Measuring discharge care quality in hospitalised elderly:

Development and validation of an instrument based on patients' experiences

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Scientific environment

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The study was carried out at Haukeland University Hospital, parts of it in collaboration with Haraldsplass Deaconess Hospital. The Norwegian Knowledge Centre for Health Services assisted as a discussion partner in the initial phase of the study.

The PhD fellow participated in network of researches within patient safety in the Western Norway Regional Health Authority and was a member of a journal club of PhD fellows at the Department of Patient Safety.

Abbreviations

ANOVA = Analysis of variance

ATT = Adherence to treatment

CAD = Coping after discharge

CCI = Charlson comorbidity index

CFI = Comparative fit index

CMIN/df = Minimum discrepancy

CI = Confidence interval

DICARES-M = The Discharge Care Experiences Survey Modified

EPR = Electronic Patient Record

ICC = Intraclass correlation

ICD-10 = International Classification of Diseases 10th version

NORPEQ = The Nordic Patient Experiences Questionnaire

OR = Odds Ratio

PAS = Patient Administration System

PIPD = Participation in discharge planning

RMSEA = Root mean square error of approximation

SD = Standard Deviation

SF-12 = The 12-Item Short-Form Health Survey

SHC = Subjective Health Complaints

SRMR = Standardised root mean square residual

Acknowledgements

It was a cold, rainy day in November. I was on duty at the nursing home, waiting at the main entrance for one of the female residents returning from hospital. My heart dropped when I saw this thin, frail lady step out of the taxi. She was dressed in large, leached hospital pyjamas. She shrunk when her eyes met mine and looked totally lost. Did anybody responsible of this lady's discharge actually ask what mattered to her? I very much doubt this. At that very moment, the first seed of this thesis was planted in me.

Abstract

Background: Elderly patients account for a majority of hospital admissions. Their wellbeing and safety are at risk in the discharge process due to quality deficiencies, thus, accurate and vigorous instruments to monitor quality in discharge care are important. Further, use of patient experience data to target improvement work and research constitute a basis for quality indicators. A review of literature reveals that validated instruments aimed at measuring quality of hospital discharge from the perspective of elderly patients are currently lacking.

Aim and objectives: The overall aim of this study was to develop a feasible and brief survey instrument for measuring the quality of care based on elderly patients' experiences with hospital discharge and self-care after hospitalisation. The objectives were twofold: to examine the psychometric properties and validate the instrument, and to investigate a clinical application of the instrument.

Methods: We conducted two studies using a cross-sectional design, including patients aged 65 years and older. In Study 1, a total of 419 patients discharged from one orthopaedic and five medical wards at Haukeland University Hospital were included. Study 2 included 1,418 patients from two medical wards at Haukeland University Hospital and Haraldsplass Deaconess Hospital. Both studies gathered data through a paper-based survey that was distributed approximately one month after discharge.

A systematic literature search identified 16 candidate-items of the Discharge Care Experiences Survey Modified (DICARES-M). Intraclass correlation between the items was examined for consistencies in the test re-test measure. Factors analysis was applied to identify and validate the factor structures of the internal reliability consistency of the instrument. For the purpose of external validation, the final DICARES-M was correlated to scores from the Nordic Patient Experiences Questionnaire, the 12-Item Short-Form Health Survey, Subjective Health Complaints, and the quality indicator emergency readmission (i.e. emergency readmission within

30 days after discharge). To test the recognised three-factor structure of the DICARES-M more rigorously, we applied confirmatory factor analysis. A subset of experience data from Study 2 was analysed to measure the association between the discharge conversation and discharge quality. The association between the usefulness of the discharge conversation and the scores on the quality indicators DICARES-M and NORPEQ were evaluated.

Results: A total of 270 (64%) patients completed the survey in Study 1 (Paper I). The mean age of the patients were 77 years (SD=7) and 58% were men. The factor analysis showed a 10-item, three factor instrument explaining 64% of the total variance. The Cronbach's α for the three factors were acceptable (≥70). The overall intraclass correlation was 0.76. A moderate Spearman correlation was found between the total mean DICARES-M score and the total mean score of the Nordic Patient Experiences Questionnaire (rho = 0.54, P <0.01). An inversely association was found between the total mean DICARES-M score and emergency readmission.

Totally, 493 patients (35%) responded to Study 2 (Paper II), with a mean age of 79 years (SD=8), and 52% were women. Confirmatory factor analysis revealed acceptable model fit. Cronbach's α for the three factors were 0.82, 0.71 and 0.66. A moderate correlation was found between DICARES-M the Nordic Patient Experiences Questionnaire (rho = 0.49, P < 0.001). Higher overall DICARES-M scores, indicating more positive experiences, were found for patients with no emergency readmissions compared to patients who were emergency readmitted within 30 days (P < 0.001).

In all, 487 (34%) patients were included in Study 2 (Paper III). Patients who reported having a discharge conversation (74%) scored higher on DICARES-M and NORPEQ compared to those who did not have this conversation (15%). Patients who considered the conversation more useful scored significantly higher to DICARES-M and NORPEQ (P < 0.001).

Conclusions:

We have developed survey instrument feasible of assessing patients' experiences with discharge and self-care after hospitalisation and thereby may have established an indicator of quality in the discharge process. DICARES-M has demonstrated satisfactory psychometric properties, further; it appears to capture the quality care of the discharge process sensitively in terms of emergency readmission and independently in terms of patient comorbidity. Thus, we suggest DICARES-M as an additional instrument in improvement work of discharge care in elderly patients. An application of the instrument showed a significant association between discharge conversation and discharge quality, where higher scores on reported usefulness of the conversation were positively associated with patients' experience.

List of papers

Paper I

Boge RM, Haugen AS, Nilsen RM, Harthug S. Elderly patients' (≥65 years) experiences associated with discharge; Development, validity and reliability of the Discharge Care Experiences Survey. PLoS One, 2018. 13(11): e0206904.

Paper II

Boge RM, Haugen AS, Nilsen RM, Bruvik F, Harthug S. Discharge care quality in hospitalised elderly patients: Extended validation of the Discharge Care Experiences Survey. PLoS One, 2019. 14(9): e0223150.

Paper III

Boge RM, Haugen AS, Nilsen RM, Bruvik F, Harthug S. Elderly patients' experiences of discharge conversation and discharge quality: a cross-sectional study. BMJ Open Quality. 2019. 8(4): e00072.

Contents

1. INTRODUCTION

1.1 Background

Elderly patients account for a vast body of hospital admissions. Hospital discharge represents the end of inpatient hospital care and is one of various transitions within the patient's care pathway (1). Hospital discharge is a complex process between multiple actors where elderly patients with multiple chronic conditions are particularly at serious risk of adverse events (1-3) and emergency admissions within 30-days of discharge from hospital (emergency readmission) (4, 5). Thus, it is important to monitor and control the quality of discharge of elderly patients from hospital.

Our life expectancy is higher than ever, and healthcare systems around the world will face significant challenges to meet the needs of an ageing population (6). According to the World Health Organization (WHO) the amount of people in the world over 60 years will increase from 12% in 2015 to 22% in 2050. Currently, 43 % of patients admitted to hospitals in the United Kingdom are over 65 years and accounting for 53 % of all bed days (6). In Norway, 34 % of all hospital admissions in 2018 were patients aged 60 years or older, accounting for 43% of all bed days (7). Ageing is associated with vulnerability due to reduced physical and mental function, and increased disease burden (8-15). The WHO sees the aligning of health systems with the needs of older population as a priority area for action, as it will enhance elderly peoples' intrinsic ability (6). Independency for as long as possible is important to the elderly persons, and this will not change in the future (16). Many will have a single-person household (at present 30%), and a large amount will manage multiple chronic illness, where up to 40% are expected to live with a severe disable condition. National Health Services, United Kingdom, England, claim there is a need to improve the way we support older people to prevent an increased need for resources and to account for changes in patient needs (17). According to the WHO, feedback about patient experiences "the sum of all interactions shaped by an organization's culture, that influence patient perceptions, across the continuum of care" (18), provide a deeper

understanding about the patients' demands, preferences and values which can help to improve the quality and safety of care (19).

To respond to the healthcare challenges of the aging population in Norway, the Norwegian Ministry of Health and Care Services implemented The Care Coordination Reform in 2012 (20). The purpose of the reform was to improve public health and healthcare services, providing more services closer to peoples' homes, with increased responsibility to the municipalities. This change resulted in an increase of patients reporting to be ready for discharge at an earlier stage than before, and more frequent emergency readmissions (20). In 2016, 16 % of patients aged 67 and older were readmitted to Norwegian hospitals (21). In Norway, as well as in many other countries, lack of collaboration and incorporation between different segments of the healthcare system is demanding (1, 22). Assessments of patient experiences of overall care quality in Norwegian hospitals show a significant potential for improvement, particularly with respect to discharge preparation (23).

Hospital discharge has been based on system constraints where health professionals, primarily the physician, determine the patients' readiness for discharge, without including the patient perspective (11). This may cause insufficiencies in adherence to therapy were complications not identified or psychologic distress affect the patients' level of functioning (24), and emergency readmission (24-26). Further, patients who are discharged premature to surroundings that is not able to meet the patients' need of care may result in emergency readmission (25). This may be prevented by use of an individualised plan in discharge planning to prepare patients' expected need of care (27). Quality of hospital discharge in elderly requires thorough planning and considerate interaction with the patients and their caretakers, as well as in collaboration health professionals within the hospital and the municipalities (28).

1.2 Quality in healthcare

Quality in healthcare is perceived as a product consisting of a combination of quantifiable and non- quantifiable, unconnected attributes or characteristics. A number of conceptual frameworks, operationalisations and measurements approaches within the topics of healthcare quality and quality indicators have been developed (29), however, there are no standards on how to evaluate hospital quality. There exists a large number of definitions of quality, in general consisting of fragments of complexity, perspectives and subjectivity (29). Institute of Medicine (IOM) (1990) define quality "to which extent health services for individuals and populations increase the likelihood of desired health outcomes and are consistent with current professional knowledge" (30). Health outcomes refer to changes in health status as a result of interventions on participants in a clinical trial (31).

In general, health interventions aim to decrease disease and/or to improve health (32). IOM's definition may reflect a more curative approach where health is defined as absence of disease, based on WHO's definition of health from 1948: "A state of complete physical, mental and social well-being and not merely the absence of disease or infirmity" (33). IOM's definition has similarities with Donabedian's definition from 1980: "Quality of health care is that kind of care which is expected to maximize an inclusive measure of patient welfare, after one has taken account of the balance of expected gains and losses that attend the process of care in all its parts" (34). Compared to the definition of IOM, the definition of Donabedian appears to be more aligned with modern definitions of medical health, where the ability of adapting to changes in external and internal circumstances are emphasised (35).

Donabedian summarise patient welfare to magnify the attainable benefits and argue that what characterizes a problem should determine its importance (36). Donabedian claims no formula exist, but that informed judgement should be used in order to prioritize with respect to frequency, seriousness, and corrigibility (36). Nylenna and colleagues (29) argue that a combination of Donabedian's and IOM's definition yield a

valuable and reasonable approach to the quality of healthcare. Quality of healthcare, as operationalised by WHO must be *safe, effective*, *timely*, *efficient, equitable and people-centred* (37). According to IOM the receiver of healthcare is the one who should decide whether the outcome is a desired health outcome, indicating a need of patient reported measurements.

The quality triad: *Structure*, *Process* and *Outcome* introduced by Donabedian (38), is commonly used to deduce indicators of whether quality is satisfactory (Figure 1). There is a relationship between the explicit components and the specific matter evaluated. The matter could be the performance of the health professionals, the care received by patients or the care received by the society. In assessment of quality, Donabedian suggests one must start with the performance of the health professionals (39). In care of elderly, quality is basically determined by aspects concerning how caregivers act towards the elderly person (40).

Structure
Facilities, appliances and human resources

Process
How the organisation is working and interaction with the patient

Outcome
Health outcomes, patient satisfaction and experiences
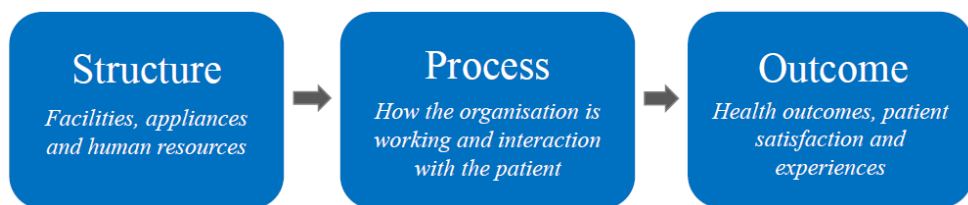
Figure 1. Donabedian's quality triad; the relationship between specific elements and explicit issues evaluated.

Patient safety, defined by the WHO as "the prevention of errors and adverse effects to patients associated with healthcare" (41) is identified as an important dimension of quality (42). Due to the awareness of safety issues in healthcare worldwide, a patient safety campaign was initiated by the Norwegian Ministry of Health in 2011, now implemented as a "Department of Quality Improvement and Patient Safety"- program (43). One of the priorities in the program is improvement of discharge using compound measures emphasizing involvement of the patient as an equal part.

From the 80', where the main focus in healthcare services was ensure quality only, there has been a shift towards ongoing quality improvement work (29). Healthcare in Norway is imposed by regulation to systematically work for quality improvement, and to use experiences from patients, users and relatives (44). To support improvement processes in Norwegian hospitals, the Plan-Do-Study-Act (PDSA) cycle is a commonly used method (45, 46). The PDSA is an advanced way of attaining learning and change in complex systems. The cycle aims to rapidly learn whether a process works in a specific surrounding, and to make adaptations to increase the possibilities of delivering and sustaining the desired improvement. In a PDSA perspective, non-success is considered to be far more valuable in building knowledge than a number of positive results (47). Generally, the PDSA-circle must be repeated several times applying in an iterative process.

1.2.1 Quality indicators

Quality indicators; measures that assess a particular healthcare process or outcome (48), are helpful instruments to guide clinical improvement processes, and may also serve as trust builders when applied as a tool to communicate with patients (29). A quality indicator needs to demonstrate relevance based on its effect on health to be relevant for use in evidence-based policy decisions. Further, it must be receptive to be influenced by the healthcare system. To meet this condition, the evaluation of an indicator comprises calculation of available reliable data, and further, includes relation to the burden of reporting. The indicator also needs to be scientifically sound (49). Patient experiences are considered as a priority for development of indicators and quality improvement of the Organisation for Economic Co-operation and Development (50, 51).

In Norway, a large number of indicators are develeped to monitor quality in healthcare service (52). Emergency readmission is one of the two official indicators reflecting quality in discharge (Emergency readmission among elderly patients within 30 days). Despite its well-known limitations, for instance patient complexity, this indicator is used to evaluate quality across several healthcare organisations (5, 49).

The second official quality indicator is patient experiences (Patient experiences with Norwegian hospitals) which is recognised as more appropriate when evaluating quality in the discharge process. The Nordic Patient Experiences Questionnaire (NORPEQ) has commonly been used as a quality indicator in Norwegian somatic hospitals for the past ten years (53).

1.2.2 Health-related quality of life

Health-related quality of life (HRQOL) is considered as an important outcome of interventions in healthcare. The HRQOL- construct contains patient and social perspectives with respect to the impact of illness to improve treatment (54). HRQOL has been explained by several researchers, and the conceptual framework developed by Wilson and Cleary is one of the most sited (55). The model was developed for the purpose of measuring specific causal relationships linked to traditional clinical variables with HRQOL (55, 56). The model is divided into five levels of outcomes: biological and physiological factors, symptoms, functioning, general health perceptions and overall quality of life. At each level, the concept integrate more variables. This makes it increasingly difficult to define, and further, measure increases as one moves from the first level variables in order to investigate and clarify the causal relationships among the components (56). A systematic review of studies applying Wilson and Cleary's framework concludes that symptom status is the most significant predictor of HROOL, indirectly and directly affecting functional status and general health perceptions (55). HRQOL is frequently measured by use of generic instruments or diagnose specific instruments.

The care received at the hospital can affect survival and HRQOL (54). The 12-item Short-Form Health Survey (SF-12) (57), is a broadly used HRQOL-measurement (58), as well as a patient-reported outcome measures–instrument (PROMs) (59). A PROM is a patient report without any interpretation of intermediaries. Valid and responsive PROMs –measurement tools produce verifiable confirmation regarding health from the patient perspective. Capturing the patients' experiences in order to evaluate and improve hospital service by PROMs and by patient-reported experiences measure

(PREMs) are increasingly focused. PREMs-instruments can be categorised as either relational or functional, and are designed to measure the patient experience of care of a specific condition or treatment (60). Donabedian showed that assessment of data from the patients' perspective is a part of the process in health services delivery, enabling recognition of dysfunctions in the organisation of care (61).

1.3 Patient experience

Patients' experiences are closely related to whether their expectations are met and positively perceived, and reach further than results of treatment received, or health status (18, 62). To receive expected healthcare services is associated with recuperation (63). Less sufficient care is correlated with non-adherence to treatment, poor understanding and withhold of medical information (64). The terms *Patient satisfaction* and *Patient experience* are often used interchangeably. However, patient experience comprises more than patient satisfaction alone and relates to engaging the patients to be an active part of their care (65). It is suggested that determination of patients' satisfaction should be based on assessing more specific questions related to experiences with care delivery, and investigate factors such as communication, respect of patient preferences, and continuity of care.

1.3.1 Patient participation

Involving patients in their own care, treatment and support have been embraced by healthcare organisations (66-69). Initiatives to improve care in transition of patients have shown mixed results. However, a number of studies support the importance of a patient-centred approach in order to improve quality of transitional care (70-72). In many Western countries, like Norway, patient participation is considered a civil right. There are different views on the term *participation* (71, 73), where individual participation refers to active patient involvement in all aspects of own care.

Historically, healthcare systems have been grounded on a paternalistic model, where patients were viewed as passive receivers of care. Contemporary healthcare services acknowledge equality and encourage the patients to play more active role in their own care, a change that has increased emphasize on communication with patients (74-76). The term "communication" refers to a range of processes and behaviours that aim to exchange information by through speaking, writing or other mediums (77). Effective and empathic communication is crucial in treatment of elderly (78), as well as a tool to ensure patient participation. Communication between health professionals and patients has mainly three motives: exchange of information, make decisions related to therapy, and to strengthen interpersonal relationship. The quality of communication in interactions between health professionals and patients can have widely applicable implications for health outcomes of patients (77). A meta-analysis of physician–patient communication revealed a significant positive association with patient adherence (79). Most of the studies have focused on interactions between physicians and patients (77).

1.3.2 Elderly patients' experiences

A literature review, applying a systematic search in databases by well-recognised methods, was conducted in order to evaluate the state of scientific knowledge on elderly patients' experiences with hospital discharge and transition to primary healthcare. The criteria for inclusion were qualitative and quantitative studies in English, Norwegian, Danish or Swedish that targeted patients of both sex from the age of 65 and above who had been discharged from somatic hospital departments. If there were more participant groups in addition to patients (i.e. next of kin, informal carers, or health professionals), the patients' experiences had to be clearly stated. Intervention studies, follow-up and evaluation studies were excluded. An academic librarian at the University of Bergen assisted in the literature search.

The literature review included searches in Medline, Embase, CINAHL, Svemed+ and PsycINFO in March 2013 and a manual search (Paper I). The search strategy combined MeSH terms such as; *Patient Discharge*, *Patient Handoff*, *Patient Transfer*, *Continuity of Patient Care* and *Patient Satisfaction*, and terms like *patient experience*

and *patient perspective*. To organize the retrieved data we used the EndNote reference management software package (Clarivate Analytics, Philadelphia, USA). More details are described in the appendix of Paper I. The last search was performed in April 2019 (Appendices), and 1309 records were identified, of these 492 were considered relevant for screening. We assessed full-text of eight papers for eligibility, of these; four papers were included additionally to the previous review. A PRISMA Flow Diagram with results from the main literature search and update is shown in Figure 2.
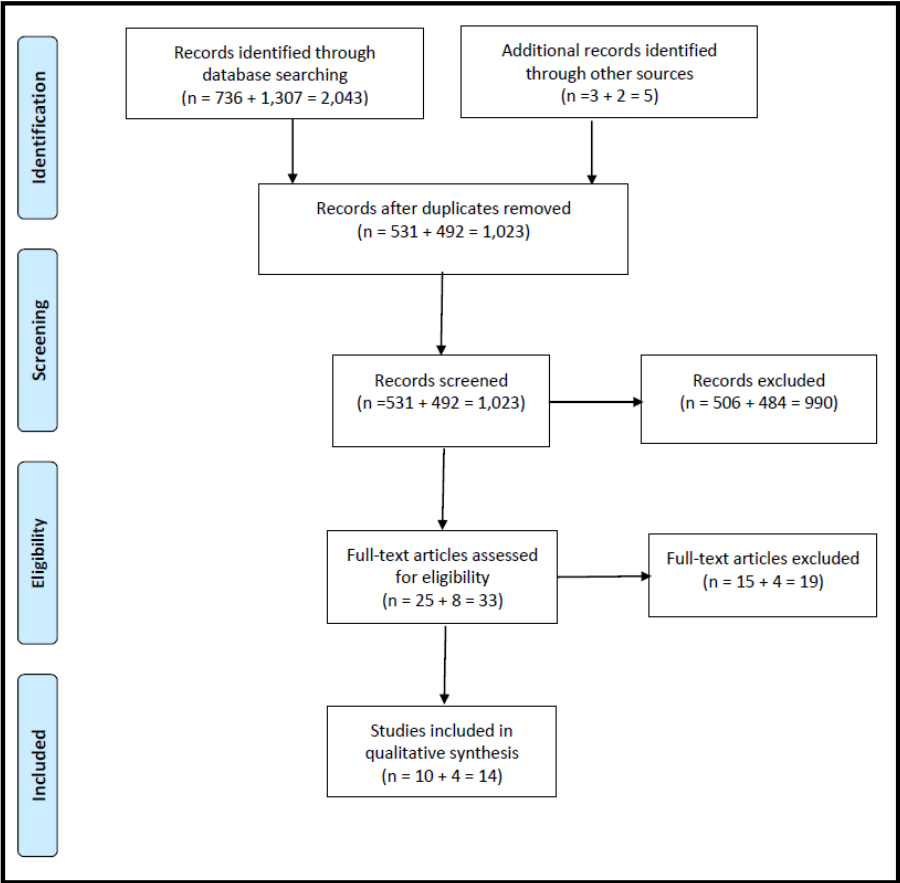
Figure 2: PRISMA Flow Diagram with results from the main systematic literature search in March 2013, and the update search in April 2019 on elderly patients' experiences with hospital discharge and transition to home.

Of 14 studies included in the review (Table 1), seven studies had a quantitative design, three studies combined qualitative and quantitative methods, whereas four studies had a qualitative study approach. Patients were recruited from medical hospital ward in 12 of the studies, and from surgical wards in two studies.

Predominantly, the patients were satisfied with the discharge process, however, the findings showed that patients' experienced to feel unprepared for discharge (80, 81). Feeling unprepared for discharge was the most important common patient reported reason for readmission in a study of Kangovi et al. (26). In a study by Jones et al. (80) investigating patients' and carers' opinions, they found that it was more likely that relatives reported that premature discharge.

The review showed that elderly patients experienced challenges associated with information, participation in discharge planning and issues related to self-care "The practice of taking action to preserve or improve one's own health" (82), after hospitalisation.

Information and participation in discharge planning

In several studies, the results showed frustration concerning complex information (83), or lack of information (81, 84-87). In the study carried out by of Fairhurst et al. (86), 78 % of the patients reported receiving only verbal information.

