Quality and organisation of acute care in internal medicine

QUALITY AND ORGANISATION OF ACUTE CARE IN INTERNAL MEDICINE

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INTRODUCTION

GENERAL INTRODUCTION

To achieve the best possible health outcomes in the population, healthcare must be easily accessible.[1] Given the growing and ageing populations worldwide, there will be an ongoing and increasing demand for acute care services responsive to life-threatening emergencies, acute exacerbation of chronic illnesses and many routine health problems.[2]

Over the last years, Emergency Departments (EDs) and emergency services all over the world have experienced an increased pressure, independent of the differences in organisational structures.[3,4] To deliver and preserve the high-quality and accessibility of acute care, it is important to evaluate the organisational structure of acute care and its impact on the quality. Lessons may be learned by comparing acute care organisations internationally.

Acute care in the Netherlands: setting

Acute care in the Netherlands is provided in primary care by General Practitioners (GPs) and specialists elderly care, and via EDs in secondary care. GPs take their role as a gatekeeper to secondary care. GPs treat patients with urgent primary care needs or decide to refer them to EDs for urgently needed specialized care. During out-of-hours, GPs mostly cooperate on rotation basis to take care of each other's patients in so-called GP-cooperatives (GPCs). To gain access to hospital care, including EDs, patients are required to have a referral from a GP or directly transferred by an ambulance. However, self-referral to an ED still takes place, despite the fact that patients have to pay an initial deductible for secondary care, including ED-visits, until the deductible excess is reached. Of these self-referrals, only 48.1 to 58.8% were deemed appropriate in 2012.[5]

To stimulate and improve collaboration within the acute care chain, the country has been divided into eleven so-called 'Regional Consultation Acute Care Chain' (ROAZ) regions, where healthcare providers representing the acute care chain in the same region are involved in the organisation of the regional acute care chain.[6] However, even within the same region, organisation of this acute care chain may differ locally. For instance, choices in ED staffing is made primarily by the medical staff and the board of directors of the local hospital. Collaboration between GPCs and EDs is locally decided by the GP organisation and the board of directors of the hospital.

During the last few years there is a slight decrease in the total number of ED visits in the Netherlands, but there has been an increase in ED visits by patients >65 years between 2013 and 2016. The number of admissions from the ED increased with 2,3% between 2013 and 2016.[7] Demographic changes and improved treatment options have led to an increased number of patients with multimorbidity and polypharmacy. In addition, governmental policy changes have forced older persons to stay at home

longer, leading to reduced surveillance. Therefore, simple problems in these patients may go unnoticed for a few days, leading to complex presentations at the ED.

Due to increasing numbers of patients presenting at the ED with a higher age, comorbidity and therefore often a greater case complexity, the speciality called "acute medicine" was launched in 2003 in the United Kingdom.[8] The Netherlands followed this initiative in 2012, by recognising acute medicine as a subspecialty of internal medicine.[9] Acute physicians aim to achieve good and coordinated care within the healthcare chain for multimorbid patients with an acute and complex medical problem.[10] However, even at this moment, the presence and active role of acute physicians at EDs in the Netherlands vary between hospitals.

COVID-19 and the organisation of care

In February 2020, coronavirus disease (COVID-19) was first detected in the Netherlands. Subsequently, the growing number of COVID-19 cases caused an extraordinary pressure on healthcare services and acute care in specific. On the 25th of March, The Netherlands together with France and Italy were the countries experiencing the highest number of cases in Europe.[11] Due to the sudden increased number of moderate to severely ill patients, the capacity in hospitals especially in the South of the Netherlands, was in jeopardy. Efforts were made to double ICU-capacity nationally, reorganise patient flow at the ED and postpone regular, non-urgent care. In order to use bed capacity as efficient as possible, the National Coordinating Centre for Patient Distribution (LCPS) was introduced on the 21st of March 2020 commissioned by the Ministry of Health.[12]

The presence of COVID-19 requires adaptation of the organisation of both acute and non-urgent care. Resilience of the healthcare system becomes increasingly important in order to provide the requested care, COVID or non-COVID related.[13] In the Netherlands, the principal of the right care at the right time in the right place, remains the key.[14] Insight in regional (and perhaps national) capacity of the healthcare chain, increasing usage of digital health and financial possibilities to establish regional collaboration in networks, is essential.[13,15] However, at this moment, it is not clear how the organisation of care, and acute care in particular, will change.

Healthcare quality

Healthcare quality is a term used in a broad sense. More than 50 years ago, in 1966, Donabedian proposed using the triad of structure, process and outcome to assess the quality of health care.[16] He determined 'structure' by the setting and resources in which health care delivery takes place, 'process' by the components involved in correctly delivering healthcare and 'outcome' in terms of recovery, survival and restoration of function. In addition, he emphasized the need for valid

and reliable measures of structure and process that could be linked to outcomes. Moreover, he called for incorporation of, amongst others, prevention, coordination, continuity of care, societal values and the patient-physician relationship in quality measurement. This framework functioned as the foundation of an influential report made by the Institute of Medicine, in which quality of care was defined as 'the degree to which health services for individuals and populations increase the likelihood of desired health outcomes and are consistent with current professional knowledge'.[17] Subsequently, in 2001, the IoM reported 6 core dimensions for the improvement of the health care quality in the 21st century: safety, effectiveness, patient-centeredness, timeliness, efficiency, and equitability.[18] Currently, quality measurement in healthcare is founded on these dimensions.

Quality measurement

Quality measurement is often performed using quality indicators. These indicators are classified in process -, structure – and outcome indicators. In the Netherlands, quality of hospital care is assessed by 23 institutions, together responsible for gathering of 3026 variables.[19] For instance, the Inspectorate of Health care and Youth (IGJ) developed in collaboration with the professional scientific associations the basis set 'medical specialised care' which is mandatory to provide each year. Using these data, the IGJ aims to improve quality of hospital care and monitor quality by benchmarking. For 2019, the mandatory basis set consisted of 237 variables.[20] In addition, the Dutch Healthcare Institute gathers 41% of all variables for the so called 'transparency calendar'. Furthermore, the registrations of the Dutch Institute for Clinical Auditing are accountable for 20% of all variables and patient associations for 9%.[19] Data of all these registries are primarily used to improve the quality of care. Secondary goals are to guarantee patient safety, innovation of care, transparency, organising care and reduce costs.[21]

Despite of the overlapping goals, the mentioned quality registries have some important flaws. Firstly, of all the gathered variables, only 9% are outcome measures. In addition, correction for case-mix is only performed in 4% of the variables, which leads to problems in interpretation of outcomes and comparison of performance.[19] Secondly, the delivery and extraction of data is associated with an administrative burden and costs.[19,22] Even more, since many variables are double requested by different organisations. Lastly, the patient perspective is barely incorporated in quality measurements.[21,23] Therefore, the use of Patient Reported Outcomes Measures (PROMs) or Patient Reported Experience Measures (PREMs) may be beneficial to improve the societal relevance of these quality registries.[21]

At this time, evaluation of the quality of acute care is disease oriented. The most well-known quality measures in acute care concern recognising sepsis and timely

administration of antibiotics in these patients and time to treatment in acute ischemic cerebrovascular accident patients.[24,25] However, most patients in acute medical care do not present themselves with a diagnosis, but with a complaint. Therefore, there is a need to evaluate the performance of acute care in a more generic way. In addition, in order to be able to compare the performance, both patient characteristics as organisation of the acute care chain should be insightful, as these may vary per hospital and can influence the acute care performance. Hence, quality measurement in acute medical care is a challenge and should aim to include performance outcomes for a heterogeneous population with incorporation of case-mix variables, structure indicators regarding the organisation of acute care and patient perspectives.

Aims of this thesis

- To investigate the organisation of acute medical care in The Netherlands in detail;
- To identify lessons to be learned from the British organisation of acute care;
- To explore relevant outcomes of acute medical care in patients presenting at the ED;
- To develop generic Patient Reported Measures in acute medical care for patients presenting at the ED;
- To recognise important values and desires of acutely admitted patients internationally;
- To evaluate and improve the quality of acute care by establishing a national quality registry.

Outline of the thesis

This thesis contains studies that investigate the organisation and quality of the acute medical care. This thesis is divided into three parts.

The first part consists of **chapter 2 and 3**, focussing on the organisation of acute medical care. In **chapter 2** we describe the results of a nationwide questionnaire-based study performed to investigate the organisation of the Dutch acute medical care in detail. In addition, we explore the differences in the role an responsibilities of acute physicians and Emergency Physicians in the Netherlands. In **chapter 3** we identify similarities and differences in the organisation of acute care in the United Kingdom and The Netherlands, aiming to learn from each other's experiences and improve the quality of acute care.

In the second part of this thesis, including **chapter 4 to 7**, we are interested in evaluating the quality of acute care from the patients' perspective. In **chapter 4** we provide an overview of patient reported outcome measures (PROMs) in acute care settings, assess their psychometric properties and provide recommendations

for their use in daily practice. In **chapter 5** we identify relevant outcomes of acute care for patients presenting at the ED. In **chapter 6** we develop Patient Reported Measures of acute medical care, aiming to evaluate and improve acute medical care from a patient's perspective. In **chapter 7** we inventory what matters most to acutely admitted patients internationally, aiming to discover common values for further directions in improving patient-centred care.

The third part of this thesis focusses on evaluating the quality of acute care nationally. In **chapter 8** we make a start in evaluating the quality of acute care on a regular basis by establishing a quality registry, taking into account organisational factors, with the ultimate aim to improve the quality of acute care.

REFERENCES

1. Milliman M. Access to health care in America. Institute of Medicine (US) Committee on Monitoring Access to Personal Health Care. National Academies Press. 1993.
2. Hirshon JM, Risko N, Calvello EJ, Stewart de Ramirez S, Narayan M, Theodosis C, et al. Health systems and services: the role of acute care. Bull World Health Organ. 2013;91(5):386-8.
3. Di Somma S, Paladino L, Vaughan L, Lalle I, Magrini L, Magnanti M. Overcrowding in emergency department: an international issue. Intern Emerg Med. 2015;10(2):171-5.
4. Morley C, Unwin M, Peterson GM, Stankovich J, Kinsman L. Emergency department crowding: A systematic review of causes, consequences and solutions. PLoS One. 2018;13(8):e0203316.
5. Kraaijvanger N, Rijpsma D, van Leeuwen H, van Dijk N, Edwards M. Self-referrals in a Dutch Emergency Department: how appropriate are they? Eur J Emerg Med. 2016;23(3):194-202.
6. Netwerk Acute Zorg Limburg. Taken ROAZ https://www.nazl.nl/taken-roaz2021 [accessed: April 2021]
7. Nederlandse zorgautoriteit. Marktscan acute zorg 2017. https://puc.overheid.nl/nza/doc/PUC_3650_22/1/; 2017. Contract No.: PUC_3650_22.
8. Dowdle JR. Acute medicine: past, present, and future. Emerg Med J. 2004;21(6):652-3.
9. Centraal College Medische Specialismen. Besluit interne geneeskunde. Netherlands: https://www.knmg.nl; 2010.
10. Nederlandse Vereniging voor Internisten Acute Geneeskunde. Visie https://www.acuteinternisten.nl/visiedocument/#: NVIAG; 2019
11. Verelst F, Kuylen E, Beutels P. Indications for healthcare surge capacity in European countries facing an exponential increase in coronavirus disease (COVID-19) cases, March 2020. Euro Surveill. 2020;25(13).
12. Landelijk Coördinatiepunt Patiënten Spreiding. Over Ons https://lcps.nu/over-ons/2020 [accessed: April 2021]
13. van Poucke A, Fitzgerald E. COVID-19: Recovery and resilience in healthcare https://home.kpmg/xx/en/home/industries/healthcare/covid-19-and-healthcare/covid-19-recovery-and-resilience-healthcare.html2020 [
14. Ministerie van Volksgezondheid Welzijn en Sport. Over ons https://www.dejuistezorgopdejuisteplek.nl/over-ons/2021 [accessed: March 2021]
15. Federatie Medisch Specialisten. Medisch Specialist 2025. Federatie Medisch Specialisten; 2017.
16. Ayanian JZ, Markel H. Donabedian's Lasting Framework for Health Care Quality. N Engl J Med. 2016;375(3):205-7.
17. Harris-Wehling J. Defining Quality of Care. In: Lohr KN, editor. Medicare: A Strategy for Quality Assurance: VOLUME II Sources and Methods. Washington (DC)1990.
18. Institute of Medicine. Crossing the Quality Chasm: A New Health System for the 21st Century. Washington (DC)2001.

19. Ikkersheim D, Wittgen H, Thijssing L. Inzicht in uitgevraagde variabelen voor kwaliteitsmetingen en handvatten voor verbetering. https://www.iqhealthcare.nl/media/124439/rapportage-inzicht-in-kwaliteitsindicatoren.pdf: KPMG Plexus; 2016.
20. Inspectie voor Gezondheidszorg en Jeugd. Bassisset medisch specialistische zorg kwaliteitsindicatoren 2019. https://www.igj.nl/publicaties/indicatorensets/2018/08/02/basisset-medisch-specialistische-zorg: IGJ; 2018.
21. Kringos DS, Horenberg F, Bal R, Lingsma H, Marang-van de Mheen P, Kievit J. Afwegingen voor de maatschappelijke relevantie van kwaliteitsregistraties. https://nfukwaliteit.nl/pdf/160624_Kringos_et_al_Afwegingen_Maatschappelijk_Relevantie_Kwaliteitsregistraties.pdf: AMC, Erasmus Universiteit, Areasmus MC, LUMC, EMGO+; 2016.
22. van den Hurk J, Bex P. Monitor ervaren regeldruk transparantie medisch specialistische zorg. https://www.zorginstituutnederland.nl/publicaties/rapport/2018/04/19/monitor-ervaren-regeldruk-transparantie-medisch-specialistische-zorg: Zorginstituut Nederland; 2018.
23. Wallenberg I, Mol T, Harmsen M, de Bruijne M. Onderzoek naar risicoselectie met de basisset kwaliteitsindicatoren ziekenhuizen: op weg naar verantwoorde keuzes. www.igj.nl; 2019.
24. NVSHA. Kwaliteitsindicatoren-uitvraag NVSHA 2019. https://www.nvsha.nl/files/5132/Kwaliteitsindicatoren%20NVSHA%202019.pdf; 2019.
25. LNAZ, Nivel, Argo. Indicatorensets ketenbrede kwaliteitsindicatoren acute zorg. https://www.nivel.nl/sites/default/files/bestanden/Ketenbrede-Kwaliteitsindicatorensets-Acute-Zorg.pdf?: Nivel; 2013.

PART I

ORGANISATION OF ACUTE MEDICAL CARE

ORGANISATION OF INTERNAL MEDICINE IN ACUTE CARE IN THE NETHERLANDS: A DETAILED OVERVIEW

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ABSTRACT

Background

Organisation of the emergency department (ED) is gaining attention due to an increased demand on emergency services, leading to crowding and influencing the quality of care. It is known that the organisation of acute care influences the performance of the ED. In the Netherlands, the organisation of EDs differs between hospitals. However, detailed information about the various organisational structures is lacking. This study aims to determine the organisational structures and the different roles and responsibilities of internists and emergency physicians (EPs) in the EDs.

Methods

We performed a nationwide observational study between January 2018 and February 2019. All hospitals with an ED in the Netherlands were identified, contacted, and surveyed. Requested information was retrieved from internists and complemented with local administrative hospital data.

Results

76 out of 89 EDs responded to the questionnaire (84%); 93% of EDs were operational 24/7. A registered acute internist was present at 47 locations (62%) and an EP at 60 EDs (79%). At 10 locations (13.2%), internists reported not being physically present at the ED. Supervision and working agreements between EPs and internists differed between the hospitals. Collaboration between EPs and internists was graded satisfactory (7.4/10).

Conclusion

This is the first study providing a detailed overview of the ED organisation in the Netherlands regarding internal medicine patients. This organisation differs in terms of staffing, presence of EPs and internists, and working agreements. The influence of the various organisational structures of EDs on quality of acute care should be the subject of future research.

INTRODUCTION

The demand on the health care systems and the emergency department in particular, is increasing.[1,2] This leads to crowding and queuing, negatively influencing the quality of care.[3] It manifests as long lengths of stay in EDs, adverse clinical outcomes, and poor patient experience.[3-5] Over the last years, it has been stated that this could impede the accessibility of the acute care, locally and internationally.[4,6,7]

For several years, there has been ongoing discussion about the reorganisation of the acute care system in the Netherlands, creating disagreement between hospital organisations and health insurers.[8] Many reports have been published on this topic, aiming to gain insight into the use and accessibility of Dutch emergency care.[1,9-13] Factors such as patient flow, healthcare costs, and predicted future demographic changes are subjects of these reports and are used in decision making processes by policymakers. Key issues for shaping the acute landscape with intended preservation of quality are, for example, centralisation of complex care and the presence of a doctor in the ED with at least one year of working experience.[14] However, organisation of emergency care for acute medical patients and of EDs especially, differs between hospitals, mainly in number of physicians, the presence of (supervising) internists in the ED, working agreements between internists and emergency physicians (EP), the presence of an Acute Medical Unit (AMU) and collaboration with the general practitioner out-of-hours services, known as General Practitioner Cooperatives (GPC).[15-17] Insight into similarities or differences of these characteristics and eventually their influence on patient outcomes would help to make well-founded choices in reshaping the acute care chain for acute medical patients.

