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A methodology to systematically analyze the hospital discharge of terminally ill patients

Annemarie Cécile Eggen, BSc^a, Mathilde Jalving, MD, PhD^a, Ingeborg Bosma, MD, PhD^b, Derkje J. Veenhuis, RN^a, Lianne J. Bosscher, RN^a, Jenske I. Geerling, NP^c, Anna Katrien Leontien Reyners, MD PhD^{a,c,*}

Abstract

To provide an appropriate method to systematically analyze the hospital discharge of terminally ill patients especially the cooperation between hospital and community nurses and the quality of the discharge handovers. To evaluate the hospital discharge process of terminally ill patients in an academic hospital in the Netherlands using the proposed method.

Data were collected from a prospective cohort of all terminally ill patients discharged from the University Medical Center Groningen, the Netherlands, between June and November 2014. The hospital discharges were assessed using 2 questionnaires: an inventory questionnaire, to determine the required care, and an evaluation questionnaire, to evaluate the care actually organized and the discharge handovers. The inventory questionnaire was completed prior to discharge and the evaluation questionnaire between 3 to 7 days after discharge.

Around 130 consecutive patients were included. The discharge took place on the desired date in 86% of cases and the average overall discharge grade on a 10-point scale was 7.4 (range: 3–9.5). In 23% of cases discrepancies between required and provided care were identified and medication queries existed in 29%.

This study provides a methodology to analyze the hospital discharge procedure of terminally ill patients that can be utilized in any hospital. Structured analysis of the discharge process is valuable and identifies where improvements can be made. Within the study cohort the home care could be arranged at short notice and was considered sufficient. However, in a significant proportion of patients a discrepancy between required and arranged care and queries about medication were identified.

Abbreviations: ACP = advance care plan, ADE = adverse drugs events, GP = general practitioner, PCA pump = patient-controlled analgesia pump, UMCG = University Medical Center Groningen.

Keywords: patient discharge, terminal care and advance care planning, terminally ill, transitional care

1. Introduction

Care transitions, such as hospital discharges, are a complex and vulnerable period in patient's management, especially for fragile, terminally ill patients discharged home to die.^[1,2] Ineffective hospital discharge can seriously impede the quality and safety of patient care. Due to the rapidly aging population and growing efforts to deliver healthcare in the community, the volume of care transitions is increasing and the need for effective and high quality handovers of terminally ill patients is increasing.^[1,3] End-of-life care at home, which provides treatment and support for continuous periods of time by healthcare professionals, allows

hospitalized terminally ill patients to be discharged home to die.^[4] Most patients prefer to die in their own homes and death at home is associated with greater satisfaction as perceived by the family members of dying patients.^[5–8] Therefore, the current strategy in end-of-life care in many countries, including the Netherlands, is to ensure that terminally ill patients can be at home.^[5,9,10] In the Netherlands, around-the-clock home care is available for terminally ill patients, defined as patients with a life expectancy of <3 months. This care, which is reimbursed by health insurance companies, facilitates the transfer of terminally ill patients to their homes.^[9] The implementation of these facilities contributed to the increasing frequency of hospital discharges in this setting.^[5]

Despite the complexity of those hospital discharges and the fact that terminally ill patients are increasingly frequently discharged home to die and, the process of discharging this vulnerable patient group has hardly been explored.^[11] During care transitions it is important that the continuity of healthcare is preserved. Discontinuity of healthcare is associated with lower quality of healthcare, decreased patient satisfaction and adverse clinical outcomes.^[12–14] Adverse clinical outcomes can lead to unnecessarily high healthcare consumption, including readmission to hospital. The continuity of healthcare can be preserved in the period around discharge through transfer of accurate and relevant data regarding diagnostic findings, treatment, complications, consultations, potential problems at discharge and arrangements for post-discharge follow-up.^[12] These observations clearly indicate the importance of performing hospital discharges of terminally ill patients in an accurate and timely manner.

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^a Department of Medical Oncology, ^b Department of Neurology, ^c Expertise Center of Palliative Care, University of Groningen, University Medical Center Groningen, Groningen, the Netherlands.

