tot dataverwerking van de **AVG** (Algemene Verordening Gegevensbescherming) **getoetst**. Wanneer goedkeuring verleend wordt door de OBC is er **geen** aparte **privacy evaluatie** nodig. Indien deze template wordt gebruikt om het protocol in te dienen bij **EC Onderzoek** (en niet OBC) is het echter nodig om ook de **privacy toets** te doen op www.kuleuven.be/pret.

Elke **herindiening of amendement** moet in '**track changes'** of in **highlight** worden gemaakt zodat aanpassingen duidelijk zijn. Verder dient ook de bestandsnaam aangepast te worden naar 'herindiening_MP###_versie#' of 'amendement_MP###_versie#'. Het MP-nummer kan je terugvinden via SCONE (overzicht masterproef), het versienummer bepaal je zelf: te beginnen bij 1 en telkens met 1 te verhogen wanneer gevraagd wordt om nieuwe aanpassingen te doen.

Important information regarding this template and how to fill it in correctly

This application can be prepared in **Dutch** or in **English**. The blue text boxes with explanation can be deleted when submitting the application.
Read the explanatory document carefully when filling out this template. You can find all **information, examples and text suggestion** belonging to the various sections in this document.(https://gbiomed.kuleuven.be/english/obc/documents-templates)
When submitting this protocol to the OBC, the data processing **requirements** of the **GDPR** (General Data Protection Regulation) **are checked**. When approval is granted by the OBC, **no** separate **privacy evaluation** is **required**. However, if this template is used to submit the protocol to **EC Research** (and not OBC), it is also **necessary** to do the **privacy screening** at www.kuleuven.be/pret.

Every resubmission or amendment should be done in '**track changes' or in 'highlight'** in order to identify the changes. The file name must also be changed to 'resubmission_MP###_version#' or 'amendment_MP##_version#'. The MP-number can be found via SCONE (overview master thesis), the version number is up to you: starting at 1 and increasing by 1 each time you are asked to make new changes.

1. APPLICANTS

Protocol - full title	Ideeën, bezorgdheden en verwachtingen van ouderen met betrekking tot de overgang van ziekenhuis naar thuissituatie.
Version 1: Date submission	Date: 03/03/2025
Version 2: Date resubmission	(to add in case of resubmission) Date: 24/03/2025
Version 3: Date third submission	(to add in case of third submission) Date: 26/03/2025
	Name: Prof. Dr. Geert Goderis

Principal Investigator – Promotor	Telephone: +32 15 37 72 80
	E-mail: geert.goderis@kuleuven.be
Following both questions should be answered:	
The principal investigator is a health professional according to the Law of 10 May 2015. **YES** ☐ NO ☐	
The supervisor has read and approved the submission for ethics approval. **YES** ☐	
Co-Investigator – Co-Promoter	**Name: Dr. Thomas Struyf**
	Telephone: +32 16 32 65 79
	E-mail: thomas.struyf@kuleuven.be
The co- investigator is a health professional according to the Law of 10 May 2015. **YES** ☐ NO ☐	
Sub-investigator – Student(s)	**Name: Sophie Jansen**
	Student number: r0675646
	Telephone: +32472588482
	E-mail: sophie.jansen@vub.be
	Name: Elisabeth Lemmens
	Student number: r0673911
	Telephone: +32473518886
	E-mail: elisabeth.lemmens@student.kuleuven.be

2. BACKGROUND AND RATIONALE

Explain the background and scientific relevance of the planned research. This should be done in a sufficiently elaborated way so that readers can get a sufficient understanding of the performed research in the area and the research questions of this project. References should be added at the end of this template.

Older adults over the age of 65 are among the most vulnerable populations in healthcare, often have complex medical conditions and shown higher rates of hospital (re)admissions. (1). Primary care, including the general practitioner (GP) plays a pivotal role in the post-hospitalization phase, serving as the cornerstone of continuity and patient-centered care. (2)(3) Studies indicate that effective communication and personalized follow-up plans can enhance patient satisfaction and improve health outcomes, which may decrease hospital (re)admissions. (4)

Despite this knowledge, limited research has focused on how older adults perceive their care needs, ideas, concerns and expectations regarding transition from hospital to home. Most existing studies emphasize clinical outcomes or hospital-related care, often overlooking the perspectives of the patients themselves. (5) Especially topics, such as perceived quality of follow-up care, the sense of feeling heard, trust in healthcare providers, and integration of personal preferences into care plans are still misunderstood. (6)(7)(8) This lack of focus on patient-reported outcomes and experiences can impact decision-making in primary care, particularly regarding recovery and rehabilitation. Older patients present unique challenges in care continuity due to multimorbidity, cognitive changes, and differing priorities compared to younger populations. (1) This complexity underscores the importance of exploring their expectations of primary care follow-up.

By exploring these topics, we set up this study with the aim to address a less-studied yet vital aspect of geriatric care by exploring the ideas, concerns and expectations of older patients regarding transition from hospital to home. Through semi-structured interviews, we seek to gather insights into their preferences, concerns, and perceived roles of caregivers (eg. nurses, GPs, etc.) in their recovery journey. Understanding these expectations will help the primary caregivers to create a more person-centered approach in primary care settings, ultimately optimizing continuity care and enhancing both recovery experiences and health outcomes.

3. STUDY OBJECTIVES

Explain the aims and objectives of your study. Describe the research questions and hypotheses of your study.

The aim of this study is to explore older patients' ideas, concerns and expectations (ICE) regarding transition from hospital to home setting in primary care. More specifically regarding medical care, nursing and wellbeing.

4. RESEARCH METHOD

Present the interview and explain potential ethical implications of the planned methodology.

The interviews are designed in a semi-structured manner following the 'Consolidated criteria for reporting qualitative research' method (COREQ method (9)). This to explore the ICE of older patients regarding transition from hospital to home setting after recent discharge. The study will start after receiving approval from the OBC.

Interviews are a valuable tool for detailing patients' perspectives. This approach allows us to gain a better understanding of the interviewees' perceptions, beliefs and feelings.

Given that our research question focused on an older population, we decided that interviews were more appropriate than other qualitative methods such as questionnaires or group discussions. Although interviews require considerable time and resources, both for conducting and transcribing, they do provide the opportunity to provide in-depth, personal insights.

Moreover, participants can answer at their own pace, which can be especially convenient for older patients. In addition, we can also reach the population of elderly people who are visually impaired or do not have (full) written command of the language.

To ensure that the interview is accessible and relevant, we will design it with simplicity in mind, using clear language and simple questions that minimize the cognitive load on older respondents. In case of misunderstanding, we still have the option in an interview to rephrase a question so that, unlike a written questionnaire, it can still be answered.

The interview (Appendix 2) includes questions on several important topics related to the transition from hospital to home setting after discharge, such as communication with caregivers, involvement in health management, physical and mental well-being.

5. SELECTION AND WITHDRAWAL OF PARTICIPANTS

5.1 Inclusion and exclusion criteria

List details such as age, sex, disease, characteristics etc., under which a participant is deemed to be suitable (eligible) to participate in the study.