It is known that the organisation of the acute care chain may influence the quality of delivered care and performance of the ED.[18] Internal factors such as staffing, number of patients, and number of treatment bays, and external factors such as demographics and underlying financial resources, have already been identified as having an influence on ED performance.[19] Moreover, these factors will also complicate evaluation and comparison of ED performance. In addition, many acute medical patients, especially the elderly, have multimorbidity or polypharmacy and present themselves to the ED with undifferentiated problems which makes it challenging to differentiate between the influence of internal factors of the ED and patient-related factors on outcomes. Given the complexity of this patient group increasingly presenting in the acute care chain, the Netherlands Association of Internal Medicine has stated in their strategic vision that internists should play a coordinating role in the acute care of patients with multimorbidity and polypharmacy.[20] Yet, an important subject in order to improve the quality of acute care, is identifying potential actors on performance and outcomes of the local hospital organisation, such as the physical

presence of internists in the ED. Therefore, it is important to create a sufficient overview of ED care, focusing on (acute) internal medicine, in the Netherlands.

When investigating the influence of organisation on patient outcomes, it is essential to first evaluate the organisation, including staffing and working arrangements between EPs and internists. We believe that this detailed overview is necessary for creating a foundation for scientific research nationally and also internationally. In addition, this will also make comparisons between care for acute medical patients in the Netherlands and internationally more insightful. Finally, we will reflect on the public discussion regarding acute care and formulate critical notes for future organisational models based on this overview, aiming to improve the quality of care for acute medical patients.

METHODS

Design

We performed a nationwide observational study, identifying the organisational structure of EDs in the Netherlands. All hospitals with an ED in the Netherlands were identified in January 2018. At the start of the study, we identified 91 EDs within 76 hospital organisations and 89 EDs at the end of the study (February 1st, 2019) due to the closure of two hospitals. An acute internist, if present, or a consultant internal medicine physician with an affinity for acute care, was contacted by e-mail to participate in the study and an online questionnaire was distributed (using Qualtrics XM, U.S.A.). In addition, administrative hospital data of patient numbers between January 1st, 2013 and December 31st, 2017 in a predefined format (supplementary data) were collected. The total number of patients visiting the ED, the number of patients older than 65 years, the number of patients visiting the ED for internal medicine, and admissions for internal medicine were requested. The results of the questionnaire including patient numbers, were directly transferred to the study database in SPSS Statistics 25.0 for Windows. The study period of the online questionnaire was between January 2018 and February 2019. Reminders were sent every 2-3 months by e-mail, to all identified physicians at the beginning of the study. Three researchers (MK, HH, PN) contacted the invited physicians who did not respond to the questionnaire by telephone. This was done in December 2018 and January 2019, in an ultimate effort to collect as much data as possible. No effort was made to retrieve missing data. A full overview of definitions used in the questionnaire is provided in appendix 1. Words that are associated with a definition in the appendix are marked with an asterisk (*). Our goal was to obtain participation of at least 66% of all EDs, divided over the country. Participation was voluntary and the study

protocol was approved by the Medical Ethics Committee of Máxima MC (study number N17.122).

Setting

In the Netherlands, 2.4 million ED visits were registered in 2016 and 840,000 (35%) patients were admitted (total country population of 17 million).[1] To gain access to hospital care in the Netherlands, including EDs, patients are required to have a referral from a GP or directly transferred by an ambulance.[15] Self-referral is possible, however a deductible reduction has been introduced to discourage self-referrals.[21] During out-of-hours, GPs in the region cooperate to provide urgent primary care on a rotation basis, taking care of each other's patients in GPCs. This ensures a gatekeeping function of the GP, around the clock. GPCs can collaborate with the local ED, varying between no collaboration to an integrated GPC in the ED.[13] In general, residents of different medical specialties staff the ED in collaboration with residents in emergency medicine, supervised by medical specialists and EPs, depending on the local organisation and working agreements. All residents are qualified doctors who are either in training to become specialists or non-trainees who are working in the hospitals to gain experience with the aim of entering a specialist training programme. Only since 2009, has emergency medicine been recognised as a specialty, however in 2000, the first hospitals started to train EPs aiming to introduce EPs into the ED.[22] Yet, until now, EPs are not fully integrated into every ED. Acute internal medicine has been recognised as subspecialty within internal medicine since 2010.[23] Internists are present in each hospital, whereas acute internists are not.

Statistical analysis

Descriptive statistics were executed using IBM SPSS Statistics 25.0 for Windows. Missing data were categorised as 'missing'.

RESULTS

In total, we gathered data from 76 out of 89 EDs (84%) within 67 hospital organisations of different types (table 1). The EDs were evenly spread over the country as is shown in figure 1. Thirteen EDs (16%) did not respond to the online questionnaire and we were unable to reach an internist at these locations by telephone. Of these, four EDs were located in a teaching hospital* and nine EDs in a general hospital*.

Table 1. Emergency department characteristics, differentiated per hospital type

	Total	University medical centre	Teaching hospital	Non-teaching general hospital
Hospital type	76 (100%)	8 (10.5%)	31 (40.8%)	37 (48.7%)
Opening hours				
24/7	72 (94.7%)	8 (100%)	30 (96.8%)	34 (91.9%)
Closed during night time	1 (1.3%)	0	0	1 (2.7%)
Closed during weekends and night time	1 (1.3%)	0	0	1 (2.7%)
Other (undefined)	(2.6%)	0	1 (3.2%)	1 (2.7%)
Acute Medical Unit				
Present	39 (51.3%)	4 (50.0%)	21 (67.7%)	16 (43.2%)
Absent	29 (38.2%)	4 (50.0%)	9 (29.0%)	20 (54.1%)
Missing	2 (2.6%)	0	1 (3.2%)	1 (2.7%)
Cardiac Emergency Department				
Present	47 (61.8%)	6 (75.0%)	20 (64.5%)	21 (56.8%)
Absent	17 (22.4%)	2 (25.0%)	6 (19.4%)	9 (24.3%)
Missing	12 (15.8%)	0	5 (16.1%)	7 (18.9%)
Collaboration with the GP out-of-hours services[17]				
No collaboration	4 (5.3%)	2 (25.0%)	0	2 (5.4%)
GP out-of-hours service located outside the hospital	6 (7.9%)	1 (12.5%)	2 (6.5%)	3 (8.1%)
Co-located (parallel)				
Shared entrance (serial)	14 (18.4%)	3 (37.5%)	1 (3.2%)	10 (27.0%)
Integrated	28 (36.8%)	0	14 (45.2%)	14 (37.8%)
Missing	19 (25.0%)	2 (25.0%)	10 (32.3%)	7 (18.9%)
	5 (6.6%)	0	4 (12.9%)	1 (2.7%)

GP = general practitioner

Figure 1. Participating emergency departments marked per hospital type

Yellow: University medical centre
Green: Teaching hospital
Blue: General hospital

ED CHARACTERISTICS

From a total of 76 EDs, 72 were operational full time (24/7). The remaining four EDs were closed during the night or reported another (undefined) schedule, as is shown in table 1. At 47 EDs (62%), a separate cardiac ED was present; 17 EDs did not have a separate cardiac ED and 12 EDs did not mention their organisation for acute cardiac patients. The type of collaboration between EDs and the GPC is shown in table 1. A GPC serial* to the ED or integrated* within the ED were the most frequently reported types of collaboration. The presence of EPs or internists in the ED was not associated with the type of collaboration with the GPC (Fisher's Exact Test: 11.08; p = 0.47, respectively 19.27, p = 0.13).

An AMU* was present at 39 locations (51%), not present at 29 locations (38%), and 8 locations (11%) did not report if an AMU was present. At locations equipped with an AMU, an acute internist was present* in 72% of these locations, while at locations without an AMU, an acute internist was only present at 55% of these locations.

Patient numbers

Between 2013 and 2017, 41 EDs reported numbers of patients visiting the ED. Of these, eight EDs did not provide numbers beyond 2016. Patient numbers were collected from eight EDs located in university medical centres*, 18 in teaching hospitals*, and 15 in general hospitals*. Since 2013, there has been a decrease in the total number of patients visiting the ED. In 2013, on average 22,359 patients (range: 7,857-42,488) visited the ED compared to 20,818 patients (range: 7,775-42,488) in 2017. This is a decrease of 6.9%. The number of patients ≥ 65 years has increased over the years by 7.3%. In 2013, 6,699 patients (range 3,685-10,245) older than 65 years visited the ED and 7,230 (range: 3,404-13,389) in 2017. EDs located in university medical centres and teaching hospitals are similar in the total number of patients visiting the ED (± 23,500 on average in 2017), while EDs in general hospitals had fewer ED visits (± 16,500 on average in 2017).

The number of patients presenting for internal medicine increased slightly from 2013 to 2016, but showed a decrease in 2017. In 2013, 3,824 patients (range: 1,227-10,403) presented to the ED for internal medicine, compared to 4,343 patients (range: 1,418-29,426) in 2016 and 3,855 patients (range: 1,505-20,832) in 2017. This decrease is only visible in EDs in general and teaching hospitals, while university medical centres showed an increase of patients presenting to the ED for internal medicine. In addition, there is a slight overall decrease in the number of patients ≥ 65 years presenting for internal medicine, but only between 2016 and 2017. The percentage of patients ≥ 65 years presenting for internal medicine, as part of the total number of patients ≥ 65 years visiting the ED, has also decreased over the last years (figure 2).

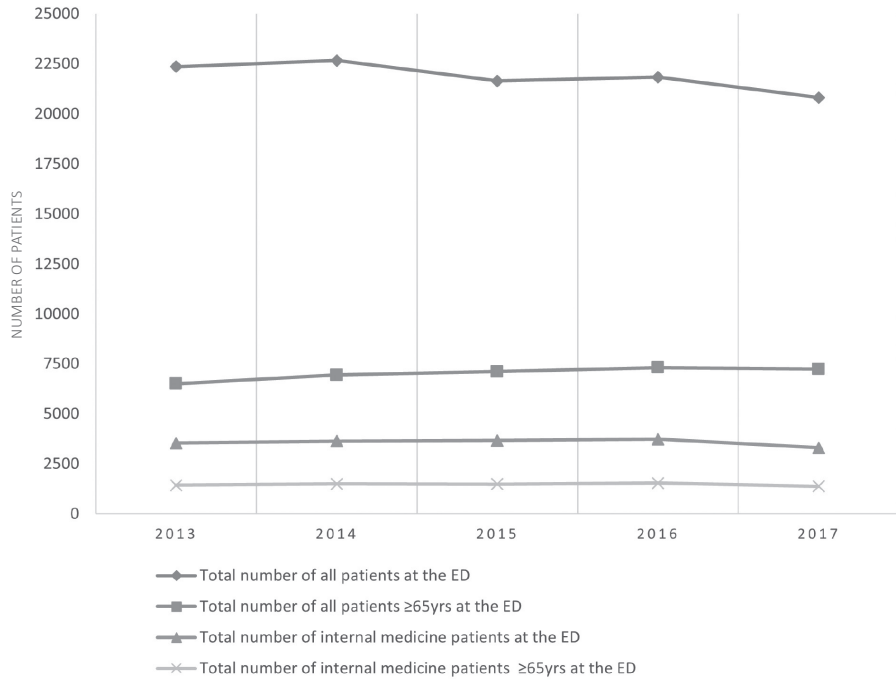

Figure 2. Mean number of patients visiting the ED per year between 2013 and 2017

ED = emergency department

ED Staffing

EPs were present in 60 EDs (79%), of which there were EPs 24/7 in 32 EDs (46%). If EPs were not present 24/7, they were mostly absent during night hours or had another (undefined) working schedule (table 2).

Table 2. Staffing and presence of internal medicine residents, internists, and EPs in the ED

	Total	University Medical Centre	Teaching Hospital	General hospital
Presence of internal medicine residents in the ED				
Only residents in training	2 (2.6%)	2 (25.0%)	0	0
Only residents not in training	12 (15.8%)	0	1 (3.2%)	11 (29.7%)
Both residents not in training/in training	51 (67.1%)	6 (75.0%)	30 (96.8%)	15 (40.5%)
No residents	11 (14.5%)	0	0	11 (29.7%)
Presence of any internist in the ED				
Not present	10 (13.2%)	0	2 (6.5%)	8 (21.6%)
Present during office-hours	38 (50.0%)	4 (50.0%)	14 (41.2%)	20 (54.1%)
Present during office-hours and evenings	9 (11.8%)	3 (37.5%)	5 (16.1%)	1 (2.7%)
On call during office hours	17 (22.4%)	1 (12.5%)	9 (29.0%)	7 (18.9%)
Other	2 (2.6%)	0	1 (3.2%)	1 (2.7%)
Presence of the EP in the ED				
Absent	16 (21.1%)	2 (25.0%)	4 (12.9%)	10 (27.0%)
24/7 present	32 (42.1%)	4 (50.0%)	13 (41.9%)	15 (40.5%)
Present during office hours and evenings	22 (28.9%)	2 (25.0%)	11 (35.5%)	9 (24.3%)
Other	6 (7.9%)	0	3 (9.7%)	3 (8.1%)

ED = emergency department; EP = emergency physician

At 51 locations (67%), a registered acute internist is employed. Absence of a registered acute internist was most common in general hospitals*: 68% absence versus 32% in teaching hospitals* and 0% in university medical centres*. While internists are employed and present in all hospitals, their presence* in the ED differs: at 10 locations (13.2%) internists reported not being able to present in the ED for supervision because of other tasks at the same time. In 17 EDs (22.4%%), the internist is on call, without a working place near the ED, and therefore may or may not be present when a patient arrives. In 9 EDs (11.8%), the internist was physically present at least during

office hours and evenings in the ED. In absence of an EP, the internist is more often present in the ED during office hours [11 out of 16 EDs (68.8%)], compared to EDs with 24/7 coverage of EPs [18 out of 31 EDs (58.1%)].

Internal medicine residents treat patients for internal medicine in 65 EDs (86%), as shown in table 2. In 11 EDs (14%), all located in a general hospital, there are no internal medicine residents treating patients in the ED. Patients in these hospitals are treated by emergency care residents, EPs, or internists. However, in the majority of university medical centres and teaching hospitals (92%), patients are seen by residents in training as well as residents not in training. Residents in training are present in 15 EDs in general hospitals (48%), while residents not in training are present in 26 EDs (84%). Supervision is provided by internists and/or EPs.

Roles and responsibilities

Internists reported having various roles in the ED: 68 internists (89.5%) were practitioners*, 57 consultants* (75.0%), 22 coordinators* (28.9%), and 15 managers

(19.7%); 3 internists did not report their role. In addition, 6 internists (7.9%) mentioned other roles, such as supervisor and trainer. Internists working in a university medical centre seemed to be more frequently a coordinator and manager in comparison with internists in teaching or general hospitals. Furthermore, the presence of an acute internist was associated with reporting these coordinating and managing roles frequently. In hospitals where EPs were not present, internists more often reported a role as practitioner compared to hospitals where no EPs were present (100% vs. 87.1%) and consultant (93.8% vs. 64.5%).

We assessed working agreements between internists and EPs by taking inventory of who was in the lead during the initial care* of medical, haemodynamically instable patients. These arrangements were different for referred* and not referred* patients. In general, the initial care of referred patients is led by the internist (39%) or internal medicine resident (46%). Non-referred patients are most often treated by the EP (60%), if present. Secondly, we assessed supervision agreements. Patients who were referred and assessed by residents were supervised by internists at 71.1% of the EDs, by an internal medicine fellow* at 7.9% of the EDs, and by EPs at 14.5% of the EDs. Fourteen EDs (18.4%) did not report their supervision agreements. Supervision of residents treating non-referred patients is equally divided between EPs and internists. Furthermore, EPs must contact the internist to admit acute medical patients at all of the 47 responding EDs. Discharging patients directly from the ED without contacting the internist is only acceptable in cases of non-referred patients at 18 of the 36 responding EDs (50.0%).

Lastly, internists graded the collaboration with EPs in the ED with a mean of 7.4 out of 10 (range: 1 to 10). There was no difference in grading in presence or absence of an acute internist. Transparent working agreements, being approachable, and logistic support were mentioned as strengths. Internists experienced variation between EPs in the quality of delivered care, especially in complex multimorbid patients. For example, one internist's opinion, "There's a continuous conflict of domains and EPs have a poor knowledge of internal medicine". In contrast, another internist reported, "We experience a perfect interprofessional collaboration and we make use of each other's expertise". In addition, some internists preferred to be contacted in an earlier stage by the EP for consultation.

DISCUSSION

We provide a detailed overview of the organisation of the Dutch acute care in the ED, focusing on acute internal medicine combined with the roles and presence of EPs. Our study shows that there is a decrease in the number of patients arriving at the ED, while there is an increase in patients of 65 years and older. However, in 2016, there was a slight decrease in patients of 65 years and older presenting to the ED for internal medicine. Furthermore, we identified differences in the presence of (acute) internists and EPs in the ED and a variability in working and supervision agreements. Internists reported their roles at the ED most often as practitioner and consultant. Internists experienced the collaboration with EPs as satisfactory.

We showed that patients 65 years and older are an increasing population in the ED in the Netherlands, which is also an international trend.[2,24] In general, internists are trained to provide complex care to acute patients regarding aging, multimorbidity, and polypharmacy. However, we assessed that patient visits for internal medicine among patients 65 years and older decreased in 2017, which is the contrast with the overall growth of this population in the ED. This decrease remained also present when correcting for missing data. Several reasons may be suggested for this decline, such as older patients encounter problems other than acute illness, or patients are triaged to specific disciplines (i.e., pulmonology, cardiology, or even geriatrics) by EPs. However, this discussion is beyond the scope of this article.