* Correspondence: Anna Katrien Leontien Reyners, University Medical Center Groningen, Hanzeplein 1, P.O. Box 30 001, 9700 RB, Groningen, the Netherlands (e-mail: a.k.l.reyners@umcg.nl).

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Structured analysis of hospital discharge procedures is essential to identify areas for potential improvements. Therefore, the overall aim of this study was to provide an appropriate method to systematically evaluate the hospital discharge procedure of terminally ill patients that can be implemented in any hospital to analyze the hospital discharge process. The cooperation between hospital and community nurses, as well as the quality of the discharge handovers composed by the ward nurses, can be evaluated using the proposed method. The hospital discharge process of terminally ill patients in an academic hospital in the Netherlands, University Medical Center Groningen (UMCG), was evaluated using the proposed method.

2. Methods

2.1. Study design and patient selection

Two questionnaires, with closed-ended questions were designed as part of this study. The questionnaires were designed by a team comprising 2 liaison nurses, a palliative care nurse practitioner and a community nurse and were based on their knowledge and experience with hospital discharges. Subsequently, a panel of community and liaison nurses, experienced in working with this patient group, refined the questionnaires. The UMCG is an academic hospital in the Netherlands, in this prospective, cohort study all patients discharged from the UMCG with terminal care (life expectancy <3 months) between June and November 2014 were included. There was no selection regarding the underlying disease. The data obtained were anonymously stored in a database using study-specific patient codes. No patient or institutional review board approval was required according to Dutch law.

2.2. Healthcare in the Netherlands

In the Netherlands all individuals have access to a general practitioner (GP) and, when needed, community nurses or medical specialists.^[16] Health insurance for common medical care is mandatory for all individuals above 18 years of age. For patients requiring long-term nursing and/or 24-hour healthcare, the Dutch government pays the healthcare costs from general tax incomes. Community nurses can provide daily healthcare for patients at home. Due to the availability of these facilities, terminally ill patients can be discharged from the hospital to their homes.

2.3. Standard discharge procedure in the UMCG

At the UMCG the liaison nurses ensure that the required equipment is available and, when required, delivered to the patient's home. The liaison nurses also arrange the home care when required. Prior to discharge, the nurse on the ward completes a screening form. This form describes the situation before admission and the care likely to be required after discharge. The liaison nurse also explores the patient's healthcare needs and preferences during a discharge interview conducted with both patient and relatives. The homecare organization that delivers the care after discharge receives a written handover from the nurses on the ward. This handover contains all the essential information about the patient. For the majority of the patients, the liaison nurse will also have contact with the community nurse by phone to provide an additional oral patient handover. The standard UMCG hospital discharge procedure is shown in Supplement 1, <http://links.lww.com/MD/C623>. On some wards within the UMCG, as part of an improvement program, the use of an advanced care plan (ACP) was implemented before the current study commenced. In an ACP,

the foreseen future problems are described, allowing both patient and caregivers to prepare for those situations.

2.4. Questionnaires

Two, closed-end, questionnaires were used to obtain a structured overview of the hospital discharge of terminally ill patients. The questionnaires examined the cooperation between hospital and community nurses, qualified the hospital discharge handovers composed by the nurses on the ward and addressed to the community nurses, and assessed how the community nurses rated the discharge handovers.

The first questionnaire was an inventory questionnaire. The questionnaire determined, prior to discharge, the required equipment and care required. The liaison nurse completed this questionnaire immediately after discharge using data collected during the discharge interview. The inventory questionnaire consisted of: patient characteristics (gender, age, and diagnosis), requested discharge date and actual discharge date, the reason for discrepancy in discharge date, discharge destination, the home-care organization involved, availability of other caregivers, equipment ordered, method of transport of the patient, scheduled first moment of care after discharge, involvement of the UMCG palliative care team and whether an ACP had been composed.