Data for this interview study will be collected through interviews. Participants will be selected from two participating medical practices; the Medical House Beersel (Sophie Jansen) and from Medi-Mine Winterslag (Elisabeth Lemmens).

Inclusion criteria

We will select the patients, male and female, of 65+ years and older, who are physically, socially and/or psychologically frail, and/or patients with multimorbidity, who were recently (< 6 months) discharged after hospital admission for any reason (infection, acute myocardial infarction, etc.). Patients' frailty will be assessed by clinical judgment of the GP. Multimorbidity is defined as the concomitant presence of two (or more) conditions with significant impact on patients' health and/or functioning.

We will use purposive sampling in the sense that we base selection on characteristics of a subject and the objective of the study.

Exclusion Criteria

Patients with a (known) Minimal Mental State score of 21 or less or those with a severe psychiatric comorbidities won't be included, as the reliability of their answers may be in question. We won't focus on patients in a palliative setting as well as patients who live in residential care, as we think different ways of caregiving are then acquired and so less appropriate to our research question. To avoid language bias we will only recruit Dutch speaking patients.

5.2 Sample size and population

Give the number of participants to be enrolled, together with the rationale for the sample size and how it relates to the total population. Does the ratio between sample size and population size makes it easy to identify participants? In case of working with a small population describe which measures will be taken to prevent re-identification.

The sample size of our research will be around 15 to 20 subjects if data saturation has been obtained. This sample size is generally considered sufficient in qualitative research to gather meaningful insights into the concept being studied. (10)

Participants will be recruited from the two participating medical practices; the Medical House Beersel (Sophie Jansen) and Medi-Mine Winterslag (Elisabeth Lemmens).

5.3 Recruitment

Specify who will recruit the participants, how this will happen, and by whom the participants will be approached for inclusion and obtainment of the informed consent form.

Sample texts you may use here can be found **in the explanatory document**. Choose the text that fits your research.

Students will contact the participants in person and invite them to participate in the study. Therefore, we will proactively reach out to potential candidates for this study directly, either via phone or during scheduled doctor visits. Additionally, we will request that our colleague family physicians inform eligible patients, who meet the established inclusion criteria, about the opportunity to participate in the study.

Once patients have given consent, their details, such as their date of birth and phone number, are added to an excel document. This document does not contain names, only a code P001, P002, etc., in order to preserve their anonymity. A separate excel document on another computer, which is secured by a two-step verification, will contain the key to pseudonymization. We will conduct the interviews at the patients' home or in the GP office, according to the patients' wishes. When the participant commits, a moment will be planned on which the investigation will take place. The informed consent (ICF) (added as annex) is provided to the participant in advance. This ICF provides clarity about the objective, method, and implications of the research, the potential benefits, risks, and drawbacks associated with participating, the possible external financing of the research, the processing of personal data, as well as the retention period and storage of this data. Audio recordings will be made on a shared device used only for the study. Once transcribed, the recordings will be stored on an external hard drive protected by password. At the end of the study, the recordings will be deleted.

This ICF is shared with the participant. This way, we give the patient time to go over it with a family member or caregiver of their choice. In addition, the day of the interview - and at the same time the day the ICF is signed - we, as the health care provider, will go over the ICF with the patient with any additional clarification. Only if the participant agrees to the study, signed the ICF and returned it to the researcher, the investigation will start. The investigation will proceed as follows: During the meeting with the participant, we will conduct the interview according to the interview guide. The conversation will be recorded to enable later review and transcription. Both in the ICF and at the start of the study it is clearly stated that the person in question is not obliged to participate. Both for participating, not participating, and for early termination of the research there are no negative consequences for the person in question. Meaning research may be terminated at any time at the request of the participant. The data of not completed studies will not be included in the data analysis and will be destroyed.

5.4 Expected duration

Specify the expected duration of the whole study, and define the beginning and ending of the study for the study participant.

The study can start as soon as the application is approved with the ethics committee. From that point on, we will approach our 65 - plus population based on our inclusion criteria and will ask for their consent in order to schedule the interviews. It is estimated that these interviews will take

several months. The study will be completed by December 2025. For the study participant, such an interview will take about 30-45 minutes.

6. ANALYSIS

Describe methods for data analysis in detail. Describe the measures taken to avoid, or at least minimize, biases.

The information gathered from the interview responses will be analyzed using thematic analysis, following the Clark and Braun method. (11) The Clark and Braun method is a qualitative approach to thematic analysis that identifies and interprets patterns or themes within data. It involves six steps: familiarization, coding, theme development, refinement, definition, and reporting. This flexible and systematic method is widely used in qualitative research to provide deep insights into complex datasets. We will use the software NVivo to support the analysis. (12)

7. DATA HANDLING AND MANAGEMENT

7.1 Data storage and management

Explain which type of data you are using, how the privacy of the participants is being protected (e.g. pseudonymisation), how the data is safely stored, how the data is safely shared and what will happen to the data at the end of the project.

For the collection and storage of my data I use (indicate what is applicable):

☐ Project or team-related storage location on the secure server of KU Leuven or UZ Leuven via my supervisor or supervisor

☐ REDCap, offered by KU Leuven and UZ Leuven

☐ **OneDrive for Business, offered by KU Leuven**

☐ `ter, protected with a strong password, two-step verification or specialized program (7-Zip, AEScrypt, …)

☐ Other, if substantiated, namely: ……..

All data will be treated confidentially and with due care during the project. In function of our research question, information about the experience of the hospital discharge will be collected on the basis of an interview. Everything the participants say during the interview will be recorded by means of sound recordings. No videos will be made. The recorded interviews will only be listened to and typed out by the researcher(s). The recordings and the personal notes of the interviewer will be destroyed immediately after transcription.

Transcriptions of the interviews will not contain any names or other information that enables identification. In the master's thesis and potential international publications, some fragments of the interviews will be quoted in an anonymous manner and in such a way that it is not possible to trace the statement back to a particular participant on the basis of a quote. The transcriptions will be kept in a secure computer document which will only be in the possession of the supervisor(s) and the students involved. If possible, the files will be stored in a project or team-specific storage location on a KU Leuven or UZ Leuven service, in OneDrive for Business, offered by KU Leuven, or in REDCap. If not, a personal computer will be used. This computer is protected with a password, two-step authentication or a specialized program such as 7-Zip or AEScrypt.

When sending a copy of confidential information or documents, they will be encrypted with a password or unique code. Belnet Filesender will be used to send large files. Applications such as Google Drive, a Personal OneDrive (with the expection of OneDrive for Business, offered by KU Leuven) or WeTransfer will be avoided at all times. At the end of the project, the files containing the transcriptions will be delivered to the promotor who will continu to be responsible for its safekeeping. In accordance with the policy of KU Leuven, these files will be kept for 10 years, after which the files will be reassessed whether it is considered useful to keep the data even longer.

7.2 Declaration of Confidentiality and Careful Management of Information and Personal Data

Please read carefully following section. By participating in this project you commit to following declaration.

