






## EMPIRICAL STUDIES

# In the footsteps of the old patient from hospital to home: A qualitative field observation study

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## Abstract

**Background:** Older people often have multiple health conditions and therefore extended care needs. The transition from the hospital back to their home requires careful planning. The fragmented healthcare system and rapid discharge from the hospital can result in limited involvement of the older patient in the discharge planning process. We aimed to explore how older hospitalised patients experienced the transition from hospital to home and how possibilities and constraints in interactions with relevant parties in the transition affected their everyday lives.

**Method:** An ethnographic participant observation study including interviews was conducted with 10 older hospitalised patients. The theoretical perspective in the study is critical psychology and data were analysed using the condition-, meaning- and reasoning analysis.

**Results:** Three themes were identified: (1) Lost in transition – the person's ability to act is limited, (2) In transition – the relatives become important, (3) At home – the home transforms into a workplace.

**Conclusion:** Lack of involvement becomes a condition for older patients as some struggle to create meaning in their transition, affecting their everyday lives. The patients experienced their relatives as important as they ensured that the HCPs got to know their values and wishes. This knowledge is important for HCPs working closely with older people both at the hospital and at home ensuring active involvement of the older person with respect and acknowledgement of the older person's wishes, needs, resources and vulnerability.

## KEYWORDS

#from hospital to home, #nursing, #older patients, #transitional care, #vulnerability

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## INTRODUCTION

Growing old is a process that brings about various changes in an individual's everyday life. Most older people [1, 2] undergo multiple transitions in later life, e.g., the loss of a spouse, acute illness, relocation from a lifelong home, retirement and increased reliance on others for assistance [3]. Older people, here defined as 65+ year olds, admitted to a geriatric department suffer from multiple health conditions [4], polypharmacy and functional decline [4] with subsequent extended care needs [5].

When discharged the patient's transition from hospital to home requires careful planning [6]. In clinical hospital care, nurses experience discharge planning to be and with a pressure for rapid discharge [7]. Research indicates that the dissemination of information regarding patient care across various healthcare settings [8, 9] is challenged and requires active involvement of the older patient [10, 11], their family members [12, 13] and healthcare professionals [8, 9]. Moreover, when discharged decisions on subsequent care needs are not adequately informed by the patient's everyday life and priorities [12]. Healthcare professionals frequently fail to inquire the patients about their preferences or the challenges they may face at home in their current health condition [14], leaving the individuals uninformed about the consequences following the discharge process [15]. Lilleheie et al. [16] revealed that although the older individuals expressed gratitude for the assistance received during the discharge process, they also experienced a loss of autonomy, feelings of helplessness and a fear of burdening their families. The study also revealed that the participants hoped to have a more independent life after discharge [16].

Little is known about how older individuals perceive the discharge information provided to them on the day of their hospital discharge, the transportation process and their early interactions with healthcare professionals or informal caregivers at home. This gap in knowledge calls for further studies of older peoples' discharge process and the critical phases of care transition.

We aimed to explore how older hospitalised patients experienced the transition from hospital to home and how possibilities and constraints in interactions with relevant parties in the transition affected their everyday lives.

## METHODS

The *epistemology* [17] of this study is based on a historical dialectic-materialistic understanding [18, 19] where a person's actions and the surroundings are reciprocally

affecting each other [20]. The *theoretical perspective* is critical psychology [18] where conditions are the person's possibilities and constraints in the interaction with others and the surroundings, e.g. society, in their conduct of everyday life [19]. The person's ability to act is explored in social practice as the person's experience, reasoning and actions affect the person's everyday life and vice-versa [19, 21]. These concepts are used to explore and understand how the interactions on the day of discharge either become possibilities or constraints in the older patient's meaning-making and how they experience and explain their actions in the transition from hospital to home and their everyday life. The *methodology* is ethnography [22, 23] and the *methods* used are participant observation [24] and interviews [24, 25]. The Standards for Reporting Qualitative Research (SRQR) [26] have guided the reporting of this study.