In general, the need for information was related to medication, equipment that might be useful to the patient after coming home and to health-services in the community. Patients in several of the studies reported lack of involvement in connection with discharge (84, 87-91). In the study by Foss et al. (88) where the average age of the respondents was 87 years, more than 40 % of the patients reported they did not experience an opportunity to be involved in issues they found important, like medical treatment, practical conditions and the time of discharge. This finding stands in contrast to results from a study conducted by Fairhurst et al. (86), where 80 % of the patients reported being sufficiently conferred about arrangements for their discharge. Further, the results are not consistent with Perry et al. (84), who found that even if the patients stated a lack of involvement in connection with discharge, they paid little

attention to this issue, expressing that it was of little significance to actively participate in the discharge planning. The authors argue that this may indicate that patients do not expect to be included in the discharge planning.

<u>Self-care after discharge</u>

In the first period after hospitalisation difficulties in performing daily activities was experienced as one of the issues in three of the studies (26, 83, 84). Patients who were discharged to home after orthopaedic surgery expressed uncertainty regarding the rehabilitation process (84). They did not have a clear picture on how long it would take before the fracture healed and were frightened to overdo activities. Issues concerning medication were illuminated (26, 81, 83), and patients in the study by Rodrique et al. (81) reported problems in understanding the medication list and the potential side effects of medications. Lack of adherence to medication was one of the main reasons for readmission according to findings in a study performed by Kangovi et al.(26). Commonly reported reasons for being unable to take medication were side effects or anxiety about side effects. In general, patients were satisfied with contact with their general practitioner (GP) (85, 89, 92). Dissatisfaction with the follow up from the GP was reported in the study by Aurora et al. (93).

Lack of satisfaction with support and treatment were other issues reported, mostly attributed to deficiency of attention with respect to provision of the services (81, 85, 92). A significant lower quality in transition was measured for patients who had an ensuing emergency visit to hospital for their index condition (90).

Table 1. Patients' experiences with discharge, and transition from hospital to primary healthcare. Results from a systematic literature search March 2013, updated in April 2019.

Authors	Design	Aim	Population / Setting	Results
Arora et al. 2010 (93)	Prospective mixed methods study	To report elderly patients' experiences with problems after hospital discharge and investigate whether their primary care physicians were aware of their hospitalisation	64 patients, (mean age: 73 years) discharged from a single academic medical centre. Inpatient interview within 48 hours after hospitalisation, and two weeks post-discharge phone interview with patients and/or proxies.	42% of the patients reported 42 different post-discharge problems. The most frequently reported problems were difficulty with follow-up appointments or tests. The patients were twice as likely to report problems when the patient's primary care physicians was not aware of the hospitalisation.
Bisset et al. 1997 (92)	Criterion-based process audit and survey	To determine general practitioners' and their patients' satisfaction with hospital and community services for stroke patients	Data collected on 150 patients six weeks after discharged to home or nursing home. The patients were blindly randomised the patients into two groups. 75% received postal questionnaires and 25% received a visit.	Response rate were 91%, mean age 72 years. Patients were generally satisfied with services. 83 patients felt that things had been well prepared for their return home. 14 patients stated that they had wanted, but not received, particular services.
Coleman et al. 2005 (90)	Cross-sectional study	To develop and test a self-report measure of the quality of care transition that capture the patients' perspective	Data were obtained for 200 patient 18 years or older six to 12 weeks after being discharged from one of three participating hospitals. The mean age was 67 years and 75 % were 60 years or older.	Patients who had a subsequent emergency department visit for their index condition experienced a significant lower transition quality.

Author/Year	Design	Aim	Method/Sample	Findings
Fairhurst et al. 1996 (86)	Semi-structured interviews. Follow-up postal questionnaires.	To assess the quality of discharge arrangements for patients (≥65 years)	Semi-structured interviews with 138 patients in their homes on average 34 days after discharged from one of the four participating hospitals. A follow-up postal questionnaire was sent to the patients six weeks after the initial interview.	110 (86%) patient responded to the survey. A large majority of patients (80%) reported arrangements for their discharge were adequately consulted. 12 patients (12%) reported being discharged too early.
Ford et al. 2016 (83)	Mixed-methods approach	To examine care transition experiences of older veterans and their caregivers	A convenience sample of 50 patients 65 years and older (range: 65 -89 years) admitted for a medical condition were contacted by telephone approximately four weeks following discharge to complete a questionnaire. Face-to-face semi-structured interviews with seven patients and six caregivers.	Most of the veterans' item responses to the questionnaire were positive. Items with the lowest scores were: not understanding the potential side effects of medications; hospital staff not taking into consideration the patients' or familys' preferences, lack of an easily understood medication list and a list of follow-up appointments; not feeling confident in taking care of their own health; and not understanding the side effects of medication. The qualitative analysis identified five themes: (1) gratitude and agreeableness, (2) frustration with complex information, (3) frustration with the timing of information delivery, (4) targeting education to caregivers, and (5) methods of delivering information.
Foss & Hofoss 2011 (88)	*Design not described*	To describe elderly patients' (≥80 years) discharge experiences on participation in the discharge planning.	Patients 80 years and older admitted to 14 hospitals in Norway from home and discharged to community care. A semi-structured face-to-face interview comprising 76 questions took place 2-3 three weeks (mean 19.2 days) following patients discharge from hospital.	254 (61,5%) patients with a mean age of 86.9 years (SD=4.9) were interviewed. The patients expressed clear preference for participation. No significant correlation between patients' wish for participation and experienced opportunity to share decisions. 65% of the patients stated that they felt a match between their own concerns and the concerns of the hospital professionals

Study	Design	Aim	Method	Findings
Hvalvik & Dale 2015 (87)	Phenomenological hermeneutic study	To describe and illuminate the lived experiences of older home residents during the transitions from hospital to home.	Seven participants were interviewed in their home 2-8 weeks after discharge from hospital.	The participants missed to be seen as human beings as well as patients during the transition process. The themes "Relating to different systems of care" with the two subthemes "feeling disregarded" and "being humble"; and the theme "Adapting to life conditions" with the two subthemes "feeling vulnerable" and "coping with alterations" emerged from analysis.
Jones and Lester 1994 (80)	Cross-sectional study	To investigate patients' and carers' opinions of hospital care and discharge	Questionnaires were sent to 1084 patients (≥65 years) three months after discharge from hospital.	A total of 960 (89%) questionnaires were completed. 38% of patients did not remember discussing discharge with hospital staff. Patients were more concerned than the carers with social and environmental issues. Carers were more likely to comment medical aspects and that discharge had been premature.
Kangovi et al.2012 (26)	Cross-sectional study	To understand the transition experiences of readmitted patients and to compare these experiences across socioeconomic status and diagnostic categories	A questionnaire was sent to 3881 patients readmitted within 30 days of a prior discharge from two hospitals.	Response rate was 33 % (n=1084) with a mean age of 56 years. The most commonly reported issues contributing to readmission were: 1) feeling unprepared for discharge (12%); 2) difficulty performing activities of daily living (11%); and 3) trouble adhering to discharge medications (6%).
Perry et al. 2011(84)	Interpretative phenomenological analysis	To explore patients' perceptions of the discharge process	Eleven participants (≥65 years) being discharged home following lower limb orthopaedic surgery. The patients were interviewed in a location of comfort and convenience to the participants within the first three months of returning home from hospital.	The patients reported 1) lack of a shared decision on when to go home, 2) dependent on family to go home and to feel confident there, and 3) trial and error rehabilitation.

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Rodrique et al. 2017 (81)	Cross-sectional study	To describe the experiences of hospitalised trauma patients 65 years and older who were discharged home	Thirty-tree participants, mean age 73 (range: 65-86) years were recruited from four surgical inpatient trauma units. The participants were interviewed at home, or by telephone, one month after discharge. Two assessment tools were used.	The patients scored less than 50% on most categories related to discharge preparedness, and reported not having received enough information about medication, available healthcare resources in the municipality, and acceptable activities.
Rustad et al. 2016 (91)	Qualitative approach with a descriptive and explorative design	To explore patients of age experienced the care transition from hospital to municipal healthcare services.	Four-teen elderly persons (≥80 years) participated in semi-structured telephone interviews including two open ended questions 1-2 weeks after discharge.	Two complementing themes appeared as a result of the analysis: "Participation depends on being invited to plan the care transition" and "Managing continuity of care represents a complex and challenging process".
Tyson and Turner 2000 (85)	Criterion-based process audit and a survey	Examines the hospital discharge process and provision of follow-up services for people with stroke	A senior physiotherapist with experience in stroke rehabilitation conducted the audit. A postal survey was sent to 93 patients within six weeks after discharge.	Thirty-nine respondents (71%) received a type of home care services. Of 59% (n=55) patients responding to the survey, 40 (43%) were offered follow-up treatment. Patients were dissatisfied with the amount of information, support services and therapy they received.
Wressle et al. 2006 (89)	*Design was not described*	Patient perspective on quality of geriatric care and rehabilitation	221 participants (89 %, mean age 79 years) were interviewed by telephone. One assessment tool was used.	The two highest scored items concerned feelings of safety and respect, while the lowest scored item was staff exposure to stress. 88% of the participants scored 'Totally agree' on the global item concerning satisfaction with care.

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* Manual search in database

1.3.3 Measuring patient experience

Measuring patients' experiences with care is recognised as a major component of quality management (94), and is a tool to discern robustness, deficiency and unmet needs in healthcare services. Florence Nightingale (1820-1910) was a pioneer in improving quality in healthcare by using statistics to illustrate how building hygiene could save many lives (95). Nightingale stated: "The ultimate goal is to manage quality. But you cannot manage it until you have a way to measure it, and you cannot measure it until you can monitor it" (96). Through use of statistical methods, healthcare services can be described from the patients' perspective for the purpose of measuring the process of care, or to evaluate the outcome of care (97). Surveys where patients are asked to rate aspects of care is a suitable way to collect data from large numbers of persons, and is commonly used to monitor quality in healthcare (98). A limitation of these instruments is that they do not identify the nature of healthcare services (65). Further, few instruments designed to measure patient satisfaction or the patients perspective have undergone basic testing (61, 99, 100). Thus, valid measurements to monitor and improve quality are needed. There exist a number of instruments measuring aspects of the patient experience of hospital quality of care (60, 62). However, instruments suitable to assess patients' experiences with the discharge process are lacking (101).

The development of a validated questionnaire (i.e. an instrument with satisfactory psychometric properties that is useful in scientific studies and clinical settings) is demanding (102). Different approaches are suggested for use in measurement scale development (102-105), where each step throughout the development process requires thoughtful considerations. Reliability and validity are essential features when choosing a questionnaire. Reliability refers to the extent of stability in results in a repeatedly administered questionnaire under different conditions (103, 106). Validation of a questionnaire using a representative sample is recommended to examine the appropriateness of use the in the intended respondent group. Validity refers to the extent to which the observed associations are real (107). Multiple questions should

express shades of a specific construct. One of the advantages of validated questionnaires is that it enables comparison between different healthcare systems. For this purpose quality criteria for measurement properties have been developed (108, 109). Even if there are at least one other candidate in the pipeline (105), to our knowledge, there exists no validated instruments developed with the potential to reflect quality in discharge care, covering important aspects related to self-care after hospitalisation.

2. AIM AND OBJECTIVES

The overall aim of this thesis was to gain new knowledge of measuring discharge care quality by use of elderly patients' experiences.

<u>Objectives:</u>

1. To develop a feasible brief survey instrument for measuring quality of care on basis of elderly patients' experiences with hospital discharge and self-care after hospitalisation.
2. To investigate the psychometric properties and validate the instrument.
3. To examine a clinical application of the instrument concerning discharge conversation and discharge quality.

3. MATERIALS AND METHODS

3.1 Design and setting

To address the aim of this thesis we used a cross–sectional design; analysing data of variables gathered across a sample population. The thesis was conducted at Haukeland University Hospital, a tertiary hospital in Western Norway. Study 2 was performed in collaboration with Haraldsplass Deaconess Hospital, a non-commercial private hospital sponsored by the same regional health authority.

3.2 Inclusion of patients

Inclusion criteria, and the approach of including patients, differed in Study 1 and Study 2. An overview of the inclusion process is shown in Figure 3.

Study 1

The patients were asked to participate by the principal investigator who visited potential eligible patients at the participating wards between June 2013 and February 2015. Before visiting the patients, the principal investigator obtained information about the patients' condition from the Electronic Patient Record (EPR) and from nurses at ward. The inclusion criteria were as follows: age 65 and older; hospitalised more than 24 hours: capable of giving consent, the ability to understand Norwegian, and the ability to complete the form without assistance. Exclusion criteria were poor general condition, reduced cognitive function, or being a nursing home residents. The majority of the results are published in Paper I, further, some additional results are presented in the results chapter.

<u>Study 2</u>

Analyses and results from Study 2 have been published in Paper II and Paper III. Data were collected as a part of a pilot testing a discharge planning tool in a medical ward at Haukeland University Hospital.

The patients were invited by postal mail during a period of 10 months (June 2015 to March 2016). Inclusion criteria were patients aged 65 and older hospitalised for more than 24 hours. If less than half of the items of the Discharge Care Experiences Survey Modified (DICARES-M[1]) were completed, these patients were withdrawn from the analysis.

In Paper III, an additional criteria for inclusion were to have completed the question: *Did you have a discharge conversation in the hospital?* with 5 response alternatives*: Yes, with a physician; Yes, with a nurse; Yes, with a physician and a nurse; No, I did not have a discharge conversation* and *Not sure.*

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[1] In Paper I and Paper II we used DICARES (Discharge Care Experiences Survey). Based on comments from the reviewers in the review process of Paper III we decided to rename to DICARES-M (Discharge Care Experiences Survey Modified)

Study 1/ Paper I

798 were eligible for inclusion

300 did not meet the inclusion criteria

498 were asked to participate

79 did not want to participate

419 (100%) received the survey

111(27%) did not return the survey
23 (5%) returned incomplete forms
14 (4%) withdrew from the study

270 (64%) were analysed

Study 2/ Paper II and III

1,418 were asked to participate
A reminder was sent to 966 (70%)

541 (385) returned the survey

48 incomplete forms were withdrawn

Study 2/ Paper II: 493 (35%) forms
were analysed

Six forms were excluded due to <50%
of the DICARES-M-items were
completed

Study 2/ Paper III: 487 (34%) forms
were analysed

Figure 3. Inclusion of patients in the study

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3.3 Collection of data

In both studies, a questionnaire was sent to the patients in a pre-stamped and pre-addressed envelope approximately 30 days after discharge. Non-responders were reminded by telephone call in the Study 1 and by postal mail in Study 2. Data were entered into a spreadsheet twice by the same research assistant. Data were quality checked by the principal investigator and a researcher. Discrepancy between the entered data sets were corrected.

3.4 Assessments

Hospital information system registers

The Patient Administration System (PAS) helped to gather information regarding the Charlson Comorbidity Index and the quality indicator emergency readmission (Paper I-III). EPR provided clinical characteristics, health condition and information regarding date and time of hospital admission (Paper I). Charlson Comorbidity Index; based on the International Classification of Diseases version 10 (ICD-10) (110), was used to determine if the DICARES-M was influenced by disease (111). We compared the DICARES-M scores and emergency readmission.

The Nordic Patient Experiences Questionnaire (NORPEQ) (Paper I-III)

NORPEQ consists of eight questions on a 5-point Likert-type scale (1 = not at all; 2 = to a little extent; 3 = to some extent; 4 = to a large extent; 5 = to a very large extent). We applied the six validated items comprising experiences with communication, confidence in health personnel, care and treatment, and possibly negligence. The NORPEQ total score is scored on a 0–100 scale from the worst experience to the best experience (112).

The Short Form -12 (SF-12) (Paper I)

For the purpose of evaluating subjective general health we used the SF-12 (version 1).

This instrument consists of 12 questions summarised in a Physical Composite Scale and a Mental Composite Scale. The SF-12 has two to five response levels, with higher scores reflecting better self-reported health (57).

Subjective Health Complaints (SHC) (Paper I)

We applied the SHC which contains 29 questions on subjective, somatic and psychosocial complaints over the last 30 days. The main categories of the SCH are musculoskeletal pain, pseudoneurological complaints like tiredness, vertigo and headaches, and gastrointestinal problems like pain, bloating and diarrhoea. The degree of each complaints is graded on a 4-point scale (0 = not at all; 1 = a little; 2 = some; 3= severe) (113).

3.5 Development of Discharge Care Experiences Survey Modified

Development of DICARES-M was based on a framework described by Pett et al. (104) including identification of the measurement framework, identification of empirical indicators of the instrument, test of the instrument inclusion and determination of the number of subject. The thesis' conceptual framework was inspired by Donabedian's triad model (38) were the relationship between discharge planning (*structure*); health professionals performance of tasks and involvement of patients (*process*), and patients' experiences and emergency readmission (*outcome*) were evaluated.
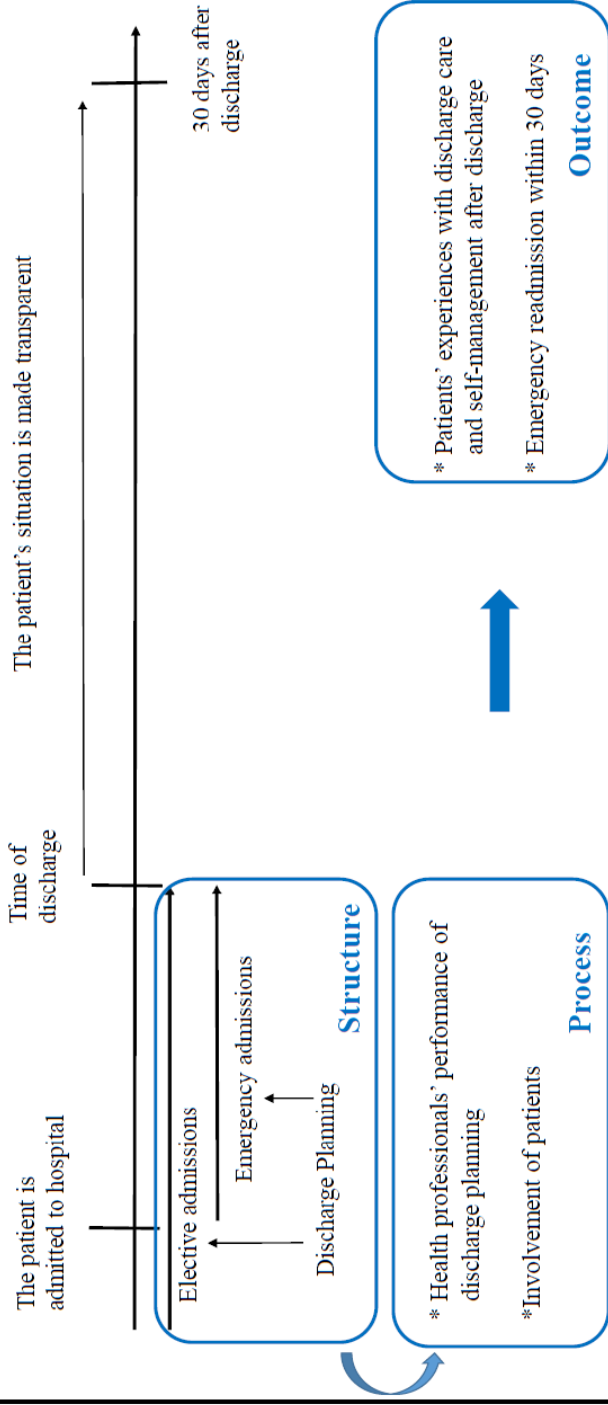
Figure 4. A conceptual framework for measuring quality of care in discharge of elderly patients from hospital.

In order to identify relevant questions, we conducted a systematic literature search and a manual search in databases (Paper I). In collaboration with an interdisciplinary expert panel, 16 candidate items (Appendices) were selected using an eclectic approach. The expert panel consisted of researchers, experienced health professionals and hospital managers (Paper I). The selection of items was based on input from patient representatives, and previous clinical experiences amongst the health professionals in the expert panel. Further, the items we selected was influenced by acquired experiences in an earlier project conducted at the Department of Medicine at our hospital to improve quality in transition of elderly patients from hospital to home (114). The questions covered communication with health professional before discharge, and issues related to self-care after hospitalisation. In order to avoid missing values and unreliable answers we aimed to simplify the items without difficult words or jargon terms. Forward and backward translations of the instrument were performed in accordance with the WHO' guidelines (115). The items were scored on a 5-point Likert-type scale (1 = not at all; 2 = to a little extent; 3 = to some extent; 4 = to a large extent; 5 = to a very large extent) (116). High scores indicate experiences that are more positive. Further details are presented in Paper I. The instrument was evaluated and adjusted by adding one item and rewording some of the items before use in Study 2. More details are described in Paper II. Figure 5 shows the process of development and validation of DICARES-M.
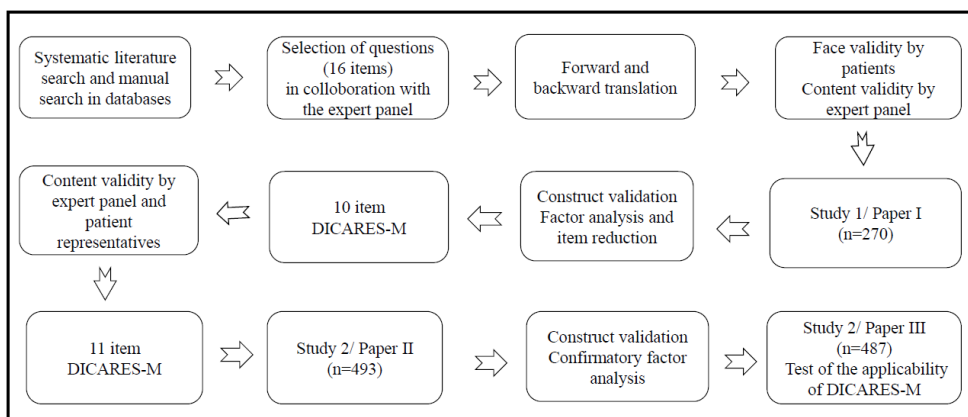
Figure 5. The process of development and validation of the Discharge Care Experiences Survey Modified.

3.5.1 Reliability and validity

To assess the psychometric properties of DICARES-M we used statistical tests. Test–retest reliability was investigated by estimating the intraclass correlation coefficient. The time interval between the two measurements were three weeks (117). We examined the internal consistency; the degree of correlations between items, by use of Cronbach's α. Further, we evaluated the validity through face validity; content validity; construct validity; discriminant validity and convergent validity (Table 2). Face validity: the relevance of a test as it appears to the participants (118) was evaluated by 19 elderly patients. Content validity; whether the items appeared to measure the construction (103) was based on the preferences of the study expert panel and patient representatives. Construct validity refers to whether scores have the expected relationships with other variables (103, 106). To investigate construct validity, we accomplished factor analysis (119, 120). In order to test the strength of the relationship of DICARES-M, SF-12, SHC and Charlson Comorbidity Index, discriminant validity was examined by correlation analyses (103, 121). Further, correlation analyses was used in investigating convergent validity (107, 108) to determine how DICARES-M was associated to the NORPEQ, partly measuring the same domain. Criterion validity, to test the relationship of DICARES-M with gold standard instruments, was not assessed in this study due to lack of relevant measurements (108).

Table 2. Methods and quality criteria used to validate the Discharge Care Experiences Survey Modified.