The most notable finding of this study is the number of internists (14%) not physically present in the EDs. In addition, some internists did not identify themselves as a practitioner* (10.5%) nor a consultant* (25%). These statements are a remarkable finding, because both observations are in contrast with the current strategic vision of the Netherlands Association of Internal Medicine, which states that internists should be the central contact for acute medical patients with multimorbidity and

polypharmacy.[20] The literature has not shown best practices on this matter yet, although one Dutch study has shown that the presence of medical specialists, including internists, leads to improved patient flow and satisfaction.[25] In addition, internists are specialised to take care of multimorbid patients with polypharmacy.[20,26] Given the increased case complexity of acute patients presenting to the ED due to multimorbidity and polypharmacy, internists can play a central role in the care for these patients.[27,28] In addition, most patients suffer from an acute deterioration of a chronic disease. These patients need a specialist with knowledge of the disease course prior to the ED visit, diagnostic and treatment possibilities considering comorbidities and medication use, and coordination of follow-up. As acute care needs teamwork, EPs can play an important role in the initial care of acute medical patients. It has been shown that activities in the patient care process and patient flow differ between internists and EPs, which may suggest that internists and EPs could be complementary to each other.[29] However, in this study, we found signs of suboptimal interprofessional collaboration between EPs and internists in some hospitals. A qualitative study about interprofessional collaboration between internists and EPs as well as a quantitative study on outcomes, could provide useful insight in this subject and the effects on quality of care.

We showed many organisational and staffing differences between different EDs across the Netherlands, such as the presence of internists at the ED, variability in working agreements in initial care* of haemodynamically instable patients, and collaboration choices with the GPCs. These data concur with research in the field of acute medical care from, for example, the United Kingdom (UK), which also showed differences in structure and staffing (in this case AMUs) and even more interesting, that patient flow also varies per hospital.[30-32] However, in contrast to the recently developed Dutch quality standards for acute care,[14] it may not be achievable and desirable to pursue one uniform organisation for all EDs in the Netherlands. It has been shown that regional and local external factors are known to influence performance of the ED and differences in organisation could be beneficial, if adapted to the local characteristics.[19,33] In this study, we identified these differences in organisational structure, which should be investigated further in order to evaluate impact on the quality of acute care. The yearly Society for Acute Medicine Benchmarking Audit performed in the UK is an interesting tool which can be used as an example to provide insight into the performance of acute medical care, which also take organisational differences into account.[32] In addition, the identified differences in organisational structure should have a place in the interpretation of scientific research concerning acute care and used as context, assuring benefit of potential changes in treatment or organisation in the local situation.[34] Finally, we would recommend to use this overview to interpret and evaluate international differences in acute care.

Recommendations and future directions

We emphasise further research on the influence of the organisation of acute care on the quality of care, aiming to make well-founded choices in the future organisation of acute medical care, at least in the Netherlands. In order to evaluate these organisational factors, we recommend a national registry for acute medical care including patient outcomes, ED characteristics, and regional organisational characteristics of the acute care chain. In addition, we believe that relevant Patient Reported Outcomes for acute care should be evaluated regularly and incorporated in this registry.[35] Structural measurements of performance in acute medical care could help to make sensible and evidence-based organisational choices.

Secondly, we recommend that internists increase their presence in the ED and availability for ED care, and aim to be the central contact for acute medical patients with multimorbidity and polypharmacy in accordance with the current strategic vision of the Netherlands Association of Internal Medicine.[20] Internists have the knowledge and expertise to treat this specific group, however, we demonstrated that in 2018, their presence was suboptimal in EDs in quite a few hospitals. As case complexity increases, patients deserve specialised care provided by a doctor who is capable of overviewing all problems and able to arrange and provide proper follow-up. Therefore, the presence of internists in the ED and their influence on the quality of care should be investigated further. This observational study could be used as a reference.

Limitations

Unfortunately, we were unable to receive responses from all EDs in the Netherlands. However, we achieved a response rate of 84% by sending reminders and even trying to reach internists by telephone. As the responding EDs were fairly divided over the country and representing university medical centres, teaching hospitals, and general hospitals, we postulate that the selection bias is minimal. Only 41 EDs reported on patient numbers and of these EDs, patient numbers beyond 2016 were not provided by eight EDs. Therefore, interpretation of these data demands some caution.

In addition, due to the use of multiple-choice questions, it was difficult to interpret answers in the local context or identify motives in organisational choices.

CONCLUSION

To our knowledge, this is the first study that provides a detailed overview of ED organisation in the Netherlands regarding internal medicine patients. Our study shows that organisation of ED care for internal medicine patients differs in terms of staffing, presence of EPs and internists and working agreements between EPs and internists. Some of these differences, such as the presence of internal care medicine residents in the ED, seem to depend on the type of hospital.

As it is known that regional and local external factors influence performance of the ED, local and regional differences in the organisation of acute medical care should be taken into account when developing nationwide quality standards for acute care and future research should be used to create a more evidence-based policy. Given the assumed increased case complexity of medical patients, we believe that internists should be the central contact for these patients and therefore should be present frequently at the ED.

REFERENCES

1. Nederlandse Zorgautoriteit. Marktscan acute zorg. 2017 [06-02-2018]. Available from: https://puc.overheid.nl/nza/doc/PUC_3650_22/
2. Baker C. Accident and Emergency Statistics: Demand, Performance and Pressure. 2017 [06-02-2018] Available from: https://commonslibrary.parliament.uk/research-briefings/sn06964/
3. Bernstein SL, Aronsky D, Duseja R, et al. The effect of emergency department crowding on clinically oriented outcomes. Acad Emerg Med. 2009;16(1):1-10.
4. Hoot NR, Aronsky D. Systematic review of emergency department crowding: causes, effects, and solutions. Ann Emerg Med. 2008;52(2):126-36.
5. Guttmann A, Schull MJ, Vermeulen MJ, Stukel TA. Association between waiting times and short term mortality and hospital admission after departure from emergency department: population based cohort study from Ontario, Canada. BMJ. 2011;342:d2983.
6. NOS. Patiëntenstop in de praktijk: op de vluchtstrook wachten op een bed. 2016 [7-3-2020] Available from: [https://nos.nl/artikel/2106802-patientenstop-in-de-praktijk-op-de-vluchtstrook-wachten-op-een-bed.html
7. Chan SS, Cheung NK, Graham CA, Rainer TH. Strategies and solutions to alleviate access block and overcrowding in emergency departments. Hong Kong Med J. 2015;21(4):345-52.
8. Baier N, Geissler A, Bech M, et al. Emergency and urgent care systems in Australia, Denmark, England, France, Germany and the Netherlands - Analyzing organization, payment and reforms. Health Policy. 2019;123(1):1-10.
9. Nederlandse Zorgautoriteit. Monitor Acute zorg. Monitor 2018. 2019 [11-01-2019] Available from: https://puc.overheid.nl/nza/doc/PUC_260889_22/1/
10. NVZ. Acute zorg, er zit meer aan vast dan u denkt! 2013 [15-01-2019] Available from: https://www.saz-ziekenhuizen.nl/wp-content/uploads/2013/09/NVZ-visie-Acute-zorg-Er-zit-meer-aan-vast-dan-u-denkt.pdf
11. Gommer AM, Gijsen R. The validity of the estimates of the national number of visits to Emergency departments on the basis of data from the Injury Surveillance System LIS. RIVM 2016.
12. Winkel E, de Kousemaeker G. Onderzoek naar duurzame inrichting spoedzorg keten voor ouderen. Fluent. 2017 18-1-.
13. Gaakeer MI, van den Brand, C L, Gips E, van Lieshout JM, Huijsman R, Veugelers R, et al. National developments in Emergency Departments in the Netherlands: numbers and origins of patients in the period from 2012 to 2015. Ned Tijdschr Geneeskd. 2016;160:D970.
14. LNAZ, Federatie Medisch Specialisten, NVSHA, Patiëntenfederatie Nederland, Ineen, NVZ, et al. Kwaliteitskader Spoedzorgketen. 2019 15-04-.
15. Thijssen WA, Giesen PH, Wensing M. Emergency departments in the Netherlands. Emerg Med J. 2012;29(1):6-9.

16. Thijssen WA, Koetsenruijter J, Giesen P, Wensing M. Emergency departments in the Netherlands: is there a difference in emergency departments with and without emergency physicians? a cross-sectional web-based survey. Int J Emerg Med. 2013;6(1):1-11.
17. Gaakeer MI, Veugelers R, van Lieshout JM, Patka P, Huijsman R. The emergency department landscape in the Netherlands: an exploration of characteristics and hypothesized relationships. Int J Emerg Med. 2018;11(1):3-5.
18. Welch SJ, Augustine JJ, Dong L, Savitz LA, Snow G, James BC. Volume-related differences in emergency department performance. Jt Comm J Qual Patient Saf. 2012;38(9):395-402.
19. Wiler JL, Welch S, Pines J, Schuur J, Jouriles N, Stone-Griffith S. Emergency department performance measures updates: proceedings of the 2014 emergency department benchmarking alliance consensus summit. Acad Emerg Med. 2015;22(5):542-53.
20. Nederlandse Internisten Vereniging. Strategische visie 2018-2022: "Cruciale schakel in de zorg. De internist als regiebehandelaar, nu en in de toekomst." 2018 [14-01-2019] Avaialble from: https://internisten.nl/sites/internisten.nl/files/NIV%20Strategische%20Visie%202018-2022%20def.pdf
21. Kremers MNT, Nanayakkara PWB, Levi M, Bell D, Haak HR. Strengths and weaknesses of the acute care systems in the United Kingdom and the Netherlands: what can we learn from each other? BMC Emerg Med. 2019;19(1):4-y.
22. Gaakeer MI, van den Brand CL, Patka P. Emergency medicine in the Netherlands: a short history provides a solid basis for future challenges. Eur J Emerg Med. 2012;19(3):131-5.
23. Centraal College Medische Specialismen. Besluit interne geneeskunde. 2010 [27-08-2019] Available from: https://www.knmg.nl
24. Statistics Denmark. ED visits by region, age and time. 2019; Available at: https://www.statbank.dk/SKAD02.
25. van der Linden MC, de Beaufort RAY, Meylaerts SAG, van den Brand CL, van der Linden N. The impact of medical specialist staffing on emergency department patient flow and satisfaction. Eur J Emerg Med. 2019;26(1):47-52.
26. NIV. De internist: cruciale schakel in de zorg: Landelijk opleidingsplan. 2019 [29-08-2019]. Available from: https://www.internisten.nl/opleiden-tot-internist/opleiden-tot-internist/opleidingseisen
27. Schouten I. 'Spoedinternist' kan acute zorg versterken. 2013 [30-08-2019]. Available from: https://www.medischcontact.nl/nieuws/laatste-nieuws/artikel/spoedinternist-kan-acute-zorg-versterken.htm
28. De Kruijf E, Arends A. Reactie artikel Volkskrant: 'eisen aan spoedzorg voor ouderen te hoog'. 2019 [18-5-2019]. Available from: https://www.internisten.nl/nieuws/reactie-artikel-volkskrant-%E2%80%9Ceisen-aan-spoedzorg-voor-ouderen-te-hoog%E2%80%9D.
29. Koks DR, Zonderland ME, Heringhaus C. Development of an observational instrument to determine variations in the patient care process and patient flow among emergency physicians and internists at the emergency department. Int J Emerg Med. 2013;6(1):1.
30. Reid LEM, Pretsch U, Jones MC, Lone NI, Weir CJ, Morrison Z. The acute medical unit model: a characterisation based upon the national health service in Scotland. Plos One. 2018;13(10):e0204010

31. Reid LEM, Lone NI, Morrison ZJ, Weir CJ, Jones MC. The provision of seven day multidisciplinary staffing in Scottish acute medical units: a cross-sectional study. QJM. 2018;111(5):295-301.
32. Society for Acute Medicine Benchmarking Audit. SAMBA18 report: a national audit of acute medical care in the UK. 2019 [12-8-2019] Available from: https://www.acutemedicine.org.uk/wp-content/uploads/2019/02/SAMBA18-National-Report.pdf
33. Fanelli S, Ferretti M, Zangrandi A. The impact of regional policies on emergency department management and performance: the case of the regional government of Sicily. Int J Health Plann Manage. 2017;32(1):e83-e98.
34. Raad voor Volksgezondheid en Samenleving, (RVS). Zonder context geen bewijs. 2017 [12-8-2019] Available from: https://www.raadrvs.nl/documenten/publicaties/2017/06/19/zonder-context-geen-bewijs
35. Kremers MNT, Zaalberg T, van den Ende ES, et al. Patient's perspective on improving the quality of acute medical care: determining patient reported outcomes. BMJ Open Qual. 2019;8(3):e00073-000736.

Appendix 1. Definitions per chapter in alphabetic order

ED characteristics

Acute Medical Unit	A dedicated facility within a hospital that acts as the focus for acute medical care for patients who have presented as medical emergencies to the hospital and have to be admitted

Collaboration with GP out-of-hours services[17]

No collaboration	The GP out-of-hours service and ED are located separately. No working agreements are in place.
Located Separately	The GP out-of-hours service and ED are located separately, but there is a form of collaboration (for example, working agreements).
Parallel	The GP out-of-hours service is located at the hospital and has its own reception desk. There is a separate triage procedure for the ED and GP out-of-hours service.
Serial	The GP out-of-hours service is located at the hospital, with the reception desk earlier in line than the EDs. Self-referred patients are encouraged to visit the GP first. There is a separate triage procedure.
Integrated	The GP out-of-hours service and ED share a common reception desk. There is a common triage procedure.
General hospital	A hospital with the aim to provide basic specialised care and treat non-specific populations or diseases. Some of these hospitals provide a part of the training of medical specialists.
Teaching hospital	A hospital providing basic specialised care and complex care in one or more specific areas. A teaching hospital performs research and all hospitals provide (a part of) the training of medical specialists.
University medical centre	A hospital affiliated to a university, aiming to provide high-complex care, perform research and train medical specialists.

ED staffing

Acute internist	An internist trained in acute medicine and registered for the subspecialty acute internal medicine.
Fellow internal medicine	A resident in internal medicine, specialising in a specific subspecialty within internal medicine during the last two years of residency, such as acute medicine.
Presence in the ED	Having a working place at or nearby the ED, facilitating presence in the ED before or during arrival of the patient. The working schedule facilitates timely presence, without having other clinical or teaching tasks at the same time.

Roles and responsibilities

Consultant	A medical specialist, such as an internist, providing consultation of a patient, as requested by another medical specialist.
Coordinator	Any healthcare professional streamlining the patient flow at the ED
Non-referred	Patients arriving at the ED without a referral from the general practitioner, i.e., self-referral or arrival by ambulance.
Practitioner	A medical specialist, such as an internist, primarily accountable for the care of a patient at the ED.
Referred	Patients arriving at the ED with a referral from the general practitioner.
Initial care	Primary care for a patient presenting at the ED with threatened vital functions.

ED = emergency department; GP = general practitioner

STRENGTHS AND WEAKNESSES OF THE ACUTE CARE SYSTEMS IN THE UNITED KINGDOM AND THE NETHERLANDS: WHAT CAN WE LEARN FROM EACH OTHER?

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ABSTRACT

Background

The demand on Emergency Departments and acute medical services is increasing internationally, creating pressure on health systems and negatively influencing the quality of delivered care. Visible consequences of the increased demand on acute services is crowding and queuing. This manifests as delays in the Emergency Departments, adverse clinical outcomes and poor patient experience.

Overview

Despite the similarities in the UK's and Dutch health care systems, such as universal health coverage, there are differences in the number of patients presenting at the Emergency Departments and the burden of crowding between these countries. Given the similarities in funding, this paper explores the similarities and differences in the organisational structure of acute care in the UK and the Netherlands. In the Netherlands, less patients are seen at the ED than in England and the admission rate is higher. GPs and so-called GP-posts serve 24/7 as gatekeepers in acute care, but EDs are heterogeneously organised. In the UK, the acute care system has a number of different access points and the accessibility of GPs seems to be suboptimal. Acute ambulatory care may relieve the pressure from EDs and Acute Medical Units. In both countries the ageing population leads to a changing case mix at the ED with an increased amount of multimorbid patients with polypharmacy, requiring generalistic and multidisciplinary care.

Conclusion

The acute and emergency care in the Netherlands and the UK face similar challenges. We believe that each system has strengths that the other can learn from. The Netherlands may benefit from an acute ambulatory care system and the UK by optimizing the accessibility of GPs 24/7 and improving signposting for urgent care services. In both countries the changing case mix at the ED needs doctors who are superspecialists instead of subspecialists. Finally, to improve the organisation of health care, doctors need to be visible medical leaders and participate in the organisation of care.

BACKGROUND

The demand on Emergency Departments (ED) and acute medical services is increasing internationally, creating pressure on health systems and negatively influencing the quality of delivered care.[1,2,3] Demographic changes and governmental policy changes play an important role in this increasing demand.[4] A direct association between an aging population and increased utilization of emergency services exists.[5] In addition, medical patients presenting at the ED are often characterized by multimorbidity and polypharmacy leading to complex clinical presentations needing more diagnostics and multidisciplinary care.[6]

Visible consequences of the increased demand on acute services are crowding and queuing: a situation wherein the need for emergency services exceeds available resources at the ED or in the hospital.[7] This manifests as delays in the EDs, adverse clinical outcomes and poor patient experience.[3,8] Factors that influence crowding across Europe are an ageing population, improved treatment modalities, limited human and physical hospital resources and delayed ancillary services.[9]

Despite the similarities in the UK's and Dutch health care system, such as universal health coverage, there are differences in the number of patients presenting at the EDs and the burden of crowding between these countries. There are 0.54 EDs per 100,000 people in the Netherlands, compared to 0.33 in England.[10] The amount of available hospital beds per capita in the Netherlands is 2.4/1,000 (in 2015) and 2.6/1,000 in the UK (in 2016).[11,12] Both countries have a comparable level of prosperity and healthcare is funded by a mix of private and public payments. The UK spent 9.9% of their Gross Domestic Product (GDP) on healthcare in 2015, whereas the Netherlands 10.6% of its GDP in the same year (table 1).[13] Given the similarities in funding, this paper explores the similarities and differences in the organisational structures of the acute care systems in these countries, focussing on the acute medical (non-trauma) care, and discuss potential lessons. In addition, we will suggest directions for a future-proof organisation of acute medical care based on integrating the strengths of both systems.