## Setting

In Denmark, the healthcare system is tax-funded and healthcare service is free of charge [27] both in primary and secondary healthcare. The hospitals are operated by the five Regions and in the 98 municipalities local city councils are responsible for providing home care and nursing care [27]. Furthermore, policies on cross-sectoral collaboration are agreed upon [28] to ensure consistent patient care.

The study was conducted at a geriatric department with a capacity for 32 patients, at a university hospital in a large Danish city within a large municipality. The department treats acute geriatric patients and the majority are discharged to home-based care. The collaboration between the hospital and the municipality is guided by a collaboration agreement [29], which prescribes communication and coordination between healthcare professionals, patients and relatives [29].

Hospital-based healthcare professionals involved in the discharge planning included registered nurses (RN), social and health care assistants, dietitians, physiotherapists, occupational therapists and physicians. The RNs are responsible for completing and sending a digital communication report to healthcare professionals in the municipality. In the municipality, home-based care (e.g., home-based care, nursing care and rehabilitation) is assigned on a needs assessment [30] and the designated care is provided by RNs, social and health care assistants, or social and health care workers. In this study, also unskilled persons delivered care.

In the following, the healthcare professionals (HCP) will be specified into the above-mentioned groups when relevant to the study.

## Data generation

### Recruitment

We used a purposive sampling approach [31], where we aimed to include a diversity of older people according to age, gender, social and cultural background. RNs in the geriatric department functioned as gatekeepers [25] and identified patients who met the following inclusion criteria: (a) aged 65 years or older, (b) resident in an urban municipality, (c) receiving home-based care after discharge and (d) assessed by the RNs at the hospital to be cognitively capable to consent and participate. The first author informed patients who met these criteria face-to-face about the project and invited them to participate.

### Participants

In total, 11 patients received the information and were invited to participate. Of these, 10 accepted the invitation; one declined due to multiple appointments when back in his dwelling and fearing a lack of energy when participating in the project. The participants' characteristics are presented in Table 1. Further, the patients will be referred to as *participants*.

### Participant observation

After the patient gave consent to participate the observations began. During the observations, the first author followed the participant facing the same direction as the participant [25] when interacting with HCP or relatives, but when engaged in informal interviews they sat face to

face. During the observations, the participants interacted mainly with three different groups of persons: HCPs at the hospital, relatives and HCPs from the municipality. Observations were guided by Spradley's nine domains of social situations: space, actor, activity, object, act, event, time, goal and feeling [24] to ensure observations of both the context and actions [25].

The observations lasted between 5 and 8 h (on average 6 h). Field notes were written during the observations and informal interviews [24] with the participants were conducted when the situation allowed for it both at the hospital and in the participant's home. The informal interviews were conducted to nuance and verify the observations and to explore if and how the transition from hospital to home affected the participant's everyday life. The field notes and informal interviews were transcribed into anonymized data by the first author at the end of each observation to ensure detail in the context and in the interactions that were observed. During the first (3) observations, the first author experienced that the observations in the older person's home revealed circumstances and situations that could not be fully understood with observations during the set frame (transition from hospital to home). Therefore, interviews were added to follow-up on aspects of the transition that were revealed during the home-coming observation but could not be fully understood with observations only. As a result, all remaining (7) participants were invited also to participate in a follow-up interview at the participant's homes a week after discharge.

## Analysis

The fieldnotes and interviews were read several times and in an iterative process, authors SHB and DSN worked

**TABLE 1** Characteristics of the participants.

| Participant ID | Gender | Age (years) | Civil status | Living status | Relative                    | Homecare before hospital admission | Transport to home |
|----------------|--------|-------------|--------------|---------------|-----------------------------|------------------------------------|-------------------|
| 1              | Female | 84          | Married      | Together      | Husband, two sons           | Yes                                | Regional          |
| 2              | Male   | 85          | Married      | Together      | Wife                        | Yes                                | Regional          |
| 3              | Male   | 93          | Widower      | Alone         | Niece                       | Yes                                | Regional          |
| 4              | Male   | 79          | Married      | Together      | Wife, one son, one daughter | No                                 | Relatives         |
| 5              | Male   | 78          | Married      | Alone         | Wife                        | Yes                                | Ambulance         |
| 6              | Female | 79          | Married      | Alone         | Husband                     | Yes                                | Regional          |
| 7              | Male   | 94          | Widower      | Alone         | One daughter                | No                                 | Regional          |
| 8              | Male   | 87          | Married      | Together      | Wife                        | Yes                                | Regional          |
| 9              | Female | 77          | Widow        | Alone         | Niece                       | No                                 | Regional          |
| 10             | Female | 91          | Widow        | Alone         | Three daughters             | Yes                                | Regional          |