The second questionnaire, the evaluation questionnaire, was used to assess the actual care organized and, in this questionnaire, the community nurses could rate the discharge handover. To complete this questionnaire, the community nurses were phoned by one of the 2 liaison nurses or by the palliative care nurse practitioner involved in the project, 3 to 7 days after discharge. The evaluation questionnaire addressed: medical professionals involved (liaison nurse, nurses on the ward and/or member(s) of palliative team), quality of the oral handover, availability and quality of the written handover, actual care organized (match between requested and provided care), first time-point of care at home (discrepancy and, if so, the reason), experiences with the ACP, presence of required equipment, queries regarding medication and overall grading of the quality of the discharge. The quality of the handovers was rated on a 5-point Likert scale: poor, moderate, adequate, good, and outstanding. The community nurse graded the overall discharge on a 10-point scale with a number ranging from 1 (worst) to 10 (optimal situation). Both study questionnaires are shown in Supplement 2, <http://links.lww.com/MD/C623> and the study procedure is displayed parallel to the standard UMCG discharge procedure in Supplement 1, <http://links.lww.com/MD/C623>.

2.5. Analyses

Descriptive analyses of the data were performed using SPSS Version 23.0 (SPSS Inc., Armonk, NY: IBM Corp). For 116 cases all data were complete. For analysis of each variable all available data were included. When only complete cases were analyzed the conclusions were unchanged. The results were expressed in a descriptive manner; continuous variables were reported with means and standard deviation or median and range and categorical variables with numbers and percentages.

3. Results

3.1. Patient characteristics

Between June and November 2014, 130 consecutive patients were included. For 1 patient the evaluation questionnaire was not completed (the patient died during transport) and for 12 patients

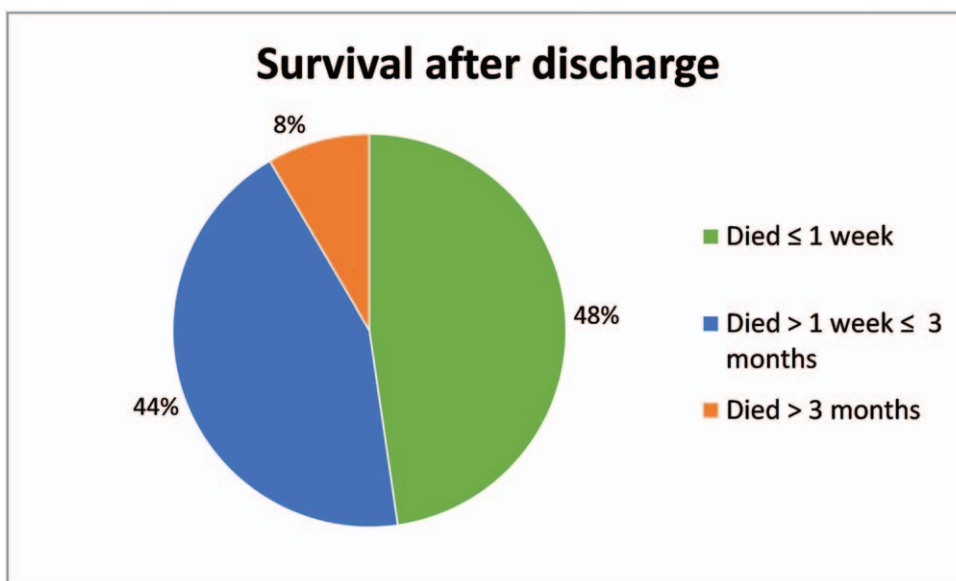


Figure 1. Survival after discharge, in percentages (%).

at least one variable of one of the questionnaires was missing. In total 36 values (0.5%) were missing. The median age was 65 years (range: 4–93) and 53% (n=69) were male. The most common diagnoses of patients in this study were lung cancer (n= 16, 12%), hematologic malignancies (n=16, 12%), and intestinal cancers (n=13, 10%). Thirty-two patients (25%) suffered from end-stage nonmalignant diseases. The indicated primary caregiver was mostly the spouse (n=47, 36%) or one of the children (n=24, 19%). Almost half of the included patients died within the first week after hospital discharge (Fig. 1).

