

## Review Article

# Perspectives on Transitional Care for Vulnerable Older Patients: A Qualitative Study

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## Abstract

**Background:** Transitional care for vulnerable older patients after acute hospitalization back home is increasingly important. Despite previous studies, optimal transitional care of vulnerable older patients remains undefined.

**Purpose:** This study explores what is needed to satisfy these patients with transitional care, from the perspectives of these patients themselves, informal caregivers and nurses.

**Methods:** Patients (n=13) and informal caregivers (n=10) were interviewed after hospital discharge. Hospital and home care nurses (n=9) participated in two focus groups. Verbatim transcriptions were analyzed according to the framework method.

**Results:** Patients (mean age 85.5) and informal caregivers indicated transitional care is optimal if, on top of the organization of this transition, they have trust in the professionals involved. Elements of this organization and trust together stimulated three preferred outcomes of transitional care: the patient going home, the patient reaching adequate health and feeling safe. Nurses indicated no other elements or outcomes.

**Conclusion:** Transitional care for vulnerable older patients is optimal if, on top of the organization of transitional care, these patients and their informal caregivers have trust in the professionals involved. Regarding the challenge of organizing increasingly complex transitional care for vulnerable older patients, the focus should shift towards optimizing trust.

**Keywords:** Discharge Planning; Nurse-Patient Relationships; Older Adults; Patient Perspectives; Primary/Secondary Care Interface

## Background and Purpose

The population of older persons is growing and the length of hospital stays decreased over the last decades. These trends together cause a rapid increase in the number of older patients experiencing hospital discharge while still being in a vulnerable status [1]. For these patients, rehabilitation for a larger part takes place outside the hospital, under the responsibility of primary care providers [2]. Besides, the proportion of Dutch older persons receiving primary care by home care organizations has increased [3]. Hence, transitional care, the continuity of care between the inpatient hospital care and primary care back home, is increasingly important for vulnerable older patients.

In reaction to these trends, many interventions have been developed to optimize transitional care for vulnerable older patients over the last decades. Among others, interventions were developed that implemented communication between hospital and primary care providers before hospital discharge [4], discharge planning [5], geriatric assessments and post discharge support [6,7] into organizational structures. Many of these interventions aim to reduce length of hospital stays, number of ED visits after discharge or to improve quality of life. Reviews showed that several of these interventions indeed do so [8,9]. However, the underlying mechanism improving these outcomes remained unknown [8].

Accordingly, patients' experiences with transitional care often remain suboptimal [5,10-12]. Little is still known about what is needed to optimize transitional care from the perspectives of vulnerable older patients [13,14]. Until today the majority of qualitative studies regarding transitional care for vulnerable older patients focused on the perspectives of professional care providers. However, their perspectives are divergent [11,15]. Exploring the perspectives of vulnerable older patients on transitional care and comparing their perspectives to the perspectives of health care providers may help to point further research, health care innovations and policy development on optimizing transitional care in the right direction.

## Methods and Procedures

### Design

This study has a qualitative design using semi-structured interviews and focus groups. We conducted interviews with vulnerable patients aged 70 years old and over, who were recently discharged after acute hospitalization with an indication for home care, and their informal caregivers. Elements of optimal transitional care were identified from their perspectives. Focus groups were conducted with hospital and home care nurses to explore major differences and similarities between the perspective of these professionals and the perspective of vulnerable older patients and their informal caregivers. The interviews and focus groups were performed between April and

November 2017 in the South Holland province of the Netherlands. Participants were recruited from an academic hospital, a regional hospital and several home care organizations.

### Participants

Vulnerable older patients were selected from the hospitals' electronic patient files by entitled geriatric and transfer nurses in March 2017. Inclusion criteria were age of 70 years old or over, acute hospitalization and vulnerability during the hospital stay according to the Dutch 'VMS screening' that regards age, delirium, falling, malnutrition and physical limitations [16]. Exclusion criteria were terminal illnesses, language barriers and living outside the study area. Eligible patients were contacted by telephone to ask for their participation in an interview at home about their experiences around their hospital discharge, preferably together with one of their informal caregivers. The aim was to recruit approximately fifteen patients to be able to reach data saturation.

