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original research

“It’s like two worlds apart”: an analysis of vulnerable patient handover practices at discharge from hospital

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Oliver Groene7

ABSTRACT
Background: Handover practices at hospital discharge are relatively under-researched, particularly as regards the specific risks and additional requirements for handovers involving vulnerable patients with limited language, cognitive and social resources.

Objective: To explore handover practices at discharge and to focus on the patients’ role in handovers and on the potential additional risks for vulnerable patients.

Methods: We conducted qualitative interviews with patients, hospital professionals and primary care professionals in two hospitals and their associated primary care centres in Catalonia, Spain.

Results: We identified handover practices at discharge that potentially put patients at risk. Patients did not feel empowered in the handover but were expected to transfer information between care providers. Professionals identified lack of medication reconciliation at discharge, loss of discharge information, and absence of plans for follow-up care in the community as quality and safety problems for discharge handovers. These occurred for all patients, but appeared to be more frequent and have a greater negative effect in patients with limited language comprehension and/or lack of family and social support systems.

Conclusions: Discharge handovers are often haphazard. Healthcare professionals do not consider current handover practices safe, with patients expected to transfer information without being empowered to understand and act on it. This can lead to misinformation, omission or duplication of tests or interventions and, potentially, patient harm. Vulnerable patients may be at greater risk given their limited language, cognitive and social resources. Patient safety at discharge could benefit from strategies to enhance patient education and promote empowerment.

INTRODUCTION

Clinical handover, the transfer of information about and responsibility for a patient from one healthcare professional to another, has become an important area of research aimed at improving healthcare.1 Deficiencies and process failures in communication during handover are at the root of many patient safety problems. While much of the research has focused on handovers in a clinical setting, here we discuss handover practices between organisations, particularly transfer of information on coordination of care after discharge.2 Poor coordination of care across settings may result in discontinuity of care, confusion and patient harm, and has been identified as a factor in re-hospitalisations that are costly, potentially harmful and often avoidable.3 Since hospital readmissions adversely affect patients, payers and providers, identifying the solution requires the involvement of stakeholders across the patient care continuum.4 5

Studies have shown that a significant proportion of patients (ranging from 33% in New Zealand to 60% in Germany) report a suboptimal discharge experience from hospital.6 Healthcare professionals’ perceptions of the quality of handovers at hospital discharge echo patients’ comments about problems with quality and continuity of care.7 8 Various international and national bodies have supported research on and the implementation of patient handover practices. For example, the WHO has encouraged research and action in this field as part of their initial High 5s programme, focusing on medication accuracy during transitions of care and on communication processes during patient care handovers.9 The Australian Commission on Safety and Quality in Health Care10 and the British National Patient Safety Agency11 have published comprehensive guides on handover improvement.

In Catalonia, Spain, research has investigated patients’ and healthcare professionals’ perspectives on factors that have a negative impact on care coordination.12 13 These
findings mirror reports in the literature that identify context-specific factors (such as local cultures, professional values and referral mechanisms) and wider organisational determinants (such as the organisation of services, payment and financing systems) that mediate communication processes and impact on the continuity of care.

While research into handovers has addressed different clinical conditions and organisational settings, the role and engagement of patients in the handover process and whether some patients or patient groups may be differentially at risk for poor quality of care during handovers with potential associated risks have not been studied to date. Previous studies have demonstrated deficiencies in handovers at the primary–secondary care interface, including insufficient attention to informational needs, emotional stress, social problems, untimely follow-up care and conflicting medication regimes. The frequency of problems appears to be associated with patient characteristics such as age, cognitive function and limited social networks, and may lead to suboptimal quality of care, in particular to unnecessary readmissions. A systematic review has addressed interventions to improve discharge from hospital to home for elderly patients, who are clearly at risk because of declining cognitive function and often living alone. However, studies have primarily focused on the effectiveness of supportive discharge programmes and not on the factors through which such patients are potentially exposed to harm. The specific roles of patients and their family members in the handover process are under-studied and relevant to efforts to improve patient safety.

Previous research has shown that patients of lower socio-economic status and/or with limited health literacy are less engaged in the medical encounter, have less understanding of information provided, have poorer self-management after follow-up and have higher utilisation of services. This might also have important implications for clinicians caring for these patients, in particular with regard to components of patient handovers such as history taking, transmitting information and motivational counselling for self-management or follow-up care.