3.2. Discharge overview

The transfer succeeded on the desired discharge date in the majority of patients (n = 112, 86%). Patients could be transferred within 24 hours after the discharge was requested in 46% (n = 60). If patients

could not be discharged on the desired date, the median interval between the desired discharge date and the actual discharge date was one day (range: 1–4). The most common reason for delayed transfer was that the homecare organization was not able to deliver the required care in time (n=6). After discharge, most patients went home (n=114, 88%; Fig. 2). Of the 114 patients who went home, 64 (56%) of the patients received daytime home care. The first care time-point after discharge was pre-arranged in 94% (n= 122) at time of discharge and in most patients (n= 110, 85%) the care was provided at the arranged time.

3.3. Patient handover

The community nurses received a written handover in 88% of patients (n = 113). The ratings for these handovers were good or outstanding (n = 55, 49%), sufficient (n = 42, 38%), and for 14

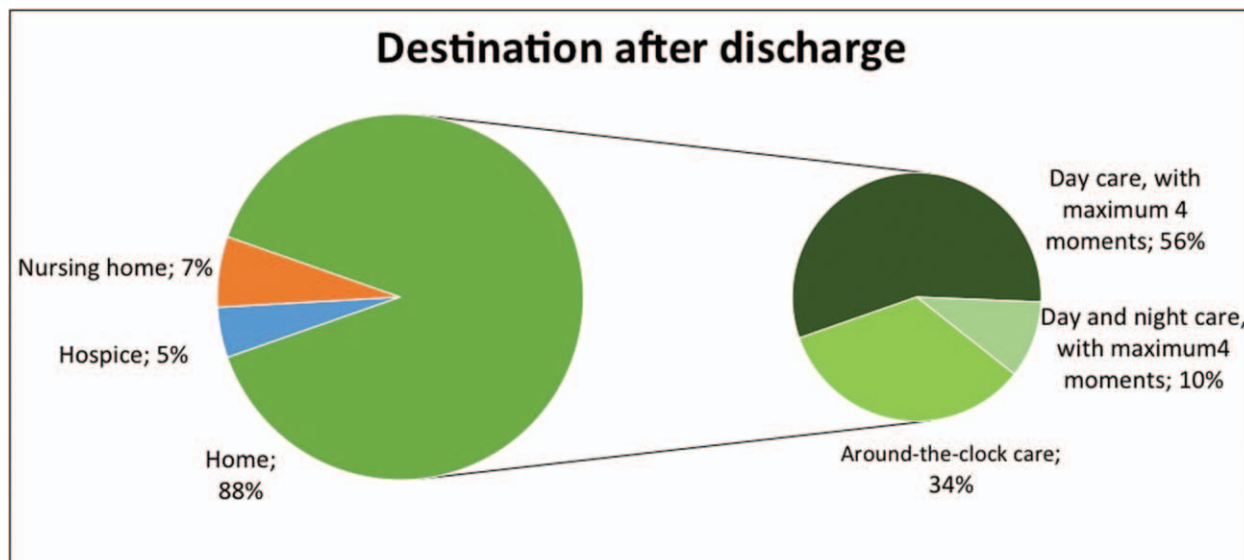


Figure 2. Destination after hospital discharge, in percentages (%).

patients (13%) poor or moderate. An incomplete handover was the most common reason to qualify the handover as poor or moderate. In 98% (n = 126) of the patients the community nurses had been in direct contact with the liaison nurse and in 10% (n = 13) of cases the community nurses had also been in direct contact with a nurse tending to the patient during hospital admission. The community nurses rated the telephone contact prior to discharge as good or outstanding in 63% (n = 83).

On one ward the use of an ACP had been implemented in the discharge protocol. Around 68% (n = 28) of the patients discharged from this ward had an ACP. A total of 31 (24%) discharge handovers included an ACP document. When the ACP was used by the community nurses (n = 21) it was considered useful. For the remaining 10 patients the community nurse did not use the ACP, in 6 patients this was because the community nurse was not informed that an ACP had been provided. Written handovers including an ACP were rated as good or outstanding in 60% (n = 18) compared to 41% (n = 39) for handovers without ACP.