together and conducted the initial analysis. This initial analysis was discussed with all authors to validate the interpretations and insights derived from the data and to create themes. Data were analysed with the condition-, meaning- and reasoning analysis [19, 32], exploring how the care and the interactions between HCP and relatives become conditions for the participant and how it influences their meaning and reasoning in their everyday life see Table 2 below. Using this analysis, we were able to situate the data in the context and data were analysed with the perspective of duality [20], more specifically, how the HCPs and relatives affect the participant and vice versa during the transition from hospital to home. By analysing the first-person perspective [32], it is possible to view how the person acts in a specific situation, e.g., how the participant received information on medication before discharge and to get a deeper understanding of the interaction and enlighten how the same practice creates different conditions for the individual participant [21].

## Reflexivity

The first author is a Registered Nurse, who specialised in the field of geriatric medicine and worked as a clinical

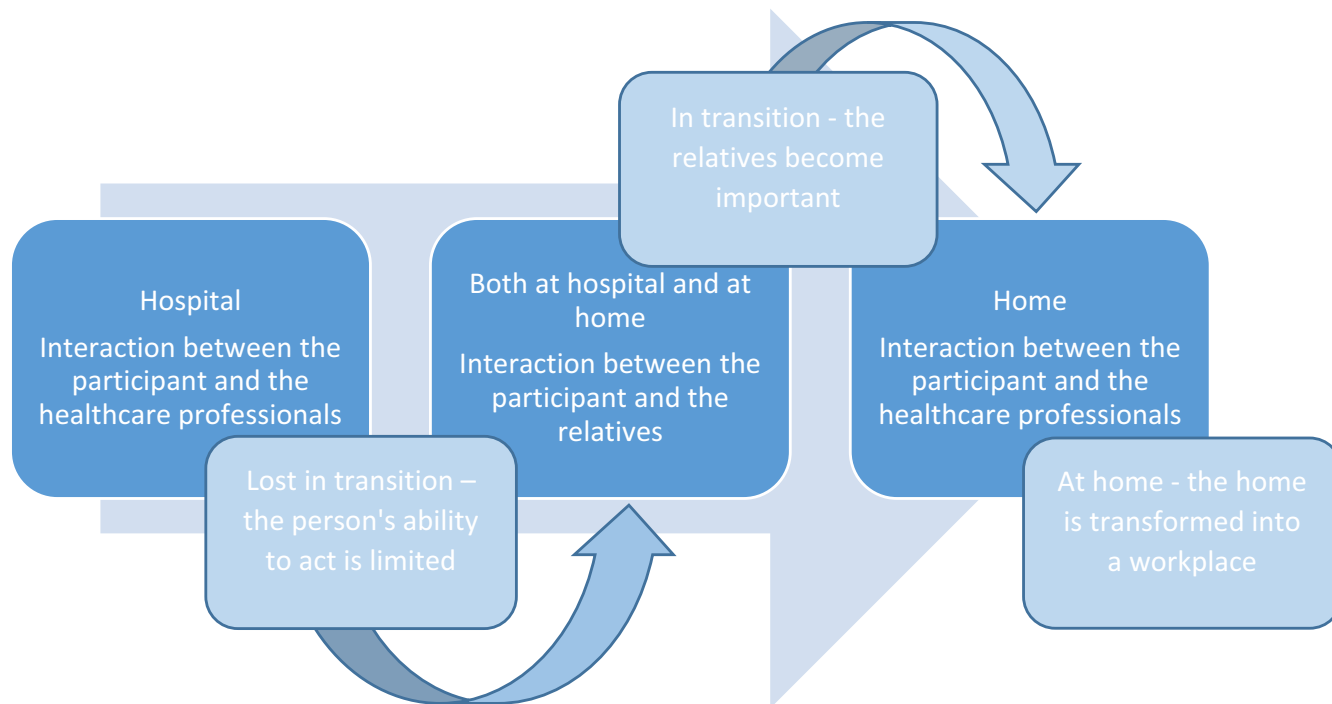
nurse specialist in the department of geriatric medicine before the study took place. This position allowed her to be familiar with the practice, services provided and the staff at the ward as well as assess the quality of nursing care services provided [24]. Reflections on positioning and change of perspective [25], including the objective of the study were performed during the observations. Reflexive notes regarding shifting positions between being a researcher and an RN, e.g. in one situation where a participant was about to fall when she stood up and the first author intervened in the situation were discussed with two supervisors to ensure positional and ethical awareness during the study period.