To invite hospital and home care nurses for participation in a focus group, an e-mail was sent to care managers of the four largest home care organizations in the area and to the heads of three hospital departments per hospital. The aim was to organize two focus groups in which various home care organizations and the two hospitals would be represented. There were no exclusion criteria.

All participants gave oral and written informed consent before the start of their interview or focus group. The area's medical ethical committee 'CME' did not need to approve upon the study, since the study was not subject to the Dutch Medical Research Involving Human Subjects Act (WMO).

### Data Collection

The semi-structured interviews were guided by topic lists. To compose this topic list, we selected questions possibly relevant to vulnerable older patients and their informal caregivers in transitional care from four well known Dutch and European existing questionnaires on continuity of care [17], hospital care [18], pre-operative care [19] and general practice care [20], and from a topic list of an earlier qualitative study about elderly persons' experiences with participation in hospital discharge process [21]. The topic list was checked by members of a regional older person's advisory board and a pilot interview was performed. The topic list included questions about continuity of care, alignment, information provision, patient participation, interaction with professional care providers, feelings, overall satisfaction, points for improvement and demographic characteristics. All interviews took place at the patients' homes and were performed by a master student.

For the semi-structured focus groups, a topic list was written as well. The main question of this topic list was 'What is the ideal transition of care for vulnerable older patients?'. Other questions were about the organization, barriers, improvements, target group, tips and tops of transitional care for vulnerable older patients and demographic characteristics. Focus groups took place in the academic hospital within the study area and were moderated by a junior researcher and observed by a senior researcher. All interviews and focus groups were audio recorded and field notes were made.

### Qualitative Analysis

The audio recordings were transcribed verbatim. For

familiarization with the data, all audio recordings were listened. Analyses were performed by two researchers according to the framework analysis as described by Green and Thorogood. [22], in Microsoft Office Word and Excel as follows. Based on elements of optimal transitional care identified from openly coding the focus group transcripts and two interview transcripts and from literature, a framework of codes was made. Subsequently, all transcripts were coded with this framework. New codes and sub-codes were added throughout the coding process. Some codes were grouped into plausible elements of transitional care according to the researchers. By re-reading and re-coding, elements were organized into a conceptual model about which consensus was reached between the researchers. Participants' demographic characteristics were described by making use of IBM SPSS Statistics version 23 descriptive statistics.

### Results

Of the selected 25 patients eligible for participation, 6 were excluded because of terminal illness (n=2), language barriers (n=3) or living outside the region (n=1). Of the 19 vulnerable older patients approached, thirteen (68%) agreed upon participation in an interview. All interviews took place seven to thirteen days after hospital discharge and lasted for 25 minutes to one hour. In Table 1 the characteristics of the participants from the interviews and the focus groups are presented. The patients' mean age was 85.5 years old (SD 1.5, range 77 to 95), 8 of them (61.5%) of them were female and their hospital stay ranged from 3 to 14 days (mean 8.0 days (SD 1.0)). In 10 of the 13 executed interviews, an informal caregiver participated as well. The informal caregivers of two patients had work obligations at the moment of the interview and one patient did not have any informal caregivers. The informal caregivers were spouse (n=3) or offspring (n=7) of the patient. Interviewed patients and informal caregivers graded their satisfaction with the transition of care in a range from 6 to 10 on a 0-10 scale (patients: mean 8.1 (SD: 0.3), informal caregivers: mean 7.8 (SD 0.5)). Data saturation was reached.

The 10 nurses who signed up to participate were divided over two focus groups. 9 of them (90%) showed up. In total, 5 of them were hospital nurses and 4 were home care nurses. They represented an academic hospital, a regional hospital and three home care organizations in the study area. Both focus groups lasted approximately 75 minutes.