We selected patients with limited language comprehension or health literacy, or a lack of social resources or support, as ‘vulnerable’ patients who are likely to be at greater risk during inter-organisational handovers. The objective of our study was to explore the role and engagement of patients in the handover process with a particular focus on these vulnerable patients. We collected information on how these patients experience their handovers at discharge from hospital, the characteristics of their contribution to the handover (either active or passive), and the quality and safety implications for these patients.

METHODS

This qualitative study was part of a larger research effort addressing patient handovers at the hospital to primary care interface in countries participating in the HANDOVER project (The Netherlands, Spain, Poland, Italy and Sweden). The study focused on clinical handovers at admissions (handovers from primary to secondary care) and discharge (handovers from secondary to primary or follow-up care).

Setting and participants

We conducted qualitative interviews in two hospitals in Catalonia, Spain and in primary care facilities in the catchment area of these hospitals. Germans Trias i Pujol Hospital (within the Nord Metropolitan Regional Management) is a reference and high technology centre with 15 primary care teams, and Hospital de la Esperança (within the Municipal Institute of Health Assistance) offers an integrated health service that consists of a tertiary care hospital, a municipal institute for medical research and 11 primary care centres in two districts of Barcelona.

The participants in this study included patients, hospital healthcare professionals (ie, doctors, nurses, social workers and intercultural mediators) and primary care professionals (ie, doctors, nurses and social workers). We included patients due to be discharged from hospital who were over 18 years of age and had a diagnosis of chronic obstructive pulmonary disease, diabetes, asthma or cardiac failure, or were prescribed more than five drugs at discharge. The rationale for the focus on chronic conditions and patients prescribed multiple drugs was that these patients are known to be at greater risk of adverse events and would benefit from a more comprehensive discharge handover.

Patients for the study were identified from discharge lists and pharmacy records and a supported discharge programme which sought to identify patients with particular needs after discharge to the community. These needs are mostly characterised by a requirement for ongoing nursing care at home to support the patient’s condition given a lack of social resources or support. We provided comprehensive briefings to study nurses and hospital coordinators on the study objectives to guide patient recruitment. We also developed and distributed screening criteria and a screening tool to identify vulnerable patients. Each patient was asked a series of questions to characterise their level of vulnerability. The variables included were income level, occupation, educational level, nationality, Spanish language skills, time living in Spain, and other characteristics recorded by social workers or cultural mediators (see box 1).
Once a patient was identified, the responsible hospital physicians and nurses were invited to participate and, upon discharge, the corresponding primary care professionals were contacted and invited to join the study. This sampling strategy allowed us to assess current handover practices from the viewpoint of both patients and professionals, and capture the handover experiences at the moment of discharge and upon continuing healthcare in the community. The study nurse explained the aims of the study and obtained informed consent from all participants.

The study was approved by the Utrecht University Hospital Ethics Committee and each of the participating hospitals.

Data collection

Interview guides for patients and professionals were developed by the research team for the larger HANDOVER project.24 The guide addressed the attributes of handovers, including the degree of communication between levels of care, characteristics of the current communication strategy, information requirements, the main limitations of current handover practices, critical incidents, and barriers and facilitators for communication. Minor adjustment were made for the particular group of interviewees: the patient interview guide laid particular emphasis on patients’ personal experience of having to navigate from secondary to primary care, while the healthcare provider interview guide focused on the sources of information healthcare professionals in both settings needed to provide treatment, and the experience of gaining this information, either through patients directly or through other means.

Interviews were conducted by two researchers (ROG, LO) in person, mostly on the premises of the participating hospitals, the primary care centres, and for patients unable to attend the health centre, in the patient’s home. All interviews were audio-recorded and transcribed using F4 software that links the audio and word files and allows timing to be registered for each statement.25 Transcription was performed according to guidelines established by the project team. Interviews were transcribed as soon as possible after the audio-recording and the text was not grammatically changed.

Data were collected and analysed between October 2009 and March 2010. A total of 12 patients and 22 professionals participated in the interviews. Theme saturation was reached after this number of interviews as no new information emerged. Individual interviews with patients were often short, lasting on average around 30 min (see table 1). The healthcare professionals interviewed had direct relationships as care providers with the 12 patients. The responses by healthcare professionals to the interview questions generally matched the responses given by their patients. The participant characteristics are summarised in table 2. Details of the patient screening tool are provided in box 1.