In the framework of our master's thesis, we will have access to all kinds of data, information, results, and documents, including personal data which is not exclusively limited to patient data (the "Information"). In order to ensure the confidentiality of this Information and the privacy of those involved, within the framework of our master's thesis we shall always deal with the Information with the greatest care and discretion.
Data collected in the framework of our master's thesis, in particular research related to patients and including the collection and analyses of personal data, requires the utmost of care and discretion. Therefore, at all times we must observe complete confidentiality with respect to the information we have collected during the course of our master's thesis.
In performing this research, we commit ourselves to the following confidentiality obligations:

- We accept during and after the completion of the master's thesis, the obligation to strictly observe the confidentiality of the Information we have collected and the activities to which we have participated, and regarding the patients, healthy volunteers and the staff members with whom we come into contact;
- We will only process and collect data that is relevant and necessary for our master's thesis;
- We will not share information with persons not directly involved within the framework of our research; only the investigator, possible group members and our supervisor will have access to the data;
- We will take all necessary steps to protect the confidentially of Information and the privacy of those involved;
- We will handle with care and responsibility the Information and the access granted to us to information systems and digital media;
- We will discuss the confidentiality, storage and sharing of files with our supervisor. We will use anonymisation or pseudonymisation in order to limit the risks of data leaks and data loss.
- If pseudonymisation is used, we will treat the pseudonymisation key or the encryption table containing the pseudonyms and the identifiable information fields with the same confidentiality as the original data. We will never store the key or encryption table at the same device (e.g. laptop or desktop) as the work file or database containing the pseudonymised data.
- Wherever possible, we will use a **project based or team based storage location** for storing and exchanging data. We will contact our supervisor to discuss the possibility of using an internal or external service of KU Leuven or UZ Leuven to save data. If not possible, we will use OneDrive for Business, provided by KU Leuven, REDCap,provided by KU Leuven and UZ Leuven, or a

password protected device for storing collected data. Applications such as **Google Drive, a personal OneDrive** (except OneDrive for Business, provided by KU Leuven) **or WeTransfer will be avoided at all times**.

- We will always encrypt confidential information and files with a password, two-step verification or specialized program such as 7-Zip or AEScrypt.
- When sharing a copy of strictly confidential data, we will always **encrypt** the data with a secure password or unique code. For sharing large files, a **secure application** such as Belnet Filesender will be used.
- In the event of a **data breach** we will immediately contact our supervisor

As this research is conducted in the context of a Master's Thesis, the legal basis for the processing of personal data is the public interest. This research will generate knowledge and new insights that (directly or indirectly) will benefit society.

All investigators shall treat all information and data relating to the study as confidential and shall not disclose such information to third parties or use such information for any purpose other than the performance of the study. The collection, processing and exchange of personal data, such as contact details, health information and medical information, is subject to compliance with the General Data Protection Regulation (GDPR).

When approval is given by the Ethics Committee, it is confirmed that the proposed processing of personal data meets the requirements of the GDPR. Consequently, from a GDPR perspective, there is no objection to start the processing operations. When approval is given, this application will, In accordance with the GDPR, become included in KU Leuven's register of processing activities in the context of research and public service. For this type of study submitted through the OBC, no separate privacy request has to be submitted.

8. ASSESSMENT OF RISKS AND SAFETY

In case of safety issues (adverse events / serious adverse events) the student will promptly contact the Principal Investigator / Promotor who will be responsible for follow up. Please describe possible adverse events following your research and confirm that the name of the Principal Investigator and other relevant point of contacts have been integrated in the ICF to the participants.

None.

9. APPROVAL

Data can only be collected in an institution if the head of the institution or department where the data will be collected has been informed of the study and has approved the study. If applicable, please confirm this approval.

Hereby we confirm that data collection is performed with approval of the head of the respective unit(s) or department(s) where data collecting is taking place, namely Medi-Mine Genk and Medical House Beersel.

10. PUBLICATION POLICY

Please read carefully following section. By participating in this project you commit to following declaration.

Publications will be coordinated by the Principal Investigator. Authorship to publications will be determined in accordance with the KU Leuven policy on authorship.

11. DIRECT ACCESS TO SOURCE DATA AND DOCUMENTS

Please read carefully following section

The investigator(s) and the institution(s) will permit study-related monitoring, audits, ethical review and regulatory inspections (where appropriate) by providing direct access to source data.

12. REFERENCES

Please add references here

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11. Braun V, Clarke V. (2006). Using thematic analysis in psychology. Qual Res Psychol, 3(2), 77-101. Available from: http://www.informaworld.com/smpp/content~db=all~content=a795127197~frm=titlelink`
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13. ANNEXES

1. *A template of the **ICF** has been developed and is available on Documenten OBC — Groep Biomedische Wetenschappen (kuleuven.be). This must be used as a basis and adapted where necessary.*

   In case an alternative template is being used, a motivation should be provided here.

2. *Please add the **interview guideline**. An approval will not be given if an application doesn't contain the interview guideline.*

3. *Every **advertisement, flyer, poster**, etc. that will be used in the study should be added.*
   *If recruitment will be done through **social media** or by **mail**, please also add the text or illustration that will be used.*

4. *Other (if applicable)*

13.1 Informed Consent

Exemplaar voor de deelnemer

Titel van de studie: Ideeën, bezorgdheden en verwachtingen van oudere patiënten met betrekking tot de overgang van ziekenhuis naar thuissituatie.

Onderzoeksinstelling: KU Leuven

Ethisch comité: EC Onderzoek UZ/KU Leuven

Onderzoekers:

- Dr. Elisabeth Lemmens, huisarts in opleiding, KU Leuven, Faculteit Geneeskunde, Herestraat 49/bus 400, 3001 Leuven, België. elisabeth.lemmens@student.kuleuven.be

Dr. Sophie Jansen, huisarts in opleiding, VUB, Health Campus, Laarbeeklaan 103, België. sophie.jansen@vub.be

Dr. Thomas Struyf, promotor, KU Leuven, ACHG, Kapucijnenvoer 33 blok J, bus 7001, 3000 Leuven, België. thomas.struyf@kuleuven.be

Prof. Dr. Goderis, co-promotor, KU Leuven, ACHG, Kapucijnenvoer 33 blok J, bus 7001, 3000 Leuven, België. geert.goderis@kuleuven.be

I Noodzakelijke informatie voor uw beslissing om deel te nemen

Inleiding

U bent uitgenodigd om mee te doen aan een onderzoek. We willen begrijpen hoe ouderen denken over de zorg die ze nodig hebben na een ziekenhuisopname. Dit gaat over de hulp van de huisarts en andere zorgverleners als ze weer thuis zijn.

Om te beslissen of u wilt meedoen, vragen we u deze informatie goed door te lezen. Zo kunt u een bewuste keuze maken. Dit heet "geïnformeerde toestemming."

Lees de volgende pagina's aandachtig door. U kan hierbij altijd beroep doen op een zorgverlener naar keuze of een familielid. Heeft u daarnaast nog vragen? Dan kunt u die stellen aan de onderzoeker.

Dit document bevat belangrijke informatie voor uw beslissing, een formulier om uw toestemming te geven en extra uitleg over sommige onderwerpen.