### Perspectives of Patients

Patients and informal caregivers indicated what Informal Caregivers elements of the transition of care contributed to the quality of this care for vulnerable older patients. Some of these elements had to do with the underlying need for 'organization' of the transition and some with the underlying need 'trust' in professionals. Both organization and trust contributed to three preferred outcomes vulnerable older patients and their informal caregivers have in the transition of care: going home, adequate health and feeling safe.

### Preferred Outcomes

The most prominent preferred outcome of vulnerable older patients and informal caregivers in transitional care was 'the patient going home' (quote 1). A second preferred outcome was both the patient and informal caregiver feeling safe. The third preferred outcome was the patient reaching an adequate health status, which

**Table 1:** Baseline characteristics.

|                                     |                                   | Vulnerable older patients (n=13) | Informal caregivers (n=10) | Nurses (n=9) |
|-------------------------------------|-----------------------------------|----------------------------------|----------------------------|--------------|
| Age                                 | Median (IQR)                      | 86 (81-89)                       | 63 (55-80)                 | 33 (28-33)   |
| Sex                                 | N (%) female                      | 8 (62%)                          | 8 (80%)                    | 9 (100%)     |
| Satisfaction care 0-10              | Mean (SD)                         | 8.1 (1.1)                        | 7.8 (1.5)                  |              |
| Education level                     | N (%)                             |                                  |                            |              |
|                                     | primary school                    | 5 (39 %)                         |                            |              |
|                                     | secondary or vocational education | 6 (42,2%)                        |                            |              |
|                                     | (applied) university              | 2 (15,4%)                        |                            |              |
| Length of hospital stay in days     | Mean (SD)                         | 8.0 (1.0)                        |                            |              |
| Reason for hospital admission       | N (%)                             |                                  |                            |              |
|                                     | cerebral hemorrhage/ -infarction  | 2 (15%)                          |                            |              |
|                                     | shortness of breath               | 2 (15%)                          |                            |              |
|                                     | myocardial infarction             | 1 (7.7%)                         |                            |              |
|                                     | pneumonia                         | 1 (7.7%)                         |                            |              |
|                                     | delirium                          | 1 (7.7%)                         |                            |              |
|                                     | other                             | 3 (23%)                          |                            |              |
|                                     | unknown                           | 3 (23%)                          |                            |              |
| Subjective health at homecoming     | N (%)                             |                                  |                            |              |
|                                     | sufficient, good                  | 3 (23%)                          |                            |              |
|                                     | moderate                          | 6 (46%)                          |                            |              |
|                                     | bad, insufficient                 | 4 (31%)                          |                            |              |
| Informal caregiver-patient relation | N (%)                             |                                  |                            |              |
|                                     | spouse                            |                                  | 3 (30%)                    |              |
|                                     | offspring                         |                                  | 7 (70%)                    |              |
| Nursing position                    | N (%)                             |                                  |                            |              |
|                                     | home care                         |                                  |                            | 4 (44%)      |
|                                     | hospital (geriatrics)             |                                  |                            | 3 (33%)      |
|                                     | hospital (discharge)              |                                  |                            | 1 (11%)      |
|                                     | hospital (transfer)               |                                  |                            | 1 (11%)      |
| Years of experience nursing         | Median (IQR)                      |                                  |                            | 5.0 (1.8-16) |

was specified as recovery, as reaching independency or as prevention of rehospitalization. These three preferred outcomes sometimes contributed to one another (quote 2). If preferred outcomes were already fulfilled, the organizational elements and elements of trust were experienced as less important.

- **Quote 1:** “I had heard about homesickness before, homesickness, what nonsense is that? Nonsense. But then I actually was homesick. Oh, if only I could go home, if only I could go home. That’s my only wish.” (female patient)

- **Quote 2:** “She was rather weakened, but seeing how much my mother likes to be home again, in her own environment where she feels safe, with her cat, and the visits of alternately us and the formal care givers that comforts me.” (a patient’s son)

### Organization of Transitional Care

Study participants indicated that various organizational aspects contributed to optimal transitional care; involvement of the informal caregiver, attention for the patient’s and informal caregiver’s wishes

and situation, information provision towards the patient and/or informal caregiver and professionals being informed. These organizational aspects enabled participants to reach the preferred outcomes.