	Description of concepts	Methods	Quality criteria
Reliability			
Internal consistency	The degree of correlations between items in a questionnaire scale (Bland 1986) (122)	Cronbach's α	Satisfactory ≥ 0.70 (Nunally 1967, Terwee 2007) (108, 123) Accepted > 0.60 (Loewenthal 2004)(124)
Reliability	The extent of stability or consistency in results in a repeatedly administered questionnaire. (Bland 1986) (122)	Intraclass correlation	Excellent r >0.75, Good (0.74> r >0.60) (Cicchetti 1994) (117)
Validity			
Face validity	The relevance of a test as it appears to the participants (Holden 2010) (118)	Evaluated by patients	The target population evaluates all items in the questionnaire to be relevant, and considers the questionnaire to be complete (Terwee 2007) (108)
Content validity	The items appear to measure what they actually are intended to. Appropriate coverage of the subject (Streiner 2015) (103)	Assessed by expert panel and patient representatives	
Construct validity	The proposed underlying hypothetical construct of the measurement that explain the relationship to other variables (Streiner 2015) (103)	Principal component analysis	Factors should explained at least 50% of the variance (Terwee 2007) (108)
		Confirmatory factor analysis	Minimum discrepancy (CMIN/df < 3.0) (Kline 1998) (125), Comparative fit index (CFI ≥ 0.95) (Schreiber 2006) (126), Root mean square error of approximation (RMSEA < 0.06) (Cohen 2003) (121), Standardised root mean square residual (SRMR < 0.05) (Byrne 2010) (127)
Discriminant validity	The extent of correlation between different measures expected to measure different construct of a concept (Streiner 2015) (103)	Spearman's correlation coefficient	(0.49≥ r ≥0.30) (Cohen 2003) (121)
Convergent validity	Extent to which the results of the test correlate with gold standard tests known to measure the same domain (Van Der Vleuten 1996) (107)	Spearman's correlation coefficient	Correlation with an instrument measuring the same construct ≥50 %, and correlation with related constructs is higher than with unrelated constructs (Terwee 2007) (108)

3.5.2 Statistical analysis

Statistical analyses were performed by SPSS version 23.0 (IBM Corp., Armonk, NY), Stata SE version 15 (StataCorp, College Station, Texas), and AMOS version 23.0 (IBM SPSS, Chicago).

Study sample characteristics were estimated using descriptive statistics. Categorical variables were described as absolute numbers and percentages. Continuous data were described as means with standard deviation. Spearman's correlation coefficient was applied to correlation analyses in the study. Two-sample t-tests were used to compare mean scores between groups.

In Paper I, principal component analysis with Varimax rotation was applied to identify the factor structure of the DICARES-M. Eigenvalues >1 were used to recognize the number of factors. Factor loadings ≥ 0.30 were included in the model. To examine how DICARES-M was associated to the quality indicator emergency readmission, multiple logistic regression analyses were performed.

In Paper II, we tested the goodness of fit of the pre-hypothesised DICARES-M factor using confirmatory factor analysis. The following goodness of fit values were reported; minimum discrepancy (CMIN/df), comparative fit index (CFI), root mean square error of approximation (RMSEA) and standardised root mean square residual (SRMR). Linear regression analysis was used to estimate the association of DICARES-M scale, and its factors, with emergency readmission.

In Paper III, we used chi-square tests for categorical data, and one-way analysis of variance (ANOVA) for continuous data to estimate differences in the characteristics between patients with and without a discharge conversation. Linear regression analysis was applied to evaluate the association of usefulness of discharge conversation with scores on the quality indicators DICARES-M and NORPEQ.

In this study, all P values were two-sided and values < 0.05 was chosen as the level of statistical significance.

3.6 Ethical aspects

This study conformed to the principles in the Declaration of Helsinki (128) and was approved by the Western Norway Regional Committee for Medical and Health Research Ethics (Ref.: 2013-401b and 2015/329). An introduction letter to potential participants contained information regarding the purpose of the study and outlined the right to withdraw from the study at any time. In Study 1, patients signed a written consent form before leaving the hospital. In Study 2, a declaration of consent was attached to the survey. Patients who returned the survey with a signed consent form were included in the study. Patient characteristics for all invited patients were obtained anonymously at group level from PAS. Data from the survey were stored in a designated research server at the hospital. Anonymised forms were stored in a locked cabinet according to hospital regulations.

4. RESULTS

4.1 Study 1/Paper I

A total of 270 patients (64%) responded to the study. The mean age was 77 years and 58 % of the respondents were men. Most of the results are presented in Paper I. However, some additional findings will be presented in the following. The mean scores for SF-12, Mental Composite Scale and Physical Composite were 45.1 (SD 10.8) and 31.5 (SD 9.7), respectively. We observed the highest mean SHC scores for category Pseudoneurology (0.77, SD 0.56). Patients who were readmitted reported significantly lower SF-12 and SHC scores (Table 3). Approximately one out of four patients (73 %, n=197) reported to have a discharge conversation at the hospital. More details are presented in Paper I.

In Paper I, we described the development and validation of a survey instrument; the Discharge Patient Experience Survey (DICARES-M), for the purpose of measuring elderly patients' experiences related to the discharge process. Principal component analysis reduced the 16 item DICARES-M candidate into a 10-item, three-factor instrument reflecting discharge care, explaining 64 % of the total variance. Two of the factors were related to self-care after hospitalisation and named *coping after discharge* and *adherence to treatment*, whereas the third factor was named *participation in discharge planning.* The results revealed satisfactory Cronbach's α (≥70) and overall intraclass correlation (0.76). A moderate Spearman correlation was found between the total mean DICARES-M score and total mean NORPEQ score (rho= 0.54, P<0.01). An inversely association with emergency readmission was found for the total mean DICARES-M score (OR 0.62, CI 95: 0.41- 0.95, P = 0.028).

Table 3. (Additional results): Scores for the 12-item Short-Form Health Survey and Subjective Health Complaints in all patients, and comparison of scores between patients not readmitted, and those readmitted, within 30 days after hospital discharge

Items	All patients		Not readmitted		Readmitted	
	N	Mean score (SD)	N	Mean score (SD)	N	Mean score (SD)	P value
The 12 Item Short Form Survey (SF-12)							
Physical Composite Scale	260	31.5 (9.7)	189	32.3 (10.3)	71	29.2 (7,4)	0.020
Mental Composite Scale	260	45.1 (10.8)	189	46.6 (10.6)	71	41.2 (10.6)	<0.001
The Subjective Health Complaints (SHC)							
Musculoskeletal pain	207	0.66 (0.54)	147	0.63 (0.54)	60	0.73 (0.54)	0.258
Pseudoneurology	212	0.77 (0.56)	154	0.70 (0.53)	58	0.99 (0.57)	0.001
Gastrointestinal problems	206	0.40 (0.41)	148	0.36 (0.39)	58	0.49 (0.46)	0.055
Allergies	209	0.57 (0.50)	146	0.53 (0.50)	63	0.64 (0.52)	0.149
Flu	226	0.70 (0.79)	159	0.63 (0.75)	67	0.86 (0.87)	0.046

4.2 Study 2/ Paper II

In this paper we examined the psychometric properties of the DICARES-M with three factors and its association with other quality indicators. In total, 493 (35%) patients (mean age 79 years, 52% women) responded to the survey. Confirmatory factor analysis confirmed a three-factor model, disclosing satisfactory fit: CMIN/df 2.45, CFI 0.97, RMSEA 0.055 (90% CI 0.041, 0.068) and SMRM 0.048. Cronbach's α was 0.82 for the factor *coping after discharge*, 0.71 for the factor *adherence to treatment* and 0.66 for the factor *participation in discharge planning*. The DICARES-M was moderately correlated with NORPEQ (rho = 0.49, P < 0.001). Higher DICARES-M scores were associated with decreased risk of emergency readmissions (P < 0.001).

4.3 Study 2/ Paper III

In Paper III the results of the association between discharge conversation and discharge quality as determined by elderly patients' experiences are presented. The findings revealed that the patients (n=487) predominantly experienced having a discharge conversation (74%, n=360), and that these patients scored significantly higher to DICARES-M and NORPEQ. The usefulness of these conversations was positively associated with scores on these quality measures. However, the scores on the category *Usefulness of discharge conversation* and emergency readmission were not associated (P = 0.160).

5. DISCUSSION

I this study we have developed a brief questionnaire, DICARES-M, for the purpose of measuring quality in discharge based on elderly patient experiences. To validate the DICARES-M, we used established quality indicators and validated health related instruments. The feasibility of DICARES-M was tested by investigating the association between discharge conversation and discharge quality.

5.1 Methodological considerations

5.1.1 Development of DICARES-M

We developed DICARES-M in cooperation with an expert panel by applying literature reviews and manual search. A larger number of candidate items than ultimately needed in a final version were selected (129). To strengthen the content validity of the study we could have used focus group interviews with a group of elderly using open ended question regarding their discharge experiences, which could have resulted in additional questions and/or change in items (104, 129). However, patient representatives in the study acknowledged the initially 16 questions selected, and evaluated the content of the 11item DICARES-M questionnaire to be relevant.

Our approach has similarities with methods used in a newly published study by Oikonomou et al. (105) developing the Partners at Care Transitions Measure (PACT-M). The instrument was designed to assess patients experience three times after discharge; within one week, one month, and three months respectively. Similar to the first version of DICARES-M (Paper 1), PACT-M consists of 16 items. Both instruments focus on information and support including patient participation and medication management. Unlike DICARES-M, the PACT-M included items on infection, falls, and problems in getting health and care supplies. Eight of the PACT-M items had a 5-point Likert-type scale, six items had dichotomous responses (Yes/No), whereas two of the questions had open-ended response alternatives. The psychometric properties of the instrument PACT-M is still unexplored (105).

5.1.2 Data collection and data quality

In this thesis a cross-sectional design was used. The benefits of using this kind of observational study approach is that it makes it possible to collect a large number of data in relatively quick, inexpensive and simple way. The disadvantage is that the method cannot reveal causal relationships. We analysed two study samples with similarities in patient characteristics using different data collection methods. The highest response rate was achieved in Study 1 (Paper I) where the principal investigator selected, and asked, potential eligible participants at the hospital ward. This approach is a recommended, though comprehensive time consuming and expensive method (130). Gratitude towards health professionals' may influence the patients' willingness to participate in the study. Thus, the principle of "freely given" consent may be discussed using this collection method (131).

An ethical issue is that potential participants could have been excluded on the basis of principal investigator's subjective considerations of data from the EPR, observations, and information from nurses responsible for the patients. Another ethical issue is that the inclusion criteria omitted a number of patients, for instance patients with cognitive impairment and nursing home residents. Several authors have criticised the exclusion of these patients (131, 132) claiming that patients' with mild dementia, and even patients' with moderate or severe dementia, usually have the capacity to consent and preservation should be made to secure their inclusion. Thus, there are unanswered questions on how to treat these patients optimally (133).

In Study 2 we included all patients' in the postal survey, independently of the patient health condition. This is a commonly used data collection method at our hospital. The results in Study 2 confirm findings by Kelley et al. (99) that in general the response rate in postal surveys is low (< 20%) (134). In the '90s, response rates < 50% were regarded unacceptable in scientific studies. Today, there are countless requests to participate in studies, and the response rates have decreased (135). Further, elderly people are less likely to participate in studies compared to younger age groups (136).

In addition, face-to-face interviews or presence of the principal investigator when patients completed the survey would have helped to achieve higher response rates (134). Nonetheless, such an approach requires substantial utilisation of resources and was not feasible in this study. The consequences of a low response rate is that we do not know whether the non-responders would have differed in their responses. Those who did not answer could have more positive, or more negative experiences. We have limited information with respect to those who did not respond to the surveys, however, we found that there were significantly fewer men in the group of non-responders compared to the responders (Paper 1). We also found that the non-responders in Study 1 did not differ significantly in age compared to the responders.

In research studies of elderly patients, missing data is a particular challenge due to physical or cognitive impairments that impact the ability to accomplish assessments (137). Therefore, thorough reviews need to be emphasised when designing questionnaires to use in the elderly population. In this study, the amount of missing data were acceptable, nevertheless, the number of missing data was more than 10% for some of the individual items in DICARES-M.

In Study 1, the lowest score for single items included in the final DICARES-M –model was "I had the opportunity to tell the staff what I myself considered important in order to manage after discharge". In Study 2, the score increased to 90% to an adjusted formulation "In connection with being discharged I had an opportunity to notify hospital personnel about what I thought was important". We believe the rewording may have increased the response rate. Another possibility is that the results might be attributed to lower disease burden in Study 2 (Charlson Comorbidity Index 1.6 versus 0.9). Examination of face validity of DICARES-M did not reveal problems in understanding the questions. However, the examination did not include cognitive interviews, which could have been beneficial in the initial phase of Study 1 in order to identify problems with the clarity of the wording.

5.1.3 Reliability and internal validity

Test-retest results of the 16 items included in the initial DICARES-M candidate showed an excellent overall intraclass correlation (Paper I). We choose 50 patients who had completed the first questionnaire and filled in each of the individual 16 DICARES-M items. It is possible that the patients selected to the test-retest were healthier and had a better cognitive function than the average of patients included in Study 1. A random selection of patients would have provided more heterogeneity across patients and might have decreased the intraclass correlation of the test-retest somewhat.

Corresponding to evaluation of the NORPEQ (138), we applied principal component analysis to identify the DICARES-M factor structure. Principal component analysis is a suggested (108), and commonly used method to component model–based factor extraction for explorative factor analysis (139). However, its use is criticised for the purpose of describing psychological and educational data. The main objection is that the principal component analysis assumes measurement without error, and that it can generate inflated values of variance accounted for by the components (139). An alternative approach could have been to apply principal axis factoring analysis that incorporates measurement error.

In Study 2, a confirmatory factor analysis revealed acceptable fit. One of the fit indices, RMSEA, is recognised as a particular informative criterion to report in applied sciences due to that approximations usually differ from their corresponding population parameter, and RMSEA takes into account the error of estimation in a population (127, 140). There cut off value of RMSEA is discussed, and values closer to zero are considered beneficial. According to MacCallum et al. (141), values between 0.08 and 0.10 provide moderate quality, while values below 0.08 are considered a good fit. On the other hand, Hu & Bentler (142) suggest values equal to or less than 0.06 are a good fit. An advantage in interpretation of this fit index is that a confidence interval can be computed around its value of RMSEA. In our study the RMSEA value (0.055) and

confidence interval (CI 90%) was within acceptable upper and lower bounds, 0.041 and 0.068 respectively.

Chi-square (CMIN/df) is an original fit indicator (143). CMIN/df values below 3.0 are acceptable (125) (Paper II), and low P values indicate a good model- of- fit (143). However, the chi-squared test is sensitive to sample-size, and in large samples P values increases above 0.05, even though the model shows good fit (143). In our study the sample size was large, hence this indicator was not reported.

5.1.4 External validation

We conducted the analyses in two different study samples with similarities in characteristics, but with different approaches with respect to inclusion criteria and recruitment of patients in the study. A systematic review by Van Melle et al. (144) showed that in the field of transitional care studies it is common that only one perspective is measured and that valid comparators, or reference standards, are absent (144). In our study, we chose to measure several perspectives. In the first study we used the SF-12 and the SHC to discriminate between quality and health related issues. In both studies, we examined the external validation by comparing DICARES-M scores with scores from NORPEQ. Further we compared DICARES-M with data on the quality indicator emergency readmission. This differs from a study conducted by Smirnova et al. (135) were aggregated scores were compared on the department level within the hospital. It also differs from a study by Skudal et al. (138) investigating differences in NORPEQ scores between Nordic hospitals. We believe our approach strengthens the external validation of the study with respect to differences in design of Study 1 and Study 2, and the use of validated instruments and quality indicators in investigation of several patient related perspectives. However, the study was conducted in a limited sample of medical patients mainly, and further testing of DICARES-M in a broader population is needed.

5.2 Discussion of the results

5.2.1 Patient reported experiences

Despite a significant disease burden, and poorer health status compared to results in corresponding studies (145-148), the majority of patients in our study reported positive self-care experiences after hospitalisation. Higher comorbidity index scores and the presence of geriatric conditions are correlated with poor health outcomes (149). Hospitalised elderly patients often have geriatric conditions and a combination of diagnoses, which lead to reduced physical and cognitive function (149). A study conducted by Boyd et al. (150) showed that patients who were discharged with a new diagnosis or with a decline in activities to daily living compared to baseline data, had a significantly lower functional status after 12 months. However, the patients predominantly sustained their ability in performing activities of daily living if they were discharged at their baseline functional status. We believe there is a possibility that the majority of the patients who responded to our survey did not experience significant changes in activities of daily living after hospitalisation (150). This assumption attributes to the inclusion criteria used in Study 1, and that the principal investigator excluded potential eligible patients when geriatric conditions were identified. In Study 2, we attribute the relatively low response rate to possible severe health issues, geriatric conditions and age (15, 136).

The patients experienced physical and psychological issues (Paper I), and almost one of three patients experienced issues in performing daily activities (Paper I & Paper II). In spite of the general positive experiences reported in the current study, our findings may support results in a qualitative study by Birkeland and Natvik (151) who found that older persons adapted to physical restraints by performing activities that are easy to execute without the need for physical power. The authors claimed that the older persons' adaptation was influenced by reconciliation and submissive acceptance, which are linked to both anxiety and depression (152, 153).

Readmitted patients reported significant lower scores on Physical Composite Scale and Mental Composite Scale in the SF-12 (Table 3), indicating higher levels of stress and

depression compared to those who were not readmitted. Comorbidity is associated with increased risk of emergency readmission. Comorbidity affects the relationship between coping and stress (12), and increased comorbidity is associated with higher severity levels of both depression and generalised anxiety (9). Kavalniene et al. (154) found that patients with anxiety, and/or depression reported lower satisfaction with healthcare than those who did not have such problems. Another possibility is that this finding may be related to insecurity. In a study carried out by Hestevik et al. (153) insecurities related to adapting to a new situation at home were found to be one of the main challenges faced by older persons after being discharged from hospital.

The patients reported they would like more people to talk to after hospitalisation (Paper I). However, the modified version of DICARES-M do not include this item. This is undoubtedly important data to collect, however, as the aim of this study was to establish an instrument feasible for measuring discharge quality it was excluded from the modified version of DICARES-M. Based on the expert panel's evaluation of Study 1, the need of social support after hospitalisation was considered to be out of scope in relation to hospitals responsibility in discharge planning.

Generally, the patients reported positive discharge experiences, which corresponds well with results in previous studies investigating factors related to the discharge process (83, 86, 89, 92). There may be several explanations for this result. One explanation may be that the results indicate that the patients' expectations were met satisfactory. Nyleanna et al. (29) argue it is difficult to identify and define outcome of healthcare services, and even more challenging with respect to expectations from the receivers. The authors claim prosperous communities expectations to healthcare are higher than in impoverished societies, consequently call for a higher outcome (29). Accomplishment of expectations and patient-reported experiences are linked to overall patient satisfaction with hospital care services (155). On the other hand, the results may indicate that the patients had restrained expectation to delivery of care. A study by Bowling et al. (63) exploring the field of patients' expectations, showed that patients had lower expectations to hospital services, especially to doctors in hospital,

than to their general practitioner (GP). Having said that, the results might reflect gratitude and thankfulness to a system they are dependent on, which may surpass potential unmet expectations.

The lowest mean score in Study 2 was observed for item "I got information about effects and side effects of my medication". This result corresponds with findings in previous studies where patients' perspectives on received information on medication were assessed (81, 83, 156, 157). Perez-Jover et al. (158), reviewing inappropriate use of medicines, found that only 50% of patients knew what their prescribed treatment was. Despite the lack of information, most of the patients in the current study reported few issues in understanding the purpose of their medication (Paper I & II). This may indicate that the patients used the Internet or other resources to obtain information. However, several studies have shown that health professionals, in particular physicians and pharmacists (159), are considered as the most trustworthy source regarding medicine information (159, 160). Medlock et al. (160) found that even if elderly used the Internet for health information, health professionals were the primary source of information on questions regarding medications and side effects.

5.2.2 Discharge conversation and quality of care

In the current study, nearly three of four patients reported having a discharge conversation (Study 1 and Study 2). In contrast, only 10 % reported having a discharge conversation in a study by Foss et al. (157). Patients who reported having a discharge conversation had more positive experiences than those who did not have, or were unsure, whether or not they had such conversation (Paper III). Further, higher scores on reported usefulness of the conversation were positively associated to patients' experience. These findings are supported in studies of health information pointing out that elderly patients expect health professionals to supply them with essential information (160), primarily face-to-face (159). Further, the results are in accordance with the acceptability component in Donabedian's model of quality, where patient expectations and desires are essential factors (36). Still, a limitation is that data obtained from the EPR confirming on whether or not a discharge conversation literary was completed in hospital were not approachable. That said, we believe a planned

discharge conversation is a key component in preparing the patients for the period after hospitalisation. A result that support this is the high score we observed for the factor *adherence to treatment* in the readmitted patients (4.04) (Study 2). Efficient health professional-patient communication is associated with patient adherence (79). Discharge conversation was not associated with emergency readmission, whereas usefulness of conversation was associated to higher DICARES-M scores. This may indicate that the high score for the factor *adherence to treatment* in this group of patients might be attributed to positive experiences with discharge conversation. Another factor is that even if significant lower mean scores were found in the group of readmitted patients, the scores were relatively high. This result correspond to findings in a study by Rising et al. (161) who found that the patients experienced the process satisfactory at their index discharge, and that fear and uncertainty about health condition were primary reasons for emergency readmission.

5.2.3 Discharge quality outcomes

Emergency readmitted patients scored significantly lower on all three DICARES-M factors, indicating problems in activities of daily living, more stress and depressive symptoms (Paper II). A study of readmitted patients by Lowthian et al. (162) found that more than one out of four patients were either experiencing depressive symptoms or having a depression. Feeling uprepared for discharge were the most frequently reported reasons for emergency readmission in a study by Kangovi et al. (26). In the current study, 35 % (Study 1) and 21 % (Study 2) of the patients who were emergency readmitted reported to be discharged too early. This may indicate inadequate discharge preparation. Our findings are supported in other studies (10, 26, 81, 86). However, emergency readmission is not only reflecting hospital care quality, but a diversity of internal and external factors in the patients' lives (26, 163, 164).

With the respect to the predominantly positive scores in the current study, and the positive association between usefulness of having a discharge conversation and discharge quality (Paper III), it is reasonable to question that the lowest mean scores were reported for the factor *participation in discharge planning*. Our results are

consistent with analyses of patient experience data in other studies (84, 87, 88, 91, 165, 166). Admittedly, involvement in questions related to own preferences are not necessarily essential, or desirable, to all elderly (167). However, several studies show that elderly patients, even the very old, consider it important to be involved in questions regarding own healthcare needs (84, 87, 88, 91, 165). In the study by Rustad et al. (91) almost none of the patients experienced to take part in a formal discharge meeting organised to plan future care needs. The study of elderly female patients by Efraimsson et al. (165) showed that the women found it difficult to participate in the conversation as they had problems in understanding what the health professional talked about. Also, the women expressed difficulties in receiving too much information, drowning in a flow of talk. Nevertheless, our findings are not in accordance with important goals of contemporary healthcare policies where involving patients in their own care, and to enhance the patients' intrinsic recourses, is considered as a priority in Norway (168-170), as well as internationally.

DICARES-M consists of specific items aimed at capturing target improvement in the discharge process. Several authors have argued the need of such measurements that reflect satisfaction through patients' experiences (90, 101, 105, 171). The use of patient experiences in quality improvement work was newly published in a systematic review conducted by Bastemeijer et al. (172). The results showed that 20 of the 21 included intervention studies reported one or more improvements in patient experience scores. Most of the studies applied several quality improvement strategies; however, all strategies were related to changing ward procedures or staff behaviour. Further, repeatedly assessment of patient experiences were referred to as important factors in preserving a culture of change in healthcare (172).