Als u aan deze studie deelneemt, moet u weten dat:

- Deze studie opgesteld is na evaluatie door de Ethische Commissie (EC) Onderzoek UZ/KU Leuven, MP035368
- Uw deelname is vrijwillig; er kan op geen enkele manier sprake zijn van dwang. Voor deelname is uw ondertekende toestemming nodig. Ook nadat u hebt getekend, kan u de onderzoeker laten weten dat u uw deelname wilt stopzetten zonder hiervoor een reden op te geven.
- De gegevens die in het kader van uw deelname worden verzameld, zijn vertrouwelijk. Bij de publicatie van de resultaten is uw privacy verzekerd.
- Indien u extra informatie wenst, kan u altijd contact opnemen met de onderzoekers.

Doelstellingen en verloop van de studie

Deze studie gaat over wat oudere patiënten (65 jaar en ouder) belangrijk vinden na een ziekenhuisopname. We willen weten hoe zij denken over de hulp van hun huisarts en andere zorgverleners als ze weer thuis zijn.
Oudere patiënten hebben vaak veel zorg nodig na een ziekenhuisverblijf. Ze hebben tijd nodig om te herstellen en kunnen daarbij ondersteuning gebruiken, zowel voor hun lichaam als voor hun mentale welzijn. Artsen kijken nu vooral naar medische gegevens en testresultaten, maar we weten nog niet goed wat patiënten zelf belangrijk vinden in deze periode.
Met dit onderzoek willen we beter begrijpen welke verwachtingen ouderen hebben van hun huisarts en andere zorgverleners na hun ontslag uit het ziekenhuis. Zo kunnen artsen en zorgverleners hun zorg beter afstemmen op de wensen en behoeften van ouderen. Dit helpt om zorg te geven die echt bij de patiënt past.

Hoe verloopt het onderzoek?

We willen graag met u in gesprek via een interview met open vragen. Tijdens dit gesprek bespreken we onderwerpen die te maken hebben met uw zorg na een ziekenhuisopname. We zijn benieuwd naar uw verwachtingen van de huisarts en andere zorgverleners, uw ervaringen met de zorg na ontslag en eventuele bezorgdheden. Daarnaast horen we graag hoe u denkt

dat de nazorg beter kan. De antwoorden van alle deelnemers worden samen geanalyseerd om te ontdekken welke aspecten van nazorg voor patiënten het belangrijkst zijn.

Wie kan deelnemen?

We nodigen u uit om deel te nemen aan deze studie omdat u 65 jaar of ouder bent en in de afgelopen zes maanden in het ziekenhuis werd opgenomen. In totaal zullen vijftien tot twintig mensen deelnemen. We zoeken ouderen met een lichamelijke, sociale of psychische kwetsbaarheid of mensen met meerdere gezondheidsproblemen.
Niet iedereen komt in aanmerking voor deelname. U kan niet deelnemen als u in een woonzorgcentrum woont of palliatieve zorg krijgt. Ook mensen met ernstige geheugenproblemen of een psychiatrische aandoening kunnen niet meedoen. Daarnaast richten we ons enkel op Nederlandstalige deelnemers, zodat we de antwoorden correct kunnen verwerken.

Wat houdt deelname in?

Als u deelneemt, nodigen we u uit voor een gesprek van ongeveer dertig tot vijfenveertig minuten. We zullen samen bespreken hoe u de zorg na ontslag uit het ziekenhuis hebt ervaren en wat uw verwachtingen en behoeften zijn. Het gesprek gebeurt op een moment dat we samen afspreken en op een locatie die voor u het meest comfortabel is. Dit kan bij u thuis of in de dokterspraktijk.

Tijdens het interview maken we een geluidsopname met een voice recorder. Deze opname wordt enkel gebruikt om het gesprek uit te schrijven en wordt daarna definitief verwijderd.

Beschrijving van de risico's en van de voordelen

U krijgt zelf geen direct voordeel van dit onderzoek, maar door uw ervaringen te delen, helpt u ons te begrijpen wat belangrijk is voor patiënten in de zorg na een ziekenhuisopname. Zo draagt u bij aan verbeteringen waar toekomstige patiënten baat bij hebben.

Intrekking van uw toestemming

U beslist zelf of u meedoet aan het onderzoek. Deelname is volledig vrijwillig. Als u besluit niet mee te doen, hoeft u verder niets te doen. U hoeft niets te tekenen. U hoeft ook niet te zeggen waarom u niet wilt meedoen.

Als u wel meedoet, kan u zich altijd bedenken en toch stoppen, ook tijdens het onderzoek. U hoeft hiervoor geen reden te geven

Als u aan deze studie deelneemt, vragen wij om:

- Ten volle mee te werken voor een correct verloop van de studie.
- Geen informatie over uw gezondheidstoestand, de geneesmiddelen die u gebruikt of de symptomen die u ervaart te verzwijgen.
- De onderzoekers de toelating te geven tot contact met uw huisarts voor het verzamelen van aanvullende informatie.

Contact

Als u bijkomende informatie wenst, maar ook in geval van problemen of als u zich zorgen maakt, kan u contact opnemen met de onderzoekers Elisabeth Lemmens en/of Sophie Jansen via (sophie.jansen@vub.be en/of elisabeth.lemmens@student.kuleuven.be) de hoofdonderzoeker (professor Prof. Dr. Geert Goderis) via het telefoonnummer +32 15 37 72 80 (werkuren) of via e-mail (geert.goderis@kuleuven.be).

Als u vragen hebt met betrekking tot uw rechten als deelnemer aan de studie, kan u contact opnemen met de Ethische Commissie Onderzoek UZ/KU Leuven (ec@uzleuven.be; 016 34 86 00 (werkdagen tussen 10 en 11 uur))

Titel van de studie: Ideeën, bezorgdheden en verwachtingen van oudere patiënten met betrekking tot de overgang van ziekenhuis naar thuissituatie.

II Geïnformeerde toestemming

Deelnemer

Ik verklaar dat ik geïnformeerd ben over de aard, het doel, de duur, de eventuele voordelen en risico's van de studie en dat ik weet wat van mij wordt verwacht. Ik heb het informatiedocument en de bijlagen ervan doorgenomen.

Ik heb voldoende tijd gehad om na te denken en indien gewenst met een door mij gekozen persoon te overleggen.

Ik heb alle vragen kunnen stellen die bij me opkwamen en ik heb een duidelijk antwoord gekregen op mijn vragen.

Ik begrijp dat mijn deelname aan deze studie vrijwillig is en dat ik vrij ben mijn deelname aan deze studie stop te zetten. Daarvoor hoef ik geen reden op te geven en ik weet dat er geen nadeel voor mij kan ontstaan.

Ik begrijp dat er tijdens mijn deelname aan deze studie gegevens over mij zullen worden verzameld en dat de onderzoekers de vertrouwelijkheid van deze gegevens verzekeren overeenkomstig de Europese en Belgische wetgeving ter zake.

Ik wil graag/ Ik wil niet geïnformeerd worden (doorhalen wat niet van toepassing is) over de algemene onderzoeksresultaten van de studie.

Ik heb een exemplaar ontvangen van de informatie aan de deelnemer en de geïnformeerde toestemming.