The first mentioned element in organization was involvement of the informal caregivers in transitional care. Informal caregivers were important in receiving information, since some of the patients could not remember or understand all information given. This made patients feel safe (quote 3). Furthermore, involvement of the informal caregiver helped the patient to go home as soon as possible; often part of the care needed after discharge could be given by the informal caregiver. One patient suggested to structurally have discharge conversations between hospital care providers, patient and informal caregivers.

- **Quote 3:** “I was lying there and it all just happened to me. That’s how it felt. Again, I had back-up from my daughters of course. I actually wasn’t a patient on my own, I still had those three girls

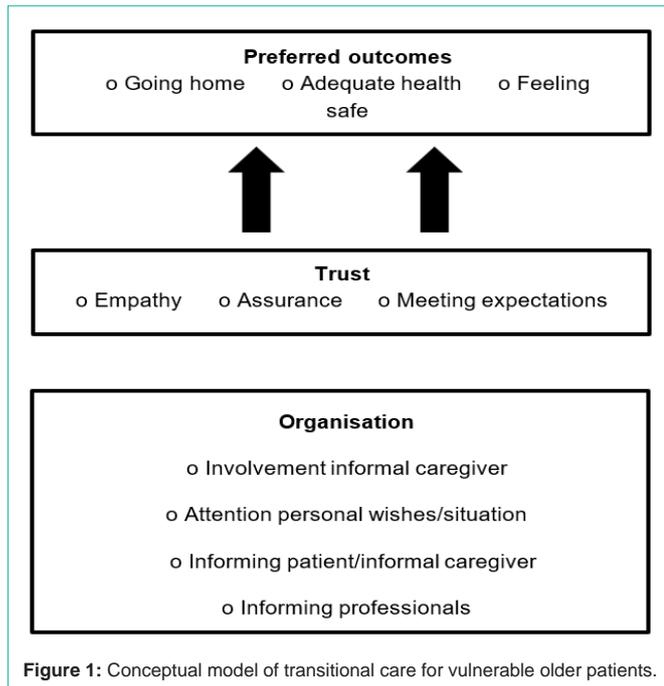


Figure 1: Conceptual model of transitional care for vulnerable older patients.

around me” “I am a nervous patient. I am quickly worried about something as soon as something is going on, so I have one of the three.” (female patient).

Secondly, attention for the patients’ and informal caregivers’ wishes and situation was an important element of organization facilitating the preferred outcomes. However, the amount of attention being sufficient differed per person; some patients highly valued privacy. One informal caregiver explained she especially found home care nurses’ attention for her father’s situation important; he was fully dependent on these nurses (quote 4). Variety in professionals caring for a patient was experienced as a barrier towards attention for personal wishes and situation.

- **Quote 4:** “You are completely dependent on whoever visits you so you need people who understand the situation someone is in. Some just do their job and others really understand my father’s situation.” (a patient’s daughter).

Thirdly, several participants stressed the importance of them being informed. They wanted to receive information about the patient’s health status, applicable health indicators, treatment risks, expected date of discharge, reasons for discharge, aftercare and medication prescriptions. This information helped patients to take control over their own rehabilitation and reach an adequate health status (quote 5) and to feel safe. However, too many spoken information at once was counterproductive and inconclusive information was displeasing.

- **Quote 5:** “I want to know what’s going on with me. I want to stay in control. And make sure that I get well as quickly as possible.” (female patient).

Fourthly, several participants indicated the importance of professionals being informed. Some patients illustrated that the General Practitioner (GP) and home care nurses being informed about their discharge and situation was crucial to recover and a

prerequisite to go home. Several participants thought this supply of information was the responsibility of the hospital care providers (quote 6).

- **Quote 6:** “I think the GP should know what’s going on, so if I call him, he knows why he should come. At hospital discharge, a message is supposed to go to the GP immediately I shouldn’t have to call him.” (female patient).