Table 1. Numbers and properties of the Dutch and British acute care systems in 2016.

	The Netherlands	England
Number of EDs per 100,000 people	0.54†	0.33
Hospital beds per 1,000 people	2.4‡	2.6
Percentage of GDP spent on healthcare	10.6‡	9.9‡
Available GPs per 10,000 people	5.8	7.6¥
Number of ED visits per year	2,400,000	15,900,000≠
ED attendance rate	14.1	24.2≠
Number of acute admissions per year	840,000	4,300,000
Acute admission rate	4.9	6.6
Percentage of acute admissions for the total ED visits	35.0	27.0≠

≠Data based on type 1 and 2 Emergency Departments only.
¥ Data retrieved over 2013
† Data retrieved over 2014
‡ Data retrieved over 2015

The Dutch system

Acute care in the Netherlands is mainly provided by general practitioners (GP) and via EDs (figure 1). GPs take care of patients with urgent primary care needs, while EDs provide care for patients who urgently need specialized care. There were 5.8 GPs available for a population of 10,000 in 2016.[14] To gain access to hospital care, including EDs, patients are required to have a referral from a GP or directly transferred by an ambulance. However, some patients still attend the ED directly, despite the fact that patients have to pay an initial deductible for self-referral to the ED. Interestingly, the introduction of the deductible resulted in a substantial reduction of self-referrals. Care provided by the GP or out-of-hours GP services is covered by compulsory health insurance without an initial deductible.

During out-of-hours, GPs mostly cooperate to provide urgent primary care on rotation basis, taking care of each other's patients in so-called GP-posts. This ensures the gatekeeping function of the GP 24/7. A GP-post can be reached out-of-hours by phone, upon which a nurse under supervision of a GP will carry out triage using the Dutch Triage Standard.[15]

In 2016 in the Netherlands 2.4 million ED visits took place for a population of 17 million. This means an attendance rate of 14%. 840,000 patients were admitted, which is 35% of all patients visiting the ED and 4.9% of the population.[1] Fifty-six percent of the patients were referred to the ED via a GP and 23% was self-referred.

The remaining 21% was presented at the ED by ambulances via emergency calls.[1] One organisational innovation to improve inappropriate use of the ED is a collaboration between GPs and EDs: an Emergency Care Access Point (ECAP). GPs and EDs both have their own departments, while sharing the same entrance and joint triage by a nurse. In this situation, 75% of the self-referred patients are seen by a GP, which is safe and cost-effective.[16] However, ECAPs are only present in 22% of all Dutch EDs.[1]

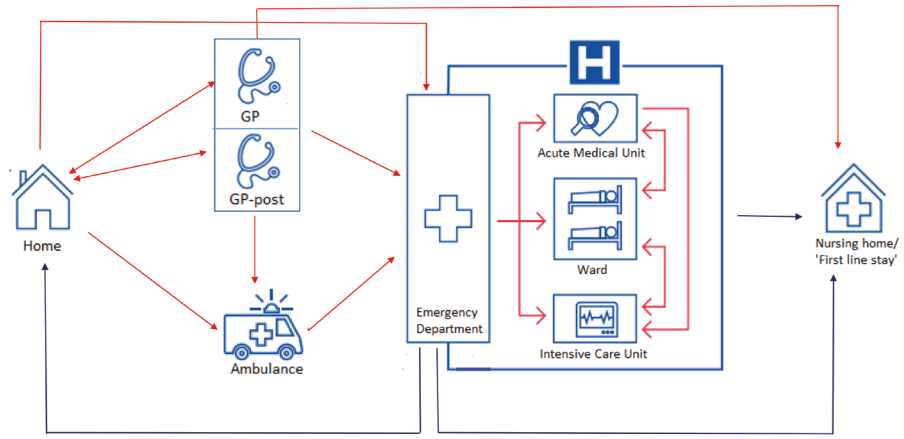

Figure 1. The acute care chain in the Netherlands. (Adapted with permission from design by LS van Galen for her thesis "Patient Safety in the Acute Healthcare Chain: is it safer@home?")

Instead of referring a patient to the ED, GPs can also refer patients needing admission due to medical or social reasons, but not in need for specialized care, to a so called 'first line stay'. This is a medical institution runned by GPs or elderly care physicians, providing care for a maximum duration of 3 months. These 'first line stays' may prevent unnecessary ED visits, especially in elderly patients, which is needed for a sustainable acute care system taking the increased demand of ED services by patients >65 years into account. Since the 1st of April 2018 regional coordination points for first line care have been introduced, aiming for more efficient bed management by providing 24/7 insight in available beds. However, in September 2018 GPs mentioned that only in 21% of all cases they were able to find a first line bed on the same day of presentation. On top of that, GPs still experience difficulties in obtaining information about the available beds, especially during out-of-hours shifts.[17] As a consequence, many low-complex patients are still being admitted to the hospital via the ED. Of all patients >65 years presenting at the ED in 2017, 17% could have received the needed care at a first line stay facility.[18]

In the Netherlands, the staffing of the EDs is heterogeneously organized: emergency physicians are not present in every hospital, nevertheless their role as coordinators of care in many EDs is increasing. Historically, residents of different medical specialties staff the ED in collaboration with residents in emergency medicine. They are fully qualified doctors who either are in training to become specialists or non-trainees who are working in the hospitals to gain experience with the aim of entering a specialist training programme later. Residents are remotely supervised by consultants, such as internists and surgeons. Only since 2009 emergency medicine was recognized as a specialty. While acute physicians are increasingly present at the ED, consultants from other specialties are rarely present at the ED. The quite inexperienced residents in these specialities are taking care of the patients with complex problems. Although ED physicians can see these patients initially and stabilize them, multidisciplinary teams with more specific expertise are needed to treat complex patients presenting at the ED.

During the last few years there's a slight decrease in the total number of ED visits, but there has been a 14% increase in ED visits by patients >65 years between 2013 and 2016. However, the percentage of people >65 years in the population increased from 16,8% in 2013 to 18,2% in 2016, which is only an 8% increase.[1,19] The number of admissions from the ED increased from 33,2% in 2013 to 35,5% in 2016.[1] The governmental policy changes have forced elderly patients to stay at home longer, leading to reduced surveillance. A simple problem in these patients therefore may go undetected for a few days leading to complex presentations.

From the ED, patients can be admitted to an Acute Medical Unit (AMU), in general for up to 72 hours, or a medical ward. AMUs in the Netherlands are often used by medical as well as surgical specialities. Although possible, it is uncommon to admit patients directly from the outpatient department at the AMU.

The British system

In the UK the National Health Service (NHS) is responsible for providing acute and emergency care. The organisation of the acute care chain differs between the four UK nations in terms of structure, but from a patient perspective is broadly similar.

In England, acute care has a number of different access points (figure 2), which may vary across the different regions. EDs are located within hospitals and the level of service varies: type 1 EDs are major EDs that provide a consultant-led 24-hour service with full facilities for resuscitating patients and type 2 EDs are consultant-led facilities but for single specialities. Besides EDs, type 3 departments such as Walk in Centres (WiC), Minor Injury Units (MIU) and Urgent Care Centres (UCC) provide urgent care, treating at least minor injuries or illnesses. These centres are co-located with an

ED or sited in the community and can be accessed without an appointment. For completeness in the description of the acute care, Major Trauma Centres function as hubs within a trauma network, mostly placed in larger hospitals. As our analysis focuses only on acute medical care, we have decided to exclude these centres from our overview.

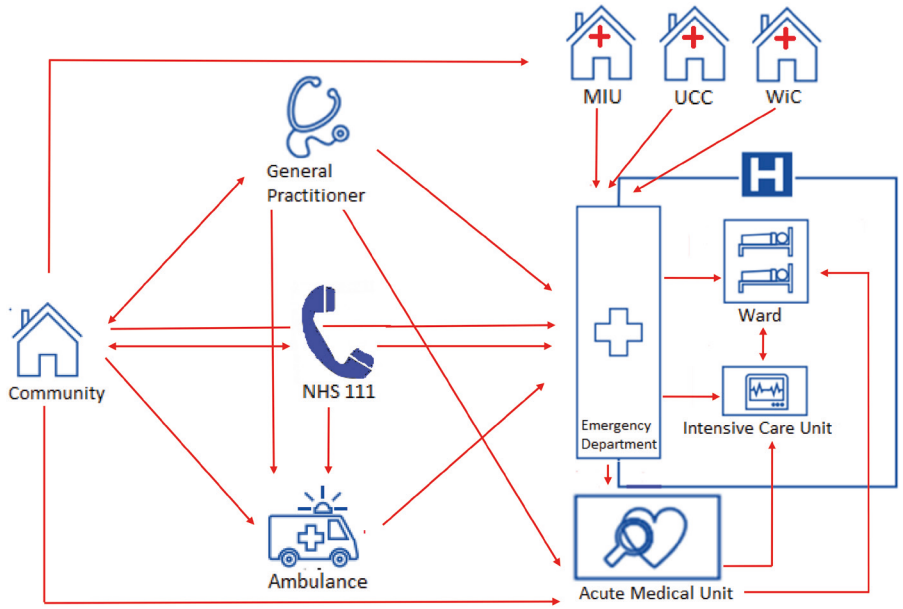

Figure 2. The acute care chain in the UK.

Aiming to guide patients through this system, the NHS provides a telephonic helpline staffed by trained advisers (NHS 111). Depending on the level of perceived urgency these advisors may suggests several alternatives, ranging from self-care to a referral or even sending an ambulance.

In England, there were 7.6 GPs available for a population of 10,000 in 2013.[20] GPs provide urgent care as well, however the accessibility of GP services, particularly out-of-hours and weekend is suboptimal. The most recent NHS GP patient survey showed that 11% of all participants reported not being able to get a timely appointment with their GP.[21] In addition, one publication suggests that a quarter of all self-referred ED visits is due to an unsuccessful attempt to obtain a convenient GP appointment.[22]

At the ED several triage models are in place, differing amongst the UK countries, from which the majority using nurse practitioners to assess patients as they arrive and

some of them co-locate GPs at the front door of EDs. Most ED care is provided by emergency physicians and they can decide to admit a patient. Experienced specialty consultants rarely treat patients at the ED.

In 2016 in total 23.4 million ED visits took place in England, of which 32% in type 3 departments. 15.9 million ED visits took place in type 1 and 2 departments, for a population size of 65.6 million, resulting in a 24.2% attendance rate. Since 2007 the ED visits have shown a 2.3% increase per year, while the average population growth is 0.8%. 4.3 million patients were admitted acutely in England, which is 27% of all type 1 and 2 department visits and 6.6% of the total population.[23]

This increased demand for emergency care combined with high bed occupancy levels and the increased complexity of care, is a threat to the safety and timeliness of delivering acute care in the UK: 10% of the inspected EDs were rated inadequate on safety and 55% required improvement.[24,25] Part of the NHS Constitution is the 4 hour standard: 95% of patients should be admitted, transferred or discharged within 4 hours of arrival at an ED. In March 2018 84.6% of patients were seen within 4 hours in all EDs, compared to 90% in March 2017. It's the lowest performance since introducing this standard.[26]

From the ED, most acute medical patients requiring admission will be admitted to an AMU with exception of acute myocardial infarction and hyperacute stroke patients. The average length of stay in an AMU is < 24 hours with a proposed maximum of 48-72 hours.[27] During this period patients are discharged directly or transferred to an in-patient specialty ward. AMUs are consultant-led, with a core team of acute physicians supported by specialty physicians. Stable GP referred patients should be admitted directly via the AMU. Another option for stable patients not requiring admission is acute ambulatory care, which can relieve the pressure on EDs and AMUs, although consensus on the level of risk that is appropriate for home-based care has to be reached. Ambulatory care may be provided in 4 different care models: a 'hospital at home' setting, quick decision units, out-patient care or observation units.[28]

CONCLUSION

Acute medical care in the Netherlands and the UK face similar challenges: an increased pressure on the acute care system due to an increased number of (older) patients attending the ED over the last years, combined with high bed occupancy levels and the increased complexity of care. This leads to an elevated workload, pressure on timeliness and accessibility of acute care and high healthcare costs. In

England the number of ED visits per year, per capita is three times higher than in the Netherlands, but the percentage of admissions via type 1 and 2 EDs is 8% lower. However, in England the percentage of acute admissions on a population basis is 1.7% higher than in the Netherlands. Potentially, the triage of patients presenting at the ED in England is less efficient compared to the Netherlands.

The Dutch acute care system finds it strengths in a strong 24/7 primary care system constraining patient flow to the ED. Despite that the concept of first line stays needs further development, it's a valuable incentive assuring low-complex health care for low-complex cases.

One of the challenges in the Dutch system is the heterogeneously organized emergency care, which makes it hard to establish uniform quality standards for acute care. In addition, differences in organisation can lead to variation in practice, warranted and unwarrented. The staffing of the ED in particular deserves attention, assuring competent and experienced doctors for the care of the most complex patients.

The British acute health care system finds it strengths in the presence of emergency physicians at all EDs. ED physicians can initially see and stabilize patients. Thereafter, acute medical teams operating as part of a multidisciplinary team with specific expertise are needed to treat complex patients who require in-patient care. The organisation of the acute care in the UK is fragmented, leading to ambiguity for patients about which available acute care service they should use. Most important, the increased number of patients visiting the ED combined with high bed occupancy levels and the increased complexity of care, leads to crowding which may potentially affect the timeliness and quality of care.

Recommendations

By comparing these countries, we believe that lessons in organisation of acute care can be learned from each country. The British organisation of acute care can be improved by strengthening the primary care and community systems by improving access closer to home, increasing the accessibility (24/7) of GPs and optimising use of out of office hours GP services. Introduction of a small fee for patients referring themselves to the ED despite alternative options could help in reducing crowding in EDs, but may be politically hard to achieve. The Dutch ECAP model prevents unnecessary ED visits and reduces the volume pressures in the ED. It is also important that we improve the signposting for urgent care services so patients can more easily navigate the complex system in the UK and access services in a timely manner.

The Dutch system can learn from the British by improving ambulatory care to reduce pressure on in-patient beds and improve patient experience, rather than the more traditional models of out-patient care. Ambulatory emergency care can provide an appropriate support to primary care when escalation is needed, and reduce the use of the inpatient bedbase, thereby facilitating more treatment of acute illnesses from a community setting.[29] In general, The Dutch traditional out-patient care is not focussed on acute illnesses and lacks an adequate availability of 'acute generalists' as well as infrastructure facilitating not only a diagnostic, but also a therapeutic response to acutely unwell patients.

Secondly, the roles of emergency physicians and acute physicians should be clear and complementing which may be reached by more uniform staffing. Given the increased complexity of care, experienced consultants need to be present at the ED, providing optimal care pathways, training junior doctors and improving timely and right decision-making and patient flow. It has been shown that presence of consultants at the ED, beside Emergency Physicians, leads to a shorter Length of Stay and higher patient satisfaction.[30]

In both countries the ageing population has led to a changing case mix at the ED with an increased amount of multimorbid patients with polypharmacy. As a result ED presentations are becoming increasingly complex. This requires specialists who are able to deal with these problems, such as internists and geriatricians, and generalists with the ability to coordinate care for these complex patients, such as Emergency Physicians and acute physicians. A way to reach this broader expertise and treat patients in a holistic way, is assuring superspecialism instead of subspecialism for at least internists. Superspecialism requires persisting interest in areas beyond the subspecialty and willingness to practice medicine in a patient-oriented way, in contrast to subspecialism which focusses on a specific area of interest leading to treatment of a disease rather than treating a patient.[31] Therefore, a proportion of all medical specialists should change their attitude and adapt their training and daily practice to superspecialism, which will match the demand of the future case mix. Furthermore, ED-care should be adapted to the elderly: frailty screening, trained medical and para-medical staff, and special care pathways focused on the enablement of the complex needs group of patients may be keys to future-proof acute healthcare.

Finally, to improve the organisation of health care, we believe that doctors need to be visible medical leaders and participate in the organisation of care. Doctors should use their experience and medical knowledge to establish the best acute care working with patients and introduce changes in the organisation in concert with the managers. Medical leadership is considered to play an important role in

improving organisational performance, including quality of care, patient safety and cost-efficient care. Furthermore, medical leadership may be necessary to overcome the divide between medical and managerial logics.[32] To assure medical leadership in the future, medical students and residents have to be educated in medical leadership and be shown by role models that leadership will improve the quality of care.