Naam, voornaam, datum en handtekening van de deelnemer

Onderzoeker

Ik ondergetekende Sophie Jansen/ Elisabeth Lemmens (doorhalen wat niet van toepassing is),onderzoeker, verklaar de benodigde informatie inzake deze studie mondeling te hebben verstrekt evenals een exemplaar van het informatiedocument aan de deelnemer te hebben verstrekt.

Ik bevestig dat geen enkele druk op de deelnemer is uitgeoefend om hem/haar te doen instemmen met deelname aan de studie en ik ben bereid om op alle eventuele bijkomende vragen te antwoorden.

Ik bevestig dat ik werk in overeenstemming met de ethische beginselen zoals vermeld in de "Verklaring van Helsinki", de "Goede klinische praktijk" en de Belgische wet van 7 mei 2004 inzake experimenten op de menselijke persoon.

Naam, voornaam, datum en handtekening van de onderzoeker

Titel van de studie: Ideeën, bezorgdheden en verwachtingen van oudere patiënten met betrekking tot de overgang van ziekenhuis naar thuissituatie.

III Aanvullende informatie

2: Aanvullende informatie over de bescherming en de rechten van de deelnemer

Ethisch comité

Deze studie werd geëvalueerd door EC Onderzoek UZ/KU Leuven, dat een gunstig advies heeft uitgebracht. Ethische comités hebben als taak de personen die aan studies deelnemen te beschermen. De ethische comités zijn niet betrokken bij het opstellen of het uitvoeren van het onderzoek, het comité beoordeelt de studie als onafhankelijke partij.

U dient het positief advies van het Ethisch Comité in geen geval te beschouwen als een aansporing om deel te nemen aan deze studie.

Vrijwillige deelname

Stel gerust alle vragen die u heeft voordat u tekent. Neem de tijd om erover te praten met iemand die u vertrouwt, als u dat wilt.
U bent vrij om niet mee te doen of om op elk moment te stoppen, ook als u eerst wel had toegestemd. U hoeft geen reden te geven, en dit heeft geen negatieve gevolgen voor u. Als u besluit mee te doen, ondertekent u het toestemmingsformulier. De onderzoeker tekent ook om te bevestigen dat u alle nodige informatie heeft gekregen. U krijgt een kopie van het formulier.

Kosten in verband met uw deelname

U zult geen vergoeding krijgen voor uw deelname aan deze studie. Uw deelname zal echter voor u geen bijkomende kosten met zich meebrengen.

Vertrouwelijkheidgarantie

Uw deelname aan de studie betekent dat de onderzoekers gegevens over u verzamelen en gebruiken voor onderzoek en in het kader van wetenschappelijke en medische publicaties.

Uw gegevens zullen worden verwerkt overeenkomstig de Europese Algemene Verordening inzake Gegevensbescherming (AVG) en de Belgische Wetgeving betreffende de bescherming van natuurlijke personen met betrekking tot de verwerking van persoonsgegevens. KU Leuven is de verwerkingsverantwoordelijke voor uw gegevens. VUB is verder niet betrokken bij deze studie.

U heeft het recht om aan de onderzoekers te vragen welke gegevens zij over u hebben verzameld en waarvoor ze gebruikt worden in het kader van de studie. U hebt het recht om deze gegevens in te kijken en om verbeteringen te laten aanbrengen indien ze fout zouden zijn[2].

De onderzoekers zijn verplicht om deze verzamelde gegevens vertrouwelijk te behandelen.

Dit betekent dat zij zich ertoe verbinden om uw naam nooit bekend te maken in het kader van een publicatie of een conferentie en dat zij uw gegevens zullen coderen (uw identiteit (naam) zal worden vervangen door een identificatiecode in de studie). De overgedragen persoonlijke gegevens omvatten geen combinatie van elementen waarmee het mogelijk is u te identificeren [3].

De (gecodeerde) onderzoeksgegevens kunnen doorgegeven worden aan Belgische of andere regelgevende instanties, aan de ethische comités, aan andere onderzoekers en/of instellingen die samenwerken met de opdrachtgever. Dit gebeurt dan steeds in gecodeerde vorm.

Om de kwaliteit van de studie te controleren, kan uw medisch dossier worden ingekeken door personen die gebonden zijn aan het beroepsgeheim zoals vertegenwoordigers van de ethische comités, van de opdrachtgever van de studie of een extern auditbureau. Dit kan enkel gebeuren onder strikte voorwaarden, onder de verantwoordelijkheid van de hoofdonderzoeker en onder zijn/haar toezicht (of van één van zijn/haar onderzoek medewerkers).

De opdrachtgever verbindt zich ertoe om de verzamelde gegevens enkel in het kader van deze studie te gebruiken.

Als u beslist om niet langer mee te doen aan de studie, blijven de gegevens die al anoniem verwerkt zijn bewaard. Alle andere gegevens, zoals niet-verwerkte informatie en geluids- of videofragmenten van (on)voltooide interviews, worden niet gebruikt en zullen worden vernietigd. Dit zorgt ervoor dat de studie correct blijft verlopen. Er wordt geen nieuwe informatie meer doorgestuurd naar de opdrachtgever.

2

Deze rechten zijn bepaald door de Europese Algemene Verordening Gegevensbescherming (AVG), door de Belgische Wetgeving betreffende de bescherming van natuurlijke personen met betrekking tot de verwerking van persoonsgegevens en door de wet van 22 augustus 2002 betreffende de rechten van de patiënt.

3 De database met de resultaten van de studie zal dus geen elementen bevatten zoals uw initialen, uw geslacht en uw volledige geboortedatum (dd/mm/jjjj).

Indien u vragen hebt over hoe wij uw gegevens gebruiken of uw recht op inzage, correctie, eventueel stopzetting van de verdere verwerking wil uitoefenen, dan kan u hiervoor steeds terecht bij uw arts-onderzoeker op volgend contactadres: (verduidelijken). Indien u naderhand nog bijzondere aandachtspunten heeft of klacht wenst neer te leggen, kan u terecht bij het privacy team van de KU Leuven op privacy@kuleuven.be

Tot slot, indien u een klacht heeft over de verwerking van uw gegevens, kunt u contact opnemen met de Belgische toezichthoudende instantie die toeziet op de naleving van de grondbeginselen van de bescherming van persoonsgegevens:

De Belgische toezichthoudende instantie heet:
Gegevensbeschermingsautoriteit (GBA)
Drukpersstraat 35,
1000 Brussel
Tel. +32 2 274 48 00
e-mail: contact(at)apd-gba.be
Website: www.gegevensbeschermingsautoriteit.be

Exemplaar voor de onderzoeker

Titel van de studie: Ideeën, bezorgdheden en verwachtingen van oudere patiënten met betrekking tot de overgang van ziekenhuis naar thuissituatie.

Onderzoeksinstelling: KU Leuven

Ethisch comité: EC Onderzoek UZ/KU Leuven

Onderzoekers:

- Dr. Elisabeth Lemmens, huisarts in opleiding, KU Leuven, Faculteit Geneeskunde, Herestraat 49/bus 400, 3001 Leuven, België. elisabeth.lemmens@student.kuleuven.be

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I Noodzakelijke informatie voor uw beslissing om deel te nemen

Inleiding

U bent uitgenodigd om mee te doen aan een onderzoek. We willen begrijpen hoe ouderen denken over de zorg die ze nodig hebben na een ziekenhuisopname. Dit gaat over de hulp van de huisarts en andere zorgverleners als ze weer thuis zijn.