After the hospital discharge, queries regarding the prescribed medication existed in 28% (n = 37) of the patients. In total, 40 questions regarding medication use were reported. These included uncertainties about which medication the patient had been prescribed (n = 25), about the medication dose (n = 8) or both (n = 5).

3.4. Consistency between requested and arranged care

Eleven percent of the patients (n = 14) required more care than anticipated prior to hospital discharge and 12% (n = 15) required less care than anticipated. In Table 1 the equipment ordered and missing equipment at time of discharge are shown. General medical equipment (hospital bed, medical air mattress, bedside commode, wheelchair, or transfer sheet) were ordered for most patients (n = 87, 68%), with a median number of pieces of general medical equipment of 2 (range: 0–5). For 37 patients (28%) a total of 42 technical medical devices (oxygen-, infusion-, enteral feeding-, and patient-controlled analgesia (PCA) pumps) were ordered. In 80% (n = 103) the required equipment (medical and general) was available at the time of discharge. Forty out of 298 (technical) medical devices (13%) were not delivered on time. The most common reason why the equipment was missing was that,

although the equipment was needed prior to discharge, it was not ordered (n = 21).

3.5. Overall discharge grade

The average score on the overall discharge grade on a 10-point scale was 7.4 (± 1.2; range: 3–9.5). The discharges were evaluated as insufficient (grade < 5.5) for 13 patients (7.3%; Fig. 3).

4. Discussion

The aim of this study was to provide an appropriate method to evaluate the hospital discharge procedure of terminally ill patients. Although hospital discharge procedures may differ within hospitals and across borders, the proposed method could be used in any hospital to systematically analyze the discharge procedure to determine in which particular part of the hospital discharge procedure problems arise. The most important conclusions, regarding the analyses of the hospital discharges in the study cohort, were that the home care could be provided at very short notice and the hospital discharge was considered sufficient. Almost half of the terminally ill patients could be discharged within 24 hours after the first request and most patients were discharged on the desired date. However, in a significant amount of patients a mismatch in the required- and provided care was found.

High quality transitional care is required to ensure safe transitions between different care settings, whereby the continuity of care is preserved and preventable adverse outcomes are avoided.^[2,17] To ensure the continuity of care, discharge handovers for community nurses should include up-to-date information about medication and required healthcare after discharge, treatment during hospital admission, division of tasks between hospital, GP and community care and coordination of responsibilities between hospital, GP and community care.^[18] In our study it appeared that when the discharged handovers were qualified as poor or moderate it was because the discharge handover was incomplete. When crucial discharge information, related to patient's treatment or illness and about what is expected in terms of tasks and responsibilities, is missing it is often difficult for the community nurses to provide accurate and

Table 1

Requested equipment prior to discharge and missing equipment after discharge from the hospital.

	Ordered prior to discharge, n (%)	Missing equipment, ordered prior to discharge, n	Missing equipment, not ordered prior to discharge, n
General medical equipment	256 (100%)	9	18
Medical bed	75 (29%)	4	3
Medical air mattress	63 (25%)	4	5
Bedside commode	43 (17%)	-	2
Wheelchair	20 (8%)	-	1
Transfer sheet	29 (10%)	1	6
Other	26 (10%)	-	1
Medical technical equipment	42 (100%)	3	10
Oxygen	17 (40%)	1	1
Infusion pump	2 (5%)	1	-
Enteral feeding pump	4 (10%)	-	-
PCA pump	18 (43%)	1	-
Wound dressing materials	-	-	3
Other	1 (2%)	-	6

PCA pump = patient-controlled analgesia pump.