Data analysis

All analyses of interview data were carried out in Spanish, using the ATLAS.ti software package for the analysis of qualitative data.26 The codes were developed based on a thematic analytical approach within the European HANDOVER research team. To account for local contexts, additional codes were identified based on a grounded-theory approach. Codes were built based on concurrent analysis of interviewees’ responses and were formulated as close to the text as possible. All interviews were coded by at least two researchers who first coded the data independently and then compared the results. Concurrent and post hoc member checks were regularly performed to ensure the validity of the findings. In the final step, codes were given definitions and grouped into categories that constituted the final codebook used by the researchers.27 For the qualitative analysis of transcripts, a list of quotations was generated. The main findings were synthesised and are reported with supporting quotes. Quality assurance standards were developed within the HANDOVER research consortium based on the COREQ28 and other criteria for reporting qualitative research29 as part of a concurrent quality assurance effort within the HANDOVER project.30

RESULTS

In keeping with the aims of our study, the findings are presented as the participants’ characterisation of the discharge handover, the patients’ role in the handover, and attributes of discharge handovers that may place vulnerable patients at particular risk.
Characterisation of the discharge handover

Key themes characterising the handover process included information transfer and communication, use of discharge and/or referral letters as handover tools, and use of other handover artefacts, such as shared information systems or electronic health records (EHRs). The interviews revealed that there are no commonly accepted standard operating procedures for the exchange of information between secondary care and primary care, and where direct communication does exist, it is often due to existing personal contacts:

Well, ... with some specialists, for example with the cardiologist, we send electronic mails to each other. I ask her for information by e-mail. It is a very personal thing and because we have met each other. It is not a thing that is established. (Primary care physician 1)

Professionals reported they communicated mostly via referral or discharge letters resulting in a lack of personal contact, and pointed out the potential to miss out on crucial information. One hospital physician (Hospital physician 2) gave the example that hospital care focuses more on the disease associated with the current admission, while primary care doctors take a broader social approach to identifying risk factors for the illness and taking a more complete history.

Professionals responsible for organising follow-up care also noted that patient referral information is often limited and frequently does not include information on nursing requirements or the socio-economic situation at home, which is important to anticipate and could have implications for preventing problems after discharge. The primary care nurses reported they considered the report prepared by hospital nursing staff of particular importance, especially when home care, wound care or palliative care was required. They noted, however, that this report was often missing, incomplete or not provided in a timely manner.

All professionals considered a shared EHR on a common information technology (IT) platform, and EHR data to support the discharge handover as a possible solution to address handover problems. Information systems integration and inclusion of discharge handover information in the EHR, however, are not currently used in the context of inter-organisational handovers. Professionals also did not perceive them to be an effective solution, as not all healthcare providers have access or contribute data to such systems.

Patients reported they often were not informed about the nature of the information being transferred and were left wondering what information had been passed on and what else might be required or was missing:

They [the doctors] have information on their computers but I don’t know how much ... If you go 50 times to the hospital the doctor still has no idea. (Patient 8)

There will probably be some sort of communication but I have no idea to what extent, because they don’t tell you. (Patient 2)

The contribution of patients to the handover process

Patients and healthcare professionals characterised the patient’s role in the discharge handover as limited to a passive conduit function whereby patients are handed their referral or discharge letters and instructed to hand them to their community general practitioner:

I do [am] the middle man because I take these papers to the doctor ... and then he reads it and more or less he asks me about it. (Patient 3)