Om te beslissen of u wilt meedoen, vragen we u deze informatie goed door te lezen. Zo kunt u een bewuste keuze maken. Dit heet “geïnformeerde toestemming.”

Lees de volgende pagina's aandachtig door. U kan hierbij altijd beroep doen op een zorgverlener naar keuze of een familielid. Heeft u daarnaast nog vragen? Dan kunt u die stellen aan de onderzoeker.

Dit document bevat belangrijke informatie voor uw beslissing, een formulier om uw toestemming te geven en extra uitleg over sommige onderwerpen.

Als u aan deze studie deelneemt, moet u weten dat:

- Deze studie opgesteld is na evaluatie door de Ethische Commissie (EC) Onderzoek UZ/KU Leuven, MP035368
- Uw deelname is vrijwillig; er kan op geen enkele manier sprake zijn van dwang. Voor deelname is uw ondertekende toestemming nodig. Ook nadat u hebt getekend, kan u de onderzoeker laten weten dat u uw deelname wilt stopzetten zonder hiervoor een reden op te geven.
- De gegevens die in het kader van uw deelname worden verzameld, zijn vertrouwelijk. Bij de publicatie van de resultaten is uw privacy verzekerd.
- Indien u extra informatie wenst, kan u altijd contact opnemen met de onderzoekers.

Doelstellingen en verloop van de studie

Deze studie gaat over wat oudere patiënten (65 jaar en ouder) belangrijk vinden na een ziekenhuisopname. We willen weten hoe zij denken over de hulp van hun huisarts en andere zorgverleners als ze weer thuis zijn.
Oudere patiënten hebben vaak veel zorg nodig na een ziekenhuisverblijf. Ze hebben tijd nodig om te herstellen en kunnen daarbij ondersteuning gebruiken, zowel voor hun lichaam als voor hun mentale welzijn. Artsen kijken nu vooral naar medische gegevens en testresultaten, maar we weten nog niet goed wat patiënten zelf belangrijk vinden in deze periode.
Met dit onderzoek willen we beter begrijpen welke verwachtingen ouderen hebben van hun huisarts en andere zorgverleners na hun ontslag uit het ziekenhuis. Zo kunnen artsen en zorgverleners hun zorg beter afstemmen op de wensen en behoeften van ouderen. Dit helpt om zorg te geven die echt bij de patiënt past.

Hoe verloopt het onderzoek?

We willen graag met u in gesprek via een interview met open vragen. Tijdens dit gesprek bespreken we onderwerpen die te maken hebben met uw zorg na een ziekenhuisopname. We zijn benieuwd naar uw verwachtingen van de huisarts en andere zorgverleners, uw ervaringen met de zorg na ontslag en eventuele bezorgdheden. Daarnaast horen we graag hoe u denkt dat de nazorg beter kan. De antwoorden van alle deelnemers worden samen geanalyseerd om te ontdekken welke aspecten van nazorg voor patiënten het belangrijkst zijn.

Wie kan deelnemen?

We nodigen u uit om deel te nemen aan deze studie omdat u 65 jaar of ouder bent en in de afgelopen zes maanden in het ziekenhuis werd opgenomen. In totaal zullen vijftien tot twintig mensen deelnemen. We zoeken ouderen met een lichamelijke, sociale of psychische kwetsbaarheid of mensen met meerdere gezondheidsproblemen.
Niet iedereen komt in aanmerking voor deelname. U kan niet deelnemen als u in een woonzorgcentrum woont of palliatieve zorg krijgt. Ook mensen met ernstige geheugenproblemen of een psychiatrische aandoening kunnen niet meedoen. Daarnaast richten we ons enkel op Nederlandstalige deelnemers, zodat we de antwoorden correct kunnen verwerken.

Wat houdt deelname in?

Als u deelneemt, nodigen we u uit voor een gesprek van ongeveer dertig tot vijfenveertig minuten. We zullen samen bespreken hoe u de zorg na ontslag uit het ziekenhuis hebt ervaren en wat uw verwachtingen en behoeften zijn. Het gesprek gebeurt op een moment dat we samen afspreken en op een locatie die voor u het meest comfortabel is. Dit kan bij u thuis of in de dokterspraktijk.

Tijdens het interview maken we een geluidsopname met een voice recorder. Deze opname wordt enkel gebruikt om het gesprek uit te schrijven en wordt daarna definitief verwijderd.

Beschrijving van de risico's en van de voordelen

U krijgt zelf geen direct voordeel van dit onderzoek, maar door uw ervaringen te delen, helpt u ons te begrijpen wat belangrijk is voor patiënten in de zorg na een ziekenhuisopname. Zo draagt u bij aan verbeteringen waar toekomstige patiënten baat bij hebben.

Intrekking van uw toestemming

U beslist zelf of u meedoet aan het onderzoek. Deelname is volledig vrijwillig. Als u besluit niet mee te doen, hoeft u verder niets te doen. U hoeft niets te tekenen. U hoeft ook niet te zeggen waarom u niet wilt meedoen.

Als u wel meedoet, kan u zich altijd bedenken en toch stoppen, ook tijdens het onderzoek. U hoeft hiervoor geen reden te geven

Als u aan deze studie deelneemt, vragen wij om:

- Ten volle mee te werken voor een correct verloop van de studie.
- Geen informatie over uw gezondheidstoestand, de geneesmiddelen die u gebruikt of de symptomen die u ervaart te verzwijgen.
- De onderzoekers de toelating te geven tot contact met uw huisarts voor het verzamelen van aanvullende informatie.

Contact

Als u bijkomende informatie wenst, maar ook in geval van problemen of als u zich zorgen maakt, kan u contact opnemen met de onderzoekers Elisabeth Lemmens en/of Sophie Jansen via (sophie.jansen@vub.be en/of elisabeth.lemmens@student.kuleuven.be) de hoofdonderzoeker (professor Prof. Dr. Geert Goderis) via het telefoonnummer +32 15 37 72 80 (werkuren) of via e-mail (geert.goderis@kuleuven.be).

Als u vragen hebt met betrekking tot uw rechten als deelnemer aan de studie, kan u contact opnemen met de Ethische Commissie Onderzoek UZ/KU Leuven (ec@uzleuven.be; 016 34 86 00 (werkdagen tussen 10 en 11 uur))

Titel van de studie: Ideeën, bezorgdheden en verwachtingen van oudere patiënten met betrekking tot de overgang van ziekenhuis naar thuissituatie.

II Geïnformeerde toestemming

Deelnemer

Ik verklaar dat ik geïnformeerd ben over de aard, het doel, de duur, de eventuele voordelen en risico's van de studie en dat ik weet wat van mij wordt verwacht. Ik heb het informatiedocument en de bijlagen ervan doorgenomen.

Ik heb voldoende tijd gehad om na te denken en indien gewenst met een door mij gekozen persoon te overleggen.