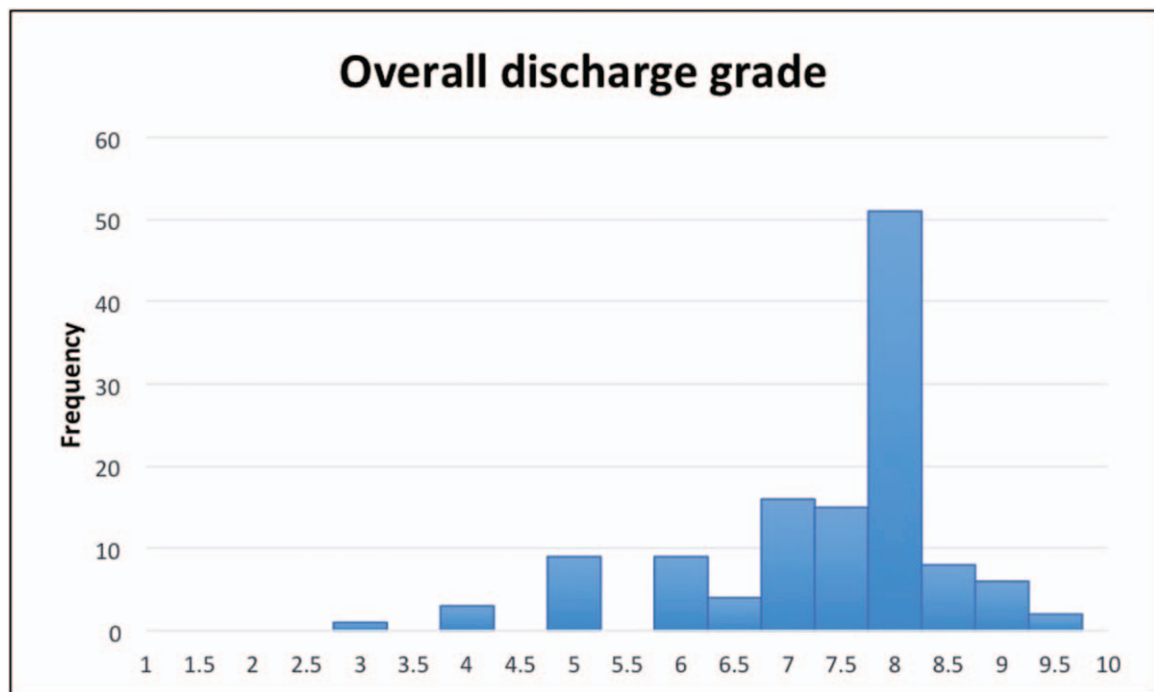


Figure 3. Histogram of overall discharge grade on a 10-point scale (0–10) expressed by community nurses. The mean overall discharge grade was 7.4 (± 1.2 ; range: 3–9.5) and the median overall discharge grade was 8.0.

high quality healthcare.^[1,2,19] Not surprisingly, it has been shown that ineffective handovers at hospital discharge decrease the quality and safety of care.^[18]

Currently, the information for the discharge handover, for example, medication usage, is not transferred directly from the electronic patient records to the discharge handovers. The discharge of terminally ill patients often takes place within a short period of time. The caregivers need to provide all relevant information within this short timeframe. This might result in incomplete handovers or missing information. By providing discharge handovers in connection with the electronic patient record in a standardized discharge procedure, the frequency of incomplete handovers can be reduced and thereby the transitional care can be improved. In the standard UMCG discharge handover used at this time of this study, the division of tasks between hospital, GP and community care and the coordination of care was not specified. To ensure continuity of care and thereby the patient’s safety, it is important that the coordination of responsibilities and division of tasks are clearly stated and are implemented in a standardized discharge handover.