## Ethical considerations

The study was conducted adhering to the Helsinki Declaration [33] and approved by the management of the department and the municipality. The study was approved by the Ethical Committee (Projekt-ID: S-20210157) and the Data Protection Agency in the (Journal nr.: 21/57714). At the hospital, participants were informed in writing and verbally about the aim and methods of the study before written consent was

**TABLE 2** Example of the analysing process of theme 1 'Lost in transition – the person's ability to act is limited'.

| Analysis       | Sub-themes  | Theme   |
|----------------|---|---|
| Conditions     | Expressing concerns about not being ready to go home<br>Disarming responses from healthcare professionals<br>Lack of being involved, seen and listened to by healthcare professionals<br>Distress<br>Physical dependence on healthcare professional | 'They say, I am ready, but I am so confused' (Field notes, ID 9)<br>'You should go home – it's best for you'<br>'Do you think I'll receive help with a shave before I go home?' (Field notes ID 5)  |
| Meanings       | The participants experienced the situation as stressful<br>Only being able to do as told<br>A feeling of being forgotten<br>Lack of control<br>The feeling of not being respected as a person   | 'I am so confused, I have to go to the hospital tomorrow again, but that she did not say anything about' (Field notes, ID 9)<br>'Some of the RNs are very nice and we can talk, others I wish I never had to see again, but that I cannot control' (Field notes ID 5) |
| Reasoning      | Concerns about being confused<br>Concerns about their home being dirty<br>The participants became passive and quiet<br>Described feeling disconnected in the transition<br>Concerns about being dropped on the floor                                | 'They say, I am ready, but I am so confused, ...and my home, I was so sick before I came here, there must be so dirty' (Field notes, ID 9)<br>'Will I be dropped on the floor again?' (Field notes ID 5)  |
| Ability to act | Inability to act, e.g., by not asking questions about their upcoming discharge<br>Expressed their worries (informal interviews)<br>Restless walking around<br>Passive<br>Feeling vulnerable   | 'Do you think she has forgotten me?' (Field notes ID 5)   |



**FIGURE 1** Illustrates the transition on the day of discharge from hospital to home and an overview of the three themes.

obtained. For the two participants not able to read due to visual impairment, the information was read to them before they signed the consent. Some participants would like to have their relatives informed before participation and then the first author contacted the relative. During the observations, the first author was sensitive to the participant's situation, listening and giving time and ensuring that the participant still consented to participate. The relationship was respectful and caring. The first author used her professional background, her familiarity with the population and the routines in the hospital. The HCPs and others involved in the care of the participant were informed about the project in either a written document and/or verbally at the time of observation. All data was stored on a secure server.

## RESULTS

The analysis revealed three themes: (1) Lost in transition – the person's ability to act is limited, (2) In transition – the relatives become important and (3) At home – the home transforms into a workplace. The transition process, places for observation and the three themes are presented in Figure 1. To validate the meaning and reliability of the themes, field notes and quotes from the observations and interviews are presented in the themes.