Ik heb alle vragen kunnen stellen die bij me opkwamen en ik heb een duidelijk antwoord gekregen op mijn vragen.

Ik begrijp dat mijn deelname aan deze studie vrijwillig is en dat ik vrij ben mijn deelname aan deze studie stop te zetten. Daarvoor hoef ik geen reden op te geven en ik weet dat er geen nadeel voor mij kan ontstaan.

Ik begrijp dat er tijdens mijn deelname aan deze studie gegevens over mij zullen worden verzameld en dat de onderzoekers de vertrouwelijkheid van deze gegevens verzekeren overeenkomstig de Europese en Belgische wetgeving ter zake.

Ik wil graag/ Ik wil niet geïnformeerd worden (doorhalen wat niet van toepassing is) over de algemene onderzoeksresultaten van de studie.

Ik heb een exemplaar ontvangen van de informatie aan de deelnemer en de geïnformeerde toestemming.

Naam, voornaam, datum en handtekening van de deelnemer

Onderzoeker

Ik ondergetekende Sophie Jansen/ Elisabeth Lemmens (doorhalen wat niet van toepassing is),onderzoeker, verklaar de benodigde informatie inzake deze studie mondeling te hebben verstrekt evenals een exemplaar van het informatiedocument aan de deelnemer te hebben verstrekt.

Ik bevestig dat geen enkele druk op de deelnemer is uitgeoefend om hem/haar te doen instemmen met deelname aan de studie en ik ben bereid om op alle eventuele bijkomende vragen te antwoorden.

Ik bevestig dat ik werk in overeenstemming met de ethische beginselen zoals vermeld in de "Verklaring van Helsinki", de "Goede klinische praktijk" en de Belgische wet van 7 mei 2004 inzake experimenten op de menselijke persoon.

Naam, voornaam, datum en handtekening van de onderzoeker

Titel van de studie: Ideeën, bezorgdheden en verwachtingen van oudere patiënten met betrekking tot de overgang van ziekenhuis naar thuissituatie.

III Aanvullende informatie

2: Aanvullende informatie over de bescherming en de rechten van de deelnemer

Ethisch comité

Deze studie werd geëvalueerd door EC Onderzoek UZ/KU Leuven, dat een gunstig advies heeft uitgebracht. Ethische comités hebben als taak de personen die aan studies deelnemen te beschermen. De ethische comités zijn niet betrokken bij het opstellen of het uitvoeren van het onderzoek, het comité beoordeelt de studie als onafhankelijke partij.

U dient het positief advies van het Ethisch Comité in geen geval te beschouwen als een aansporing om deel te nemen aan deze studie.

Vrijwillige deelname

Stel gerust alle vragen die u heeft voordat u tekent. Neem de tijd om erover te praten met iemand die u vertrouwt, als u dat wilt.
U bent vrij om niet mee te doen of om op elk moment te stoppen, ook als u eerst wel had toegestemd. U hoeft geen reden te geven, en dit heeft geen negatieve gevolgen voor u. Als u besluit mee te doen, ondertekent u het toestemmingsformulier. De onderzoeker tekent ook om te bevestigen dat u alle nodige informatie heeft gekregen. U krijgt een kopie van het formulier.

Kosten in verband met uw deelname

U zult geen vergoeding krijgen voor uw deelname aan deze studie. Uw deelname zal echter voor u geen bijkomende kosten met zich meebrengen.

Vertrouwelijkheidgarantie

Uw deelname aan de studie betekent dat de onderzoekers gegevens over u verzamelen en gebruiken voor onderzoek en in het kader van wetenschappelijke en medische publicaties.

Uw gegevens zullen worden verwerkt overeenkomstig de Europese Algemene Verordening inzake Gegevensbescherming (AVG) en de Belgische Wetgeving betreffende de bescherming van natuurlijke personen met betrekking tot de verwerking van persoonsgegevens. KU Leuven is de verwerkingsverantwoordelijke voor uw gegevens. VUB is verder niet betrokken bij deze studie.

U heeft het recht om aan de onderzoekers te vragen welke gegevens zij over u hebben verzameld en waarvoor ze gebruikt worden in het kader van de studie. U hebt het recht om deze gegevens in te kijken en om verbeteringen te laten aanbrengen indien ze fout zouden zijn[4].

De onderzoekers zijn verplicht om deze verzamelde gegevens vertrouwelijk te behandelen.

Dit betekent dat zij zich ertoe verbinden om uw naam nooit bekend te maken in het kader van een publicatie of een conferentie en dat zij uw gegevens zullen coderen (uw identiteit (naam) zal worden vervangen door een identificatiecode in de studie). De overgedragen persoonlijke gegevens omvatten geen combinatie van elementen waarmee het mogelijk is u te identificeren [5].

De (gecodeerde) onderzoeksgegevens kunnen doorgegeven worden aan Belgische of andere regelgevende instanties, aan de ethische comités, aan andere onderzoekers en/of instellingen die samenwerken met de opdrachtgever. Dit gebeurt dan steeds in gecodeerde vorm.

Om de kwaliteit van de studie te controleren, kan uw medisch dossier worden ingekeken door personen die gebonden zijn aan het beroepsgeheim zoals vertegenwoordigers van de ethische comités, van de opdrachtgever van de studie of een extern auditbureau. Dit kan enkel gebeuren onder strikte voorwaarden, onder de verantwoordelijkheid van de hoofdonderzoeker en onder zijn/haar toezicht (of van één van zijn/haar onderzoek medewerkers).

De opdrachtgever verbindt zich ertoe om de verzamelde gegevens enkel in het kader van deze studie te gebruiken.

Als u beslist om niet langer mee te doen aan de studie, blijven de gegevens die al anoniem verwerkt zijn bewaard. Alle andere gegevens, zoals niet-verwerkte informatie en geluids- of videofragmenten van (on)voltooide interviews, worden niet gebruikt en zullen worden vernietigd. Dit zorgt ervoor dat de studie correct blijft verlopen. Er wordt geen nieuwe informatie meer doorgestuurd naar de opdrachtgever.

Indien u vragen hebt over hoe wij uw gegevens gebruiken of uw recht op inzage, correctie, eventueel stopzetting van de verdere verwerking wil uitoefenen, dan kan u hiervoor steeds terecht bij uw arts-onderzoeker op volgend contactadres: sophie.jansen@vub.be of elisabeth.lemmens@student.kuleuven.be. Indien u naderhand nog bijzondere aandachtspunten heeft of klacht wenst neer te leggen, kan u terecht bij het privacy team van de KU Leuven op privacy@kuleuven.be

Tot slot, indien u een klacht heeft over de verwerking van uw gegevens, kunt u contact opnemen met de Belgische toezichthoudende instantie die toeziet op de naleving van de grondbeginselen van de bescherming van persoonsgegevens:

De Belgische toezichthoudende instantie heet:
Gegevensbeschermingsautoriteit (GBA)

4

Deze rechten zijn bepaald door de Europese Algemene Verordening Gegevensbescherming (AVG), door de Belgische Wetgeving betreffende de bescherming van natuurlijke personen met betrekking tot de verwerking van persoonsgegevens en door de wet van 22 augustus 2002 betreffende de rechten van de patiënt.