REFERENCES

1. Nederlandse Zorgautoriteit. Marktscan acute zorg, september 2017.
2. Baker C. Accident and Emergency Statistics: Demand, Performance and Pressure. Briefing, House of Commons Library. 21-2-2017
3. Bernstein SL, Aronsky D, Duseja R, et al. The effect of emergency department crowding on clinically oriented outcomes. Acad Emerg Med 2009;16:1–10
4. Brouwers C, Merten H, Willems M, et al. Improving care for older patients in the acute setting: a qualitative study with healthcare providers. The Neth J of Med. 2017; 75:335-343
5. George G, Jell C, Todd BS, et al. Effect on population ageing on emergency department speed and efficiency: a historical perspective from a district hospital in the UK. Emerg Med J. 2006; 23:379-83
6. Schrijver EJ, Toppinga Q, de Vries OJ, et al. An observational cohort study on geriatric patient profile in an emergency department in the Netherlands. Neth J Med. 2013;71:324-330
7. Royal College of Emergency Medicine. (Accessed: July 2018) Tackling emergency department crowding. Retrieved from: https://www.rcem.ac.uk/docs/College%20Guidelines/5z23.%20ED%20crowding%20overview%20and%20toolkit%20(Dec%202015).pdf
8. Hoot NR, Aronsky D. Systematic review of emergency department crowding: causes, effects, and solutions. Ann Emerg Med 2008;52:126–136
9. Jayaprakash N, O'Sullivan R, Bey T et al. Crowding and delivery of healthcare in Emergency Departments: the European perspective. Western J of Em Med 2009;10:233-39
10. Baier N, Geissler A, Bech M, et al. Emergency and urgent care systems in Australia, Denmark, England, France, Germany and the Netherlands – Analyzing organisation, payments and reforms. Health policy, 2018;123:1-10
11. Kingsfund. (Accessed: April 2019) What's going on with A&E waiting times? https://www.kingsfund.org.uk/projects/urgent-emergency-care/urgent-and-emergency-care-mythbusters
12. Staat volksgezondheid en zorg. (Accessed April 2019) Ziekenhuisbedden. https://www.staatvenz.nl/kerncijfers/ziekenhuisbedden
13. Eurostat. (Accessed August 2018) Healthcare expenditure statistics. Retrieved from: http://ec.europa.eu/eurostat/statistics-explained/index.php/Healthcare_expenditure_statistics
14. Van der Velden LFJ, Kasteleijn A, Kenens RJ. (Accessed April 2019) Cijfers uit de registratie van huisartsen; peiling 2016. Retrieved from: https://nvl004.nivel.nl/nivel-2015/sites/default/files/cijfers-uit-de-registratie-van-huisartsen-peiling-januari-2016.pdf
15. Jansen T, Smits M, Verheij R. (Accessed August 2018) Zorg op de huisartsenpost - Triage. From: NIVEL Zorgregistraties eerste lijn. Retrieved from: www.nivel.nl/node/5397
16. Smits M, Rutten M, Keizer E, et al. The development and performance of After-Hours primary care in the Netherlands. Annals of internal medicine, 2017;166:737-742
17. Landelijke Huisartsen Vereniging. (Accessed April 2019) Eerstelijnsbedden: snelle oplossing voor patiënten vaak niet gevonden. https://www.lhv.nl/actueel/nieuws/eerstelijnsbedden-snelle-oplossing-voor-patienten-vaak-niet-gevonden

18. Fluent. (Accessed April 2019) Onderzoek naar duurzame inrichting spoedzorg keten voor ouderen._http://fluent.nl/wp-content/uploads/2018/02/ActiZ_onderzoek-naar-duurzame-inrichting-spoedzorgketen-voor-ouderen_door-fluent_5-feb-2018_DEF.pdf
19. Centraal Bureau voor de Statistiek. (Accessed April 2019) Bevolking; kerncijfers. https://statline.cbs.nl/Statweb/publication/?DM=SLNL&PA=37296ned&D1=a&D2=0,10,20,30,40,50,63-66&HDR=G1&STB=T&VW=T
20. Local Government Association. (Accessed April 2019) Ratio of GPs per 10,000 population in England. https://lginform.local.gov.uk/reports/lgastandard?mod-metric=3713&mod-area=E92000001&mod-group=AllRegions_England&mod-type=namedComparisonGroup
21. NHS England. (Accessed April 2019) Improving access to general practice. Retrieved from: https://www.england.nhs.uk/wp-content/uploads/2017/11/improving-access-general-practice-national-slidedeck.pdf
22. Cowling TE, Harris MJ, Watt HC, et al. Access to general practice and visits to accident and emergency (A&E) departments in England: cross-sectional analysis of a national patient survey. Br J Gen Pract2014;64:e434-9
23. NHS England and NHS Digital. (Accessed July 2018). Hospital Accident and Emergency activity 2016-2017. Retrieved from: https://files.digital.nhs.uk/pdf/m/4/acci-emer-atte-eng-2016-17-rep.pdf
24. Kingsfund. (Accessed April 2019) NHS hospital bed numbers: past, present, future. Retrieved from: https://www.kingsfund.org.uk/publications/nhs-hospital-bed-numbers#:~:text=The%20total%20number%20of%20NHS,bed%20numbers%20in%20recent%20years.
25. Care Quality Commission. (Accessed April 2018) The state of care in NHS acute hospitals: 2014 to 2016. Retrieved from: www.cqc.org.uk/sites/default/files/20170302b_stateofhospitals_web.pdf
26. NHS. (Accessed March 2018) A&E attendances and emergency admissions, statistical commentary. Retrieved from: https://www.england.nhs.uk/statistics/wp-content/uploads/sites/2/2018/04/Statistical-commentary-March-2018-uC145.pdf
27. Acute Medicine Task Force. Acute Medical care: the right person, in the right setting – the first time. Report. 2007 Oct.
28. Lasserson DS, Harris C, Elias T, et al. What is the evidence base for ambulatory care for acute medical illness? Acute medicine. 2018; 17(3): 148-153
29. Cottrel E, Mallen CD, Lasserson DS. Ambulatory emergency care: how should acute generalists manage risk in undifferentiated illness? British Journal of General Practice. 2018; 68: 12-13.
30. Van der Linden MC, de Beaufort RAY, Meylaerts SAG, et al. The impact of medical specialist staffing on emergency department flow and satisfaction. Eur J Emerg Med. 2019; 26: 47-52
31. Levi M. Generalism in modern subspecializing medicine. Eur J Intern Med. 2017; 39: 36-38.
32. Berghout M, Fabbricott I, Buljac-Samardzic M, et al. Medical leaders or masters? – a systematic review of medical leadership in hospital settings. PlosOne, 2017;12(9)

PART II

PATIENT-CENTREDNESS IN THE QUALITY OF ACUTE CARE

EVALUATING QUALITY IN ACUTE CARE USING PATIENT REPORTED OUTCOME MEASURES: A SCOPING REVIEW

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ABSTRACT

The aim of this scoping review is to identify patient reported outcome measures (PROMs) in acute care settings, assess their psychometric properties and provide recommendations for their use in daily practice. We performed a search in the PubMed database to identify publications concerning PROMs in an acute care setting. The COSMIN checklist was used to assess the psychometric properties of the reported PROMs. We found 1407 publications and included 14 articles, describing 15 measures. Most publications provided limited information on psychometric properties. Three generic PROMs were deemed of adequate quality for use in acute care. We recommend future development and evaluation of PROMs focussing on acute care to further evaluate and improve the quality of acute care.

INTRODUCTION

Quality of care in an emergency setting can be assessed in terms of outcomes, such as mortality or readmission rates and process measures, such as treatment time. These outcomes are routinely and periodically measured by most, if not all, emergency departments (EDs). Quality of care from a patient perspective however is not frequently measured in acute care settings.

The Institute of Medicine has identified patient-centred care as one of six elements which is important for quality of healthcare assessment.[1] Patient reported outcomes (PROs) can be used to evaluate patient-centred care and gained attention in the past years. A PRO is directly reported by the patient without interpretation of the patient's response by a clinician or anyone else and pertains to the patient's health, quality of life, or functional status associated with health care or treatment. In order to assess these PROs, patient reported outcomes measures (PROMs) have been developed.[2, 3] PROMs can be divided into three categories; generic PROMs, such as the short form 36 (SF-36), which have been developed to assess health status and outcomes of patients. The purpose of these generic PROMs is to measure the well-being of an individual within certain dimensions, generally consisting of measures of physical function, social function and psychological function. Additionally, various disease specific PROMs, such as the PROMIS-Cancer measures have been used in practice as well.[3, 4] Lastly, some PROMs focus merely on symptoms patients present themselves with, such as the Functional Assessment of Chronic Illness Therapy (FACIT) – Fatigue Scale.[5]

PROs in acute care are as important as they are for example in cancer care, where disease specific outcomes are integrated in specialised care pathways.[6] In the ED however, patients often come without a diagnosis, but only with signs and symptoms. Many hope to end their ED-visit with a diagnosis, which is seen as an essential step to fulfil other needs, such as an explanation for their symptoms and treatment.[7] Determining PROs for patients in the ED is difficult because patients can suffer from a wide variety of (possible) diagnoses and relevant outcomes can therefore be diverse. Especially in these patients, it is important to assess their perceived quality of care and health related quality of life.

The assessment of the quality of care is necessary in order to improve healthcare so that health care providers can gain insight into their performance and collect information concerning aspects of the care process which need improvement. PROMs can be used to provide feedback on the quality of care that is delivered. However, to do so, it is imperative these PROMs are scientifically sound, usable in the appropriate healthcare setting and easy to implement.[8] Especially in an acute

care setting, where care is delivered at a high pace and patients with symptoms and illnesses are presenting themselves, there is a need for accurate patient centred outcome measurements. Considering the ED context, validated questionnaires could be used to detect patient groups with a higher risk for possible adverse outcomes, but also to improve the quality of care and therefore minimise this risk.

An evaluation of the methodological quality and clinical utility of PROMs which can be used in an ED- or/acute setting, utilising the COSMIN checklist, has not been reported to date. Therefore, a review concerning the quality of psychometric properties and clinical utility of PROMs used in an acute care setting, can provide useful insights for healthcare professionals interested in quality of care.

The objective of this scoping review is to identify PROMs used in acute care settings. Additionally, we plan to assess the psychometric properties, i.e. validity, reliability and responsiveness, of these PROMs with the ultimate goal of providing elaborate information and recommendations for the use of PROMs in daily practice and therewith improve patient-centred care in the ED.

METHODS

Study design

We performed a scoping review on PROMs in acute care settings. The review was conducted according to Preferred Reporting Items for Systematic Reviews and Meta-analyses (PRISMA) guidelines and the COSMIN methodology for systematic reviews of Patient-Reported Outcomes Measures.[9]

Eligibility criteria

The search was restricted to studies including PROMs and Patient Reported Experience Measures (PREMs) in acute medical care, i.e. including the specialties internal medicine, neurology, pulmonology, rheumatology, gastro-enterology and cardiology. PREMs were initially included to ensure completeness, while hypothesising that an overview of only PROMs might be limited. Studies concerning PROMs in acute paediatric-, trauma-, psychiatric- or obstetric care were excluded. This was done to minimise the heterogeneity and provide an overview of PROMs, primarily of use for acute physicians. Additionally, the article needed to meet the following criteria: 1) a description of psychometric properties of the PROMs, such as validity and reliability; 2) the PROM was used or tested in Emergency Services, Emergency Department or Acute Medical Unit settings. In case of an author publishing more than one article on the same PROM, the article describing the PROM and its psychometric properties

best, was included. Only articles written in English or Dutch with full-text availability were included.

In addition, bibliographies of relevant systematic reviews or overview articles identified during the search were also reviewed to identify additional relevant studies.

Information sources and search

The PubMed® (Medline Ovid) database was searched and the latest comprehensive search was conducted on the 19th of August 2020.

The search terms used for searching the database were 'Patient Reported Outcome Measures', 'Emergency Department', 'Emergency Services', 'Acute Medical Unit', 'psychometrics' and related synonyms. The search strategy and queries were developed by a biomedical information specialist for the PubMed® database. (See Appendix 1 for the complete syntaxes)

Study selection

Duplicates of articles were removed using EndNote for Windows (Thomas Reuters, version X9). Two investigators (EM and MV) independently screened all identified studies for inclusion based on title and abstract, making use of Rayyan QCRI.[10] Of the selected studies, the full-text was assessed by the same investigators. Any contrasting results in the selection process were discussed and solved by a third investigator (MK).

Data collection process and data items

The following data were extracted from each included article (if available): authors, year and journal of publication, country in which the study was performed, inclusion and exclusion criteria for the patient population, patient characteristics (e.g. sex, mean age), construct of the PROM, type of PROM (i.e. generic, symptom specific, disease specific), objective of the study, study setting. Data were extracted by two researchers (EM, MV).

Risk of bias in individual studies

The quality of the included PROMs was assessed according to the COSMIN methodology, using the Risk of Bias checklist.[9] This is a guideline that helps to provide a comprehensive overview of the quality (i.e. measurement properties) of instruments. Two researchers (EM, MV) independently assessed and scored the quality of all included PROMs. When data on measurement properties were not presented in the included study, an additional search (using the COSMIN database or Medline) on relevant validation studies was performed with the aim to minimise missings. Results based on prior validation studies are marked in the table presenting

study quality. If any of these data was still missing, it was reported as not specified (NS). The risk of bias was assessed on the domains of study design, structural validity, internal consistency, cross-cultural validity, reliability, measurement error, criterion validity, construct validity and responsiveness. In case of incongruent results, deliberation with a third researcher (MK) took place and consensus was reached. A cross-check on the quality of the studies was performed by a third researcher (MK).

Data analysis

The primary outcome was to provide an overview of used PROMs in acute care settings. PROMs were categorised based on setting of use, type of PROM, study population and purpose (i.e. evaluation, discrimination or prediction). Additionally, evaluation of psychometric properties was presented with the aim of providing insight in the quality of the PROM.

RESULTS

Study selection

The initial search provided 1407 articles, of which 336 were duplicates. The screening of 1071 abstracts led to the selection of 51 articles concerning patient reported measures which were used in an acute care setting. Following further screening of these articles, 23 articles were excluded because they concerned only patient reported experience measures (PREMs) instead of PROMs. Additionally, fourteen articles were excluded because these studies were not performed in an acute setting, or there was no PROM involved, or the article was not in English or Dutch, or because the article was describing a treatment validation study or the article was a review. Through snowballing of the reviews, two additional articles concerning PROMs were reviewed. Furthermore, two articles were excluded because full-text was not accessible. Eventually, 14 articles concerning various PROMs used in an acute care setting were included in the scoping review based on the predetermined inclusion criteria (Figure 1).

The included measures were the Adult Sickle Cell Quality of Life Measurement (ASQ-Me QOC),[11] Short-form Chronic Respiratory Disease Questionnaire (SF-CRQ),[12] Patient Health Questionnaire Somatic Symptom Severity Scale (PHQ-15),[13] Short Form Health Survey (SF-36), EQ-5D[14], Verbal Dyspnoea rating scale (VDRS),[15] Acute Asthma Quality of Life Questionnaire (AQLQ),[16] visual analog scale (VAS),[17] Migraine Disability Assessment (MIDAS) questionnaire,[18] Nausea Profile,[19] Uncertainty Scale (U-scale),[20] Patient-reported Outcome Measurement at the Emergency Department (PROM-ED),[21] Roland-Morris Disability Questionnaire (RMDQ),[22] Poverty related quality of life (PQoL-17),[23] and the Dyspnoea Descriptor Questionnaire (DDQ).[24]

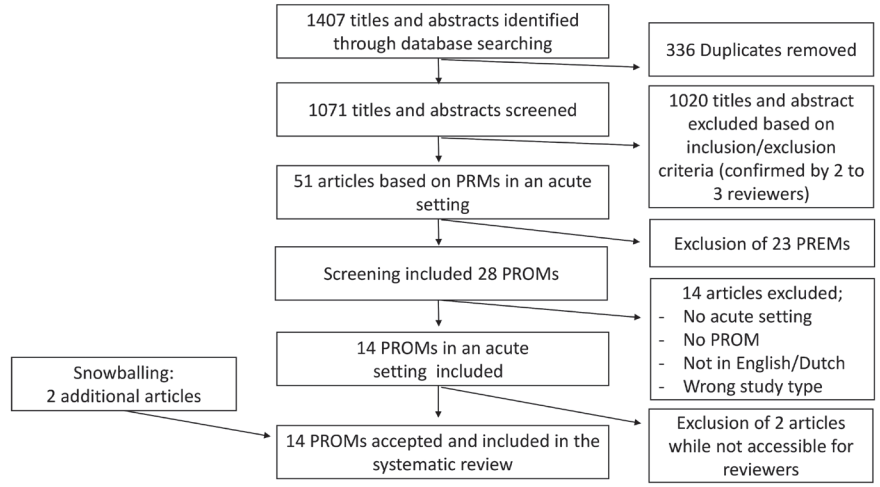

Figure 1. Flow diagram for the included PROMs in an acute setting

Study characteristics of acute care PROMs

The study characteristics regarding the included PROMs are shown in table 1. The various PROMs are quite evenly distributed among three categories; six PROMs are generic (PHQ-15, SF-36, EQ-5D, PROM-ED, PQoL-17, U-scale), five PROMs are disease specific (ASQ-Me QOC, SF-CRQ, AQLQ, MIDAS, RMDQ), and four PROMs are symptom-specific (VDRS, VAS, Nausea profile, DDQ). Generic PROMs measure the functional health and well-being of patients within certain domains, such as physical, psychological and social functioning, general health and vitality. The SF-36 is the most comprehensive generic PROM, additionally the EQ-5D and the PQoL-17 cover various areas important for health-related quality of life. The PQoL-17 differs from the SF-36 and the EQ-5D because its objective is to identify poverty and adapt patient care accordingly. Therefore, the PQoL-17 is a screening tool and not evaluative as the other generic PROMs. Furthermore, the PHQ-15 and the U-scale are also generic PROMs, but instead of evaluating quality of life in general, the purpose of these measures is more narrowed. The U-scale measures the inability of patients to determine the meaning of illness-related events. The PHQ-15 inquires about 15 somatic symptoms or symptom clusters that account for more than 90% of the physical complaints reported in the outpatient setting. Another generic PROM, but especially developed for an ED-setting is the PROM-ED. It measures outcomes within four domains, determined as important for patients presenting in the ED. The disease specific PROMs are focused on sickle-cell disease (ASQ-Me QOC), chronic obstructive pulmonary disease (SF-CRQ), asthma (AQLQ), migraine (MIDAS) and lower

back pain (RMDQ). The ASQ-Me QOC assesses the access and quality of adult sickle cell care. In contrast, the SF-CRQ, the MIDAS and the RMDQ all evaluate the grade of disability patients experience due to their disease. Additionally, the SF-CRQ evaluates the amount of distress patients experience due to an acute asthma exacerbation. When we assess the symptom specific PROMs, they are focused on nausea (Nausea profile), dyspnoea (DDQ and VDRS) and acute abdominal pain (VAS). All these PROMs aim to evaluate the severity of the symptoms patients experience.