DICARES-M includes three factors were several questions illuminate some essential subjects related to interaction between patients and health professionals, as well as potential barriers with respect to self-care after hospitalisation in elderly. Our proposal to use DICARES-M in improvement work correspond with the approach by Donabedian who emphasised that the efforts to improve the structure, processes, and

outcomes of healthcare are inextricably linked to the authentic care and related to the needs of the patients (173). Further, this also meet with recommendations of Manary et al. (174) who claim that patient experience measurements should focus on activities found to be associated with both satisfaction and outcomes, and assessment of data should be made in a timely manner. Based on these authors' recommendation, DICARES-M appears to be a robust instrument capturing aspects of discharge quality that have so far have not been measurable. This indicate that DICARES-M may be a useful tool in improvement work. Another factor that support the use of DICARES-M in improvement work is that it is sensitive to emergency readmission. In contrast, the quality indicator NORPEQ did not show sensitive properties with respect to readmitted patients in our study. Brief questionnaires represent a low burden for the patients and are commonly used to measure dimensions of quality in healthcare delivery (175). Nevertheless, an instrument covering several important dimensions of care in few question, like in NORPEQ, the response is dependent on precise understanding of each of the individual questions.

In summary, our findings correspond well with results in the newly published study by Oikonomou et al. (105) who observed that even if elderly patients may rate their overall transition satisfactory, the patients may still report some care issues, and experiences of losing autonomy or dignity. Jenkinson et al. (65), found similar results in a study of hospitalised patients.

6. CONCLUSIONS AND IMPLICATIONS

6.1 Conclusions

We have developed a survey instrument feasible of assessing patients' experiences with discharge and self-care after hospitalisation and thereby may have established an indicator of quality in the discharge process. DICARES-M has demonstrated satisfactory psychometric properties, further; it appears to capture the quality care of the discharge process sensitively in terms of emergency readmission and independently in terms of patient comorbidity. Thus, we suggest DICARES-M as an additional instrument in improvement work of discharge care in elderly patients. An application of the instrument showed a significant association between discharge conversation and discharge quality, where higher scores on reported usefulness of the conversation were positively associated with patients' experience.

6.2 Clinical implications

We suggest inclusion of DICARES-M into existing instruments monitoring healthcare quality in Norwegian medical hospitals wards. Further, DICARES-M data may be routinely obtained. Patient experience data is helpful only when it is used, and assessment of such data requires wards to show responsibility in using the information to improve care.

Implementation of systematic, clear and effective discharge conversations appears to be a key factor in optimizing discharge care in elderly. Training of health professionals in this conversation should be of high priority in hospitals.

6.3 Proposals for further research

1. In order to apply DICARES-M in a general hospital population it should be scientifically tested in larger and broader sample of patients from other clinical settings.

2. Both qualitative and quantitative studies should be performed to obtain more knowledge on how elderly patients' experiences the first week after discharge in order to get a clearer picture of areas of improvement with respect to prevention of adverse events and emergency readmissions.

3. Intervention studies on "safe discharge " should be performed, including a bundle of interdisciplinary team measures known to impact the process, preferably in combination with a checklist for the discharge planning.

4. To gain more knowledge about how to improve the efficiency of discharge care we suggest use of simulation sessions where the main purpose is training of health professionals. We consider simulation of the discharge conversation in interdisciplinary team important to prioritise.

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8. APPENDICES

Appendix I

Update of systematic literature search April 2019

Update of systematic literature search of patients' experiences with discharge and transition from hospital to community health services.

Ovid MEDLINE(R) and Epub Ahead of Print, In-Process & Other Non-Indexed Citations and Daily <1946 to April 25, 2019> , 26.April 2019

1   exp Patient Discharge/ or Patient Handoff/ (27745)
2   exp Patient Transfer/ (7717)
3   "Continuity of Patient Care"/ (18000)
4   ((hospital adj3 discharge) or (patient* adj3 (transition or transfer or discharge))).tw. (52876)
5   1 or 2 or 3 or 4 (92507)
6   limit 5 to "all aged (65 and over)" (31173)
7   exp Patient Satisfaction/ (83350)
8   (patient adj2 (perspective or experience*)).tw. (21718)
9   7 or 8 (102848)
10   6 and 9 (1279)
11   Primary Health Care/ (71618)
12   exp Community Health Services/ (288563)
13   (primary adj2 (care or "health care" or healthcare)).tw. (125848)
14   (("home based" or "homebased" or "home-based" or home or short term or short-term or shortterm) adj2 care).tw. (24765)
15   exp Nursing Homes/ (37531)
16   "nursing home*".tw. (28082)
17   11 or 12 or 13 or 14 or 15 or 16 (471872)
18   10 and 17 (389)
19   ("early support* discharge" or "early discharge").tw. (2713)
20   18 not 19 (366)
21   Follow-Up Studies/ (612150)
22   20 not 21 (323)
23   limit 22 to "therapy (maximizes specificity)" (34)
24   limit 22 to "therapy (best balance of sensitivity and specificity)" (37)
25   22 not 24 (286)
26   therapy.fs. (1762215)
27   25 not 26 (241)

Explanations of searches in Ovid databases:

- Exp = Expands the search results of terms entered and include all of its narrower, more specific subject headings
- / = the term is a subject heading from the controlled vocabulary MeSH
- Tw. = The Text Word (TW) index is an alias for all of the fields in a database which contain text words and which are appropriate for a subject search. The Text word index in Ovid MEDLINE(R) includes Title (ti) and Abstract (ab). The Textword field in Embase includes Title (TI), Abstract (AB), and Drug Trade Name (TN).
- Fs. = floating subheading, which means a subheading not connected to a specific subject heading

Embase (Ovid)<1974 to 2019 April 25>, search date: 26 April 2019

1   hospital discharge/ (109758)
2   "continuity of patient care".tw. (350)

3   ((hospital adj3 discharge) or (patient* adj3 (transition or transfer or discharge))).tw. (86903)
4   1 or 2 or 3 (160306)
5   limit 4 to aged <65+ years> (43704)
6   patient satisfaction/ (127373)
7   (patient adj2 (perspective or experience*)).tw. (35816)
8   6 or 7 (160282)
9   5 and 8 (1308)
10   primary health care/ (61329)
11   exp community care/ (109610)
12   (primary adj2 (care or "health care" or healthcare)).tw. (166523)
13   exp home care/ (68737)
14   (("home based" or "homebased" or "home-based" or home or short term or short-term or shortterm) adj2 care).tw. (29921)
15   nursing home/ (48994)
16   "nursing home*".tw. (35355)
17   10 or 11 or 12 or 13 or 14 or 15 or 16 (409774)
18   9 and 17 (236)
19   ("early support* discharge" or "early discharge").tw. (4384)
20   18 not 19 (214)
21   follow up/ (1388164)
22   20 not 21 (175)
23   limit 22 to "therapy (maximizes specificity)" (5)
24   limit 22 to "therapy (best balance of sensitivity and specificity)" (41)
25   22 not 24 (134)
26   th.fs. (1419850)
27   25 not th.fs. (121)

CINAHL (Ebsco) 1985-current
26.4.2019

S1   (MH "Patient Discharge+") OR (MH "Hand Off (Patient Safety)+")   27,824
S2   (MH "Continuity of Patient Care+")   16,566
S3   TI (hospital AND discharge) OR AB (hospital AND discharge)   27,529
S4   TI (patient* AND (transition or transfer or discharge)) OR AB (patient* AND (transition or transfer or discharge)) 54,192
S5   S1 OR S2 OR S3 OR S4   86,803
S6   S1 OR S2 OR S3 OR S4   22,883
S7   (MH "Patient Satisfaction")   47,873
S8   TI (patient AND (perspective or experience*)) OR AB (patient AND (perspective or experience*))   136,070
S9   (S7 OR S8)   177,788
S10   S6 AND S9   3,483
S11   (MH "Primary Health Care")   54,341
S12   (MH "Community Health Services+")   367,891
S13   TI (primary AND (care or "health care" or healthcare)) OR AB (primary AND (care or "health care" or healthcare))   105,902
S14   TI (("home based" or "homebased" or "home-based" or home or short term or short-term or shortterm) AND care) OR AB (("home based" or "homebased" or "home-based" or home or short term or short-term or shortterm) AND care)   58,079
S15   (MH "Nursing Homes+")   24,262
S16   TI "nursing home*" OR AB "nursing home*"   19,275
S17   S11 OR S12 OR S13 OR S14 OR S15 OR S16 524,444
S18   S10 AND S17 1,250

S19   (MH "Early Patient Discharge")904
S20   TI ("early support* discharge" or "early discharge") OR AB ("early support* discharge" or "early discharge")   1,156
S21   (MH "Prospective Studies+")   381,414
S22   S18 NOT (S19 OR S20 OR S21)   950
S23   S22 NOT (TI randomized or AB randomized or MH treatment outcomes or PT clinical trial)
       805

In search 23 a filter for therapy studies (best balance) is used, see for details:
https://connect.ebsco.com/s/article/What-are-the-search-strategies-used-by-CINAHL-Clinical-Queries?language=en_US

PsycINFO (Ovid) <1806 to April Week 4 2019>, 26.4.2019

1   hospital discharge/ or client transfer/ or discharge planning/ (2558)
2   exp "Continuum of Care"/ (1681)
3   ((hospital adj3 discharge) or (patient* adj3 (transition or transfer or discharge))).tw. (7200)
4   1 or 2 or 3 (9786)
5   limit 4 to "380   aged <age 65 yrs and older>" (2454)
6   client satisfaction/ (5212)
7   (patient adj2 (perspective or experience*)).tw. (4444)
8   6 or 7 (9439)
9   5 and 8 (95)

We decided not to further limitate the search with terms about primary care, and rather select relevant articles manually.

Svemed+ (Karolinska institutet), 26.4.2019

1   exp:"Patient Discharge"550
2   exp:"Patient Transfer"   168
3   exp:"Patient Handoff"   17
4   noexp:"Continuity of Patient Care"   685
5   "hospital discharge" OR "patient* transition" OR "patient* transfer" OR "patient* discharge"
       691
6   #1 OR #2 OR #3 OR #4 OR #5 1319
7   exp:"Aged"   17323
8   #6 AND #7   385
9   exp:"Patient Satisfaction"   1667
10   "patient* perspective" OR "patient* experience*"   285
11   #9 OR #10   1845
12   #8 AND #11   45

Appendix II

DICARES-M candidate, 16 items (Paper I)

Erfaringer knyttet til utskriving og tiden etter sykehusoppholdet

Vi ønsker å vite mer om hva pasienter erfarer i forbindelse med utskriving og tiden etter sykehusoppholdet. Målsettingen er å forbedre kvaliteten på tilbudet pasienter får. Alle svaralternativene kan benyttes, men _sett kun ett kryss på hvert spørsmål_.

	Ikke i det hele tatt	I liten grad	I noen grad	I stor grad	I svært stor grad	Ikke aktuelt
Erfaringer knyttet til utskriving:						
1. I forbindelse med utskrivingen fikk jeg fortalt sykehuspersonalet hva jeg selv mente var viktig	☐	☐	☐	☐	☐	☐
2. Da sykehuspersonalet vurderte hvilke helsetjenester jeg kom til å ha behov for etter sykehusoppholdet, tok de hensyn til hva jeg og mine pårørende ønsket	☐	☐	☐	☐	☐	☐
3. Ved utskriving fra sykehuset hadde jeg god forståelse for hva som var mitt ansvar for å ta vare på egen helse	☐	☐	☐	☐	☐	☐
4. Ved utskriving fra sykehuset forsto jeg klart hensikten med å ta de forskjellige medisinene mine	☐	☐	☐	☐	☐	☐
5. Det var viktig for meg å ha innflytelse på når jeg skulle bli utskrevet fra sykehuset	☐	☐	☐	☐	☐	☐
6. Jeg opplevde å bli for tidlig utskrevet	☐	☐	☐	☐	☐	☐
Erfaringer knyttet til tiden etter sykehusoppholdet:						
7. Jeg har hatt problemer med å <u>forstå</u> instruksjonene jeg fikk ved utskriving fra sykehuset	☐	☐	☐	☐	☐	☐
8. Jeg har hatt problemer med å <u>følge</u> instruksjonene jeg fikk ved utskriving fra sykehuset	☐	☐	☐	☐	☐	☐
9. Jeg har hatt problemer med å få hjelp fra min fastlege	☐	☐	☐	☐	☐	☐
10. Jeg har hatt problemer med å ta medisinene mine	☐	☐	☐	☐	☐	☐
11. Jeg har hatt problemer med å få tak i medisiner	☐	☐	☐	☐	☐	☐
12. Jeg har hatt problemer med å få i meg tilstrekkelig næring	☐	☐	☐	☐	☐	☐
13. Jeg har hatt problemer med å utføre daglige aktiviteter (f.eks. personlig hygiene, påkledning eller matlaging)	☐	☐	☐	☐	☐	☐
14. Jeg har vært stresset	☐	☐	☐	☐	☐	☐
15. Jeg har vært deprimert	☐	☐	☐	☐	☐	☐
16. Jeg skulle gjerne hatt flere personer å snakke med, og støtte meg til, etter at jeg ble utskrevet fra sykehuset	☐	☐	☐	☐	☐	☐

Appendix III

DICARES-M, 11 items (Paper II & Paper III)

Discharge Care Experiences Survey Modified, 11 items.

	Norwegian version	Scale	English version
1.	Jeg har følt meg stresset[a]	Ikke i det hele tatt, I liten grad, I noen grad, I stor grad, I svært stor grad	I have felt stressed[a]
2.	Jeg har følt meg nedfor[a]	Ikke i det hele tatt, I liten grad, I noen grad, I stor grad, I svært stor grad	I have felt blue[a]
3.	Jeg har hatt problemer med å utføre daglige aktiviteter (f.eks. personlig hygiene, påkledning eller matlaging)[a]	Ikke i det hele tatt, I liten grad, I noen grad, I stor grad, I svært stor grad	I have experienced problems in performing daily activities (e.g. personal hygiene, getting dressed or cooking)[a]
4.	Jeg har hatt problemer med å få i meg tilstrekkelig næring[a]	Ikke i det hele tatt, I liten grad, I noen grad, I stor grad, I svært stor grad	I have experienced problems in getting sufficient nutrition[a]
5.	Jeg fikk fortalt sykehuspersonalet det jeg mente var viktig for å kunne klare meg hjemme etter utskriving	Ikke i det hele tatt, I liten grad, I noen grad, I stor grad, I svært stor grad	In connection with being discharged, I had an opportunity to notify hospital personnel about what I thought was important
6.	Ved utskriving fra sykehuset forsto jeg klart hensikten med å ta de forskjellige medisinene mine	Ikke i det hele tatt, I liten grad, I noen grad, I stor grad, I svært stor grad, *Ikke aktuelt*	When I was discharged from hospital, I understood thoroughly the purpose of taking my medication
7.	Jeg fikk informasjon om virkninger og bivirkninger av mine medisiner[b]	Ikke i det hele tatt, I liten grad, I noen grad, I stor grad, I svært stor grad, *Ikke aktuelt*	I got information about effects and side effects of my medications[b]
8.	Ved utskriving fra sykehuset, var det klart for meg hva jeg hadde ansvar for når det gjaldt helsen min	Ikke i det hele tatt, I liten grad, I noen grad, I stor grad, I svært stor grad	When I was discharged from hospital, I had a good understanding of my responsibility in terms of looking after my health
9.	Jeg har hatt problemer med å forstå instruksjonene jeg fikk ved utskriving fra sykehuset[a]	Ikke i det hele tatt, I liten grad, I noen grad, I stor grad, I svært stor grad, *Ikke aktuelt*	I have experienced problems in understanding the instructions I received when I was discharged from hospital[a]
10.	Jeg har hatt problemer med å følge instruksjonene jeg fikk ved utskriving fra sykehuset[a]	Ikke i det hele tatt, I liten grad, I noen grad, I stor grad, I svært stor grad, *Ikke aktuelt*	I have experienced problems in following the instructions I received when discharged from the hospital[b]
11.	Jeg opplevde å bli for tidlig utskrevet[a]	Ikke i det hele tatt, I liten grad, I noen grad, I stor grad, I svært stor grad	I felt I was discharged too early[a]

[a]Negative statements were inverted to a positive scale, [b] item not included in the first version of DICARES
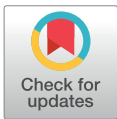
Papers I - III

I

Elderly patients' (≥65 years) experiences associated with discharge; Development, validity and reliability of the Discharge Care Experiences Survey

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Abstract

Background

A review of the literature reveals a lack of validated instruments that particularly measure quality in the hospital discharge process. This study aims to develop and validate a survey instrument feasible for measuring quality (≥65 years) related to the discharge process based on elderly patients' experiences.

Methods

Construction of the Discharge Care Patient Experience Survey (DICARES) was based on 16 items identified by literature reviews. Intraclass correlation for test–retest was applied to assess consistency of the survey. Explorative factors analysis was applied to identify and validate the factor structures of the DICARES. Cronbach's α was used to assess internal reliability. To evaluate the external validity of the final DICARES questionnaire the patients' scores were correlated with scores obtained from the three other questionnaires; the Nordic Patient Experiences Questionnaire, the 12-Item Short-Form Health Survey and Subjective Health Complaints. The DICARES association with readmissions was examined.

Results

A total of 270 patients responded (64.4%). The mean age of participants was 77.1 years and 57.8% were men. The exploratory factor analysis resulted in a 10-item instrument consisting of three factors explaining 63.5% of the total variance. The Cronbach's α were satisfactory (≥70). Overall intraclass correlation was 0.76. A moderate Spearman correlation (rho = 0.54, p <0.01) was found between the total mean DICARES score and total mean score of the Nordic Patient Experiences Questionnaire. The total mean DICARES score was inversely associated with the quality indicator based on readmissions (OR 0.62, CI 95: 0.41–0.95, p = 0.028)

Conclusion

We have developed a 10-item questionnaire consisting of three factors which may be a feasible instrument for measuring quality of the discharge process in elderly patients. Further testing in a wider population should be carried out before implementation in health care settings.

Background

To discharge elderly patients from hospitals or transfer these patients between different levels of health care institutions is one of the most significant challenges in health care services [1–4]. The discharge process includes a wide range of care professionals in a variety of settings, and it's a coordinated, patient-centred, transparent process starting before admission if possible, or as soon after admission as suitable [5]. To recover and gain health after hospitalization adherence to therapy is crucial [6, 7]. According to the National Health Services (NHS), England, United Kingdom, people have a key role in protecting their own health, and to choose suited treatment and handle long-term conditions. Self-management/self-care is a term used to include all initiatives a person do to acknowledge, treat, and maintain his own health [7]. This may be done independently or in association with the healthcare system. The wellbeing and the safety in elderly patients are particularly at risk in the discharge process, because aging makes us more vulnerable due to loss of physical and mental function, and also the increased disease burden [8, 9]. Hence, quality in the discharge process requires caring interaction with the patients and their caregivers, and it involves considerable and accurate cooperation within the hospital as well as with the municipalities. Despite this knowledge, patients and caregivers are commonly unprepared for what will emerge after discharge, and they are frustrated by having to perform tasks their health care practitioners have left undone [10]. Introduction of experience surveys that provide feedback to the hospital departments can be one of several measures to improve the quality of the discharge process [1]. Even though readmission rate is nonspecific and may be affected by various conditions many healthcare organizations use it as an overall quality indicator [11]. There is a need for a more suitable approach to assess hospital performance in the patient discharge process. Patient experience; "*the sum of all interactions influenced by all interactions shaped by an organization's culture across the continuum of care*" [12], has been recognized as an important facet of understanding quality since it reveals strengths and weaknesses in respect of efficiency and safety [12–14]. A survey about the experiences may be directed against specific parts of the care, not only as a global indicator.

Patient satisfaction and patient experiences are overlapping and both are important parts of healthcare quality [15]. The main difference between the concepts' is that if patients are asked to rate how satisfied they are, the ratings tend to be very positive, while specific questions about the patients' experiences with respect to certain processes provide more variation and are useful to customize interventions [16]. A systematic review by Doyle et al. [17] shows a positive association between examinations of patient experience, patient safety and clinical efficacy, and patient experience surveys may therefore pose as an appropriate basis of a quality indicator in general. Elderly patients express a clear preference to participate, but experience that the actual practice of involving old people in the discharge process is not well developed [18, 19]. Few studies have explored quality by use of patients' experiences, and this deficiency of understanding the patient perspective has delayed the ability of hospitals to establish interventions which address these underlying causes of readmission [20]. Tools to measure patient

experiences of quality of hospital care have been developed [1, 21], but the feasibility for use in quality improvement work is limited due to methodological weaknesses such as questionnaire design, patient selections, the data collection process, and data entry errors [22]. Patient experience surveys can be applicable as targeted tools of good scientific standards if performed by skilled scientists [22].

The discharge process must emphasize the patients' ability to take care of themselves after hospitalization [7], tools for quality assessments in the discharge process should therefore cover questions about how patients' experience the first period after hospitalization. These experiences may reflect the quality of the tasks performed by health care personnel during the discharge process. However, we have not been able to find such appropriate and validated instruments. This study aimed to develop a feasible brief survey instrument to identify elderly patients' experiences with the hospital discharge process and with the following period after hospitalization, and to examine its reliability, internal validity, and to test the external validity.

Methods

Design

A cross–sectional study design was chosen to develop and validate the Discharge Care experience Survey (DICARES), http://dx.doi.org/10.17504/protocols.io.sm2ec8e.

In the planning phase of the study we discussed the object of the study with an established group of patient representatives at our hospital. Input from the group was included in the design of the questionnaire.

Setting and study sample

Hospitals in Norway are owned by the state and the municipalities are committed to give health care services to their inhabitants when needed [3]. There is a written agreement between our hospital and the municipalities within the regional health authority. The municipality will be informed within 24 hours after admission if it is likely that the patient will need health care services from the municipality after discharge. The discharge planning start as soon after admission as possible for patients acutely admitted to hospital, and before admission for elective patients, if required. Elderly patients unable to take care of themselves after hospitalization are provided home based care services or nursing home facilities. Discharge planning includes assuring that the patients have got necessary aid equipment's at home, and to inform the municipality or caregivers whether the patient is at risk of malnutrition, fall or pressure ulcers, with a plan for follow up when needed. Before leaving the hospital the patients will have an updated list of medication, a written patient information letter, have got a follow up appointment if required, and have had a discharge conversation with health care personnel responsible for the treatment. The patient's general practitioner will receive a discharge letter from the hospital a week after discharge. To what degree health care personnel conform to these procedures is not documented.

In order to include elderly patients with significant comorbidities we recruited inpatients from five medical wards and one orthopaedic ward at a large tertiary teaching hospital in Bergen, Norway. Patients 65 years and above were included if hospitalized for more than 24 hours and were able to give their written informed consent. Patients living in nursing homes and patients with recognized reduced cognitive function were not included. Patients that met the inclusion criteria were invited to participate in the study by personal contact with the corresponding author. A paper-based survey including a pre-paid return envelope was sent to the patients approximately 30 days after hospital discharge during June 2013 to February 2015. Patients that did not respond within three weeks were reminded once by phone. Age and sex

were recorded anonymously for non-responders. Data were plotted twice by two research assistants, and quality controlled for errors.

Survey development

In order to develop the DICARES we conducted a systematic literature search (S1 File) during February and March 2013 in the databases Medline, Embase, Cinahl, SveMed and PsycINFO. We adapted several elements from the PRISMA checklist as guidance. None of the databases used *patient experience* as MeSH term, therefore we applied *patient satisfaction* and *patient perspective*, and further *patient discharge*, *patient transfer*, *continuity of patient care*, *patient hand over*, *patient hand off*, *primary health care*, *home based care*, *nursing homes*, *community health services and*, *community based care*. The literature review identified 736 matches, reduced to 528 after duplicate control. Twenty–four abstracts met the inclusion criteria; qualitative and quantitative studies in English, Norwegian, Danish or Swedish, aimed at patients of both sex ≥ 65 years with hospital stays in somatic departments. If there were other participant groups in addition to the patients, for example relatives and / or healthcare personnel, it had to be clear what the patient's experience was. Research before year 2000 had to be available both as an abstract and in full electronic text to be included. Intervention, follow-up and evaluation studies were excluded. Relevant matches were read in full text, and eight articles filled the criteria. Further we did a literature review in order to find questionnaires that included questions concerning the discharge process and the following weeks after hospitalization. To include candidate items for the new DICARES questionnaire based on the literature reviews we used an eclectic approach. An expert panel evaluated if the items were relevant to be included in the questionnaire. The expert panel consisted of researchers, health care personnel, and leaders at the hospital. Three items regarding patient participation were derived from a 15-item validated survey developed by Coleman et.al. [2] designed to be used by patients 18 years and older. The complete 15-item survey does not provide substantial more information than the three core questions selected [23]. Two more items on patient participation were obtained from a study of elderly patients by Foss et.al. [18]. Further, we included eleven items based on a 36-item survey developed by Kangovi et.al. [20]. These items are related to daily lives activities, adherence to discharge medications and emotional problems following the period after hospitalization from readmitted patients' perspective. A total of 16 candidate items were translated and adjusted to fit our setting with respect to language, design, formatting and methodology (Table 1).