### Theme 1: Lost in transition – The person's ability to act is limited

All participants were aware that they were to be discharged from the hospital, but most participants did not know the time of discharge or could not recall if they had received the information about the time of discharge. Several participants expressed concerns about not being ready to go home when they talked with the HCPs about their upcoming discharge. Most times the participants' concerns were dismissed with a disarming response like 'It's going to be fine' and 'You should go home – it's best for you.' In situations where the participant's concerns were not met, the participant seemed more distanced in the subsequent contact and dialogues with the HCPs and most participants withdrew and became quiet, making it difficult for the participants to ask questions regarding their upcoming discharge.

Lack of being involved, seen, heard, or understood became a constraint in the participant's ability to act in the situation and only being able to do as told. The participant's inability to act on discharge plans and not being listened to generated a vulnerable situation for the participant. The following excerpt illustrates a situation between a participant and a nurse:

'Are you ready to go home?' the nurse asks as she sits down on a chair next to the bed. The



participant looks up and replies slowly ‘They say, I am ready, but I am so confused, ...and my home, I was so sick before I came here, there must be so dirty.’ The nurse replies in an optimistic tone: ‘You must take it little by little when you go home, maybe somebody can help you,’ as she continues the talk about other topics regarding the discharge. After the nurse left the room, the participant shook her head and said: ‘I am so confused, I have to go to the hospital tomorrow again, but that she did not say anything about.’

(Field notes, ID 9)

Most participants experienced the upcoming discharge as stressful. Distress was a condition all participants experienced during the discharge, but they managed it in diverse ways. Some started nervously reflecting on the upcoming discharge and expressed their worries verbally during the informal interviews and non-verbally it was observed that some participants became restless walking around and others became more uncommunicative, closing their eyes. The participants often shared their concerns after the HCPs had left the room:

One participant who wasn't able to stand said that the paramedics had by accident dropped him twice when trying to help him to stand even though he had told them he was unable to do so. He was concerned about the upcoming transition and said: ‘Will I be dropped on the floor again?’

(Field notes ID 5)

As all the participants were physically dependent on the HCPs and in different situations experienced not being heard when expressing their concerns, it created an uneven relationship where the participants became dependent on and also dependent on the mercy of the HCPs who became in charge of the situation where the participants needed help. This had consequences for the participant's ability to act in the situation and a condition for interacting with the HCPs as the participants had no control over the situation:

At the hospital, the participant didn't receive help with shaving during the morning routine, but the social and health care assistant had said she would help him later. During the morning, he says several times ‘Do you think she has forgotten me?’ ‘Do you think I'll receive help with a shave before I go home?’ ‘Now she left the room again.’ Later, he reflected on the feeling of being dependent: ‘Some of the HCPs are very

nice and we can talk, others I wish I never had to see again, but that I cannot control’.

(Field notes ID 5)

The participants expressed a lack of control and not being involved and respected as a person with individual needs. As a result, some participants developed a distrust of the HCPs and feared receiving the right help when needed. The lack of involvement and being listened to by the HCPs became a constraint for the participants in the transition; they became passive and disconnected from the process of discharge.

## Theme 2: In transition – The relatives become important

Observations at the hospital revealed that having a relative present was important and created possibilities for the participants to manage their situation and upcoming discharge. In the presence of their relatives, the participants seemed calmer in the interactions with the HCPs and relied on their relatives to help understand, remember and coordinate, e.g., picking up medicine at the pharmacy, or going grocery shopping. Thus, the participants did not have to worry about that when coming home from the hospital. In several situations, the HCPs delivered essential information only on the day of discharge:

At the hospital, the participant is sitting together with his wife. He says that he is now readmitted for the third time. The doctor enters the room for the daily ward round. The participant sits quietly and looks at the doctor while she talks. The doctor tells them what symptoms to be aware of after discharge and when to go to their general practitioner. His wife finds her notebook and takes notes of what is said and asks for specific answers to blood samples, she says ‘I have to write it down to remember’.

(Field notes ID 4)

In situations where the spouse or other relatives were present, the spouse or relative took responsibility for coordinating and became active representatives for the participant in planning the discharge. In the informal interviews, the participants expressed their gratitude for their relatives' active involvement in their discharge one participant said:

‘I could not have managed picking up medicines at the pharmacy and going grocery shopping on my own.’