Furthermore, the number of items on each PROM ranged from 1 (VDRS, VAS) to 36 (SF-36), with various subscales and possibilities to rate or answer these items. Most of the PROMs use a Likert scale, sometimes combined with open-ended questions or yes/no answer possibilities. In addition, some PROMs used a thermometer scale (VAS, MIDAS, EDQ-5D). These various response scales have been widely accepted for their use in PROMs.[25, 26]

Table 1. Description and characteristics of PROMs evaluated

Measure	Study	Population/Description	Purpose	Country
Generic				
Poverty related quality of life (PQoL-17)	Boyer, 2014	*Population:* 619 patients, mean age 38.3 years old. A 17 item questionnaire used for detecting vulnerable patients, describing seven dimensions of poverty related quality of life (QOL); self-esteem/vitality, psychological well-being, relationships with family, relationships with friends, autonomy, physical well-being/access to care, future perception). All items are rated on a 5 point Likert scale with higher scores indicating a better perceived health-related QOL.	Predictive	France
Patient Health Questionnaire (PHQ-15)	Hyphantis, 2014	*Population:* 303 patients, age ranged from 18 to 92 years old with an median age of 73 years old. A 15-item questionnaire designed to assess somatic symptom severity. The PHQ-15 inquires about 15 somatic symptoms or symptom clusters that account for more than 90% of the physical complaints (other than upper respiratory) reported in the outpatient setting.* Symptoms are rated on a 0-2 Likert Scale, so total score ranges from 0 to 30. Higher scores indicate higher levels of somatisation [43].	Evaluative	Greece

Table 1. (Continued)

Measure	Study	Population/Description	Purpose	Country
Short Form Health Survey (SF-36) & EuroQol-5D (EQ-5D)	Tsounis, 2013	*Population:* 108 patients, mean age 65.4 years old SF-36: A 36-item health related quality of life (HRQOL) measure with 8 scales; physical and social functioning, physical and emotional role, bodily pain, general and mental health, and vitality. Items are rated on Likert scales and raw scores are linearly transformed into 0 to 100 scales with higher transformed scores indicating better HRQOL. ED-Q5: A two-part descriptive, generic instrument. The first part consists of five dimensions of health: mobility, self-care, usual activities, pain/discomfort and anxiety/depression, rated on a 3 point Likert-scale. The second part consist of a visual analogue scale, where patients rate themselves in order to capture variations in health status. Scores can be converted by an algorithm, with higher scores indicating a higher level of self-reported well-being.	Evaluative Evaluative	Greece
Patient-reported Outcome Measurement at the Emergeny Department (PROM-ED)	Vaillancourt, 2020	*Population:* 444 patients, mean age 60.4 years old. A 22-item questionnaire measuring patient-centred outcomes of importance to patients receiving care in the ED, covering four domains (symptom relief, understanding, reassurance and having a plan). It allows patients to report on outcomes that are important to them. Patients score on 4 or 5 Likert-scales, with higher scores indicating a higher satisfaction/better experience on these specific domains.	Evaluative	Canada

Table 1. (Continued)

Measure	Study	Population/Description	Purpose	Country
Uncertainty Scale (U-scale)	Rising, 2018	*Population:* 156 patients, aged between 18 and 29 years old. A 30-item questionnaire to measure uncertainty in patients that may result in individuals' decision to seek care. It covers seven domains: diagnosis and severity, self-treatment for symptoms, psychosocial concerns, trust, treatment quality, care accessibility and finances. Questions are rated on a 5-point Likert-scale, with higher scores indicating a higher level of uncertainty.	Evaluative	USA
Disease specific				
Adult Sickle Cell Quality of Life Measurement (ASQ-Me QOC)	Evensen, 2016	*Population:* 556 patients, most were between ages of 18 and 34 years old. 18% aged 45 years and older, no maximum age defined. A 27-item questionnaire measuring patient self-reported experiences of quality of care (across care-settings and over time), covering four domains (Access to care, provider communication, ED-care, ED pain treatment). Higher scores indicate better outcomes)	Evaluative	USA
Roland-Morris Disability Questionnaire (RMDQ)	Friedman, 2015	*Population:* 322 patients, mean age 38 years old. A 24-item health status questionnaire, covering aspects of physical and mental function who are likely to be affected by low back pain. Patients check yes/no at each item, items are not weighted. Scores range from 0 to 24 with higher scores indicate a higher disability due to lower back pain.	Evaluative	USA

Table 1. (Continued)

Measure	Study	Population/Description	Purpose	Country
Acute Asthma Quality of Life Questionnaire (AQLQ)	Juniper, 2003	*Population:* 88 patients, median age 44 years old. An 11-item questionnaire measuring self-reported functional items in patients who are presenting with an acute asthma exacerbation, consisting of two domains; symptoms and emotions. It is interview administered wherein patients are asked about how they have felt during the previous half hour, scoring a 0-7 Likert scale at each question. Lower scores indicate a higher level of distress. It can be used to evaluate the effectiveness of interventions.	Evaluative	Canada
Verbal Dyspnoea Rating Scale (VDRS)	Saracino, 2008	*Population:* 253 patients, mean age 60.6 years old. A measure of the severity of shortness of breath (SOB) in patients presenting at the ED, by asking one verbal question 'On a scale from 0 to 10 how bad is your SOB?' With zero being no SOB and 10 the worst SOB they could ever imagine.	Evaluative	Australia
Short-form Chronic Respiratory Disease Questionnaire (SF-CRQ)	Tsai, 2007	*Population:* 301 patients, median age 69 years old An 8-item questionnaire to measure short term quality of life (QOL) changes in patients with COPD exacerbations, consisting of multiple domains: dyspnoea, fatigue, emotional function and mastery. Symptoms are rated on a 7 point Likert-scale with lower scores indicating a lower health-related QOL and sense of well-being.	Evaluative	USA & Canada
Symptom specific				
Migraine Disability Assesment (MIDAS) questionnaire	Aliprandi, 2004	*Population:* 45 patients, mean age 38 years old. A 5-item questionnaire in which patients score the days they had headache-associated complaints. Higher scores correlate with a higher burden of symptoms [44].	Evaluative	Italy

Table 1. (Continued)

Measure	Study	Population/Description	Purpose	Country
Nausea Profile	Cloutier, 2010	*Population:* total of 536 patients of the two descripted phases, mean age 39 years old A 10-item multifactorial nausea scale, in which both physical and psychological symptoms are measured. The physical scale is a direct measure of physical symptoms of nausea, and on the other hand the psychological scale measures other aspects of the nausea experience. These scales are independent and can be used together or separately. Patients score each item on Likert scales ranging from 0-10, with higher scores indicating a higher level of nausea-experience. It can be used to evaluate the effects of therapy.	Evaluative	USA
Visual analog scale (VAS)	Gallagher, 2001	*Population:* 101 patients, mean age 40 years old A visual analog scale indicating pain severity on a 100mm scale to measure the intensity of acute abdominal pain. Patients are asked to rate their pain severity by placing a vertical mark on the horizontal VAS.	Evaluative	USA
Dyspnoea descriptor questionnaire (DDQ)	Parshall, 2001	*Population:* 34 patients, mean age 64 years old. A 13-item questionnaire consisting of dyspnoea descriptors, subjective items of which the patient is asked to endorse. Symptoms are rated on a 10 point Likert-scale, with higher scores indicating a more severe sensation of dyspnoea.	Evaluative	USA

Quality assessment – psychometric properties

The results of the quality assessment of the evaluated PROMs based on the COSMIN criteria are demonstrated in table 2. A brief explanation concerning the concepts in evaluating quality of PROMs, based on content validity, construct validity, structural validity, reliability, internal consistency and responsiveness, is presented in table 3. Out of the 14 reviewed articles, three PROMs were found to be adequate to good on all domains. These publications concerned the SF-36, the EQ-5D and the PROM-ED. Of the remaining 11 studies, we found inadequacies in one or more domains. The structural validity was not described for five PROMs (VRDS, VAS, AQLQ, MIDAS, RMDQ) and the internal validity was not described for three PROMs (VRDS, VAS, AQLQ, MIDAS). It is important to mention that the VRDS and VAS are unidimensional measurement tools. Therefore, their structural validity and internal consistency cannot be assessed.

The construct validity and responsiveness were deemed adequate to good in most reviewed PROMs. However, five and four PROMs could not be evaluated within these domains respectively, while no description was provided concerning the construct validity and responsiveness.[11, 17, 19, 21, 24]

Content validity was inadequate in one study (RMDQ) as the content was not assessed in an acute care setting. In four PROMs (U-scale, PQoL-17, DDQ, ASQ-Me QOC) the content validity was deemed doubtful and not described in the other nine articles.[12-19, 21] The AQLQ, the MIDAS and the DDQ have an inadequate reliability, while no repeated measurements were carried out or patients were unstable in the interim period of the measurements.

Furthermore, the study population is also of importance for the quality of the study and therefore the validity of the PROM. Most of the studies have a suitable patient population to assess the measurement tool in an acute setting. However, two studies appear to have a small study population with the inclusion of respectively 45 patients (MIDAS) and 34 patients (DDQ). While the difference in study population size might stand out, it is important to address whether this has any consequences for the validity of the study. The evaluation of the descriptors of the dyspnoea descriptor questionnaire has been done qualitatively, therefore a study population of 34 patients is good. The MIDAS study has enrolled 45 patients for a quantitative study which is deemed low. Furthermore, the gender of the study populations of the PROMs was evenly distributed with a slight proclivity to the female gender. Lastly, the mean age of eight of the PROMs is below 45 years of age, the other six PROMs have been evaluated in a study population with a mean age of 60 years and above.

Table 2. Evaluation of psychometric properties according to the COSMIN criteria of PROMs

Measure	Study	Structural/ Unidimen-sional	COSMIN General design	COSMIN content validity	COSMIN structural validity	COSMIN internal consistency	COSMIN Reliability	COSMIN responsive-ness	COSMIN Construct validity
Generic									
Poverty related quality of life (PQoL-17)	Boyer, 2014	Structural	+/-	+/-	+	++	NS	++	++
Patient Health Questionnaire (PHQ-15)	Hyphantis, 2014	Structural	+/-	NS	+	+	+	++	+
Short Form Health Survey (SF-36) & EQ-5D	Tsounis, 2013	Structural	+	NS	+	+	NS	+	+
Patient-reported Outcome Measurement at the Emergeny Department (PROM-ED)	Vaillancourt, 2020	Structural	+	NS	++	++	+	+	NS
Uncertainty Scale (U-scale)	Rising, 2018	Structural	+/-	+/-	+	++	NS	+	+

Table 2.(Continued)

Measure	Study	Structural/ Unidimen-sional	COSMIN General design	COSMIN content validity	COSMIN structural validity	COSMIN internal consistency	COSMIN Reliability	COSMIN responsive-ness	COSMIN Construct validity
Disease-specific									
Adult Sickle Cell Quality of Life Measurement (ASQ-Me QOC)	Evensen, 2016	Structural	+/-	+/-	++	++	NS	NS	NS
Roland-Morris Disability Questionnaire (RMDQ)	Friedman, 2015	Structural	+/-	-	NS	+	+	+	++
Acute Asthma Quality of Life Questionnaire (AQLQ)	Juniper, 2003	Structural	+/-	NS	NS	++	-	++	++
Verbal Dyspnoea Rating Scale (VDRS)	Saracino, 2008	Unidimensional	+	NS	NA	NS	+/-	++	++

Table 2.(Continued)

Measure	Study	Structural/ Unidimen-sional	COSMIN General design	COSMIN content validity	COSMIN structural validity	COSMIN internal consistency	COSMIN Reliability	COSMIN responsive-ness	COSMIN Construct validity
Short-form Chronic Respiratory Disease Questionnaire (SF-CRQ)	Tsai, 2007	Structural	+/-	NS	+/-	++	+/-	++	+
Symptom-specific									
Migraine Disability Assesment (MIDAS) questionnaire	Aliprandi, 2004	Structural	+/-	NS	NS	NS	-	+	+
Nausea Profile	Cloutier, 2010	Structural	+/-	NS	++	+	NS	NS	NS
Visual analog scale (VAS)	Gallagher, 2001	Unidimensional	+	NS	NA	NS	+	NS	NS

Table 2.(Continued)

Measure	Study	Structural/ Unidimen-sional	COSMIN General design	COSMIN content validity	COSMIN structural validity	COSMIN internal consistency	COSMIN Reliability	COSMIN responsive-ness	COSMIN Construct validity
Dyspnoea descriptor questionnaire (DDQ)	Parshall, 2001	Structural	+/-	+/-	+/-	+	-	NS	NS

Quality graded as follows; inadequate; -, doubtful; +/-, adequate; +, good; ++. NA; not applicable, NS; not specified.

Table 3. Explanation of concepts regarding quality of PROMs

Concept	Meaning
Content validity	The degree to which the content of a PROM is an adequate reflection of the construct to be measured
Construct validity	The degree to which a PROM measures the construct(s) it purports to measure
Internal consistency	The degree of the interrelatedness among the items
Structural validity	The degree to which the scores of a PROM are an adequate reflection of the dimensionality of the construct to be measured
Reliability	The proportion of the total variance in the measurements which is due to 'true' differences between patients
Responsiveness	The ability of a PROM to detect change over time in the construct to be measured

From: COSMIN manual for systematic reviews of PROMs [9]

DISCUSSION

This is the first scoping review to assess PROMs in an acute care setting utilising the COSMIN checklist. The use of PROMs in an acute setting is limited, even though the introduction of value-based healthcare created a need for transparency of healthcare quality aiming to increase value for patients. Value should always be defined around the customer in a well-functioning health care system, therefore value in health care is measured by the outcomes achieved, relevant for patients.[27] Especially in an acute care setting, where an ED visit can be considered as a stressful life event and is associated with adverse effects on the patient's mental and emotional state, is it important to understand the patients views on the outcomes of received care and perceived health-related quality of life.[28] In addition, there is evidence that the use of PROMs in clinical practice could enhance communication between patients and their clinicians.[29, 30]

PROMs are multidimensional measurement tools and can be used to measure a great variety of concepts, which consist of several domains. Response scales (VAS, VRDS) also provide insight on the patients' well-being, yet are strictly not PROMs but unidimensional measurement tools that can be used to indicate a specific aspect or dimension within a PROM. A PROM can be used as an evaluative, descriptive or predictive measure, depending on the setting and the outcome of interest. In daily

practice, clinicians need to consider which PROM is most applicable based on the category and objective of the PROM and its validity. However, the importance of suitability of the target population and patient acceptability of the PROM must not be overlooked. A PROM needs to be a relevant, comprehensive and comprehensible tool for patients in the setting in which it will be used to optimise content validity. Therefore, it is advised to involve patients in the development and selection of PROMs used in daily practice or research.[31]

When evaluating the quality of PROMs based on the COMSIN-checklist, only three PROMs were deemed adequate to good on all domains. By chance, these were only generic PROMs (PROM-ED, SF-36 and EQ-5D). The PROM-ED focusses on assessing specific domains within the heterogeneous ED-population, namely understanding the diagnosis, having a plan, symptom relief and reassurance. The SF-36 and EQ-5D are widely used generic PROMs evaluating health-related quality of life, initially developed in chronic care but appear to be of adequate use in acute care settings. Consequently, methodological issues were present in the majority of the PROMs included in this review. These issues included: missing information on measurement error, a lack of prior described hypotheses and non-reporting on the domains content-validity, reliability and construct validity. Therefore, some generic PROMs (PQoL-17, PHQ-15 and the U-scale), the disease specific PROMs and symptom specific PROMs, need further validation testing in order to address the identified gaps. These issues are in line with other reviews of PROMs for specific health conditions.[32-34]

Regarding reliability testing, we noticed lacking reports on this domain, which may be a consequence of the challenge in executing reliability testing in acute care settings. For example, patients in the DDQ-study were unstable in the interim period of the two measurements. Patients were asked to fill out the DDQ twice at the ED, once based on their recollection of health status one week before the ED visit, once based on how they were feeling at that moment in time. It is probable that patients went to the ED because of a clinical worsening of their symptoms and therefore were not stable between the two measurements. The principle of reliability is that applying the PROM in different occasions produces similar results.[35] However, in acute care, health outcomes can change rapidly which may hamper the results of test-retesting as patients are not stable over time. Gallagher et al, showed that performing test-retest reliability by asking the same question within 2 minutes time is possible,[17] although, it is questionable if this timeframe can be considered adequate for the purpose of evaluating the reliability of a PROM.

Furthermore, the assessment of content validity for most of the PROMs used in acute care settings could not be performed, while no information concerning the relevance, comprehensiveness and comprehensibility for patients and healthcare

professionals was described. Content validity is vital for the development and use of PROMs, while it ensures that the PROM actually measures the concept of interest which it intends to measure. It appears that the minimal focus on content validity is not only apparent in PROMs for acute settings and is often not considered while developing PROMs.[36-39] The lack of PROMs with well described and adequate content validity remains a hurdle in the use of PROMs in acute care, while content validity is one of the most important psychometric properties of a PROM and has great impact on the overall validity.