Forward translation of the DICARES was performed by two Norwegian registered nurses / researchers with knowledge of English language. Backward translations were completed by two independent native English translators with no prior knowledge of the questionnaire [24]. Inadequate expressions or concepts of the translation were discussed within the bilingual expert panel. All items were scored on a five point Likert-like scale: *Not at all*, *To a little extent*, *To some extent*, *To a large extent and To a very large extent*, and assigned values 1, 2, 3, 4 and 5, respectively. Values from negative statements (number 6, 7, 8, 9, 10, 11, 12, 13, 14, 15 and 16) were inverted to positive values. High score means a better condition for the patient. The total score was calculated as the mean of the items' scores.

Our survey consisted of four questionnaires, with a total of 66 questions. This included the 16-item DICARES-candidate and three validated questionnaires: the eight-item Nordic Patient Experiences Questionnaire (NORPEQ) measuring quality of care in general in Norwegian hospitals based on six validated items [25, 26], the 12-Item Short-Form Health Survey (SF-12) assessing general health status (Physical Composite Scale and Mental Composite Scale) [27], and the 29-item symptom specific questionnaire Subjective Health Complaints

Table 1. Sixteen items were identified in the literature to be included in the new questionnaire.

Item number	Original phrasing	Adjusted phrasing
1	I got the opportunity to tell the staff what i myself considered important in order to manage after discharge [b]	In connection with being discharged, I had an opportunity to notify hospital personnel about what I thought was important [b]
2	The hospital staff took my preferences and those of my family or caregiver into account in deciding what my health care needs would be when I left the hospital [c]	The hospital staff took into account the wants and needs of both myself and my relatives in deciding which healthcare services I would need when I was discharged from hospital [c, d]
3	When I left the hospital, I had a good understanding of the things I was responsible for in managing my health [c]	When I was discharged from hospital, I had a good understanding of my responsibility in terms of looking after my health [c]
4	When I left the hospital, I clearly understood the purpose of taking each of my medication [c]	When I was discharged from hospital, I understood thoroughly the purpose of taking my medication [c]
5	How important was it to you to influence the time of discharge? [b]	It was important for me to be able to influence when I was to be discharged from hospital [b, d]
6	Did you feel like you needed to stay a bit longer the first time you were admitted, and you were discharged too early? [a]	I felt I was discharged too early [a]
7	Did you have trouble understanding the discharge instructions? [a]	I have experienced problems in understanding the instructions I received when I was discharged from hospital [a]
8	Did you have trouble following the discharge instructions? [a]	I have had problems in following the instructions I received when discharged from the hospital [a]
9	Did you have trouble getting help from your outpatient doctor? [a]	I have experienced problems receiving help from my GP [a, d]
10	Did you have trouble with taking your medications? [a]	I have experienced problems taking my medicines [a, d]
11	Did you have trouble getting your medications after you last left the hospital? [a]	I have experienced problems getting hold of medicines [a, d]
12	Did you have trouble with your daily activities since you last left the hospital, for example bathing, **eating**, and using the bathroom? [a]	I have experienced problems in getting sufficient nutrition [a]
13	Did you have trouble with your daily activities since you last left the hospital, for example bathing, eating, and using the bathroom? [a]	I have experienced problems in performing daily activities (e.g. personal hygiene, getting dressed or cooking) [a]
14	Did you struggle with stress or depression? [a]	I have felt stressed [a]
15	Similar to item number 14 [a]	I have been depressed [a]
16	Did you wish you had more people to talk to and give you moral support after you got home from the hospital? [b]	I wish I had more people to talk to, to support me following discharge from hospital [b, d]

The 16 statements were based on items retrieved from the following studies

[a] Kangovi et al.2012

[b] Foss et al.2011, and

[c] Coleman et al. 2005

[d] Item not included in the final DICARES questionnaire

(Musculoskeletal pain, Pseudoneurology, Gastrointestinal problems, Allergies and Flu) (SHC) [28, 29]. Additional one question about readmission within 30 days was included. Readmission data within 30 days [30] was also recorded from the electronically patient administrative system. Further information from this system included age, sex, date of admission, length of stay, International Classification of Diseases-10th version (ICD-10) codes [31], and a calculated Charlson comorbidity index [32] based on the ICD-10 codes.

Survey validation and statistics

When planning the study to explore the psychometric properties sample size was calculated to be at least 250 for detecting differences in the total DICARES score with outcome readmission, expected exposure 20%, power 80% and p<0.05. Population mean score values for each item were imputed if eight or more items scores in the initial 16 -item DICARES were completed. To investigate face validity [33] the first 22 patients who returned the survey, and had completed the 16 initial DICARES items, answered five additional identical questions, assessing whether the items were understandable, meaningful, relevant, easy to answer, and whether they were too personal. Nineteen patients returned the evaluation form, and based on the findings no items required to be changed. In order to assess test-retest reliability, fifty respondents were asked to complete the DICARES a second time after 21 days. Intraclass correlation (ICC) between the items was examined for consistencies in the test re-test measure. ICC estimates and their 95% confidence intervals (CI) were calculated based on a mean-rating (k = 2), absolute-agreement, two-way mixed-effects model [34], and was estimated using the following interpretation: Poor (0.40> r), Fair (0.59> r >0.40), Good (0.74> r >0.60 and Excellent (1.00> r >0.75) [35]. Explorative factor analysis was applied to identify the factor structure of the DICARES questionnaire as described by Pett et al. [36]. To assess the sampling adequacy, we used the Kaiser-Meyer-Olkin measure, and the Bartlett's test of sphericity [36]. Principal component analysis with Varimax rotation was applied to identify factors structures of the initial 16 candidate items measuring patient experiences. Eigenvalues >1 was used to identify the number of factors, and absolute value for factor loadings was ≥0.30. If an item loaded moderate or strong to more than one factor, the item was allocated to the factor where it got the highest loading. The item with the highest loading was placed first in the factor.

Inter-correlation between the items of each factor was examined for internal reliability using Cronbachs'α and values ≥0.7 were considered acceptable [37]. Construct validity was assessed by inter-correlation of the factors, and by correlation of the final total DICARES score to the NORPEQ, the SF-12 and the SHC, using Spearman's correlation coefficient. Moderate correlation coefficients between 0.30–0.49 were considered satisfactory [38]. Further, for external validity mean score of the final total DICARES score was compared with the mean NORPEQ score for the readmitted and non-readmitted patients, and tested using a two-sample t-test. For comparison with the previously validated NORPEQ questionnaire the total DICARES score was transformed to a 0–100 scale by subtracting one from the mean score of each item and then multiplying with 25. The external validation comprised a multiple stepwise, backward logistic regression analysis including DICARES total score, Charlson Comorbidity Index, sex, and age as independent variables and readmission within 30 days as a binary dependent variable. Missing data in the regression analysis were handled using complete case analysis. Statistical analyses were performed with SPSS version 23.0 (IBM Corp., Armonk, NY). All p-values were two-sided, and values <0.05 were considered statistically significant.

Ethics

Ethics approval and consent to participate. This study was conducted in accordance with the Helsinki Declaration [39], and was accepted by the Western Norway Regional Committee for Medical and Health Research Ethics (Ref.: 2013-401b). The study was also approved by the respective hospital managers. Patients involved in the process signed a consent form prior to hospital discharge. Data from the survey, and questionnaires, were stored in a designated server at the hospital.

Results

Study sample

A flow chart of the recruitment to the study is shown in Fig 1. Initially, a total of 798 patients were eligible for inclusion and 419 of the 498 patients who met the inclusion criteria consented to participate. Of these 270 returned completed questionnaires, yielding a response rate of 64.4%.

Patient characteristics. The mean age of participants was 77.1 year (SD 7.2; range 65–98), and men accounted 57.8% of the sample (Table 2). The mean length of hospital stay was 8.3 days (SD 8.8; range 2–80; median 6.0) and 90% of the patients were discharged from medical wards. Fifty-one percent of the patients had more than three diagnoses, and the mean Charlson Comorbidity Index was 1.61 (SD 1.5). Seventy-two patients (26.7%) were readmitted to hospital within 30 days after discharge. The mean age for non-responders (n = 228) was 78.8 years (range: 65–94), and did not deviate significantly from the responders. There were significantly fewer men among non-responders than responders (34.4% versus 57.8%, p <0.001).
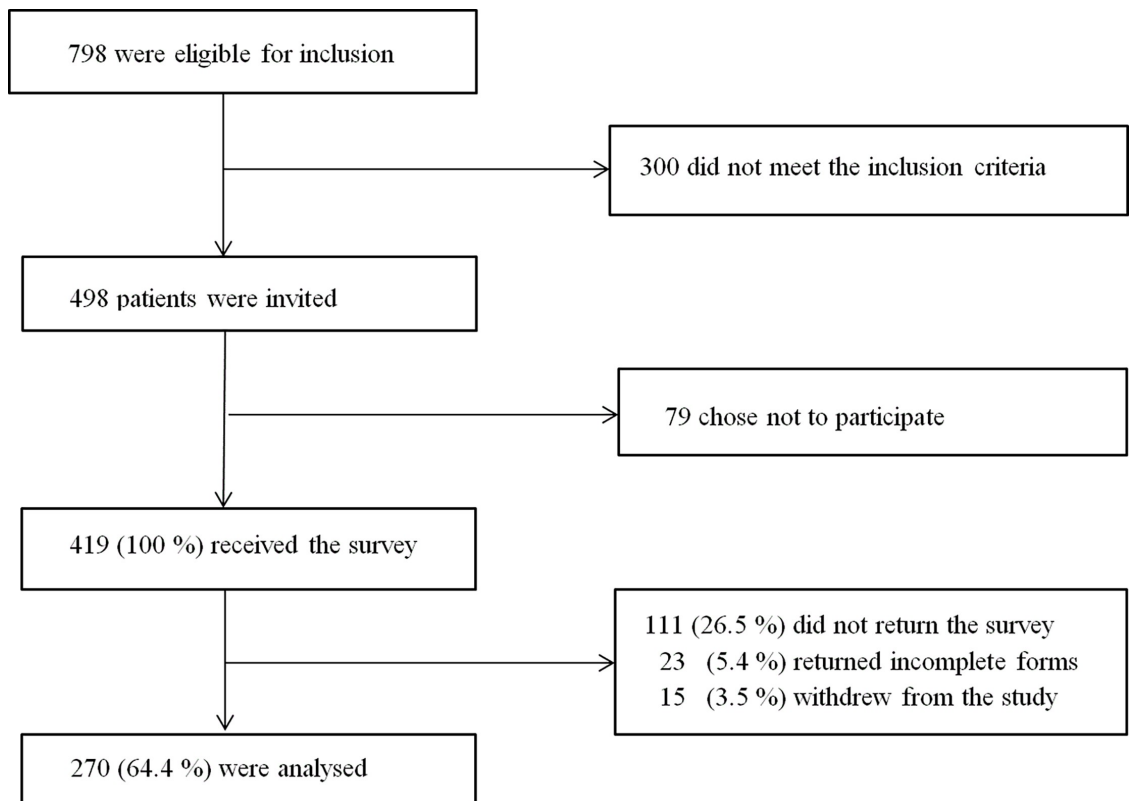

Fig 1. Flow chart of patient inclusion in the study. Elderly inpatients (≥65) were recruited from five medical wards and one orthopaedic ward at Haukeland University Hospital, Bergen, Norway.

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Table 2. Characteristics of the participants included from Haukeland University Hospital, Bergen, Norway.

Variables	n (%)
All patients	270 (100)
Age groups (years), mean (SD)	77.1 (7.2)
• 65–75	127 (47.0)
• 76–85	99 (36.7)
• 86–98	44 (16.3)
Sex	
• Women	114 (42.2)
• Men	156 (57.8)
Marital status	
• Married or cohabitant	165 (62.5)
• Not married/cohabitant	14 (5.2)
• Widow /widower	66 (24.4)
• Separated/divorced	19 (7.0)
• Not answered	6 (2.2)
Length of in-hospital stay by days, mean (SD)	8.3 (8.8)
Departments	
• Medical departments [a]	243 (90.0)
• Orthopaedic department	27 (10.0)
Readmitted	72 (26.7)
Charlson Comorbidity index, mean (SD)	1.61(1.5)
• 0 points	60 (22.2)
• 1 point	100 (37.0)
• ≥ 2 points	110 (40.7)

[a] Department of Pulmonary Diseases, Department of Heart Diseases, and Department of Medicine.

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The DICARES scores

Nineteen questionnaires had less than 50% of the 16 items completed. The completion rate of the individual 16 items varied from 79.6% to 99.3% (Table 3). The total mean score for the 16 candidate items was 4.06 (SD 0.57). The lowest score was observed for item *Opportunity to notify what was important* (2.93, SD 1.13), whereas the highest score was observed for item *Problems taking medicines* (4.78, SD 0.67). Forty-five (90%) of the 50 re-test questionnaires were returned. The overall ICC was Excellent (0.76, CI 95; 0.70, 0.82), results for single-item measures are shown in Table 4.

Extracting factors from items. Results from the exploratory factor analyses are shown in Table 5. The Kaiser-Meyer-Olkin measure of sampling adequacy was estimated to be 0.75, whereas the p-value for the Bartlett's test of sphericity was <0.001. The estimated communalities varied between 0.4 and 0.8. Eigenvalues were 3.65, 1.63 and 1.06 for the three factors, and a total of 10 items were included in the final DICARES-model, explaining 63.5% of the common variance. All 10 items loaded satisfactorily (range of factor loadings 0.50–0.91) in the rotated component matrix. The three factors were named: *Coping after discharge* (three items), *Participation in discharge planning* (three items) and *Adherence to treatment* (four items). The corresponding Cronbach's α for internal reliability were 0.73, 0.71 and 0.70, respectively. A moderate relationship between the three factors ranged from a Spearman's correlation coefficient for internal validity was 0.32 to 0.47 (p = 0.01). The DICARES total mean score (10 items) was 4.04 (SD 0.65).

Table 3. Item scores of the initial 16-item Discharge Care Experience Survey (DICARES) (n = 270).

	Items (abbreviated)	Respondents n (%)	Number of scores of the five point scale (%)										Mean (SD)
			1		2		3		4		5		
1	Opportunity to notify what was important	222 (82.2)	33	(12.2)	56	(20.7)	51	(18.9)	58	(21.5)	24	(8.9)	2.93 (1.13)
2	The hospital staff took into account wants and needs [a]	215 (79.6)	31	(11.5)	29	(10.7)	39	(14.4)	75	(27.8)	41	(15.2)	3.31 (1.18)
3	Understanding of health responsibility	252 (93.3)	11	(4.1)	14	(5.2)	43	(15.9)	129	(47.8)	55	(20.4)	3.81 (0.95)
4	Understanding the purpose of medication	259 (95.9)	4	(1.5)	14	(5.2)	22	(8.1)	104	(38.5)	115	(42.6)	4.20 (0.90)
5	Influence when to be discharged [a]	237 (87.8)	28	(10.4)	36	(13.3)	66	(24.4)	78	(28.9)	29	(10.7)	3.19 (1.11)
6	Discharged too early [b]	262 (97.0)	145	(53.7)	42	(15.6)	42	(14.5)	16	(5.9)	17	6.3)	4.08 (1.22)
7	Problems in understanding the instructions [b]	249 (92.2)	158	(58.5)	57	(21.1)	23	(8.5)	6	(2.2)	5	(1.9)	4.43 (0.86)
8	Problems in following the instructions [b]	250 (92.6)	157	(58.1)	62	(23.0)	22	(8.1)	7	(2.6)	2	(0.7)	4.43 (0.86)
9	Problems receiving help from GP [a, b]	244 (90.4)	179	(66.3)	33	(12.2)	13	(4.8)	12	(4.4)	7	(2.6)	4.50 (0.95)
10	Problems taking medicines [a, b]	262 (97.0)	229	(84.8)	17	(6.3)	8	(3.0)	17	(6.3)	2	(0.7)	4.78 (0.67)
11	Problems getting hold of medicines [a, b]	259 (95.9)	219	(81.1)	20	(7.4)	12	(4.4)	5	(1.9)	3	(1.1)	4.73 (0.73)
12	Problems in getting sufficient nutrition [b]	265 (98.1)	149	(55.2)	49	(18.1)	48	(17.8)	11	(4.1)	8	(3.0)	4.21 (1.06)
13	Problems in performing daily activities [b]	267 (98.9)	108	(40.0)	69	(25.6)	51	(18.9)	27	(10.0)	12	(4.4)	3.88 (1.17)
14	Felt stressed [b]	263 (97.4)	119	(44.1)	77	(28.5)	46	(17.0)	15	(5.6)	6	(2.2)	4.10 (1.01)
15	Been depressed [b]	268 (99.3)	142	(52.6)	51	(18.9)	56	(20.7)	12	(4.4)	7	(2.6)	4.15 (1.06)
16	More people to talk to [a, b]	254 (94.1)	103	(38.1)	62	(23.0)	45	(16.7)	30	(11.1)	14	(5.2)	3.83 (1.20)
	Total mean score 16 items	270[c] (100)											4.06 (0.57)

[a] Not included in the final DICARES model

[b] Negative statements were inverted to a positive scale

[c] Population mean score values for each item were imputed if eight or more items were completed.

Comparison of the DICARES to validated instruments, age and comorbidity. The DICARES total score correlated moderate positively to the NORPEQ score (Spearman's rho = 0.54), SF-12 Mental Composite Scale score (Spearman's rho = 0.55), and inversely with SHC Pseudoneurology (Spearman's rho = -0.47), and SHC Musculoskeletal (Spearman's rho = -0.36) (Table 6). Patients readmitted within 30 days scored significantly lower to the DICARES than those not readmitted (Table 7). Equivalent results were not recognized for the NORPEQ. As shown in Table 8, the DICARES and the Charlson Comorbidity Index were significantly associated with readmission.

Discussion

In this study we have developed a questionnaire instrument for use in quality improvement work. The DICARES is a three factor questionnaire measuring patient experiences based on 10 items concerning discharge from hospital, and the following period after hospitalization. The DICARES showed moderate correlation to the validated quality survey instrument NORPEQ. In contrast to NORPEQ, low scores on the DICARES were associated to readmission.

Birkelien and Madison have developed a framework for improving quality by use of patient experience in hospitals [40]. The DICARES may be a useful tool to measure and monitor targeted interventions emanating from the multifaceted components suggested in this framework. We did not find validated patient experiences instruments that explicit measured quality in the discharge process. However, Bettie et al. identified 11 instruments in a systematic review

Table 4. Test-retest of the initial 16-item Discharge Care Experience Survey (DICARES).

	Items (abbreviated)	Item scores 30 days after discharge		Item scores 51 days after discharge		Intraclass correlation (95% CI)
		n	Score (SD)	n	Score (SD)	
1	Opportunity to notify what was important	34	3.0 (1.1)	37	2.8 (1.1)	0.56 (0.26, 0.76)
2	The hospital staff took into account wants and needs [a]	34	3.8 (1.3)	35	3.3 (1.3)	0.76 (0.57, 0.88)
3	Understanding of health responsibility	44	3.9 (0.8)	44	4.0 (0.8)	0.60 (0.36, 0.76)
4	Understanding the purpose of medication	45	4.3 (1.0)	44	4.2 (0.9)	0.69 (0.49, 0.82)
5	Influence when to be discharged [a]	38	3.0 (1.1)	40	3.0 (1.1)	0.65 (0.41, 0.81)
6	Discharged too early [b]	44	4.6 (0.7)	44	4.2 (1.2)	0.63 (0.40, 0.78)
7	Problems in understanding the instructions [b]	43	4.6 (0.7)	43	4.5 (0.7)	0.48 (0.21, 0.68)
8	Problems in following the instructions [b]	43	4.5 (0.9)	43	4.6 (0.6)	0.42 (0.13, 0.64)
9	Problems receiving help from GP [a, b]	44	4.9 (0.4)	43	4.6 (1.0)	0.65 (0.43, 0.79)
10	Problems taking medicines [a,b]	44	4.8 (0.5)	45	4.8 (0.5)	0.52 (0.27, 0.71)
11	Problems getting hold of medicines [a, b]	44	4.4 (0.9)	44	4.8 (0.5)	0.86 (0.75, 0.92)
12	Problems in getting sufficient nutrition [b]	45	4.1 (1.0)	45	4.2 (1.0)	0.76 (0.61, 0.86)
13	Problems in performing daily activities [b]	45	4.3 (1.0)	44	4.2 (1.0)	0.61 (0.39, 0.77)
14	Felt stressed [b]	45	4.3 (1.0)	45	4.2 (1.1)	0.73 (0.55, 0.84)
15	Been depressed [b]	43	3.9 (1.3)	44	4.2 (1.1)	0.81 (0.68, 0.90)
16	More people to talk to [a, b]	43	3.9 (1.3)	44	3.8 (1.1)	0.73 (0.55, 0.84)

[a] Item not included in the final DICARES questionnaire

[b] Negative statements were inverted to a positive scale.

of instruments to measure patient experience of healthcare quality in hospitals [1]. Three instruments from Hong Kong, Ethiopia and India respectively are not discussed in the present study for consideration of possible cultural differences. Four of the eight remaining instruments included questions related to the discharge process and/or transition; The NHS Inpatient Survey (NHSIP), the Scottish Inpatient Patient Experience Survey (SIPES), the Picker Patient Experience Questionnaire (PPE-15) and the Hospital Consumer Assessment of Healthcare Providers and Systems (HCAHPS). However, differences in approach, methodology and timing of administration limited comparison with the DICARS. In contrast to Kangovi et al. [20] we could not find that these four instruments included questions regarding self-care during the first period after the hospital stay. The SIPES got yes/no and three or more response alternatives, with timing of administration between four and five months after discharge, The PPE-15 got the same response alternatives whereas time of administration was within a month. The HCAHPS included the three Coleman's items similar to the DICARES. Mode of administration of the HCAHPS was by mail, telephone, and interactive voice recognition, where data were collected between 48 hours to six weeks, and the instrument got a four-point Likert like scale. The Consumer Quality Index (CQI) questionnaire is based on the HCAHPS and was used by Smirnova et al. [41] in a study from 2017 that included almost 23,000 patients and where nearly half of the respondents were 65 years or older. The results showed that variations in the measurement of patient experiences could be attributed to variation in quality of care. Five items in the DICARES cover communication between the patients and the health care personnel, who has emerged as more important than previously thought [41]. The total mean score of the DICARES was 4.04, and somewhat higher than the score on the subscale *Information at discharge* according to the study of Smirnova et al. [41] with mean score 0.7, corresponding to 77% and 70% of maximum scores, respectively. Even if the results

Table 5. Factors of the Discharge Care Experience Survey (DICARES) according to explorative factor analysis.