(Interview ID 7)

The relatives interacted in both practical matters and in ensuring that the HCPs got to know the participant's values and wishes, as the participants did not express their needs. A few times, it was observed that the relative had a dialogue with the municipal HCP about the participant's wishes to regain function, e.g., cooking and the possibility of being assisted in those activities.

Living alone with no close relatives present or living with a spouse who was not present during discharge, seemed to have negative consequences for the participants, as they were unable to remember the information given or engage in the conversation. In one situation the participant was waiting to go home from the hospital:

The participant is informed about what nutrition and meals would be good to eat at home after discharge; they talk about the nutritional drinks he likes. Once in the participant's home we, i.e., the participant, his wife and I talk about the food the wife says she cooks, but they also often buy ready-prepared meals to heat in the microwave. She is the one in charge of the grocery shopping but is dependent on their son to drive to the supermarket. She says that the participant has tried the nutritional drinks from the store, but he does not like them, so she will not buy them anymore.

(Field note 8)

It was observed and talked about that two of the participants had a spouse, with whom they did not live together. The spouses were very engaged in the care of the participants as the participants were dependent on their help as they experienced that home-based care was limited to certain tasks:

In one family the spouse had moved into the family's holiday house. However, she was still involved in caring for her husband. She took responsibility for practical issues like paying the bills, cooking, or helping with changing batteries in the hearing aids. Help with changing batteries and care for other technical aids were experienced as tasks that were not conducted by home-based care, so the participant was highly dependent on help from his spouse.

(Field notes ID 5)

All participants were grateful for the help received from their relatives but felt at the same time that they were a burden to them.

### Theme 3: At home – The home is transformed into a workplace

Upon arrival at home after discharge, the participants were either met by a social and health care assistant, a social and health care worker, or an unskilled person. Some participants had experienced a functional decline due to the acute illness leading to hospitalisation and needed more help or were new to home-based care. In some cases, it was observed that the participants were not involved in the decisions regarding which kind of assistive aids they would need in their home, nor how and where in the home the aids should be put, or how the house should be re-arranged:

When the participant gets into the kitchen in his house, he sits on a chair. A social and health care assistant and an apprentice were present. The apprentice is preparing lunch and the social and health care assistant is throwing old food out of the refrigerator. She says 'I ordered a hospital bed and a toilet chair for you to have in your living room after I saw that you needed a wheelchair for the transportation home' still moving between the refrigerator and bin. The participant replies 'I don't want a bed in my living room.' The social and health care assistant says, still facing the other way: 'You can't take the stairs to your bedroom on the first floor.' The participant looks down and moves a little on some newspapers on the table.

(Field notes ID 3)

Not being involved in changes made in the participant's home or installation of different equipment impacted the participant's everyday life and feeling of autonomy in their home. More participants expressed that they felt they no longer were in control in their own homes. Also, it affected their relations with their spouses. In one family the participant and his wife expressed the importance of the participant staying at home, so they had planned for the future deciding on how to redecorate the house. In three families, the spouses had to move out of their bedrooms to make room for both a hospital bed, a wheelchair and a working space for the HCPs:

The spouse showed how they had arranged 'a new bedroom' for him at one end of the living room and tried to divide the living room into separate rooms (Field notes ID 1). In another home, the living room was turned into a

bedroom as it was the only room in the house accessible for the hospital bed.

(Field notes ID 5)

The transition from living in a *home* to living in a *workplace* was also observed when HCP entered the participant's home after hospitalisation. Most HCPs entered the participants' homes without knocking and some even without presenting themselves or saying 'hello' to the participant:

When the social and health care assistant entered the house for the first time she knocked on the door and said out loud 'Hi, it is Lisa from homecare'. Without asking further, she entered the house, looked around, by herself tried to find the refrigerator and then started preparing food and soft drinks. The participant was sitting passively, she looked around nervously, having a stranger going around in her kitchen.

(Field notes ID 9)

Some of the participants expressed that being discharged from the hospital while feeling frail and dependent on various HCPs caused a lot of distress and worry. Most participants expressed they felt a lack of dignity in their lives, which had an impact on their sense of self and their zest for life. During the observations, none of the participants were asked about their physical or mental well-being and their resources and wishes were not explored. During the informal interviews, two participants expressed:

'It is not a worthy life.'