5 De database met de resultaten van de studie zal dus geen elementen bevatten zoals uw initialen, uw geslacht en uw volledige geboortedatum (dd/mm/jjjj).

Drukpersstraat 35,
1000 Brussel
Tel. +32 2 274 48 00
e-mail: contact(at)apd-gba.be
Website: www.gegevensbeschermingsautoriteit.be

13.2 Semi-structured Interview Guide

Naam interviewer:

Naam participant:

Leeftijd participant:

Datum interview:

Introductie van het onderzoek

Samen overlopen van de informatiebrief/informed consent.

Hartelijk dank om tijd vrij te maken voor dit interview. Wij zijn Elisabeth Lemmens en Sophie Jansen, twee huisartsen-in-opleiding aan respectievelijk de KU Leuven en VUB. Wij voeren dit onderzoek uit in het kader van onze masterproef binnen onze vervolgopleiding: Master in de Huisartsgeneeskunde. Met dit onderzoek willen wij nagaan hoe u het ontslag uit het ziekenhuis heeft ervaren. Daarnaast willen we graag weten hoe u de voortzetting van de nodige zorg in de thuisomgeving heeft ervaren. De vragen zullen gaan over uw persoonlijke ervaringen, wat u ervan vindt, wat u er goed of niet goed aan vindt en wat u zou willen verbeteren.

Het interview zal ongeveer 45 minuten in beslag nemen. We zouden dit graag opnemen via 'voicerecorder' zodat we het interview achteraf volledig kunnen uitschrijven en verwerken zonder informatie te missen. Dit gebeurt uiteraard zonder uw naam te vermelden. Daarnaast zullen al uw gegevens verwerkt en bewaard worden volgens de GDPR wetgeving waarbij anonimiteit wordt gegarandeerd. Tussendoor zullen we ook notities nemen. We starten het interview met het tekenen van een document waarmee u verklaard akkoord te zijn om deel te nemen aan onze interviewstudie. Als u nog verdere vragen hebt, mag u deze steeds stellen.

I. Inleidende vragen

- Hoe gaat het nu met u?

- Waarom werd u opgenomen?
    - Was het voor u voldoende duidelijk waarom u werd opgenomen?
- Hoelang werd u opgenomen?
- Op welke dienst(en) bent u verbleven?
- Via welke weg bent u binnengekomen in het ziekenhuis?
    - Bijvoorbeeld: via verwijzing (huisarts, specialist…), via spoed

Notities:

II. (Voorbereidend) ontslag in het ziekenhuis

- Hoe heeft men u voorbereid op uw ontslag?
    - Wanneer werd u ingelicht dat u naar huis mocht gaan?
        - Hoeveel dagen was dit op voorhand?
    - Wat werd er voor u geregeld?
        - Hoe hebben ze u hierover geïnformeerd?
        - Was u hier tevreden over?
            - Zo nee, hoe had u het graag anders gezien?
- Hoe verliep (de communicatie van) uw ontslaggesprek?
    - Was er toen iemand, zoals een familielid, die met u mee luisterde?
    - Welke informatie kreeg u bij dit gesprek?
        - Bijvoorbeeld: informatie over uw opname zelf, over uw medicatielijst, over thuiszorg, over uw vervolgafspraken…
    - Hoe werd u en/of uw familielid betrokken bij dit gesprek?
    - Had u nog vragen bij dit ontslaggesprek?
        - Zo ja, zijn die beantwoord?
- Wat vond u van uw ontslag, met andere woorden: wat liep er goed en wat liep er minder goed?
- Welke zaken zou u veranderen om (de voorbereiding op) het ontslag aangenamer te maken?

Notities:

III. Verloop ontslag uit ziekenhuis en aankomst thuis

- Hoe verliep de dag van uw ontslag?
- Hoe bent u thuis geraakt?
    - bv. met welk vervoermiddel?
    - bv. was er iemand bij u?
    - bv. wie had er de huissleutels bij?
    - Was er eten voorzien? Stond de verwarming aan?
- Wie heeft u opgevangen bij thuiskomst?
    - Was er direct hulp of heeft u even moeten wachten?
    - Zo onmiddellijk, welke hulp was er?
        - Werd dit op voorhand al meegedeeld?
    - Zo nee, had u het graag anders gezien? (En hoe?)
- Hoe tevreden bent u over uw ontslag, met andere woorden: wat liep er goed en wat liep er minder goed tijdens de dag?
- Welke zaken zou u veranderen om de overgang aangenamer te maken?

Notities:

IV. Thuiszorg

Praktisch

- Hoe werd de zorg georganiseerd na uw opname?
    - Welke bijkomende hulp werd er voorzien? (Bijvoorbeeld: thuisverpleging, poetshulp, familiehulp, kinesiste …)
    - Wie regelde de hulp voor u of van wie kreeg u hulp om de zorgverleners te contacteren?
- Welke thuishulp kreeg u reeds voor uw opname?
    - Waren de zorgverleners op de hoogte van uw thuiskomst?
        - Had u instructies/papieren van het ziekenhuis voor hen meegekregen?
    - Hoe veranderde de thuishulp na uw opname?
        - Bijvoorbeeld: verandering in de dagelijkse/wekelijkse routine?
- Hoe tevreden bent u van de thuiszorg na uw opname, met andere woorden: wat liep er goed en wat liep er minder goed bij de organisatie van de thuiszorg?
- Welke zaken zou u veranderen om de thuiszorg aangenamer te maken?

Verpleging

- Had u voor uw opname reeds verpleging?
    - Zo ja: was dit na uw opname dezelfde persoon?
    - Zo neen: wie regelde dat er verpleging aan huis kwam of van wie kreeg u hulp?
- Wanneer zag u voor het eerst de verpleging?
- Waar helpt de verpleging u vooral bij?
        - Is dit voor u voldoende of zijn er zaken die u nog extra zou willen?
- Hoe tevreden bent u van de verpleging in de thuissetting, met andere woorden: wat liep er goed en wat liep er minder goed bij de organisatie?

Huisarts

- Wanneer zag u voor het eerst uw huisarts?
- Hoe werd dit eerste contact georganiseerd?
    - Nam de huisarts zelf contact met u op?
        - Zo nee: wie nam contact op met de huisarts?
- Wat werd er met u besproken tijdens deze eerste afspraak?
    - Heeft dit geholpen om uw weg te vinden? Zo ja: hoe? Zo nee: wat had u dan verwacht?
- Was het voor u duidelijk wanneer uw volgende afspraak met hem/haar zou zijn?
- Hoe tevreden bent u over de opvolging van uw huisarts na uw ontslag uit het ziekenhuis, met andere woorden: wat liep er goed en wat liep er minder goed?

Notities:

Afronding

1. Vragen of de patiënt nog vragen heeft of nog iets wil toevoegen aan het interview.
2. Vragen aan patiënt of we hem/ haar in een later stadium opnieuw mogen contacteren om bijkomende input te geven voor het project, eventueel via een andere manier van werken.
3. Afspraken rond de terugkoppeling van de resultaten.
4. Dankwoord ter afsluiting van het gesprek