Factors	Item/ total correlation	Explorative Factor Analysis [a]	Cronbach's α
		Loading	
Coping after discharge			0.73
1.I have felt stressed [b]	0.47	0.91	
2. I have been depressed [b]	0.55	0.86	
3. I felt I was discharged too early [b]	0.43	0.50	
Participation in discharge planning			0.71
4. When I was discharged from hospital, I had a good understanding of my responsibility in terms of looking after my health	0.39	0.84	
5.When I was discharged from hospital, I under-stood thoroughly the purpose of taking my medication	0.45	0.76	
6. In connection with being discharged, I had an opportunity to notify hospital personnel about what I thought was important	0.32	0.72	
Adherence to treatment			0.70
7. I have experienced problems in getting sufficient nutrition [b]	0.31	0.77	
8. I have had problems in following the instructions I received when discharged from the hospital [b]	0.62	0.68	
9. I have experienced problems in performing daily activities (e.g. personal hygiene, getting dressed or cooking) [b]	0.56	0.64	
10. I have experienced problems in understanding the instructions I received when I was discharged from hospital [b]	0.59	0.64	
Item—total correlation			0.79

Table footnote:

[a] Rotated Component Matrix. Extraction Method: Principal Component Analysis. Rotation Method: Varimax with Kaiser Normalization

[b] Negative statements were inverted to a positive scale.

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in the study of Smirnova et al. may be hampered by relatively low response rate and by methodological issues discussed by Felix et al. [22], we found this comprehensive study appropriate to compare with the DICARES, attributable to the large group of eldery patiets included in the

Table 6. Correlation between The Discharge Care Experience Survey (DICARES) and relevant measurements (n = 270).

Questionnaires	Spearman's rho
The Nordic Patient Experiences Questionnaire (NORPEQ) (n = 266)	0.54 [a]
The 12 Item Short Form Survey (SF-12) (n = 269)	
• Physical Composite Scale	[a]
• Mental Composite Scale	0.55 [a]
The Subjective Health Complaints (SHC) (n = 250)	
• Musculoskeletal pain	-0.36 [a]
• Pseudoneurology	-0.47 [a]
• Gastrointestinal problems	-0.26 [a]
• Allergies	-0.29[a]
• Flu	-0.13 [b]

[a] Spearman's correlation is significant at the 0.01 level (2-tailed)

[b] Spearman's correlation is significant at the 0.05 level (2-tailed).

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Table 7. Comparison of the DICARES [a] and the NORPEQ [b] to 30 days readmission.

	n	Not readmitted Mean % (SD)	n	Readmitted [d] Mean % (SD)	P-value [e]
The DICARES [c]	198	77.5 (15.4)	72	72.0 (17.8)	0.014
The NORPEQ	196	75.2 (14.8)	70	75.0 (14.8)	0.930

[a] The Discharge Care Experience Survey

[b] The Nordic Patient Experiences Questionnaire

[c] The DICARES factors were converted to a scale from 0 to 100, where 100 is the best possible experience of care

[d] Patient journal data and patient reported data from the DICARES

[e] Two-sample t-test.

study. The NORPEQ was included in the present study for comparison since it is used as a quality measurement in Norwegian hospitals [26]. Similar to the DICARES, the NORPEQ has statements scored on a five point Likert like scale and applies explorative factor analyses, which strengthen the credibility of comparison of the instruments.

The DICARES differed significantly in scores with respect to readmitted patients. This finding is in contrast to Felix et al. [22], who found results of the post discharge questionnaires were not associated with readmission. However, our finding regarding the DICARES, as compared to NORPEQ and readmission, is consistent to findings reported by Felix et al. [22]. In the development of the DICARES we have implemented some of the recommendations such as graded response scale instead of yes / no questions, which partly could explain the fact that we succeeded in identifying patients at risk of readmission. Another explanation for this result may be that DICARES covers statements related to self-care the first four weeks after discharge.

The DICARES items correspond with quality in the discharge process, for instance drug errors at the time of discharge can be a consequence of incomplete or inaccurate information, and as such, are important issues to survey [42]. The lowest response rate scores were found for the item *Opportunity to notify what was important*. This might reflect that older patients may encompasses rejection of own need, and are grateful and humble to the systems of care despite the lack of information and participation in the transition process [43]. It is less associated with instruments measuring health status (SF-12), or subjective health complaints (SHC). This is an argument for the DICARES as a questionnaire instrument reflecting quality in the discharge process. After adjusting for age and sex, a significant association was found between the DICARES, the Charlson Comorbidity Index and readmission, not unexpectedly the DICARES and the Charlson Comorbidity Index were independent determinants.

Table 8. Logistic regression analyses of factors correlated to readmission (n = 270) [a].

Independent variables	Unadjusted model OR	95% CI		P-value	Final adjusted model OR	95% CI		P-value
The DICARES [b]	0.60	0.40	0.91	0.015	0.62	0.41	0.95	0.028
Charlson Comorbidity Index	1.32	1.11	1.57	0.002	1.31	1.10	1.55	0.003
Sex	1.13	0.66	1.95	0.656				
Age	1.03	0.49	2.17	0.939				

[a] Number of valid responses

[b] The Discharge Care Experiences Survey.

Factor analyses were performed to explore if the items included would give meaningful input in terms of understanding shortfalls in the discharge process, and to investigate whether the DICARES could provide hospitals with a tool for monitoring improvement processes. Validity testing of the instrument was considered satisfactory, and three factors were classified as acceptable. Naming of the factors; *Coping after discharge*, *Participation in discharge planning* and *Adherence to treatment* were suggestive as to what dimension each factor represents [36]. Participation in discharge planning has been recognized as important, even for very old patients [18], and it is advantageous at all levels in healthcare to empower patients and to improve services and health outcomes [44].

Coping is, according to Lazarus and Folkman, defined as *"constantly changing cognitive and behavioural efforts to manage specific external and/or internal demands that are appraised as taxing or exceeding resources of the person"* [45]. Comorbidity affects the relationship between coping and stress [4] and increased comorbidity is associated with higher severity levels of both depression and generalized anxiety [8]. Adherence require the patient's agreement to recommendation, and is defined as *"the extent to which a person's behaviour–taking medication, following a diet, and/or executing lifestyle changes-corresponds with agreed recommendations from a healthcare provider"* [46]. The World Health Organization claims that improving adherence to therapy would provide a significant advantage on investment through primary prevention [6].

A limitation is that our study was performed in one hospital on elderly patients predominantly from different medical departments, and one might argue that the study group is somewhat homogenous. However, the group included a satisfactory range of ages, sex and different medical conditions, and the final DICARES was acceptable with respect to missing data. We have no explanation for the relatively higher proportion of men among the responders than non-responders. The mean hospital stay was approximately eight days, which is somewhat higher compared to other studies [2, 4, 20, 25]. As compared to the national mean for all hospitalised patients, the readmission rate was above double. Higher age, and significant disease burden, may explain these findings [47]. After ethical considerations we decided to not include patients with reduced cognitive capacity, which also may represent a weakness in this study. These differences in population characteristics may influence the results, and limit the comparison with other studies. On the other hand, the study is performed in a well-defined patient population, and with careful sampling of data. The corresponding authors' meeting with each patient, and that the consent form had to be signed before the patients' were discharged probably contributed to the high response rate [48]. A limitation is that of the eligible 798 patients only 498 (38%) met the inclusion criteria and the most vulnerable patients were therefore not included in this study. To monitor and improve the discharge quality of patients not able to give informed consent, other methods than self–completing questionnaires should be employed. We do not know the reason for non-response and there is a potential for selection bias among the respondents even with the relatively high response rate.

A challenge with surveys performed after discharge is that many, especially frail elderly, might have a problem in remembering events four to five months after a hospital stay as used by some studies [1]. We chose a shorter time lag as this was relevant due to comparison with the quality indicator readmission within 30 days. It is possible that the moment that some respondents were asked to fill out the DICARES questionnaire coincided with their readmission. This might have negatively biased their perceptions of their previous hospitalization producing a recall bias. We chose to develop and validate a questionnaire on elderly patients' experiences. This may be a weakness with respect to the fact that younger patients may have the same issues [49]. However, the largest numbers of patients on medical wards are elderly and they are also in particular at risk of unplanned hospital readmission ascribable to

morbidity and functional decline [50]. Coleman's three items obtained from the 15-item Care Transition Measure has the limitation that it was derived from a small single health plan in the USA and might over-represent behaviours specific to that plan, or the patients' selection may be biased. They may not represent local European problems at discharge, which may be county / hospital / unit/ condition specific [51]. The psychometric properties of the DICARES were considered satisfactory.

Conclusions

This hospital based study suggests that the DICARES may be a feasible questionnaire instrument for measuring quality based on experiences of the discharge process among elderly patients (≥65 years). Our study also indicates that the DICARES is capable of monitoring the quality of care of important issues concerning the discharge process, and can be used as an additional tool for quality improvement care processes in hospitals. To further develop this instrument, it needs to be tested in a larger sample with a broader representation of patients in different hospital departments. The three-factor structure should be confirmed using a confirmatory factor analysis.

Supporting information

S1 File. Search strategy. Systematic literature search of patients' experiences transition from hospital to community health services.
(PDF)

S2 File. Available data. Anonymous data set including 270 respondents.
(XLSX)

S3 File. The Norwegian version of the initial 16 item DICARES questionnaire. Erfaringer knyttet til utskriving og tiden etter sykehusoppholdet.
(PDF)

Acknowledgments

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II

RESEARCH ARTICLE

Discharge care quality in hospitalised elderly patients: Extended validation of the Discharge Care Experiences Survey

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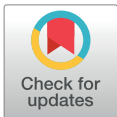
Abstract

Background

The Discharge Care Experiences Survey (DICARES) was previously developed to measure quality of discharge care in elderly patients ($\geq$ 65 years). The objective of this study was to test the factorial validity of responses of the DICARES, and to investigate its association with existing quality indicators.

Methods

We conducted a cross-sectional study at two hospitals in Bergen, Western Norway. A survey, including DICARES, was sent by postal mail to 1,418 patients 30 days after discharge from hospital. To test the previously identified three-factor structure of the DICARES we applied a first order confirmatory factor analysis with corresponding fit indices and reliability measures. Spearman's correlation coefficients, and linear regression, was used to investigate the association of DICARES scores with the quality indicators Nordic Patient Experiences Questionnaire and emergency readmission within 30 days.

Results

A total of 493 (35%) patients completed the survey. The mean age of the respondents was 79 years (SD = 8) and 52% were women. The confirmatory factor analysis showed acceptable fit. Cronbach's α between items within factors was 0.82 (*Coping after discharge*), 0.71 (*Adherence to treatment*), and 0.66 (*Participation in discharge planning*). DICARES was moderately correlated with the Nordic Patient Experiences Questionnaire (rho = 0.49, P < 0.001). DICARES overall score was higher in patients with no readmissions compared to those who were emergency readmitted within 30 days (P < 0.001), indicating that more positive experiences were associated with fewer readmissions.

Conclusions

DICARES appears to be a feasible instrument for measuring quality of discharge care in elderly patients ($\geq$ 65 years). This brief questionnaire seems to be sensitive with regard to readmission, and independent of comorbidity. Further studies of patients' experiences are warranted to identify elements that impact on discharge care in other patient groups.

Background

Hospital discharge is a complex process starting before admission where possible, or immediately after admission [1]. In recent years, modern medical treatment and cost-effective use have ensued shorter length of hospital stay and pressure on discharge of patients [2]. A variety of adverse events are related to discharge such as drug errors, hospital-acquired infections, and procedure-related complications [3], were elderly patients are particular at risk of poorer outcomes and admissions to hospital as an emergency within 30 days of discharge (emergency readmission) [4]. A vast body of literature focuses on the patient's condition, especially cognitive impairment and vulnerability, can complicate care in the discharge process [5, 6], and cause difficulties in managing post hospitalization care [2]. Vulnerability may be related to a number of challenges, such as side effects of new drugs [7], reduced mobility and increased risk of falls [8, 9], depression [10], and lack of support system [11]. Additionally, insufficient discharge documentation and poor communication may limit the patient's ability to cope with health issues after hospitalization, contributing to increased risk of adverse events [11, 12], and rehospitalisation [11].

Over the past years, special emphasis has been placed on patient participation by involving the patients and their care givers in their own care, in accordance to their individual needs, circumstances and priorities [13]. Patient participation may be described as the state when patients' themselves become the distinct starting point for all care actions [14]. The extent of patient participation is an important indicator of the quality of healthcare [14], and has been associated with improved treatment outcomes [15, 16]. However, patients and their caregivers often feel frustrated by poor preparation for their discharge to home [16, 17], or experience that they did not have an opportunity to be involved in issues they found important to influence; like medical treatment, practical conditions and the time of discharge [18–20].

Obviously, there is a need to monitor the quality of discharge care. Monitoring and measuring quality of hospital services has a long tradition. In the days of Florence Nightingale the ultimate goal of a hospital was to manage quality by monitoring and measuring care services [21]. Today, emergency readmissions is commonly used as a general quality indicator in hospitals despite its' many inherent limitations, for instance with higher readmission rates when comorbidity increases [2, 8, 22, 23]. Better tools to investigate central factors supporting quality of transitional care, including discharge from hospital to home has been called for [16]. I has been proposed that such tools, at least partly, should be based on measuring patients' experiences [24]. Combining data on patient experiences; "the sum of all interactions influenced by all interactions shaped by an organization's culture across the continuum of care" [25], and health outcomes, are essential components used to understand and to improve the quality of hospital care [26, 27]. Positive associations between patient experiences and health outcomes have been demonstrated in several studies [28], indicating that patient experience surveys may pose as an appropriate quality indicator. Instruments measuring health condition [29, 30], comorbidity [31], and healthcare quality have been developed and validated for in-hospital use

and use after hospitalisation [26]. However, discharge care covers a variety of tasks that may influence the patients' self-care capability after hospitalisation [18, 32–35]. Hence, tools for measuring discharge care quality should have the potential to mirror how these tasks are performed by health care professionals by including questions related to important issues patients may experience after hospitalisation. Such instruments need to primarily reflect the quality of the care process rather than health conditions and comorbidity.

In a previous study we developed a patient experience instrument to measure the quality of discharge care in elderly patients (≥65 years) named as the Discharge Care Experiences Survey (DICARES) [36]. The first version comprised 10 items reflecting three factors related to discharge care: *Coping after discharge*, *Adherence to treatment*, and *Participation in discharge planning* [2, 35, 37]. The aim of this study was to investigate the DICARES' psychometric properties, and its previously identified factor structure, in a slightly modified survey. The psychometric properties and the factor structure were confirmed.

Methods

A cross-sectional survey was conducted at two hospitals in Bergen, Western Norway, situated within the same regional health authority trust. The largest hospital is a referral tertiary teaching hospital with all specialities and covers about one million inhabitants. The smaller non-commercial private community hospital covers emergency functions for a population of approximately 150,000 inhabitants. The patients were recruited from a 22-bed internal medicine ward specialised in gastroenterology at the largest hospital, and a 32-bed general internal medicine ward at the community hospital. The distribution of patients with diseases of the digestive system at the specialized gastroenterology ward versus the general internal medicine ward was 48% and 18%, respectively. In the planning phase of our study the protocol was discussed with the hospital patient representative committee. Patient representative also participated in the study's reference group.

Data collection

A survey was sent by postal mail to 1,418 patients ≥65 years hospitalized more than 24 hours approximately 30 days after discharge from hospital between June 2015 and April 2016. After three weeks non-responders received a reminder by mail.

The survey comprised 11 DICARES items [36], and six validated items of the Nordic Patient Experiences Survey (NORPEQ) [38, 39]. NORPEQ is commonly used as a quality indicator in Norwegian hospitals and consists of eight items designed to measure patient experiences of hospital care across the Nordic countries. The six validated items assess staff interested in problem, professional skills of nurses/doctors, nursing care, understanding doctors, and information on tests. Additionally, the survey included three questions related to patients' characteristics. Patients completing six or more DICARES-items were included in the study, corresponding to the 50% cut-off point applied in the original version of NORPEQ [38].

Data were plotted twice by the same research assistant and quality controlled for errors by two of the researchers.

Development and previous validation of DICARES

Literature reviews, including a systematic literature review in the electronic databases PubMed, Cinahl, Embase, SweMed and PsycINFO, were conducted [36]. Our search strategy comprised the following terms: *patient experience*, *patients satisfaction*, *patient perspective*, patient *discharge*, *patient transfer*, *continuity of patient care*, *patient hand over*, *patient hand off*, *primary health care*, *home based care*, *nursing homes*, *community health services* and *community based*

care. In collaboration with an expert panel 16 items were extracted. Forward-translations and back-translations were conducted in order to adjust the items to fit a Norwegian context. Face validity was assessed by a group of patients, and content validity by the expert panel. The answers for each item of DICARES had five Likert-scaled choices ranging from 1 (Not at all) to 5 (To a very large extent) [40], indicating that higher scores were associated with more positive experiences. Principal component analysis identified a three factor structure comprising 10 items [36].

The previous 10-item version of the DICARES [36] was evaluated by health care professionals. Consensus was made to adjust the instrument by adding one item: *I received information about the effects and side effects of my medication*. The additional item was included due to medical care errors are one of the most commonly reported adverse events after hospitalisation [7]. The response to negative phrased items (number 1, 2, 3, 4, 9 10 and 11) were inverted to a positive scale. Minor linguistic changes were made to the current version. Principal component analysis was applied to evaluate and approve the modification (S1 File).

Concurrent validation

We investigated concurrent validity, a type of criterion-related validity suitable for use in measuring related concepts, to examine how well DICARES correlated to two established quality indicators; the Nordic Patient Experiences Questionnaire (NORPEQ) and emergency readmission, adjusted for comorbidity. The NORPEQ- items have a five-point descriptive scale, and the NORPEQ total score is scored on a 0–100 scale from the worst experience to the best experience [38]. Emergency readmission up to 30 days to the discharging hospital was recorded from the hospitals' patient administrative system [41]. Additional information obtained from this source was age, sex, date of admission, and length of stay. Characteristics collected from the patients included educational level, housing status, and emergency readmission.

Charlson Comorbidity Index

Charlson Comorbidity Index (CCI) [31] was used to categorize comorbidity of the patients. Each comorbidity category has an associated weight (0, 1–2, 3–4 and >5), and the sum of all the weights results in a single comorbidity score for a patient. CCI was calculated based on diagnosis codes registered by the hospitals by the International Classification of Diseases, 10th version (ICD-10) [42], and the index data were added to the dataset.

Statistical analysis

To obtain optimal statistical power and to retain the same number of all data in the DICARES, missing data in items for a person were imputed using the mean of responses of other items for that person (within person imputation), as recommended by Siddiqui and colleagues when missing responses are $\leq 50\%$ [43]. The differences between the non-imputed and imputed data are shown in the results, and in the supporting information files. Dependent on the distribution of the responses and the number of missing of data on each item, the mean and standard deviation may differ slightly in both directions. To obtain a measure for internal reliability for the three developed factors *Coping after discharge* (4 items), *Adherence to treatment* (3 items), and *Participation in discharge planning* (4 items), we calculated Cronbach's α. To test the factorial validity of responses of the DICARES, we applied a first order confirmatory factor analysis with the maximum likelihood estimation method [44]. Goodness of fit was assessed by use of common model fit indices with the following acceptance levels: minimum discrepancy (CMIN/df < 3.0) [45], comparative fit index (CFI $\geq$ 0.95) [46], root mean square

error of approximation (RMSEA < 0.06) [46], and standardised root mean square residual (SRMR < 0.05) [44]. To examine the relation between DICARES and its factors with NOR-PEQ and other characteristics, we used Spearman's correlation coefficient (rho). For this analysis, we used the total mean responses of DICARES and NORPEQ, i.e., we summarized the individual responses over the relevant items, and then divided this sum on the number of items for that scale. This was also done for the three factors of DICARES, e.g., the responses of the four items of factor *Coping after discharge* for each individual were summarized and then averaged on 4. Correlation values between 0.30 and 0.49 were considered to be satisfactory [47]. Finally, we evaluated the association of the DICARES scale and its factors with the established hospital quality indicator emergency readmission within 30 days (yes/no). This was done using DICARES and its factors as dependent variables and readmission as a dichotomous independent variable in a simple linear regression model. The analysis was repeated also after controlling for patient characteristics. To avoid list-wise deletion of individuals with missing patients' characteristics and NORPEQ responses in the adjusted analysis, we used a multiple imputation technique. We created 200 imputed datasets and the imputation model included all variables that were included in adjusted regression model. Statistical analyses were performed by Stata SE version 15 (StataCorp, College Station, Texas), SPSS version 23.0 (IBM Corp., Armonk, NY), and AMOS version 23.0 (IBM SPSS, Chicago). All P-values were two sided and values P < 0.05 were considered statistically significant.

Ethics

This study was conducted in accordance with the Helsinki Declaration, and was approved by the Western Norway Regional Committee for Medical and Health Research Ethics (Ref.: 2015/329). A declaration of consent was attached to the survey. Patients who returned the survey with a signed consent form were included in the study. We obtained anonymous patient characteristics for all invited patients at group level from the patient administrative system. Data from the survey were stored in a designated research server at the hospital, whereas the anonymised forms were stored in a lockable cabinet according to hospital regulations.

Results

In all, 493 (35%) patients returned questionnaires eligible for further analysis (Fig 1). Sample characteristics are shown in Table 1. The mean age was 79 years, 52% were women, 44% had a single household, and 21% reported to have obtained higher education (high school or university). The mean length of hospital stay was 3.6 days, 25% of the participants were readmitted to the hospital within 30 days, and mean score on the CCI was 0.9 (SD = 1.4). The difference in readmission rate between the two hospital wards was insignificant (P = 0.865).

Frequency and mean item responses of the 11 DICARES items for the study sample are shown in Table 2. Missing values for single items was 4.9%. Imputing person mean for missing item response did not markedly change the means or SD for any of the items.

Cronbach's α, calculated using imputed data, was estimated to be 0.82 for *Coping after discharge* (4 items), 0.71 for *Adherence to treatment* (3 items), and 0.66 for *Participation in discharge planning* (4 items) (S2 File). Confirmatory factor analysis verified satisfactory fit of the three-factor structure of the DICARES (Fig 2): CMIN/df 2.45, CFI 0.97, RMSEA 0.055 (90% CI = 0.041, 0.068) and SRMR 0.048.