For a significant number of patients, a discrepancy between required and provided care was found. Postdischarge adverse events, such as adverse drugs events (ADE), are common occurrences.^[19,20] After hospitalization, patients often experience changes in health status and have frequently had changes in prescribed medications.^[17,21] In a cohort study performed by Forster et al,^[21] almost half of the patients (42%) who experienced an ADE sought additional healthcare, 11% visited the GP, 11% went to the emergency department and 16% were readmitted to the hospital. In this study, the queries about medication were mostly about which medication was prescribed and the dosage of the medication. Although, in this study, the consequences of the medication queries were not examined, it

does illustrate adequate communication about the medication policy with the community care providers is frequently lacking. To achieve appropriate medication management, it is important that the patient, relatives, and their caregivers fully understand the prescription changes.^[2,19,22] For the community care providers the prescription changes and ideally, the reason why the medication was changed, should be included in the patient’s discharge handovers.

The early identification and recognition of end-of-life care choices could have a positive influence on the quality of life and experiences during the end-of-life phase for terminally ill patients and their family members.^[23] An ACP is used as an anticipatory management plan, which is very useful for anticipating potential scenarios for terminally ill patients.^[24] Advance care planning is used to prepare and support patients, family and medical providers in shared decision-making to protect the patient’s autonomy and to prevent “crisis oriented” decision-making. With an ACP, end-of-life wishes are more likely to be known and followed, ensuring that the provided medical care aligns with patient’s preferences. In our study, the community nurses rated written discharge handovers including an ACP higher than handovers without an ACP. Advanced care planning should be implemented in discharge procedures for terminally ill patients. To increase the use of ACP documents, the liaison nurses should inform the community nurses about the availability and the usefulness of the ACP during the additional oral handover.^[24]

The study aligns with the Hospital Readmission Reduction Program, which has been implemented in the United States since 2012. Within this program hospitals with high hospital discharge readmission rates are penalized, with the aim to increase emphasis on transitional care and stimulate innovations that decrease preventable post-discharge events.^[15] Our proposed

method can identify potential areas of improvement in the transitional care of terminally ill patients, whereafter appropriate innovations can be implemented.

The proposed method to evaluate the hospital discharge process has several limitations. Firstly, this study did not include the opinion of the patients, their family members or the GPs about the hospital discharge and the provided end-of-life care. Our proposed method aimed to identify potential areas of improvement in the cooperation between the hospital and community nurse and we were specifically interested in the experience of the community nurses. Therefore, we decided to not include the experience of patients, families or other caregivers in this study. To tackle other issues, in the hospital discharge process of terminally ill patients, the opinions of patients, home caregivers or the GPs can be of great value. Including their opinions while analyzing the hospital discharge process should always be carefully considered. Another limitation is that the community nurses could only grade the discharge, but they were not asked for suggestions to improve the quality of the discharge procedure or to clarify their requirements or rating. For example, if the community nurses graded the written handover as insufficient due to the fact that the handover was not complete, it remained unclear which information the community nurses missed in the discharge handover and what the consequences were. The hospital discharge procedure was analyzed in one, large, academic hospital in the Netherlands. This may limit the generalizability of these outcomes, although the communication and logistical discharge issues are encountered across hospitals as well as borders.

In conclusion, discharging terminally ill patients home to die is complex. Therefore, structured analysis of discharge procedures is essential to identify areas of potential improvement. This study proposes a structured method to systematically analyze the hospital discharge of terminally ill patients, which can be applied in any hospital. The hospital discharges, in our cohort, could be arranged at short notice, but the required care mismatched with the provided care in a large proportion of the patients. To improve the transitional care the discharge procedure should include a well-structured written and oral handover with more emphasis on advance care planning and actual medication use.

Author contributions

Conceptualization: Derkje J Veenhuis, Lianne J Bosscher, Jenke I Geerling, Anna K. L. Reyners.

Formal analysis: Annemarie C Eggen.

Investigation: Derkje J Veenhuis, Lianne J Bosscher, Jenke I Geerling.

Methodology: Anna K. L. Reyners.

Project administration: Jenke I Geerling, Anna K. L. Reyners.

Supervision: Mathilde Jalving, Ingeborg Bosma, Anna K. L. Reyners.

Visualization: Annemarie C Eggen, Jenke I Geerling.

Writing – original draft: Annemarie C Eggen.

Writing – review & editing: Mathilde Jalving, Ingeborg Bosma, Anna K. L. Reyners.

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