Limitations

A limitation of this review is that studies in which psychometric properties were not described, were excluded. Therefore, the overview of PROMs evaluated in acute care settings, provided in this scoping review might be incomplete. For example, no studies concerning the use of PROMs in Acute Admission Units described psychometric properties. A feasibility study concerning the use of PROMs in Acute Admission Units was executed with positive results, but this study was not found in our search while no psychometric properties were mentioned.[40] Additionally, submitted articles concerning PROMs in acute care settings were also not included in our search. Hence, the PRMs-Acute Care which is developed based on five relevant PROs and recently tested on validity in an acute care setting, is not included in this scoping review.[41, 42]

Recommendations

We believe that the use of PROMs in an acute care setting is important in order to improve patient-centredness and the quality of care. The generic PROMs developed for or assessed in acute care settings, such as the PROM-ED, SF-36 or EQ-5D, can be used in daily practice as these are suitable for patients with various symptoms and diseases. However, the development of generic acute care focused PROMs needs attention while it is still in its infancy. PROMs such as the PROM-ED and the recently developed PRM-acute care, may be promising measures to evaluate the quality of health care and may be suitable for a broader implementation in acute care.

Disease or symptom specific PROMs can be of great value for specific patient groups in acute care settings. Our review shows that the description of the psychometric properties and therefore the validity of these PROMs in an acute setting is inadequate at this moment. Further evaluation of these PROMs in an acute setting is needed to improve their usefulness and implementation. .

When developing PROMs for acute care, the content validity needs to be established as proposed by the COSMIN guidelines. Involving patients in determining relevant PROs and development of PROMs is of major importance, because PROMs focus on

outcomes relevant for patients, which cannot be defined by healthcare professionals or researchers.

CONCLUSION

This review provides a comprehensive summary of the characteristics and quality of various PROMs available in an acute care setting. The identified PROMs are generic, disease specific or symptom specific. At this moment only a few PROMs of adequate quality are available in an acute care setting, all of which are generic. These PROMs have evaluative purposes, which makes them even more applicable to evaluate health-related quality of life or perceived quality of acute care. The implementation of PROMs, when suitable for patient groups in acute care settings, will improve the quality of healthcare as perceived by patients.

REFERENCES

1. Institute of Medicine. Crossing the Quality Chasm: a new health system for the 21st century. National Academies Press. 2001.
2. Kingsley CMBF, Patel SMBF. Patient-reported outcome measures and patient-reported experience measures. BJA Education. 2017;17(4):137-44.
3. Weldring T, Smith SMS. Article Commentary: Patient-Reported Outcomes (PROs) and Patient-Reported Outcome Measures (PROMs). Health Services Insights. 2013;6:HSI.S11093.
4. Yost KJ, Eton DT, Garcia SF, Cella D. Minimally important differences were estimated for six PROMIS-Cancer scales in advanced-stage cancer patients. 2011. p. 507-16.
5. Montan I, Löwe B, Cella D, Mehnert A, Hinz A. General Population Norms for the Functional Assessment of Chronic Illness Therapy (FACIT)-Fatigue Scale. Value in Health. 2018;21(11):1313-21.
6. Steenaard RV, Kremers MNT, Michon LA, Zijlstra M, Haak HR. Patient and Partner Perspectives on Health-Related Quality of Life in Adrenocortical Carcinoma. J Endocr Soc. 2020;4(5):bvaa040.
7. Gerolamo AM, Jutel A, Kovalsky D, Gentsch A, Doty AMB, Rising KL. Patient-Identified Needs Related to Seeking a Diagnosis in the Emergency Department. Ann Emerg Med. 2018;72(3):282-8.
8. Pronovost PJ, Nolan T, Zeger S, Miller M, Rubin H. How can clinicians measure safety and quality in acute care? 2004. p. 1061-7.
9. Mokkink LB, de Vet HCW, Prinsen CAC, Patrick DL, Alonso J, Bouter LM, et al. COSMIN Risk of Bias checklist for systematic reviews of Patient-Reported Outcome Measures. Qual Life Res. 2018;27(5):1171-9.
10. Ouzzani M, Hammady H, Fedorowicz Z, Elmagarmid A. Rayyan—a web and mobile app for systematic reviews. Systematic Reviews. 2016;5(1):210.
11. Evensen CT, Treadwell MJ, Keller S, Levine R, Hassell KL, Werner EM, et al. Quality of care in sickle cell disease: Cross-sectional study and development of a measure for adults reporting on ambulatory and emergency department care. Medicine (Baltimore). 2016;95(35):e4528.
12. Tsai CL, Hodder RV, Page JH, Cydulka RK, Rowe BH, Camargo CA, Jr. The short-form chronic respiratory disease questionnaire was a valid, reliable, and responsive quality-of-life instrument in acute exacerbations of chronic obstructive pulmonary disease. J Clin Epidemiol. 2008;61(5):489-97.
13. Hyphantis T, Kroenke K, Papatheodorou E, Paika V, Theocharopoulos N, Ninou A, et al. Validity of the Greek version of the PHQ 15-item Somatic Symptom Severity Scale in patients with chronic medical conditions and correlations with emergency department use and illness perceptions. Compr Psychiatry. 2014;55(8):1950-9.
14. Tsounis D, Ioannidis A, Bouras G, Raikou M, Giannopoulos G, Deftereos S, et al. Assessment of health-related quality of life in a greek symptomatic population with atrial fibrillation: correlation with functional status and echocardiographic indices. Hellenic J Cardiol. 2014;55(6):475-85.

15. Saracino A, Weiland T, Dent A, Jolly B. Validation of a verbal dyspnoea rating scale in the emergency department. Emerg Med Australas. 2008;20(6):475-81.
16. Juniper EF, Svensson K, Mörk AC, Ståhl E. Measuring health-related quality of life in adults during an acute asthma exacerbation. Chest. 2004;125(1):93-7.
17. Gallagher EJ, Bijur PE, Latimer C, Silver W. Reliability and validity of a visual analog scale for acute abdominal pain in the ED. Am J Emerg Med. 2002;20(4):287-90.
18. Aliprandi A, Frigerio R, Santoro P, Frigo M, Iurlaro S, Vaccaro M, et al. MIDAS questionnaire in the emergency setting. Neurol Sci. 2004;25 Suppl 3:S274-5.
19. Cloutier RL, Fuller BE, Hendrickson RG, Jones N. Measuring nausea in emergency department patients via the use of exploratory factor analysis. Acad Emerg Med. 2010;17(6):e33-9.
20. Rising KL, LaNoue MD, Gerolamo AM, Doty AMB, Gentsch AT, Powell RE. Patient Uncertainty as a Predictor of 30-day Return Emergency Department Visits: An Observational Study. Acad Emerg Med. 2019;26(5):501-9.
21. Vaillancourt S, Cullen JD, Dainty KN, Inrig T, Laupacis A, Linton D, et al. PROM-ED: Development and Testing of a Patient-Reported Outcome Measure for Emergency Department Patients Who Are Discharged Home. Ann Emerg Med. 2020;76(2):219-29.
22. Friedman BW, Dym AA, Davitt M, Holden L, Solorzano C, Esses D, et al. Naproxen With Cyclobenzaprine, Oxycodone/Acetaminophen, or Placebo for Treating Acute Low Back Pain: A Randomized Clinical Trial. Jama. 2015;314(15):1572-80.
23. Boyer L, Baumstarck K, Iordanova T, Fernandez J, Jean P, Auquier P. A poverty-related quality of life questionnaire can help to detect health inequalities in emergency departments. J Clin Epidemiol. 2014;67(3):285-95.
24. Parshall MB, Welsh JD, Brockopp DY, Heiser RM, Schooler MP, Cassidy KB. Reliability and validity of dyspnea sensory quality descriptors in heart failure patients treated in an emergency department. Heart Lung. 2001;30(1):57-65.
25. Guyatt GH, Townsend M, Berman LB, Keller JL. A comparison of Likert and visual analogue scales for measuring change in function. J Chronic Dis. 1987;40(12):1129-33.
26. Hasson D, Arnetz B. Validation and Findings Comparing VAS vs. Likert Scales for Psychosocial Measurements. 2005. p. 178.
27. Porter ME. What is value in health care? N Engl J Med. 2010;363(26):2477-81.
28. Faessler L, Brodbeck J, Schuetz P, Haubitz S, Mueller B, Perrig-Chiello P. Medical patients' affective well-being after emergency department admission: The role of personal and social resources and health-related variables. PloS one. 2019;14(3):e0212900.
29. Velikova G, Booth L, Smith AB, Brown PM, Lynch P, Brown JM, et al. Measuring quality of life in routine oncology practice improves communication and patient well-being: a randomized controlled trial. J Clin Oncol. 2004;22(4):714-24.
30. Marshall S, Haywood K, Fitzpatrick R. Impact of patient-reported outcome measures on routine practice: a structured review. J Eval Clin Pract. 2006;12(5):559-68.
31. Aiyegbusi OL, Kyte D, Cockwell P, Marshall T, Gheorghe A, Keeley T, et al. Measurement properties of patient-reported outcome measures (PROMs) used in adult patients with chronic kidney disease: A systematic review. PloS one. 2017;12(6):e0179733.
32. Elbers RG, Rietberg MB, van Wegen EE, Verhoef J, Kramer SF, Terwee CB, et al. Self-report fatigue questionnaires in multiple sclerosis, Parkinson's disease and stroke: a systematic review of measurement properties. Qual Life Res. 2012;21(6):925-44.

33. Green A, Liles C, Rushton A, Kyte DG. Measurement properties of patient-reported outcome measures (PROMS) in Patellofemoral Pain Syndrome: a systematic review. Man Ther. 2014;19(6):517-26.
34. Janssens A, Rogers M, Gumm R, Jenkinson C, Tennant A, Logan S, et al. Measurement properties of multidimensional patient-reported outcome measures in neurodisability: a systematic review of evaluation studies. Dev Med Child Neurol. 2016;58(5):437-51.
35. Health measurement scales: a practical guide to their development and use (5th edition). Aust N Z J Public Health. 2016;40(3):294-5.
36. Chiarotto A, Ostelo RW, Boers M, Terwee CB. A systematic review highlights the need to investigate the content validity of patient-reported outcome measures for physical functioning in patients with low back pain. J Clin Epidemiol. 2018;95:73-93.
37. Lloyd M, Callander E, Karahalios A, Desmond L, Karunajeewa H. Patient-reported outcome measures in community-acquired pneumonia: a systematic review of application and content validity. BMJ Open Respir Res. 2019;6(1):e000398.
38. Powell PA, Carlton J, Woods HB, Mazzone P. Measuring quality of life in Duchenne muscular dystrophy: a systematic review of the content and structural validity of commonly used instruments. Health Qual Life Outcomes. 2020;18(1):263.
39. Skogestad IJ, Kirkevold M, Indredavik B, Gay CL, Lerdal A. Lack of content overlap and essential dimensions - A review of measures used for post-stroke fatigue. J Psychosom Res. 2019;124:109759.
40. Galen LS, der Schors W, Damen NL, Kramer M, Wagner C, Nanayakkara P. Measurement of generic patient reported outcome measures (PROMs) in an acute admission unit: A feasibility study. Acute Med. 2016;15(1):13-9.
41. Kremers MNT, Zaalberg T, van den Ende ES, van Beneden M, Holleman F, Nanayakkara PWB, et al. Patient's perspective on improving the quality of acute medical care: determining patient reported outcomes. BMJ Open Quality. 2019;8(3):e000736.
42. Kremers MNT, Mols, E.M., Simons, Y.A.E, Kuijk van, S.M.J., Holleman, F., Nanayakkara, P.W.B., Haak, H.R. . Quality of Acute Care: A Patient-Centred Approach Validation and usage of the PRM-acute care in the Netherlands. PloS one. 2020;Submitted.
43. Kroenke K, Arrington ME, Mangelsdorff AD. The prevalence of symptoms in medical outpatients and the adequacy of therapy. Arch Intern Med. 1990;150(8):1685-9.
44. Stewart WF, Lipton RB, Dowson AJ, Sawyer J. Development and testing of the Migraine Disability Assessment (MIDAS) Questionnaire to assess headache-related disability. Neurology. 2001;56(6 Suppl 1):S20-8.

Appendix 1: Search method

Search	Query
#6	Search: #4 AND #5
#5	Search: psychometrics[MeSH Terms] OR psychometric*[Title/Abstract]
#4	Search: #3 NOT ((“Adolescent”[Mesh] OR “Child”[Mesh] OR “Infant”[Mesh] OR adolescen*[tiab] OR child*[tiab] OR schoolchild*[tiab] OR infant*[tiab] OR girl[tiab] OR girls[tiab] OR boy[tiab] OR boys[tiab] OR teen[tiab] OR teens[tiab] OR teenager*[tiab] OR youth*[tiab] OR pediatr*[tiab] OR paediatr*[tiab] OR puber*[tiab]) NOT (“Adult”[Mesh] OR adult*[tiab] OR man[tiab] OR men[tiab] OR woman[tiab] OR women[tiab]))
#3	Search: #1 AND #2
#2	Search: “Patient Reported Outcome Measures”[Mesh] OR “Quality of Life”[Mesh] OR prom[tiab] OR proms[tiab] OR pro[tiab] OR pros[tiab] OR HRQL[tiab] OR HRQoL[tiab] OR QL[tiab] OR QoL[tiab] OR quality of life[tiab] OR life quality[tiab] OR health index*[tiab] OR health indices[tiab] OR health profile*[tiab] OR health status[tw] OR ((patient[tiab] OR self[tiab] OR child[tiab] OR parent[tiab] OR carer[tiab] OR proxy[tiab]) AND ((report[tiab] OR reported[tiab] OR reporting[tiab]) OR (rated[tiab] OR rating[tiab] OR ratings[tiab]) OR based[tiab] OR (assessed[tiab] OR assessment[tiab] OR assessments[tiab]))) OR ((disability[tiab] OR function[tiab] OR functional[tiab] OR functions[tiab] OR subjective[tiab] OR utility[tiab] OR utilities[tiab] OR wellbeing[tiab] OR well being[tiab]) AND (outcome[tiab] OR outcomes[tiab] OR index[tiab] OR indices[tiab] OR instrument[tiab] OR instruments[tiab] OR measure[tiab] OR measures[tiab] OR questionnaire[tiab] OR questionnaires[tiab] OR profile[tiab] OR profiles[tiab] OR scale[tiab] OR scales[tiab] OR score[tiab] OR scores[tiab] OR status[tiab] OR survey[tiab] OR surveys[tiab]))
#1	Search: “Emergency Service, Hospital”[Mesh:NoExp] OR emergenc*[tiab] OR acute medical unit*[tiab] OR acute admission unit*[tiab]

AND

Search	Query
#5	Filter: validation study
#4	Search: #3 NOT ((“Adolescent”[Mesh] OR “Child”[Mesh] OR “Infant”[Mesh] OR adolescen*[tiab] OR child*[tiab] OR schoolchild*[tiab] OR infant*[tiab] OR girl[tiab] OR girls[tiab] OR boy[tiab] OR boys[tiab] OR teen[tiab] OR teens[tiab] OR teenager*[tiab] OR youth*[tiab] OR pediatr*[tiab] OR paediatr*[tiab] OR puber*[tiab]) NOT (“Adult”[Mesh] OR adult*[tiab] OR man[tiab] OR men[tiab] OR woman[tiab] OR women[tiab]))
#3	Search: #1 AND #2
#2	Search: “Patient Reported Outcome Measures”[Mesh] OR “Quality of Life”[Mesh] OR prom[tiab] OR proms[tiab] OR pro[tiab] OR pros[tiab] OR HRQL[tiab] OR HRQoL[tiab] OR QL[tiab] OR QoL[tiab] OR quality of life[tiab] OR life quality[tiab] OR health index*[tiab] OR health indices[tiab] OR health profile*[tiab] OR health status[tw] OR ((patient[tiab] OR self[tiab] OR child[tiab] OR parent[tiab] OR carer[tiab] OR proxy[tiab]) AND ((report[tiab] OR reported[tiab] OR reporting[tiab]) OR (rated[tiab] OR rating[tiab] OR ratings[tiab]) OR based[tiab] OR (assessed[tiab] OR assessment[tiab] OR assessments[tiab]))) OR ((disability[tiab] OR function[tiab] OR functional[tiab] OR functions[tiab] OR subjective[tiab] OR utility[tiab] OR utilities[tiab] OR wellbeing[tiab] OR well being[tiab]) AND (outcome[tiab] OR outcomes[tiab] OR index[tiab] OR indices[tiab] OR instrument[tiab] OR instruments[tiab] OR measure[tiab] OR measures[tiab] OR questionnaire[tiab] OR questionnaires[tiab] OR profile[tiab] OR profiles[tiab] OR scale[tiab] OR scales[tiab] OR score[tiab] OR scores[tiab] OR status[tiab] OR survey[tiab] OR surveys[tiab]))
#1	Search: “Emergency Service, Hospital”[Mesh:NoExp] OR emergenc*[tiab] OR acute medical unit*[tiab] OR acute admission unit*[tiab]

THE PATIENT'S PERSPECTIVE ON IMPROVING THE QUALITY OF ACUTE MEDICAL CARE: DETERMINING PATIENT REPORTED OUTCOMES

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BMJ Open Quality. 2019;8(3):e000736

ABSTRACT

Rationale

There is an increasing societal demand for quality assurance and transparency of medical care. The American National Academy of Medicine has determined patient-centeredness as a quality domain for improvement of health care. While many of the current quality indicators are disease-specific, most Emergency Department (ED) patients present with undifferentiated complaints. Therefore, there is a need for generic outcome measures. Our objective was to determine relevant Patient Reported Outcomes (PROs) for quality measurement of acute care.

Methods

We conducted semi-structured interviews in patients ≥18 years presenting at the ED for internal medicine. Patients with a cognitive impairment or language barrier were excluded. Interviews were analysed using qualitative content analysis.

Results

Thirty patients were interviewed. Patients reported outcomes as relevant in five domains: relief of symptoms, understanding the diagnosis, presence and understanding of the diagnostic and/or therapeutic plan, reassurance and patient experiences. Experiences were often mentioned as relevant to the perceived quality of care and appeared to influence the domain reassurance.