Estimation of Spearman's correlation coefficient, based on imputed data, showed a moderate relationship between the DICARES factors (S3 File): *Coping after discharge* vs *Participation in discharge planning* (rho = 0.38, P < 0.001), *Participation in discharge planning* vs *Adherence to treatment* (rho = 0.40, P < 0.001), and *Coping after discharge* vs *Adherence to treatment*
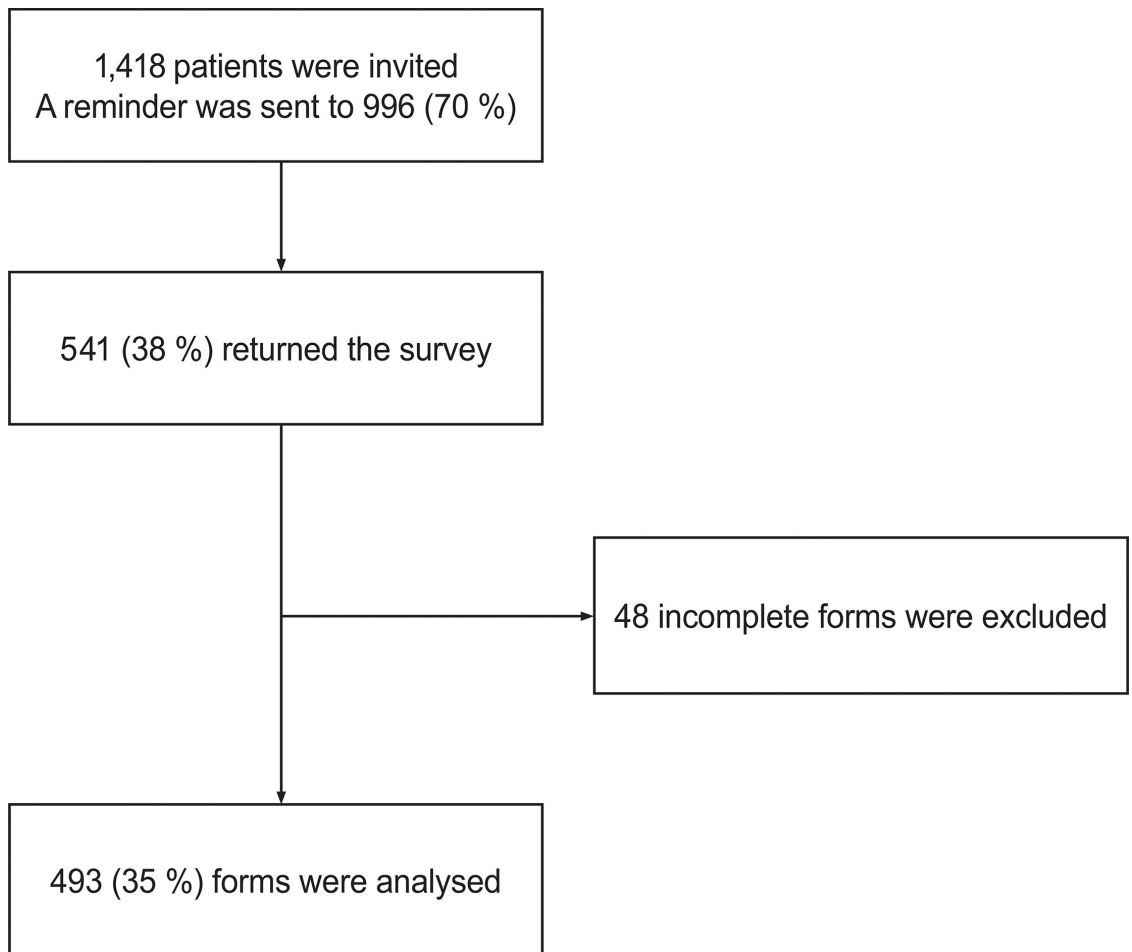
Fig 1. Inclusion of participants in the study. Elderly patients (≥65) were recruited from two hospitals in Bergen, Western Norway, situated within the same regional health authority. Data collection: June 2015 to April 2016.

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(rho = 0.49, P < 0.001). DICARES overall (11 items) correlated moderately with NORPEQ (6 items) (rho = 0.49, P < 0.001). Correlations between the two of the three DICARES factors and NORPEQ were somewhat smaller: *Adherence to treatment* vs NORPEQ (rho = 0.40, P < 0.001), and *Coping after discharge* vs NORPEQ (rho = 0.34, P < 0.001), while there was a moderate correlation between factor *Participation in discharge planning* and NORPEQ (rho = 0.51, P < 0.001). DICARES overall, and the three factors, correlated inversely with age and had no correlation with CCI (S3 File).

The relations of scores on DICARES, and the three factors, with readmission within 30 days are shown in Table 3. Patients who were readmitted to the hospital had lower mean response than those who were not readmitted to the hospital for all factors, as well as for

Table 1. Characteristics of the study sample.

Characteristics, categorical		n	%
All patients		493	100
Sex			
	Female	257	52.1
	Male	236	47.9
Patient's age, *years*			
	65–75	195	39.6
	76–85	187	37.9
	86–99	111	22.5
Household			
	Single household	218	44.2
	Shared household	266	54.0
	Missing	9	1.8
Education			
	Primary school	189	38.3
	High school low	167	33.9
	High school high /University	105	21.3
	Missing	32	6.5
Hospital discharge			
	Haukeland University Hospital, Bergen, Norway	207	42.0
	Haraldsplass Deaconess Hospital, Bergen, Norway	286	58.0
Emergency readmission [a]			
	No	372	75.5
	Yes	121	24.5
Characteristics, continuous		**Mean**	**SD**
Age, *years*		78.5	8.27
Charlson Comorbidity Index		0.93	1.36
Length of hospital stay, *days* [b]		3.59	3.29
NORPEQ [c]		4.03	0.66

Abbreviations: SD = standard deviation; NORPEQ = Nordic Patient Experiences Questionnaire

[a] Emergency readmitted within 30 days after discharge

[b] Data was missing for 4 patients on length of hospital stay

[c] Data was missing for 2 patients on the *Nordic Patient Experiences Questionnaire*

DICARES overall. The difference was upheld even after controlling for patient characteristics. Notably, no relation of NORPEQ with readmission was observed in unadjusted or adjusted analyses.

Discussion

This study tested the factor structure of the DICARES, developed for monitoring discharge care quality. We found the confirmatory factor analysis to support the three factor structure; *Coping after discharge*, *Adherence to treatment* and *Participation in discharge planning*. We observed that DICARES' correlated moderately with the NORPEQ–questionnaire [38, 39]. This finding indicates that DICARES' reflects some similar aspects as the NORPEQ, and further, provide additional knowledge particularly related to discharge care quality. We found that patients with more positive experience scores on the DICARES had significantly fewer readmissions. The DICARES did not correlate with comorbidity, as measured by the CCI.

Table 2. Item, factor, and total mean scores of the Discharge Care Experiences Survey.

	Respondents	Number of scores (valid %)						With imputation of missing data [a]	
	n (%)	1	2	3	4	5	Mean (SD)	n	Mean (SD)
Item scores									
1. I have felt stressed [b]	488 (99)	14 (3)	32 (7)	82 (17)	138 (28)	222 (45)	4.07 (1.07)	493 (100)	4.06 (1.07)
2. I have felt blue[b]	493 (100)	18 (4)	47 (9)	127 (26)	110 (22)	191 (39)	3.83 (1.15)	493 (100)	3.83 (1.15)
3. I have experienced problems in performing daily activities (e.g. personal hygiene, getting dressed or cooking) [b]	488 (99)	46 (9)	35 (7)	79 (16)	90 (19)	239 (49)	3.90 (1.33)	493 (100)	3.90 (1.33)
4. I have experienced problems in getting sufficient nutrition [b]	488 (99)	21 (4)	42 (9)	90 (18)	62 (13)	273 (56)	4.07 (1.21)	493 (100)	4.07 (1.21)
5. In connection with being discharged, I had an opportunity to notify hospital personnel about what I thought was important	445 (90)	57 (13)	53 (12)	96 (22)	161 (36)	78 (17)	3.34 (1.26)	493 (100)	3.41 (1.23)
6. When I was discharged from hospital, I understood thoroughly the purpose of taking my medication	428 (87)	45 (11)	21 (5)	43 (10)	125 (29)	194 (45)	3.94 (1.30)	493 (100)	3.94 (1.24)
7. I got information about effects and side effects of my medications	432 (88)	141 (33)	84 (19)	76 (17)	72 (17)	59 (14)	2.59 (1.43)	493 (100)	2.79 (1.46)
8. When I was discharged from hospital, I had a good understanding of my responsibility in terms of looking after my health	478 (97)	32 (7)	40 (8)	112 (23)	203 (43)	91 (19)	3.59 (1.09)	493 (100)	3.59 (1.08)
9. I have experienced problems in understanding the instructions I received when I was discharged from hospital [b]	472 (96)	15 (3)	15 (3)	32 (7)	101 (21)	309 (66)	4.43 (0.98)	493 (100)	4.38 (1.00)
10. I have experienced problems in following the instructions I received when discharged from the hospital [b]	464 (94)	12 (3)	15 (3)	37 (8)	88 (19)	312 (67)	4.45 (0.95)	493 (100)	4.38 (0.99)
11. I felt I was discharged too early [b]	484 (98)	27 (6)	34 (7)	53 (11)	78 (16)	292 (60)	4.19 (1.21)	493 (100)	4.18 (1.21)
Factor mean scores									
Factor CAD (Item 1,2,3 and 4)	493 (100)						3.97 (0.97)	493 (100)	3.97 (0.96)
Factor ATT (Item 5,6 and 7)	493 (100)						4.34 (0.86)	493 (100)	4.31 (0.85)
Factor PiPD (Item 8,9,10 and 11)	493 (100)						3.38 (0.93)	493 (100)	3.43 (0.89)
Total mean scores	493 (100)						3.85 (0.73)	493 (100)	3.87 (0.71)

Abbreviations: SD = Standard deviation; CAD = Coping after discharge; ATT = Adherence to treatment; PiDP = Participation in discharge planning

[a] Person mean imputation.

[b] Negative statements were inverted to a positive scale.

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The measured indicators CMIN/df, CFI, RMSEA and SRMR showed that the hypothesized factor structure was very well adapted to the data [45, 46]. We compared the DICARES with a large inpatient care quality study by Smirnova and colleagues from 2017 [48], that in contrast to the NORPEQ-study [39], applied confirmatory factor analysis. The study included nearly 23,000 participants, were half of the respondents were > 65 years. The mean values of the subscale *Information at discharge* were 0.7 (scale from 0 to 1) and almost identical to the mean total DICARES score (3.85 on a scale from 1 to 5), corresponding to 70% and 71% of the respective maximum values [48]. We believe these similarities support the acceptability of DICARES in terms of being useful as an additional instrument to measure hospital discharge quality. Elderly are considerable consumers of hospital care [49] and the DICARES was developed particularly to survey experiences in this vulnerable patient group, unlike the NORPEQ [38, 39].

In a systematic review Beattie and colleagues identified 11 instruments measuring patient experience of healthcare quality [26]. We were not able to find that the instruments covered questions related to patients experience the first period after hospitalisation. Additionally, differences in methodology and timing limited comparison with the DICARES [36]. We included NORPEQ as one of the comparators in the current study since it is an established general
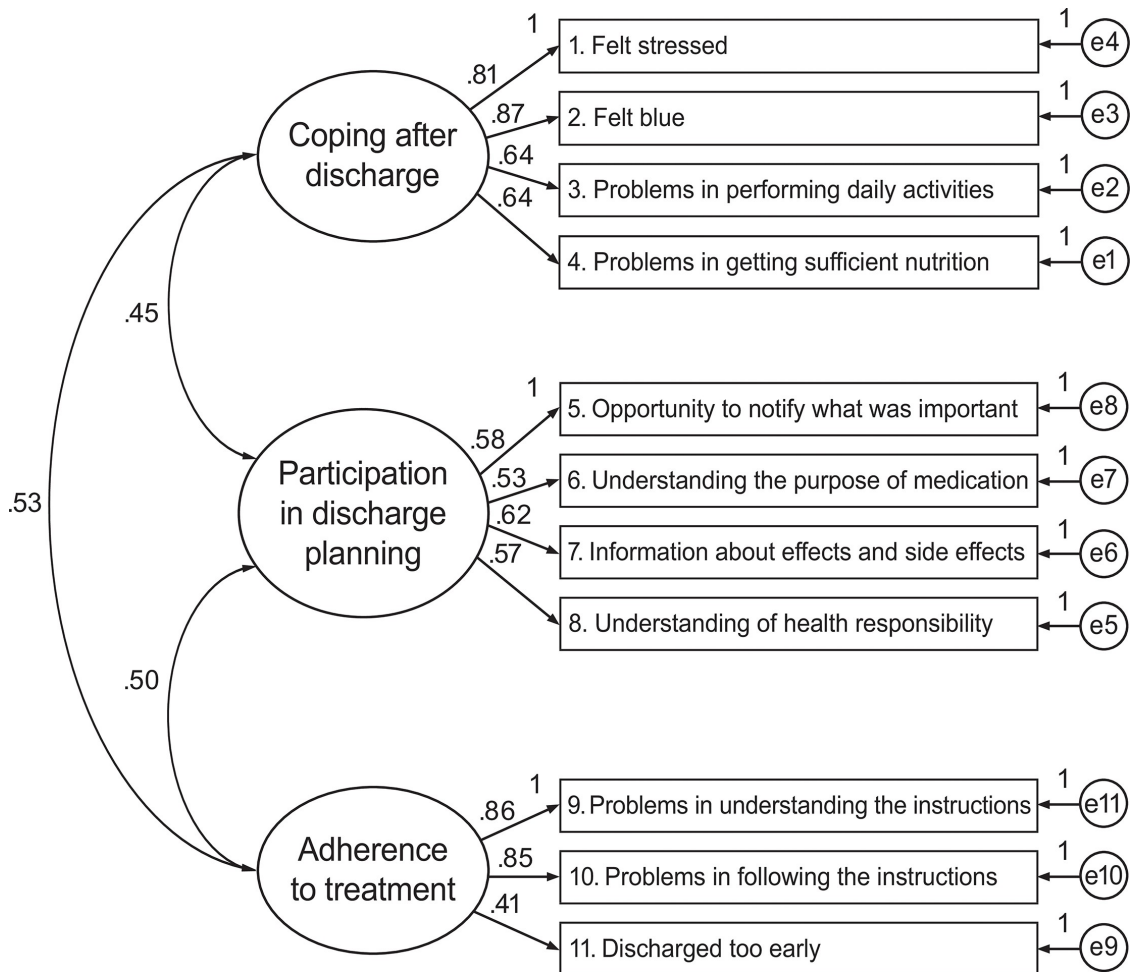
Fig 2. Confirmatory factor analysis of the Discharge Care Experiences Survey. Elderly patients (≥65) were recruited from two hospitals in Bergen, Western Norway, situated within the same regional health authority. Data collection: June 2015 to April 2016.

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quality indicator used in Norwegian hospitals [26]. NORPEQ and Smirnova claim their instruments reflect the quality of care. This is attributed to variation in the results between or within organisations and at different organisational levels [39, 48]. Such an approach has been discussed by Bezold [50], who claims that quality will then be measured from an institutional level rather than through the eyes of the patient. Our approach has been to measure discharge care quality by comparing the DICARES with external instruments covering conditions of importance for the patients in order to identify how underlying issues may reflect specific areas of discharge.

Table 3. Difference in total mean and factor mean scores between readmitted and not readmitted patients.

Scale		Emergency readmission					Estimated group difference [a]					
		No (n = 372)			Yes (n = 121)								
		Mean	SD		Mean	SD		Unadjusted *b* (95% CI)	P value		Adjusted *b* (95% CI) [b]	P value
DICARES [c]												
	Total (11 items)	4.01	0.69		3.62	0.74		-0.39	(-0.53, -0.24)	<0.001		-0.42	(-0.57, -0.28)	<0.001
	Factor CAD (4 items)	4.09	0.88		3.57	1.10		-0.52	(-0.71, -0.33)	<0.001		-0.57	(-0.76, -0.38)	<0.001
	Factor ATT (3 items)	4.40	0.78		4.04	0.99		-0.36	(-0.54, -0.19)	<0.001		-0.38	(-0.56, -0.21)	<0.001
	Factor PiDP (4 items)	3.47	0.91		3.32	0.81		-0.15	(-0.33, 0.03)	0.11		-0.20	(-0.30, -0.01)	0.035
NORPEQ												
	Total (6 items)	4.05	0.67		4.04	0.99		-0.06	(-0.20, 0.07)	0.37		-0.09	(-0.23, 0.04)	0.17

Abbreviations: SD = standard deviation; CI = confidence interval; DICARES = Discharge Care Experiences Survey; CAD = Coping after discharge

ATT = Adherence to treatment; PiDP = Participation in discharge planning; NORPEQ, Nordic Patient Experiences Questionnaire

[a] By linear regression model

[b] Adjusted for all categorical variables in Table 1; missing data in household (n = 9), education (n = 32), and Nordic Patient Experiences Questionnaire

(n = 2) was imputed using a multiple imputation technique

[c] Missing data in items for a person were imputed using the mean of responses of other items for that person (within person imputation)

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As in our previous study [36] no correlations were found between the DICARES and the CCI, indicating that comorbidity did not have a significant impact on the DICARES scores. We may have succeeded to develop an instrument that measures health service quality rather than the patients' health conditions influenced by comorbidity, in our study measured by CCI. The DICARES is simple, brief and its three factors have the potential, directly or indirectly, to reflect specific areas discharge care quality [51]. The response of each item indicates sufficient variation in the responses and normal distribution [52].

According to Manary and colleagues [53], patient experience measures do not simply reflect clinical adherence-driven outcomes, but also another dimension of quality which otherwise is difficult to measure objectively. We believe the DICARES' three-factor structure makes it possible to identify and measure underlying issues in quality of care and that suitable strategies may be developed and implemented through quality improvement work [54, 55].

In the current study we chose to use emergency readmission for concurrent validation of the DICARES. The factors *Coping after discharge* and *Adherence to treatment* were associated with readmission, indicating emergency readmission as a quality indicator, and the DICARES covers some similar aspects. This is in line with results in the study of Kangovi and colleagues who found that one of the most commonly reported issues that contributed to readmission was difficulties in performing daily tasks [34]. Factor *Adherence to treatment* was significantly lower for the readmitted patients versus the non-readmitted patients in the current study. Adherence is the primary determinant of the effectiveness of treatment and is affected by the patient-provider relationship, and also by numbers of patient-related factors such as low motivation, lack of a self-perceived need for treatment, feeling of being discharged too early from previous hospitalisation, or multiple hospital admissions [34, 54, 56–58].

Patients reported the lowest scores for the factor *Participation in discharge planning*. This result is similar to the findings in the previous DICARES' study [20], and corresponds with elderly patients' experiences of not being involved in discharge planning from hospital [18, 59, 60]. Despite the lack of participation, elderly patients' interviewed in a study of Hvalvik and colleagues [60] were humble and expressed gratefulness for the care system they were a part of. The authors claim a patient-oriented approach as essential in the process to support the elderly patients because they are challenged during the transition between hospital and

home. To support care of elderly patients, health care professionals need to understand the patient's present situation in the context and coherence of past and future [60]. Patients with positive care experiences are often more engaged in their care, more committed to treatment plans, and more receptive to medical advices [51].

A limitation of the current study may be the relatively low response rate, though it is comparable to the study by Smirnova and colleagues [48]. Low participation is a major concern in patient experience surveys [38]. One concern could be that elderly persons with a high CCI would participate to a lesser extent. In a previous study of DICARES [36] investigating patient experiences in a similar population of elderly, the response rate was 64% and the CCI was 0.7 higher than in the current study. This indicate that comorbidity may not be the reason for the limited number of responders in the current study. However, the response rate may have been influenced by geriatric syndromes; clinical conditions that is common in elderly and that do not fall into distinct disease categories, like weight loss, pain and depressive symptoms [61]. Another limitation may be that patients who completed less than six DICARES items were not included in the study. Poor condition or cognitive impairment could be reasons for lack of completion of the questionnaire. Exclusion of these patients may have biased the results.

Unlike findings in the previous study of the DICARES [20], Cronbach's α was somewhat lower for the factor *Participation in discharge planning* than required according to quality criteria for measurements [26]. However, instruments for quality improvement may tolerate lower levels of reliability in favour of other aspects of utility, such as it is brief and there are good theoretical and practical reasons for the instrument [62] due to educational impact, cost and acceptability [26]. Measurement error is not calculated, similar to results in Beattie and colleagues systematic review where only one of the studies reported on this criterion [26]. Except from these possible weaknesses DICARES' fulfils the other quality criteria for measurement properties.

The DICARES meet with recommendations of Manary and colleagues [53] who claim that patient experiences measurement should address a specific event or visit, focus on provider patient interactions, and be assessed in a timely manner. Furthermore, the DICARES is in accordance with the usual distribution of surveys to patients in clinical improvement work. We find it important to keep the questionnaire brief, otherwise elderly sick patients may find it too demanding to complete. The survey was distributed to the patients one month after discharge as this was relevant due to comparison with the quality indicator emergency readmission within 30 days. There may be patients who did not receive the questionnaire because they were already readmitted at the time the questionnaire was sent. Further, there may be patients who did not answer the questionnaire because they had already been readmitted at that time, which may have resulted in a failure to answer the questionnaire even though a poor discharge process was the reason for re-admission. Additionally, there is a risk of recall-bias that patients who have been readmitted confuse the experiences of more admissions. However, test-retest showed satisfactory results in a previous study [36]. The CCI is limited to cover only the prognostic aspect as a risk of early mortality [31], and unlike the previous study of the DICARES [36], a health status survey is not included in this study. The amount of missing data was acceptable [63]. By applying imputation the power of the analyses has been strengthen, and the risk of bias reduced.

Conclusions

The DICARES appears to be a valid questionnaire for measuring discharge care quality. The survey provides additional value to the knowledge of challenges faced by patients, and contributes to verify the feasibility of the DICARES. When compared with established hospital quality

indicators, the results indicate that DICARES could be a feasible tool to add to discharge improvement measures. DICARES seems to have sensitive properties with regard to the readmitted patients, and to be independent of comorbidity. The three factor structure may reflect directly and indirectly underlying issues related to discharge. The psychometric evaluation of the DICARES suggests acceptable internal consistency, and adequate construct validity of the instrument as a whole. DICARES is a brief, generic, non-diagnostic, and specific questionnaire. Further validation may also include elderly patients discharged from general surgical units.

Supporting information

S1 File. Principal component analysis.
(DOCX)

S2 File. Reliability analysis.
(DOCX)

S3 File. Spearman's correlation coefficient.
(DOCX)

S4 File. Available data. Anonymous data set including 493 respondents.
(XLSX)

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III

BMJ Open Quality

Measuring discharge quality based on elderly patients' experiences with discharge conversation: a cross-sectional study

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ABSTRACT

Background Discharge conversation is an essential part of preparing patients for the period after hospitalisation. Successful communication during such conversations is associated with improved health outcomes for patients.
Objective To investigate the association between discharge conversation and discharge quality assessed by measuring elderly patients' experiences.
Methods In this cross-sectional study, we surveyed all patients ≥65 years who had been discharged from two medical units in two hospitals in Western Norway 30 days prior. We measured patient experiences using two previously validated instruments: The Discharge Care Experiences Survey Modified (DICARES-M) and The Nordic Patient Experiences Questionnaire (NORPEQ). We examined differences in characteristics between patients who reported having a discharge conversation with those who did not, and used regression analyses to examine the associations of the DICARES-M and NORPEQ with the usefulness of discharge conversation.
Results Of the 1418 invited patients, 487 (34%) returned the survey. Their mean age was 78.5 years (SD=8.3) and 52% were women. The total sample mean scores for the DICARES-M and NORPEQ were 3.9 (SD=0.7, range: 1.5–5.0) and 4.0 (SD=0.7, range: 2.2–5.0), respectively. Higher DICARES-M and NORPEQ scores were found for patients who reported having a discharge conversation (74%) compared with those who did not (15%), or were unsure (11%) whether they had a conversation (p<0.001). Patients who considered the conversation more useful had significantly higher scores on both the DICARES-M and NORPEQ (p<0.001).
Conclusions Reported discharge conversation at the hospital was correlated with positive patient experiences measurements indicating the increased quality of hospital discharge care. The reported usefulness of the conversation had a significant association with discharge care quality.