(Field notes ID 2)

'If I'm not going to walk again I rather have the bolt pistol.'

(Field notes ID 7)

## DISCUSSION

This study aimed to fill a gap in the literature by exploring older people's experiences when transitioning back to their homes after hospitalisation. An observational study complemented with informal interviews gave insight into the participants' possibilities and constraints in their interactions with HCPs and relatives during the transition and how this affected their being during the transition. Sitting next to the participants and observing the interactions with HCPs and relatives made all

observations and interviews placed within the older person's life and context. Our study revealed how patients became increasingly vulnerable in the transition from hospital to home due to a lack of involvement in the transition process, assumably due to the HCP working conditions and a high degree of dependence on relatives. The observations also revealed that the participants experienced a decline in autonomy and that they struggled to maintain their ability to act. As they had not been involved in their discharge or future care, nor in the way their homes should be arranged with new aids, most participants had the feeling of being frail and vulnerable.

The term vulnerability is frequently used to categorise groups or individuals who are at risk of harm [34]. According to Spiers [34], the concept of vulnerability encompasses both an external (etic) perspective and an experiential (emic) perspective. From an etic, outsider perspective, vulnerability can be assessed through objective measures such as age, multimorbidity, socioeconomic status and ethnicity. In numerous studies, older individuals are categorised as vulnerable using this etic approach using demographic characteristics such as age, living conditions with challenged health conditions, frailty and other risk factors [10, 12, 35]. In our study, participants seemed assessed by the HCPs only from an etic perspective as vulnerable having a functional decline, being dependent on help and living alone. Assessing vulnerability from an emic perspective involves exploring four aspects within the individual's personal experience: integrity, challenge, capacity for action and multi-dimensionality [34]. In our study, the participants expressed their vulnerability as a lack of involvement and not being listened to by the HCP. Further, the participants felt a loss of autonomy and in their relationship with the HCP, they became withdrawn and quiet. Some of the participants even felt unsafe and described their situation as unworthy and with a lack of dignity.

Our results underline that most participants in the transition from being hospitalised and being discharged to their homes experienced multiple transitions, more experienced the transition from hospital to home and interaction with the HCPs left them with limited choices and a lack of ability to act. The transitions were mostly related to the participant's health and illness and occurred simultaneously [3]; the physical transition from hospital to home, the transition of being acutely ill to recovery, the transition from being independent to being dependent on help from others and for some the transition of living in a home to living in a home that also functioned as a workplace. The HCPs had a role in either promoting the participant's possibilities or being a constraint in the transition process.



In Meleis' theory on transitional care [36] she defines a transition as:

A passage from one fairly stable stage to another fairly stable stage and it is a process triggered by change. Transitions are characterized by different dynamic stages, milestones and turning points and can be defined through the processes and/or terminal outcomes.

[36, p. 11]

Transitions are typically prompted by events that require some action as they can impact a person's identity and behavioural patterns [3]. Meleis classifies transitions into three types: developmental, situational and health/illness. The transitions can either occur simultaneously as clusters of transitions or as sequential transitions where the transitions ripple over time [3]. These transitions can be perceived as healthy or unhealthy processes by the older person [3]. According to Meleis nurses may need to provide therapeutics, e.g., assessment, role supplementation, or mobilisation of the person's resources to ensure the well-being of individuals undergoing these transitions and their ability to care for themselves [36].

In Meleis' theory on transition [36], she describes that a person in transition may suffer, if he or she is not prepared for the transitional experience [36] and the multiple transitions can be experienced as undesired and create the feeling of loss [3]. We identified several different transitions where the participants were not heard or involved in the process. One example was the transition from being independent to being dependent on help from HCPs, which entailed a transformation of the patient's home into a workplace. Jarling et al. [37] found that older home care-receiving persons experienced being a guest in their own homes and that HCPs' routines are prioritised over the older person's wishes, values and needs. Also, (home) adaptation is considered a requirement not to be negotiated [37]. These findings are similar to our results as we found that absence of involvement affected the older person's ability to act and thus negatively affected the participant's ability to pick up everyday life once back in their home. Similar findings are described by Lilleheie et al. [10] who found that older hospitalised patients did not feel encouraged in the decision-making and not being asked about their preferences and needs [5]. In our study, the participants experienced a lack of autonomy and involvement when receiving help both at the hospital and at home and for some, this affected their everyday life or their zest for life. Lilleheie et al. [10] also found that in life after discharge the older patients struggled and strove to maintain everyday tasks as they described their situation with

words such as 'helplessness', 'concern' and 'fear' when depending on help from HCP at home [5].