### Trust in professional care providers

Besides organization of transitional care, aspects of trust contributed to the preferred outcomes, most explicitly to feeling safe. Firstly, empathy of professional care providers was an important element of trust. It was a recurring topic in several interviews and seemed to greatly influence participants’ overall experience of the transition of care (quote 7) and feelings of safety. Medical or organizational flaws often were forgiven if treated with empathy (quote 8).

- **Quote 7:** “When you lie in such a hospital you are very... sad, sad you could call it. The kindness of the people, that affects you most. I mean, you don’t need a pill.” (patient 10: 89 years old woman)

- **Quote 8:** SK: “And if we have a look at the people who come here to help, [do you have] trust in them as well?” Informal caregiver: “Yes, [they are] sweet, very sweet. They always wait until that device [probe feeding pump] works well. Well, today it went completely wrong. But that wasn’t her fault.” (a patient’s wife).

Secondly, concrete assurance that continuity of care was organized was important. Study participants felt unsafe when this assurance was missing, for example when primary care providers were inaccessible during holidays or when there was no guarantee the GP would read the discharge letter from the hospital in time. While some participants approached professionals to obtain this assurance themselves, others were resistant to take initiative. Assurance could be given by hospital care providers orally (quote 9), but also by primary care providers physically delivering suitable care immediately after discharge.

- **Quote 9:** “I said ‘doctor, you wouldn’t let me go home this ill right? He said ‘no, we surely won’t, whenever you go home, you will be able to move on’, and indeed they took care of that.” (female patient)

The third element important in trust was meeting expectations around hospital discharge. If expectations were not met, this negatively affected patients’ and informal caregivers’ trust in the professional care provider (quote 10). Several patients and informal caregivers had only low expectations (quote 11), for example if they believed their hospital stay was too short to expect much. These expectations were met or exceeded and their trust remained.

- **Quote 10:** “If you’re a GP you should have a little trust towards your patients, gaining trust and he does not. I never met this man, maybe he is very kind and maybe he is very busy, I do take that into account, but the first thing a GP should do is ask how it has been, he didn’t do so.” (a patient’s son).

- **Quote 11:** “A hospital is like a large family, exactly like it. Do you like the food? Yes, one thing you like better than another. At home you don’t always get good food either. And there’s a lot

of things like that. They help you; they try to please you as much as possible. But yes, sometimes something happens that you don't like that much." (female patient).

These findings from the perspective of vulnerable older patients and informal caregivers are summarized in the conceptual model in Figure 1.

### Perspective of Hospital and Home Care Nurses

No additional elements important in transitional care for vulnerable older patients were found from the perspective of hospital and home care nurses. Nurses mentioned the same organizational elements. Involvement of informal caregivers contributes to improvement of care (quote 12). Attention for personal wishes/situation was found important (quote 13) and informing patients and informal caregivers was also seen as important (quote 14), especially to make informal caregivers feel safe. Informing professionals was frequently discussed, because it contributes to improvement of care as well as to assurance of both the professionals and patients (quote 15). Absence of a strict organization of the transition of care was called dangerous. Nurses believed that clearly formulated interventions could be implemented to achieve well organized transitional care.

The nurses discussed the preferred outcomes and importance of trust less explicitly. However, the role of empathy (quote 12) and assurance (quote 15) in trust and all three the preferred outcomes (quote 12, 13, 15) seemed underlying notions in their discussions.

- **Quote 12:** "It's just when you have time for those people and you sit down next to them [informal caregivers], with a book and writing things down, I really have the feeling that you are taking away a lot [of worries] already, and that the care expires in a better way" (hospital nurse geriatrics) "Yes, we experience that at home as well." (home care nurse).

- **Quote 13:** "I had a client who was, well I don't know if she was already seventy, but she was very vulnerable, and was allowed to go home, because she was rehabilitated and well. However, she got a big wound on her foot, and she had a polluted house. So, I said she can't go home" (home care nurse).

- **Quote 14:** "We put the provisional date of discharge, the target date, on the board in the room, so the family knows about it like that." (hospital nurse geriatrics).