BACKGROUND

Effective communication between health professionals and patients involves the exchange of health information as well as empathic care that is an exceedingly important aspect of elderly patients' treatment in the hospital.[1] Indeed, patients' perception of the care they received in hospital is significantly and positively influenced by how they experienced the quality of the interaction with health professionals[2] and has a significant impact on patient adherence to treatment.[3] Further, responsiveness to patient needs is one of the key dimensions of healthcare quality.[4]

Health professionals have a critical role in preparing patients for the vulnerable period after hospital discharge (ie, the point at which inpatient hospital care ends, with ongoing care transferred to other primary, community or domestic environments),[5] as the patients will not have direct access to important health-related information when leaving the hospital. Particularly, the lack of discharge-related communication is problematic for elderly patients with complex care needs, who are at increased risk of adverse events in the acute period after hospitalisation.[6 7] Depending on the patients' care needs, discharge planning in Norwegian medical hospital units covers a range of activities including discharge conversation (figure 1).[8] Nevertheless, elderly patients quite often do not have a discharge conversation in the hospital.[9 10]

The 30-day emergency readmission rate is a commonly used quality indicator in hospitals,[11] however, this indicator may be influenced by comorbidity and other causes of hospitalisation.[12] As an additional approach, patient experiences is recognised as a key element to manage quality in healthcare.[13] Patient experiences may be defined as 'the sum of all interactions, shaped by an organisation's culture, that influence patient perceptions, across the continuum of care'.[14] Instruments reflecting patient experiences have been developed to measure and monitor quality in healthcare.[15]

Discharge planning in elderly patients

* Medication reconciliation
* Assessment of risk of malnutrition, falls and ulcers
* Follow up inpatients/outpatient appointments
* Written patient information letter
* Discharge letter to the patient's doctor (GP)
* Discharge conversation with the patient and/or next of kin

* Coordination with municipality health services when required
* Follow up plan when required
* Assure necessary medical equipment's at home
* Assure necessary aid equipment's at home
* Transportation from hospital to home or institution
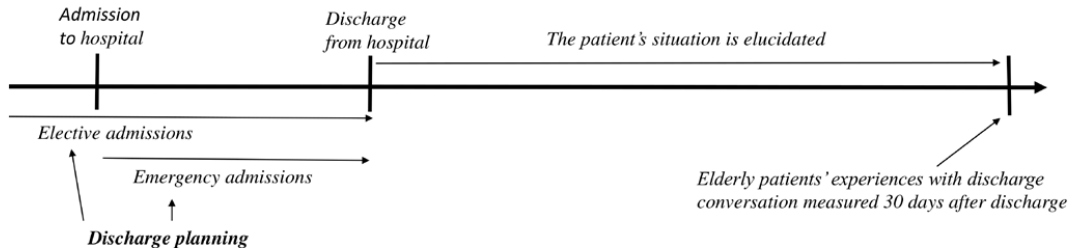
Figure 1 Tasks and activities included in discharge planning in elderly patients in Norwegian medical Hospital units. GP, general practitioner.

A number of studies have examined the factors that constitute sufficient communication from patients' perspectives, often by investigating the interactions between physicians and patients.[3 16] Evidence-based interventions aiming to improve physicians' and nurses' communication with patients have been conducted at the participating hospitals in recent years.[17 18] Some of these interventions have emphasised the discharge conversation. Several studies have investigated issues regarding discharge communication,[19–22] however, we have not been able to identify studies investigating the association between discharge conversation in the hospital, and its possible impact on discharge quality by use of validated indicators. The aim of the study was to investigate the association between discharge conversation and discharge quality as measured by elderly patient experiences.

METHODS
Design and setting
We used a cross-sectional study design to evaluate patient experiences of discharge conversation in hospital by using two questionnaires: a modified version of the Discharge Care Experiences Survey (DICARES-M)[23] and the Nordic Patient Experiences Questionnaire (NORPEQ), which is frequently used as a quality indicator in Norwegian hospitals.[24 25]

We invited all patients aged ≥65 years with a hospital stay of at least 24 hours because those with shorter stays are patients scheduled for specific procedures in the daytime. The present study presents a subset of data collected as a part of a larger study completed at two hospitals in Bergen, Western Norway. These hospitals

serve approximately 1 150 000 inhabitants. The patients were recruited from a 22-bed gastrointestinal unit from the larger hospital (a referral tertiary teaching hospital) and from a 32-bed general medical unit at the smaller hospital (a non-commercial private community hospital).

Data collection and questionnaires
The survey questionnaire, which contained the two scales and a consent form, was sent via postal mail 1 month after patients were discharged from the hospital. All these patients received treatment between June 2015 and March 2016. Non-responders were sent a reminder after 3 weeks.

To be eligible for participation, patients had to return a signed consent form with the questionnaire and respond to the question: *Did you have a discharge conversation at the hospital?*, with five response alternatives: *Yes, with a doctor, Yes, with a nurse, Yes, with a nurse and a doctor, No, I did not have a discharge conversation*, and *Unsure*. Additionally, the patients had to complete at least 50% of the items on DICARES-M and NORPEQ. This cutoff point is in line with an earlier study of NORPEQ.[20]

As quality in discharge cannot be measured by one singular question, we applied a newly developed instrument, DICARES-M, with a sum score reflecting quality.[8 23] The original first version of DICARES-M[8] that contained 10 items was evaluated by healthcare professionals and adjusted by adding one item: *I received information about the effects and side effects of my medication*. We included this item because medication errors are one of the most commonly reported adverse events after hospitalisation.[26] The modified DICARES-M version[23] contains 11 items in

three factors: *coping after discharge* (4 items), *participation in discharge planning* (4 items) and *adherence to treatment* (3 items). Negative DICARES-M statements (seven items), such as *I have experienced problems in understanding the instructions I received when I was discharged from the hospital*, were inverted to a positive scale. The NORPEQ consists of six validated items covering essential aspects of hospital care; understanding doctors professional skills of nurses/ doctors, staff interested in the problem, nursing care, information on tests and two additional items measuring global satisfaction and perceptions of incorrect treatment.[24] The DICARES-M and NORPEQ items were all scored on a 5-point Likert-type scale, as follows: *1=not at all, 2=to a little extent, 3=to some extent, 4=to a large extent* and *5=to a very large extent.*[27] Higher scores indicate more

positive experiences. The equivalent response scale was used for the additional question: *To what extent did you find the discharge conversation useful?* We categorised the responses into two groups, 'low usefulness' including *1=not at all, 2=to a little extent* and *3=to some extent* in one group, and 'high usefulness' *4=to a large extent* and *5=to a very large extent* in the other group. Data were plotted twice by the same research assistant and subsequently checked for errors by two of the researchers. An anonymous data file is available (online supplementary file).

The survey questionnaire also evaluated patients' housing status and educational level. Other patient characteristics were obtained from the hospitals' patient administrative system, including age, sex, length of hospital stay and comorbidity. In order to compare the

Table 1 Characteristics of the patients according to whether they had a discharge conversation at the Norwegian hospitals in Bergen (2015–2016).

Characteristics, categorical	N	Reported to have a discharge conversation			P value*
		Yes	No	Unsure	
		N (%)	N (%)	N (%)	
All patients	487	360 (74)	73 (15)	54 (11)	
Age groups (y)					0.003
65–79	265	212 (80)	33 (13)	20 (7)	
80–99	222	148 (67)	40 (18)	34 (15)	
Sex					0.209
Female	254	185 (73)	35 (14)	34 (13)	
Male	233	175 (75)	38 (16)	20 (9)	
Housing status†					0.120
Single household	214	153 (71)	40 (19)	21 (10)	
Shared household	264	200 (76)	32 (12)	32 (12)	
Education‡					0.530
Compulsory school	188	132 (70)	35 (19)	21 (11)	
Upper secondary school	165	125 (76)	20 (12)	20 (12)	
Higher education/ University	104	78 (75)	16 (15)	10 (10)	
Hospital					0.023
Hospital 1§	204	145 (41)	40 (55)	37 (68)	
Hosptial 2¶	283	213 (59)	33 (45)	17 (32)	
Emergency readmission**					0.824
No	368	274 (76)	55 (75)	39 (72)	
Yes	119	86 (24)	18 (25)	15 (28)	
Characteristics, continuous	**Mean (SD)**	**Mean (SD)**	**Mean (SD)**	**Mean (SD)**	**P value††**
Age (y)	78.5 (8.3)	77.8 (8.3)	80.0 (7.5)	81 (8.6)	0.130
Charlson Comorbidity Index	0.9 (1.4)	0.9 (1.4)	1.0 (1.3)	0.9 (1.5)	0.748
Length of hospital stay (d)	3.6 (3.3)	3.6 (3.3)	3.8 (3.7)	3.4 (2.9)	0.768

*χ^2 test.
†Data on household were missing for nine patients.
‡Data on education were missing for 30 patients.
§Gastroenterology unit, Haukeland University Hospital, Bergen, Western Norway.
¶General medical unit, Haraldsplass Deaconess Hospital, Bergen Norway.
**Emergency readmission within 30 days after hospital discharge.
††One-way analysis of variance.

Table 2 Mean scores on the discharge care experiences survey (modified) (n=487)

Factors with items	Mean (SD)
Coping after discharge	
1.I have felt stressed*	4.07 (1.07)
2.I have felt blue*†	3.84 (1.12)
3.I have experienced problems in performing daily activities (eg, personal hygiene, getting dressed, cooking)a	3.91 (1.33)
4.I have experienced problems in getting sufficient nutrition*	4.07 (1.21)
Participation in discharge planning	
5.In connection with being discharged, I had an opportunity to notify hospital personnel about what I thought was important	3.35 (1.26)
6.When I was discharged from the hospital, I understood thoroughly the purpose of taking my medication	3.94 (1.30)
7.I got information about effects and side effects of my medications‡	2.59 (1.44)
8.When I was discharged from the hospital, I had a good understanding of my responsibility in terms of looking after my health	3.58 (1.10)
Adherence to treatment	
9.I have experienced problems in understanding the instructions I received when I was discharged from hospital*	4.43 (0.98)
10.I have experienced problems in following the instructions I received when discharged from the hospital*	4.45 (0.96)
11.I felt I was discharged too early*	4.20 (1.20)
Total sample mean score	3.90 (0.72)

*Negative statements were inverted to a positive scale.
†Item was formulated as *I have felt depressed* in the original version of the DICARES-M.
‡Item not included in the original version of DICARES-M.
DICARES-M, Discharge Care Experiences Survey Modified.

patient characteristics for the responders versus all the invited, we obtained data in anonymous format at the group level from the patient administrative system. For those who responded to the survey with a written consent, the patient characteristics were collected on an individual level. We evaluated emergency readmission by checking the patient administrative system and asking patients directly, to account for the fact that patients might have been readmitted to other hospitals. Comorbidity was evaluated using the Charlson Comorbidity Index[28] based on the International Classification of Diseases, Tenth Revision codes.[29]

Statistical analysis

Missing data for individual items on the DICARES-M (4.8%) and NORPEQ (0.8%) were imputed using the mean of the responses of the other items for that person

(within-person imputation) to optimise statistical power and retain the same number of individuals for all analyses.[30] To examine differences in the characteristics between patients who reported to have a discharge conversation with those who did not, we used the χ^2 test for categorical data and one-way analysis of variance (ANOVA) for continuous data. Next, we examined the associations of the DICARES-M (both total and factor scores) and NORPEQ, with the usefulness of discharge conversation. We included the usefulness of discharge conversation with nurses or physicians as a dichotomous independent variable and the DICARES-M and NORPEQ scores as continuous dependent variables in linear regression models. The regression analyses were performed using crude and adjusted models, with the latter being adjusted for sex, housing status, education, hospital, age, and comorbidity. To avoid listwise deletion, missing data for the covariates were replaced by using the joint modelling algorithm and the multivariate normal distribution. The imputation model included all the above-mentioned covariates, usefulness of discharge conversation and the outcome variables. Two hundred imputed datasets were created. Pooled estimates were obtained by using Rubin's combination rules,[31] adjusted for the variability between imputation sets. All the statistical analyses were performed by SPSS Statistics V.23.0 and Stata SE V.15.

Patient and public involvement

Patient representatives took part in the planning of the study, and in the study's reference group which had two meetings to discuss and evaluate the study.

Ethics approval and consent to participate

This study was conducted in accordance with the Declaration of Helsinki[32] and was approved by the Western Norway Regional Committee for Medical and Health Research Ethics (Ref.: 2015/329) before the study began. The study was further approved by the hospitals' managers. Patients who did not return a signed consent form with the questionnaire were excluded from the study.

RESULTS

Of the 1418 invited patients, 487 (34%) returned the survey (table 1). The mean age of the participants was 78.5 years (SD=8.3) and 52% were women compared with 79.9 years (SD=8.6) and 55% for all invited. The mean length of hospital stay was 3.6 days. Overall, the patients had a significant disease burden (Charlson Comorbidity Index=0.9 for the responders and 1.10 for all the invited), and 24% were emergency readmitted within 30 days after their hospitalisation. A total of 360 patients (74 %) reported having a discharge conversation. There were differences in patients' responses to the discharge conversation item according to age groups and hospitals (table 1).

The response rate for the 11 DICARES-M items varied from 87% to 100% (table 2), whereas approximately 100% responded to each of the six NORPEQ items (table 3).

Table 3 Mean scores of the Nordic patient experiences questionnaire* (n=487)

Items	Mean (SD)
1.Were the doctors understandable?	4.06 (0.83)
2.Did you have confidence in the doctors' professional skills?	4.19 (0.69)
3.Did you have confidence in the nurses' professional skills?	4.17 (0.70)
4.Did the nurses take care of you?	4.13 (0.83)
5.Were the health personnel interested in your problem(s)?	3.85 (0.95)
6.Did you receive sufficient information about tests and examinations?	3.80 (0.98)
Total sample mean score	4.03 (0.66)
Additional questions:	
7.Overall, was the treatment and care you received in the hospital satisfactory?†	NA
8.Was there a time you thought a medical mistake was made in your treatment and care?†	NA

*Six validated questions from the original eight-item questionnaire were included in the analyses. Questions 7 and 8 are not validated.
†This question is not validated.
NA, not applicable.

The overall mean scores for the DICARES-M and NORPEQ were 3.9 (SD=0.7; range: 1.5–5.0) and 4.0 (SD=0.7, range: 2.2–5.0), respectively. The lowest mean score of the three DICARES-M factors was found for *participation in the discharge planning* (mean=3.4, SD=0.9). Patients who reported they had a discharge conversation (n=360) scored significantly higher to DICARES-M and NORPEQ than patients who reported they did not have a discharge conversation (n=73), and those who reported to be unsure whether they had such a conversation (n=54) (p<0.001) (table 4). In the regression analysis, we found that patients who reported the discharge conversation to be of 'high usefulness' had significantly higher scores on the DICARES-M (and its three factors) and NORPEQ than those who reported 'low usefulness' (table 5). No association was found between the usefulness of discharge conversation and emergency readmission (p=0.160).

DISCUSSION

We found that 74% of the patients reported having a discharge conversation and that individuals with a conversation prior to discharge had higher scores on DICARES-M and NORPEQ when compared with those who did not report having such a conversation or to

those who were unsure whether they had one. In addition, individuals who considered the conversation more useful tended to have higher DICARES-M and NORPEQ scores (table 5).

Altogether, having a discharge conversation appeared to be associated with more positive experiences. Seventy-four per cent of the patients reported they had a discharge conversation. This conflicts with a previous Norwegian study from 2012, conducted by Foss *et al*,[10] wherein only 10% of the patients (mean age=86 years) reported they had a discharge conversation. In the participating hospitals, healthcare professionals aim to hold discharge conversations with all patients, which might be one reason for the large difference in results between our study and that of Foss *et al*. However, our study has similarities with the one of Foss *et al* with respect to that the group of patients ≥80 years were less likely to report having a discharge conversation. This might be explained with ageism (ie, discrimination against people on the basis of their age), which according to the WHO is an everyday challenge for older people,[33] even among health professionals.[34] Other possible explanations could be patients' health conditions, the time of discharge or healthcare professionals' time constraints.[35]

Table 4 Differences in quality indicator scores on whether or not a discharge conversation was reported (n=487)

	Reported to have a discharge conversation†			
	Yes (%)	No (%)	Unsure (%)	
	n=360 (74)	n=73 (15)	n=54 (11)	
All patients	Mean (SD)	Mean (SD)	Mean (SD)	P value*
DICARES-M	4.02 (0.67)	3.62 (0.79)	3.60 (0.78)	<0.001
NORPEQ	4.14 (0.62)	3.63 (0.64)	3.87 (0.69)	<0.001

*One-way analysis of variance.
†Question: *Did you have a discharge conversation at the hospital?*, with response alternatives *Yes, with a doctor*, *Yes, with a nurse*, *Yes, with a nurse and a doctor*, *No, I did not have a discharge conversation*, and "*Unsure*".
DICARES-M, Discharge Care Experiences Survey Modified; NORPEQ, Nordic Patient Experiences Questionnaire.

Table 5 Differences in mean total and factor scores among responders according to reported usefulness of discharge conversation

	Reported usefulness of discharge conversation							
	Low* (n=140)		High† (n=220)		Estimated group differences‡			
	Mean	SD	Mean	SD	Unadjusted† (95% CI)	P value	Adjusted§ (95% CI)	P value
DICARES-M								
Overall (11 items)	3.74	0.71	4.21	0.57	−0.47 (−0.60 to 0.33)	<0.001	−0.45 (−0.58 to 0.31)	<0.001
CAD (4 items)	3.84	0.95	4.24	0.85	−0.40 (−0.58 to 0.21)	<0.001	−0.37 (−0.56 to 0.18)	<0.001
ATT (3 items)	4.13	0.86	4.58	0.71	−0.45 (−0.61 to 0.28)	<0.001	−0.45 (−0.62 to 0.28)	<0.001
PIDP (4 items)	3.24	0.90	3.76	0.76	−0.53 (−0.70 to 0.36)	<0.001	−0.49 (−0.67 to 0.32)	<0.001
NORPEQ								
Overall (6 items)	3.91	0.65	4.29	0.55	−0.37 (−0.50 to 0.25)	<0.001	−0.36 (−0.49 to 0.23)	<0.001

*Response alternatives 1. *Not at all*, 2. *To a little extent*, or 3. *To some extent* for the question: *To what extent did you find the discharge conversation useful?*.
†Response alternatives *4. To a large extent* or *5. To a very large extent* for question: *To what extent did you find the discharge conversation useful?*.
‡By linear regression model.
§Adjusted for sex, housing status, education, hospital, age, and comorbidity; missing data for housing status (n=9) and education (n=25) were imputed using a multiple imputation technique.
ATT, adherence to treatment; CAD, coping after discharge; DICARES-M, Discharge Care Experiences Survey Modified; NORPEQ, Nordic Patient Experiences Questionnaire; PIDP, participation in discharge planning.

The total mean scores for the DICARES-M and NORPEQ were relatively high, indicating that patients had predominantly positive experiences (tables 2 and 3). Furthermore, when patients reported the discharge conversation to be useful, they tended to score significantly higher on the DICARES-M factor of *adherence to treatment*, indicating that they had far fewer problems in understanding and following treatment instructions compared with patients who reported the conversation to be less useful (table 5). This finding is similar to results in an extensive meta-analysis performed by Zolinerek and DiMatteo.[3] They identified an increased risk (19%) of non-adherence to treatment among patients whose doctors communicated poorly compared with patients whose doctors communicated well.

The *participation in the discharge planning* factor of the DICARES-M had the lowest scores (table 4), which is consistent with findings of a previously published study of the DICARES-M,[23] and those of other studies of elderly patients' discharge experiences.[9 36 37] The lack of routines or procedures designed to make sure that patients' opinions are heard might be a reason for this result.[35] To determine whether elderly patients desire to be involved in their own healthcare, professionals must actively look for that desire.[36] Potentially, patients in the current study participated to a greater extent than is shown in the results, as health professionals might have involved patients in discharge-related issues when performing other tasks. However, a study of cultural factors that hampered or assisted person-centred care in an acute care setting revealed that nurses organised their work in reaction to the importance of the tasks and that the patients were not often involved in planning their own care.[38] Support from health professionals that affirms patients'

ability to participate might encourage elderly patients to actually participate.[9] Even minor changes in physicians' behaviour can influence patients' ability to participate actively in decision-making and problem-solving.[39] In addition, suitable lighting and a calm environment can have a positive impact on communication with vulnerable patients, so health professionals are urged to be aware of the physical environment.[40] To improve these aspects of care, it is valuable to continually monitor care quality through patient experience surveys.

We observed higher mean scores on both the DICARES-M and NORPEQ in patients who reported the discharge conversation to be useful (table 5). Patients aged ≥80 years are prone to hearing problems, and such impairments might influence the effectiveness of discharge conversations.[36] We do not have other data than high age explaining this finding. However, lower processing of information might also hamper communication, and influence on how helpful patients find the discharge conversation.[41] Hvalvik and Dale[9] found that elderly adults were typically humble and felt grateful for the care system of which they were a part. They often accepted care that was conducted or arranged without their consent. The factors discussed above might explain the relatively high DICARES-M and NORPEQ scores among patients who did not report having a discharge conversation or who felt such conversations to be of little or no help.

Similar to a previous study on the DICARES-M,[23] 24% of the patients in the current study experienced emergency readmission within 30 days after their hospitalisation (table 1). This is nearly double the percentage among 700 000 patients (mean age=78 years) in a large-scale study of hospital readmissions in Canada.[42] However, it is

only four percentage points higher than the 20% found among 11 million beneficiaries of the Medicare Fee-For-Service model (a hospital insurance programme) in the USA.[43] The relatively high emergency readmission rate in the current study might be attributed to differences in how readmission is defined between studies,[44] and the fact that admissions to the hospital in Norway are free of charge.[45] Keller *et al*[46] found that negative experiences appear to influence scores on most communication and information domains. One might assume that emergency readmission influences patients' experience negatively. However, we observed no association between the usefulness of discharge conversation and emergency readmission. This finding corresponds with those of a study by Felix *et al*,[47] wherein two out of three patients who reported satisfying discharge experiences had emergency readmissions. The emergency readmission rate might be influenced by many other factors than the quality of care,[12] and we assume that we have no reason to believe that there are other explanations for emergency readmission than medical conditions and the need for treatment.

The NORPEQ measures overall care quality and was included in the current study due to it has been used as a quality indicator for some years in Norwegian hospitals.[25] In a previous version of DICARES-M, the instrument overlaps with NORPEQ to some degree and shows a moderate correlation.[8] The DICARES-M provides greater nuance because of its three factors and is generally consistent with the NORPEQ. Our findings therefore might solidify the DICARES-M as an appropriate instrument for monitoring discharge quality, which might make it a useful means of examining the effects of interventions aiming to improve the quality of discharge among elderly patients.

Strengths and limitations

A limitation of this study is the low response rate. Non-response is a common challenge in research on patient experiences.[24 48] Possible reasons for the low response rate may relate to sex comorbidity, and age. For example, very old people (>80 years old) are less likely to respond to postal surveys.[49] A low response rate may bias study results because those who respond and those who do not respond to the survey may differ in some systematic way.[50] However, we observed no important differences in the distribution of age, sex, or Charlson Comorbidity Index between the invited patients and the responders. A personal invitation to patients before they left the hospital might have increased the response rate.[8] Furthermore, telephone interviews or holding one-to-one interviews, where trained researchers completed the questionnaire forms could have increased the response rate, particularly among the oldest and most vulnerable patients.[51] However, this was not possible in the current study due to these approaches require relatively considerable consumption of resources. Finally, cost efficiency and acceptability are important aspects of the utility of an instrument,[15] and we choose postal mail which is commonly used as a distribution method in our setting.

Another limitation is that we did not have available data from the patients' medical records on whether or not a discharge conversation actually was completed in the hospital. The results are based on patients' subjective perceptions, and there is a risk of recall bias with respect to that the patients may have forgotten whether or not a discharge conversation took place, and the content of the conversation. Further, there is a possibility that patients could have been readmitted after the index hospitalisation on which they were asked about. The patients' answers could therefore have reflected their readmission rather than the index hospitalisation or have mixed up their experiences among multiple hospital stays. However, test-retest results in a previous version of the DICARES-M showed reasonable results.[8]

This cross-sectional study included data from two hospitals, and the collection and adjustment of comprehensive information on respondents' characteristics, including age, comorbidity, length of stay education, housing status and readmission strengthen the validity of the results.

Another strength is that the survey comprised two brief validated questionnaires. The use of extensive questionnaires can exhaust participants, particularly when the target population is older adults.[52] Finally, the amount of missing data in DICARES-M and NORPEQ, which is often a challenge in clinical studies of elderly patients, was within the acceptable range of missing data.[53]

CONCLUSIONS

In conclusion, reported discharge conversation at the hospital was correlated with positive patient experience measurements indicating the increased quality of hospital discharge care. The reported usefulness of the conversation had a significant association with discharge care quality.

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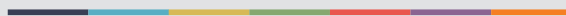
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