---

**Table 1** Participants’ characteristics

<table>
<thead>
<tr>
<th></th>
<th>Patients</th>
<th>Hospital physicians</th>
<th>Hospital nurses*</th>
<th>Primary care physician</th>
<th>Primary care nurses†</th>
</tr>
</thead>
<tbody>
<tr>
<td>Interviews</td>
<td>12</td>
<td>6</td>
<td>5</td>
<td>7</td>
<td>4</td>
</tr>
<tr>
<td>Number of interviews performed</td>
<td>28 (17–43)</td>
<td>21 (14–28)</td>
<td>27 (20–31)</td>
<td>27 (17–34)</td>
<td>23 (17–30)</td>
</tr>
<tr>
<td>Duration of interview in minutes</td>
<td>18 (10–46)</td>
<td>19 (17–30)</td>
<td>35 (13–59)</td>
<td>25 (19–36)</td>
<td>30 (25–41)</td>
</tr>
<tr>
<td>Male (number)</td>
<td>5</td>
<td>3</td>
<td>1</td>
<td>2</td>
<td>2</td>
</tr>
<tr>
<td>Female (number)</td>
<td>7</td>
<td>3</td>
<td>4</td>
<td>5</td>
<td>2</td>
</tr>
<tr>
<td>Age (median)</td>
<td>69 (63–100)</td>
<td>31 (27–38)</td>
<td>42 (40–46)</td>
<td>42 (31–57)</td>
<td>43 (31–59)</td>
</tr>
<tr>
<td>Number of years in the profession</td>
<td>NA</td>
<td>5 (3–11)</td>
<td>10 (2–20)</td>
<td>13 (4–30)</td>
<td>14 (4–29)</td>
</tr>
</tbody>
</table>

*Includes intercultural mediator.
†Includes social worker.
<table>
<thead>
<tr>
<th>Diagnosis (ICD-10), polypharmacy</th>
<th>Sex</th>
<th>Age (years)</th>
<th>Referred from PC</th>
<th>Number of drugs at Hospital admission</th>
<th>Number of drugs at Hospital discharge</th>
<th>Discharged to</th>
<th>Definition of vulnerability (living alone, low socio-economic status, low education, difficulties in comprehending information provided)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Severe COPD, polypharmacy</td>
<td>M</td>
<td>77</td>
<td>No</td>
<td>10</td>
<td>10</td>
<td>X</td>
<td>Low socio-economic status, low education, difficulties in comprehending information provided</td>
</tr>
<tr>
<td>Onset of ulcerative colitis/acute MI, polypharmacy</td>
<td>F</td>
<td>87</td>
<td>Yes</td>
<td>7</td>
<td>7</td>
<td>X</td>
<td>Low socio-economic status, low education, difficulties in comprehending information provided</td>
</tr>
<tr>
<td>Nephritic syndrome, polypharmacy</td>
<td>F</td>
<td>69</td>
<td>No</td>
<td>10</td>
<td>13</td>
<td>X</td>
<td>Low education, difficulties in comprehending information provided, lived in a deprived area</td>
</tr>
<tr>
<td>Acute pyelonephritis, polypharmacy</td>
<td>M</td>
<td>84</td>
<td>No</td>
<td>6</td>
<td>6</td>
<td>X</td>
<td>Linguistic barrier, low socio-economic status, low education, difficulties in comprehending information provided</td>
</tr>
<tr>
<td>Cellulitis and foot abscess, polypharmacy</td>
<td>F</td>
<td>67</td>
<td>No</td>
<td>Not available</td>
<td>16</td>
<td>X</td>
<td>Low socio-economic status, low education, difficulties in comprehending information provided</td>
</tr>
<tr>
<td>Bilateral carpal inflammation/COPD, polypharmacy</td>
<td>F</td>
<td>73</td>
<td>No</td>
<td>11</td>
<td>11</td>
<td>X</td>
<td>Low socio-economic status, low education, difficulties in comprehending information provided</td>
</tr>
<tr>
<td>Cardiac failure/paroxysmal AF, polypharmacy</td>
<td>F</td>
<td>Not available</td>
<td>No</td>
<td>6</td>
<td>7</td>
<td>X</td>
<td>Low socio-economic status, low education, difficulties in comprehending information provided</td>
</tr>
<tr>
<td>Mitral valve replacement/ hypertension/type II DM/CVA, polypharmacy</td>
<td>F</td>
<td>66</td>
<td>No</td>
<td>7</td>
<td>7</td>
<td>X</td>
<td>Linguistic barrier, low socio-economic status, low education, difficulties in comprehending information provided</td>
</tr>
<tr>
<td>Colorectal cancer/COPD/ hypertension/obesity/chronic heart failure, polypharmacy</td>
<td>F</td>
<td>73</td>
<td>No</td>
<td>7</td>
<td>7</td>
<td>X</td>
<td>Low education, difficulties in comprehending information provided</td>
</tr>
<tr>
<td>Pancreatitis/type II DM/bile duct cancer</td>
<td>M</td>
<td>56</td>
<td>No</td>
<td>11</td>
<td>13</td>
<td>X</td>
<td>Low socio-economic status, low education</td>
</tr>
<tr>
<td>Cardiac stent, polypharmacy</td>
<td>M</td>
<td>81</td>
<td>No</td>
<td>8</td>
<td>9</td>
<td>X</td>
<td>Low socio-economic status, low education, difficulties in comprehending information provided</td>
</tr>
<tr>
<td>Surgery for cancer of the rectum/ type II DM, polypharmacy</td>
<td>M</td>
<td>63</td>
<td>No</td>
<td>7</td>
<td>7</td>
<td>X</td>
<td>Low socio-economic status, low education</td>
</tr>
</tbody>
</table>