- **Quote 15:** "if I call you and say 'so, what have you been able to do, this and that', then I'm like 'oh nice', you know, it is going well, so she can go home and I know it will go well at home too. That lady knows that the home care nurse knows, sometimes I can already tell who will come, at what time they will come, and that's just, yes, very nice." (Home care nurse).

## Discussion

Vulnerable older patients' and informal caregivers' preferred outcomes in transitional care are the patient going home, the patients reaching adequate health and both of them feeling safe. They indicated organizational elements and elements of trust are needed to reach these preferred outcomes. The organization of transitional care for vulnerable older patients was not always optimal. However, the effect of organizational difficulties on the preferred outcomes

remained limited if the elements of trust were fulfilled.

Literature as well describes organization of care for vulnerable older patients, often with complex health problems, to be increasingly challenging [23]. Our results suggest that with this challenge trust will become more important in fulfilling the preferred outcomes. This fits the current trend towards person-centered care, as described by The American Geriatric Society Expert panel [24]. Professional care providers, as well as researchers and policy writers should take into account the importance of patients' and informal caregivers' trust and give this a place in their work.

Hospital and home care nurses recognized the same organizational elements. They also discussed trust and the preferred outcomes, although less explicitly. This indicates patients' and informal caregivers' perspectives are a valuable contribution to research.

To our knowledge we are the first to model the organization of care and trust as two aspects that count up to fulfilment of preferred outcomes in transitional care for vulnerable older patients. However, two previous studies may imply parts of our model. Firstly, a recent Dutch study, based on interviews with chronically ill patients after hospital discharge and readmission, described organizational aspects similar to the ones we found as well the importance of continuity in professionals and the feeling of being ready to go home. These last two respectively imply trust and the preferred outcome feeling safe from our results [25]. Secondly, a meta-analysis by Allen et al. [10] explained that besides optimizing efficiency in transitional care for older patients, personal attention and social processes are important [10].

The single elements of organization, involvement of the informal caregiver, attention for personal wishes/situation, informing patients and/or informal caregivers and informing professionals, were more often described in literature about older patients', informal caregivers' and professionals' perspectives on transitional care for vulnerable older patients [15,26,27]. Mainly studies that focused on patients' perspectives described the importance of trust in professionals during transitional care [13,28]. The preferred outcomes going home and adequate health were indicated before by patients in geriatric rehabilitation [29].

A limitation of the study could be selection bias. There is no data available upon the reason for 6 vulnerable older patients to reject upon participation, but they might have been more ill or less satisfied then participating patients. Nevertheless, baseline characteristics show variety in study participants.

The focus is on patients' and informal caregivers' perspectives are one of our study's strengths. Exploring their perspectives facilitated us to identify what was different from the more often studied perspectives of professional care providers. Besides, combining perspectives of patients and informal caregivers reflected how patients' perspectives are not independent of their informal caregivers' perspectives in reality [27]. A second strength was the minimization of recall bias by performing the interviews within two weeks after discharge. Besides, we noticed that the informal caregivers helped patients to remember whatever they had forgotten.

Thirdly, participants were unaware of our secondary aim to compare perspectives of vulnerable older patients and informal

caregivers to perspectives of nurses. In this way, participants stayed true to their own perspective.

## Conclusion

In conclusion, the present study contributed to a deeper understanding of what is needed to optimize transitional care for vulnerable older patients with home care indication. Consistency among our study participants and literature upon relevant organizational elements in transitional care might indicate these should be structurally implemented into practice. However, based on our results, even well-organized transitional care especially fulfilled vulnerable older patients' and their informal caregivers' preferred outcomes if they have trust in the involved professionals.

Regarding the challenge of organizing increasingly complex transitional care for vulnerable older patients, the focus on optimizing trust becomes even more important. Practicing healthcare providers, as well as future research, policies and innovations should allow for this trust between people to have a place in healthcare organization.

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## Ethical Statement

The area's medical ethical committee 'CME' did not need to approve upon the study, since the study was not subject to the Dutch Medical Research Involving Human Subjects Act (WMO).

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