In our study, the participant's relatives became of importance during the transition from hospital to home. Relatives created possibilities being present during discharge the participants experienced their values and wishes being represented; their relatives also assisted the participants with practical help during discharge. Most participants were dependent on their informal caregivers. Being able to rely on informal caregivers is also identified as crucial in other studies on the transition from hospital to home [13, 15], where relatives were identified as being significant for the older person's recovery and ensured practical help as well as support in everyday life [15]. Well-being and happiness in older adults have been examined and showed a positive effect of living with relatives than those living alone [38]. The frequency of married couples who lived apart in our study was surprisingly high, which may be a coincidence and we have not found any studies describing similar results.

In a political context, our findings can be related to the governing paradigm of New Public Management (NPM). The purpose of NPM is to make the healthcare system more efficient [39, 40]. In a Statement from The Danish Council of Ethics (Det Ethiske Råd) [41, 42], it is argued that this purpose has led to a standardisation of treatment and care with an increased quantity of guidelines, resulting in a general de-prioritisation of care-based nursing [41]. For the healthy and strong citizen, it is valuable, but an overall demand for patients and relatives to provide self-care has also a risk of increased inequality and this entails challenges for the HCP in providing the needed care and patient involvement [42–44] as experienced by the participants in our study.

## Strengths and limitations of the study

In research, older persons are often excluded due to their higher age and vulnerability [45, 46]. However, the method employed in the current study allowed for the inclusion and exploration of the perspectives of older individuals, thus giving them a voice.

The insider position of being a former employee and colleague proved beneficial in this study as it was easy to access the field and the procedures were known. Furthermore, the insider perspective was a strength as it allowed the researcher to observe and assess the quality of services provided beyond the obvious [24], which may not have been possible if an unfamiliar person in the field had conducted the observations [24, 25, 31]. However, it is important to acknowledge that this positioning may have resulted in blind spots. To address this challenge,

continuous reflections with author SHB, author KAR and author DSN, triangulation, informal interviews [25] and conscious self-awareness during data collection [31] were employed. A limitation might be the healthcare professionals were affected by the researcher's presence and could have to change their behaviour, the Hawthorne effect, where participants modify their behaviour due to being observed [47].

## CONCLUSION AND IMPLICATIONS FOR PRACTICE

Our study revealed that older patients experienced not being seen, heard and involved in the transition from hospital to home. Using participant observation made it possible to identify how the lack of involvement becomes a condition for older patients as some struggle to create meaning in their transition, affecting their everyday lives. The patients experienced their relatives as important as they ensured that the HCPs got to know their values and wishes. The transition process increases older persons' vulnerability, both from an etic and emic perspective, negatively affecting their ability to actively take part in the transition and their everyday lives. Healthcare professionals need to be more aware and sensitive and work closely together with older people, both at the hospital and at home, ensuring active involvement with respect and acknowledgement of the older person's wishes, needs, resources and vulnerability.

## AUTHOR CONTRIBUTIONS

SHB and DN contributed to the study conception and design, data collection, data analysis and discussion and drafted the manuscript at all stages. GE, KAR and AJ contributed to the data analysis, critical reflections and reviewing and approving the final version of the manuscript.

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## CONFLICT OF INTEREST STATEMENT

The authors declare that there are no conflicts of interest.

## DATA AVAILABILITY STATEMENT

The dataset of the current study is not available due to the written consent.

## ETHICS STATEMENT

Research data are not shared, due to ethical guidelines, participants' written consent and the imperative need to uphold confidentiality only authors have access.

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