AF, atrial fibrillation; COPD, chronic obstructive pulmonary disease; CVA, cerebrovascular accident; DM, diabetes mellitus; F, female; ICD-10, International Classification of Diseases, 10th edition; M, male; MI, myocardial infarction; PC, primary care.
Patients did not perceive this role as positive; they do not feel they own the information since they are not able to make sense of the technical language, and they do not feel empowered to assess the information or to add to it:

They put it in their technical words and then they [primary care physicians] will understand what happened to me ... I can’t express what is written in this paper. (Patient 5)

I have a bad habit. If I have to get an x-ray ... when I get the results I open the envelope and I read it. The doctor told me once: one day you will get scared because of something you do not understand and maybe it’s something insignificant. (Patient 1)

Patients reported they often considered the referral documentation to be of an administrative nature. Consequently, they did not always treat it with sufficient attention, resulting in documentation getting lost or transmittal being delayed. Professionals did not consider this form of data transfer safe due to the conflicting information it can produce, and to the unreliable nature of the transfer process:

... often I do not know if it is the patient who does not bring the report to the family doctor or the family doctor who does not read the report... (Hospital physician 6)

By means of the patient we do not have a good ... exchange of information ... Because by means of the patient you cannot communicate because either I don’t know what he does with the reports or he thinks that he didn’t have to bring it... (Hospital nurse 4)

Patients reported that they are aware that the handover process is not seamless but haphazard. They expected more personal attention and a smoother information flow without them acting as the conduit. Overall, patients showed little interest in the organisation of the handover process. They considered this to be the responsibility of management and professionals. This might be related to the age profile and ill health of the patients in our study, or it may reflect the fact that, as users of a system, they expect the system to be organised in a manner that ensures efficient use and transfer of information.

Interviews with professionals revealed that an information gradient existed, and that they felt that patients with greater health literacy and language skills would be more likely to navigate the health system safely as they would be in a better position to understand the information provided to them.

According to the healthcare professionals, passing the responsibility for information transfer exclusively to the patient may reduce patient safety, such as when key information is not submitted to the treating doctor because it is not considered to be of importance or has been lost or when a follow-up appointment is not made:

Prescriptions, some parts of the discharge report, sometimes [patients] have the envelope but they lose what’s inside. (Primary care physician 3)

Well, sometimes patients explain things ... I am puzzled... what are you saying? I read the discharge report, then I read it again because they explain things. What shall I do now? Shall I believe the patient or the discharge report? (Primary care nurse 2)

A frequently reported problem concerned changes in medications on hospital admission and the lack of subsequent medication reconciliation at the time of discharge. In addition, patients who experience ill health and particularly patients with language barriers and low health literacy may be unable to provide full information on the medicines they are taking, or inform their providers about allergies and possible drug reactions:

Even if drugs are different ... of course I take them ... what can I tell them? (Patient 6)

Sometimes when I go for a visit they ask me, what was is that you were allergic to? ...What if I am wrong about the name and I tell them something wrong? (Patient 5)

Patients are also often discharged with a medication different to that taken before admission, and this is not always clearly communicated to their general practitioner. In addition, if the patient does not realise that the medication is only to be taken for a short period of time, then this may increase the risk of adverse medication events:

The patient is discharged from the hospital with a different medication and only notifies the primary care physician 3 months after discharge when she starts having symptoms of high blood pressure, totally unaware of the medication she is taking. (Primary care physician 3)

Patients and their family members are expected to take on significant responsibilities in the handover process, as well as handling administrative issues related to treatment such as filling prescriptions and managing home care. When patients have language and health literacy barriers and/or when they lack family support, coordination problems between hospital care and primary care become more apparent and may contribute to errors and omissions. Managing a handover for a patient with a difficult or unstable social situation or with limited cognitive abilities is more demanding for
doctors and nurses. Some healthcare professionals reported they feel ill equipped to undertake this task:

Well it’s more time, more stress, it’s very strenuous from all points of view, you try and explain in various ways, you write down, you ask them to come accompanied by someone, but there are patients that live alone. It’s really wearing you out, it’s exhausting. (Hospital nurse 2)

In summary, while examples of good patient handovers were provided, the interviews suggested that there was a lack of standard procedures for discharge handovers. Handovers depended on personal initiative, the good will of health professionals and their relationships, and prior contact. The patients’ role in handovers is limited, many patients do not want more involvement, and vulnerable patients are at particular risk of experiencing breakdowns in communication during the handover process.

DISCUSSION

Our study identified a number of potential safety issues during handover from the hospital to the community care setting. Without sufficient information and an understanding of their diagnoses, medication and self-care needs, patients reported that they could not fully participate in their care during and after discharge from hospital. Many of the characteristics of handovers have implications for all patients. However, as patient handovers seemed to rely substantially on the assertiveness of patients and their families, patients with lower health literacy, language barriers and lack of family resources may be at higher risk of being exposed to safety incidents.

Although referral systems and discharge forms were used to ensure effective and safe handovers, patients were not informed or educated about the content of these documents. Frequently they were reduced to a ‘carrier’ function and expected to deliver handover documents to primary care professionals. Consequently, important information was not always treated with care and some of it was lost.

To improve the quality of care and prevent potential adverse events in handovers, professionals need tools and training to identify the patients at highest risk for handover failures, including those with low health literacy and language barriers and those needing complex interdisciplinary care or with a large number of prescription drugs. These vulnerable patients might benefit from nurse-arranged follow-up appointments, medication reconciliation, and health literacy strategies to enhance their empowerment, interventions that have been shown to improve the quality and safety of care.31–35 At the same time, the responsibility for handovers should not be shifted to patients and their families, as handovers are primarily an issue of coordination for health services. The fact that better informed patients ‘know their way around’ should not lead to the assumption that all patients could be educated to the same level; rather handovers should be made equally safe for all patients, independent of their capacity for participation.

Our study has a number of limitations. The research was conducted in hospitals and their affiliated primary care centres that may differ in terms of organisation of the delivery network and the availability of shared information technology, which may limit the ability to generalise from our findings to other institutions. We also identified patients mostly through the supportive discharge programme due to the study’s focus on vulnerable patients, and other selection criteria might have resulted in a different study population, and potentially, different findings. Third, the use of standardised instruments to guide the selection of patients was not feasible. While standardised measures exist to assess patient empowerment,34 health literacy35 and patient activation,36 these instruments have not been validated cross-culturally and their administration is complex and time-consuming and not practical in busy clinical settings. Work to develop such an instrument would have required extensive subjective criteria to establish thresholds for patient classification. We therefore relied on trained study nurses using a priori designed screening criteria. Finally, patients in our study had limited insight and interest in their handover practices. This may be related to their age, illness and passive experience with the handover process. Other patient groups may have different expectations and experiences, but our findings are relevant to efforts to improve handover processes for this vulnerable group.

Future studies should determine when vulnerable patients felt safe or when staff felt that that handovers involving these patients were safe and worked well. Our study identified attributes of handovers that may place vulnerable patients at higher risk, although it could not quantify the degree to which this occurs. Future research should quantitatively study the prevalence and incidence of handover problems and the consequences in this patient group.

CONCLUSIONS

Current patient handover practices at the primary–secondary care interface are often haphazard. Patients are passive participants in the handover, or transfer written and oral communication to their community healthcare professionals. These non-standardised processes lead to ambiguities and lapses in communication which may put patients at risk. Our study suggests that patients with
lower socio-economic status, language barriers, fewer family resources or low health literacy may be at particular risk in discharge handovers. Further research should address the potential implications for patient outcomes and should explore strategies to improve patient handovers. While strategies should reduce reliance on patients as the conduits of information, they should not prevent participation by patients and families wanting a more active role.

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**Contributors** ROG, CO, RS, OG: conception and design, or analysis and interpretation of data; ROG, CO, RS, OG, PB: drafting the article or revising it critically for important intellectual content and final approval of the version to be published.

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**Competing interests** None.

**Ethics approval** This study was approved by Utrecht University Medical Center and Avedis Donabedian Research Institute (FAD).

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