Conclusion

We determined five domains of relevant PROs in acute care. These domains will be used for developing generic Patient Reported Measures for acute care. The patients' perspective will be incorporated in these measures with the ultimate aim of organising truly patient-centred care at the ED.

INTRODUCTION

There is an increasing societal demand for transparency and quality assurance in medical care including Emergency Services such as the Emergency Department (ED). To ensure cost control, safety and transparency of care, many indicators have been developed with the aim of measuring the quality of healthcare.[1,2]

For example, from 2014 until 2016 the number of quality indicators in the Netherlands increased by 14% from 1,360 to 1,551 indicators. The majority of these indicators are process and structure indicators, whereas only 2% are outcomes indicators.[2] These process and structure indicators are less relevant and valid compared to outcome indicators for monitoring the effect of healthcare.[3] However, commonly used outcome indicators are generally disease specific and therefore not usable at the ED, because the patient population at the ED is heterogeneous and patients often lack a diagnosis at presentation. Patients presenting for internal medicine often suffer from multiple chronic conditions and often present with non-specific complaints.[4] Therefore, the commonly used indicators may not reflect the quality of care for this specific group of patients.

On top of that, measuring outcome indicators in the ED is hampered by the severity of acute illness, the need for rapid triage and treatment, and time constraints.[5-8]

When assessing the quality of care according to the principles of Value Based Health Care, achieving high value for patients must become the overarching goal of health care delivery. Value should always be defined around the customer and since value depends on results, value in health care should be measured by the outcomes achieved.[9]

Determining "Patient Reported Outcomes (PROs)" is one way to find out which outcomes are valued by the patient. PROs are defined as 'any report from patients about their own health, quality of life, or functional status associated with the health care or treatment they have received'.[10] Patient Reported Outcome Measures (PROMs) are developed on the basis of PROs and can be used for measurement of the quality of care.[11] There is little experience in performing PROMs related research at the ED, however recent research shows that the measurement of PROMs in Acute Medical Units is feasible.[6,12,13]

One of the 6 domains for improvement of healthcare determined by the American National Academy of Medicine (NAM) is patient centeredness, defined as: 'providing care that is respectful of and responsive to individual patient preferences, needs and values, and ensuring that patients` values guide all clinical decisions.[14] By

determining PROs in patients visiting the ED, patients' needs and values concerning their health during their ED visit can be clarified. Thereafter, establishing PROMs will lead to systematic measurement of the patient perspectives, which improves patient outcomes in several ways: it provides information only the patient can assess and improves communication between professionals and patients.[15-17] Consequently, these outcomes can be used in the conversation between patients and professionals during the decision making process and therefore may improve shared decision making. In this study we aimed to determine PROs in internal medicine patients at the ED, as a first step in the development of PROMs for acute medical care.

Objective

The primary objective of this study was to collect patient perspectives on outcomes of acute care to determine relevant PROs.

METHODS

Study design

We performed a qualitative study in 3 hospitals in the Netherlands (Máxima Medical Centre, Veldhoven; Amsterdam University Medical Centres, location VUmc and location AMC) using semi-structured interviews with patients who were treated at the ED by an internal medicine physician. One focus group and 28 individual interviews were held; the focus group took place within 21 days after the ED visit, the interviews were performed within 14 days after the ED visit. Interviews were held by two female Medical Doctors and PhD-students trained in qualitative research (MK/EvdE) and the focus groups were led by an experienced quality officer (MvB).

The procedure for determining relevant PROs in acute medical care was based on the guideline "PROs and PROMs" from the Dutch National Federation of University Medical Centres (NFU).[17]

The study protocol was approved by the Medical Ethics Committees of the participating hospitals. Written consent was obtained from all patients.

Patient involvement

Patients were not involved in the initial design of the study. However, based on comments of the first participating patients, we changed the design to diminish the burden on participants by performing interviews at patients' homes or by telephone. Interviews were evaluated after finishing and the perceived relevance of our study was discussed with participants. Patients played the central role in this study in determining relevant outcomes of acute care.

Selection of participants

Participants were recruited between March and July 2018. All patients older than 18 years presenting for internal medicine at the ED at any time of the day, were approached by their treating physician and introduced to one of the researchers. Patients who were unable to participate in an interview due to language barriers, altered mental status or inability to provide informed consent, were excluded.

Initially, patients were called within 7 days after their ED visit to provide them with additional information about the study and to schedule the research interview. A maximum of 8 attempts was made to reach each patient who agreed to be contacted. During the study, it appeared that the majority of patients was incapable or unwilling to join a focus group conducted in the hospital. Therefore, we decided to perform individual semi-structured interviews instead. Patients were provided with written information about the study and if they were willing to participate, the interview took place during their admission following the ED visit, or when discharged from the ED at patients' homes or by telephone. In some cases a relative was present during the interview.

Data collection and processing

At the start of inclusion, we did not find an existing model about PROs for ED patients in the literature. However, Patient Reported Experience Measures (PREMs) for ED care have been used for determining relevant outcome domains.[18-21] On top of that, information shared by patients about their experiences of emergency care at an online review site was used as well.[22] We designed an interview guide and topic list for the focus group and semi-structured interviews, making use of the expertise of the researchers, acute physicians and a quality officer. Questions aimed at obtaining the patients' perspectives on outcomes relevant to their ED visit. Main themes were symptoms, concerns, physical and social functioning. We also included questions about expectations of ED care, reason for presentation at the ED and experiences of the care delivered. At an early stage of our study, the study of Vaillancourt et al. was published.[12] In this study relevant PROs for patients treated and directly discharged from the ED in Canada were determined. We compared our interview guide with the questionnaire of Vaillancourt et al. and made some minor adjustments.[12] Input of the first 4 interviews was assessed, making sure all themes were covered, to determine the final interview guide (appendix 1).

The focus groups with patients lasted 2 hours and individual interviews lasted 20-30 minutes, with the interviewing investigators making sure all themes were covered in the discussion. Audio recordings were made and field notes were taken. Additional patients were interviewed until saturation was reached, i.e. no new themes came

up during the interviews, which was evaluated by two investigators (MK/TZ) during preliminary analysis.

Analysis

Interviews were transcribed from the audio tapes without returning the transcripts to the participants for comments. Two investigators (MK/TZ) coded the transcripts based on open coding in which inductive coding techniques were utilized according to the qualitative content analysis process, leading to establishment of general themes reflecting the acquired data.[23] Firstly, the 2 investigators developed, independently, a concept coding-framework. Codes in this framework were based on the research question and emerged from review of the data of the first 3 interviews. For coding of patient experiences we used domains of the Picker Patient Experience Questionnaire as a guideline.[24] For other emerging themes, the most suitable coding terms were defined by the investigators after close reading of the interviews and a line-by-line discussion. After coding 5 interviews with close reading and continuous comparison of the coding, the 2 investigators determined a final coding framework which was applied to all transcripts. Discrepancies in coding were handled through discussion. Participants did not provide feedback on the findings. Categories were composed by the same 2 investigators after coding.

For coding and analysis of the interviews, the software program *QDA miner Lite v2.0.5* was used.

RESULTS

Patient characteristics

We interviewed 30 patients who visited the ED and were treated by an internal medicine physician, 14 patients were recruited at the Máxima Medical Centre, 7 patients at the Academic Medical Centre and 9 patients at the VU University Medical Centre. 9 patients were interviewed by telephone, 2 patients participated in a focus group, 4 patients were interviewed at home and 14 patients were interviewed during admission. The mean age of participating patients was 68 years. Sixteen (53%) patients were female, 22 (73%) patients were married, 26 (87%) patients were born in the Netherlands. Twenty-eight (93%) patients were hospitalised after ED visit. Twenty-five (83%) patients were referred to the ED, which is a reliable reflection of the Dutch situation. The main reason for seeking help at the ED was experiencing symptoms and in a few cases the decision of the GP or due to laboratory results. The most frequently reported primary complaints were fever and pain (table 1).

Table 1. Patient characteristics

Patient characteristics	Interviewed (n=30)
Age, mean (range), y	68 (28-90)
Female, %	16 (53)
Married, %	22 (73.3)
Living alone, %	5 (16.7)
Children, 1 or more, %	23 (76.6)
Receiving homecare, %	7 (23.3)
Admitted after ED visit, %	28 (93.3)
Primary complaint	
Fever	9 (30%)
Pain	6 (20%)
Cardiopulmonal	3 (10%)
Gastro-intestinal	4 (13%)
Urinary tract	2 (7%)
Dermal	1 (3%)
Non specific	2 (7%)
Laboratory findings	3 (10%)
Level of education	
Unknown/not answered	2 (7%)
Less than high school	2 (7%)
High school	2 (7%)
College	13 (43%)
Postgraduate degree	11 (37%)
Country of origin	
Netherlands	26 (86.7%)
Other	4 (13.3%)
Main reason for ED visit	
Symptoms	27 (90%)
Laboratory results	3 (10%)
Way of referral	
Self-referral	3 (10%)
GP	19 (63%)
Specialist	6 (30%)
Ambulance	2 (7%)

Themes mentioned

We identified common themes mentioned by patients during the interviews. To establish a model of PROs for acute medical patients at the ED, we grouped the themes mentioned into 5 different domains: 1) relief of symptoms, 2) understanding the diagnosis and cause of symptoms, 3) presence and understanding of the diagnostic or therapeutic plan, 4) reassurance and 5) patient experiences. Table 2 represents coded subcategories and associated quotes for each domain.

Table 2. Patient reported outcomes: domains, subcategories and quotes

Domain	Subcategory	Representative quote
Relief of symptoms	Degree of relief of symptoms	*P4: It was very important for me that the vomiting and abdominal pain was relieved.* *P7: They gave me oxygen trying to relieve my shortness of breath, which I think is important.* *P24: I wanted to stop vomiting.* *P26: The pain and dyspnea were very bad. So I'm happy when they do something against it.*
	Duration until symptom relief	*P2: I wanted to get better, as soon as possible.* *P22: When someone arrives at the ED they directly have to give something against the pain. I just wanted to get rid of the pain.*
	Impact on function	*P16: They had to relieve the fever, so that I can function normally again.* *P25: I wanted to get better. The only thing I wanted was to stand on my legs again.*
Understanding the diagnosis and cause of symptoms	Understanding the diagnosis and cause of symptoms	*P2: At the ED I want to know, as quickly as possible, what the diagnosis is.* *P7: I'm worried when I don't know what is causing the shortness of breath.* *P11: I'm never ill. Therefore, I wanted to know what is making me ill?* *P21: The worst thing is not knowing what's wrong. For me it's important that they explain what they think the diagnosis is; what's the reason for my complaints?* *P28: I want to know what is causing the problem.*
	Understanding the prognosis	*P5: I want to know if the cancer is spread through my body and what that means for the treatment.* *P19: I want to know how to deal with my shortness of breath. What can I do? I just want to be able to cycle again.*

Table 2. (Continued)

Domain	Subcategory	Representative quote
Presence and understanding the diagnostic or therapeutic plan	Understanding the diagnostic plan	*P8: The fact that you know what they are going to do with you, is very important for me. They would complete some more tests after my stay at the ED to evaluate the cause of my blood loss.* *P10: I had to stay in the hospital for one night to observe my heart rate. That was very clear to me.*
	Understanding the treatment plan	*P1: Doctors repeatedly have to tell what they are going to do and why, that reassures me.* *P3: They explicitly told me what they were going to do with me. At the ED they gave me intravenous fluid and antibiotic, because the oral antibiotic I used at home didn't work well. It is important to know why they do that.* *P5: They told me I had too little red blood cells and that they had to give me a blood transfusion.* *P26: They provide me with updates on the treatment plan. That is important for me, because otherwise you might feel forgotten.*
	Understanding follow-up after discharge from the ED	*P2: They told me that I could go home with oral antibiotic pills. And they said it was important to drink enough water. That was clear to me, which gave me confidence going home.* *P18: When you arrive at the ED with fever, you know that they can't resolve the problem within 5 minutes. But it's important that they tell you something about the plan they have for you thereafter.*
Reassurance		*P1: I was worried because a friend of mine died last summer and I was afraid of dying at the ED. I needed more reassurance, not from a nurse or a medical student, but a real doctor.* *P5: It gives reassurance, when you're treated nicely and they give you enough attention.* *P8: The clear explanation about my symptoms and diagnosis reassured me.* *P14: The fact that they tell you what will happen and noticing they are doing everything possible for you, reassured me.* *P20: The expertise of the doctors and the fact they know my medical history gives me confidence.*

Table 2. (Continued)

Domain	Subcategory	Representative quote
Experiences	Coordination of care	*P4: The nurses and doctors asked me the same questions over and over again. It seemed they did not communicate.* *P29: I had to wait for the radiologist quite a long time. However, it helped that they told me that 2 critical patients at the ED needed help more urgently.*
	Continuity and transition	*P16: I went home quite insecure. I didn't know what would happen next and when I had to come back.*
	Information and education	*P26: They continuously updated me on what was going on and which diagnostics were planned. That's good.*
	Emotional support	*P6: They really listened to me and payed attention. They frequently asked if I needed anything.* *P24: The nurses did what they needed to do. They put you at ease.*
	Patient preferences	*P30: The doctor told me she thought it was better to be admitted, but she asked me wat I thought about that. That was really nice.* *P24: The doctor told me what condition I was suffering from and which treatment options were available. He explained the options really well so that I could choose which one suited me the most.*
	Family involvement	*P6(daughter): I think we were well informed at the ED. They explained what they were doing and answered all my questions.* *P12: I helped that my wife was with me, she supported me emotionally. She received all the information of the doctors and could explain it to me, while I was too ill.*

Relief of symptoms

The majority of patients reported that relief of symptoms was an important outcome of ED care. Especially in patients suffering from shortness of breath, pain or vomiting, reducing symptoms was their primary expectation regarding outcomes of care, as voiced by patient 4*: "I didn't care what they were doing to me, I just wanted less abdominal pain and something to relieve the vomiting".* Within this category, the degree of symptom relief, the duration until relief and the impact on function were mentioned as relevant and appeared to influence feelings of safety and reassurance: a prompt and adequate relief of symptoms was associated with relief of anxiety and trust in health care professionals. Patient 22 mentioned: *"I only wanted to get rid of the pain. The painkiller they gave me at the ED worked immediately, which made me feel safe."*

Understanding the diagnosis and cause of symptoms

Twenty-five patients mentioned that one of the most important outcomes was a clear explanation of their symptoms and diagnosis. The uncertainty patients experience suffering from symptoms whilst not knowing their diagnosis, underlies this important outcome: *"For me it is really important that doctors explain what they think is causing my complaints. The worst part is not knowing, feeling insecure." (P21)* A clear explanation about symptoms and diagnosis may even lead to relief of feeling insecure. In contrast, a vague explanation of diagnosis could lead to ongoing uncertainty by patients, as happened to patient 4: *"They thought I had a urinary tract infection. That wasn't clear for me because I had pain in the right upper part of my abdomen. I thought that a urinary tract infection causes pain in the lower abdomen".*

Only a few patients, most of them suffering from a chronic condition, desired information about the prognosis of their disease.

Presence and understanding of the diagnostic or therapeutic plan

Presence and understanding of the diagnostic or therapeutic plan was evaluated as an important outcome of the ED visit by 24 patients. The treatment plan encompasses both the diagnostics and treatment at the ED, and the treatment afterwards, such as instructions for home care, decision to admit and estimated duration of admission. Many patients think that having an estimation about the waiting time at the ED is very important, because feeling left alone at the ED occurs easily and causes distress: *"I just wanted someone who updated me on a regular basis. It feels good to know they are busy for you. Without information you're just lying there thinking: they probably have forgotten me." (P23)*

Patients also expressed the need for clear answers on their questions and felt frustrated if contradictive information was given. In addition, for many patients knowing and understanding the treatment plan contributed to feeling reassured

by taking insecurity away. An important item mentioned is information about being admitted or not, as patient 13 said: *I was anxious, because I did not know if I had to be admitted or would be discharged home. It took hours waiting for this decision and all that time I did not know anything."*

Reassurance

The majority of patients reported reassurance as a relevant outcome of ED care. Reassurance seems to be a broad concept, as different explanations are given. Most patients explained reassurance as relief of the feelings of anxiety or insecurity. These feelings were mostly triggered by not knowing the cause of symptoms and whether symptoms could become even more severe. In these cases, in general, reassurance could be reached by a clear explanation about the cause of symptoms or a treatment plan. For example, patient 18: *"Reassurance is important. If they tell you the diagnosis cancer, that isn`t really reassuring. However, knowing what you're suffering from is always better than not knowing. Reassurance includes being well-informed."* Others just wanted to hear "everything will be okay". In addition, experiencing symptom relief due to treatment also decreased feelings of anxiety.

For many patients reassurance included also the feeling of being in good hands, which is explained as a combination of safety and professionalism. For some patients this feeling is instantly being met by arriving at the ED, related to the diagnostic options and complex treatment possibilities. For others, the availability of their medical history and medication in an electronic patient record, a quick response to ringing alarms or prompt therapy, leads to feeling safe as patient 11 mentioned: *"The nurse immediately recognised the high fever and told me she had to follow a specific protocol and promptly administer antibiotics. She explained why this had to happen, which made me feel really safe."* Furthermore, a professional attitude of the staff, for example a kind approach, personal attention and recognition of complaints, is for many patients related to confidence in healthcare and diminishes feelings of insecurity.

Finally, some patients mention that the consequences of not being reassured may influence daily life: *"My wife and I still have concerns. Every evening before I go to bed I measure my temperature, just to be sure that's fine. I needed more reassurance, not from a nurse or a medical student but from a real doctor." (P1)*

Of the patients not mentioning reassurance as a relevant outcome of acute care, the majority suffered from chronic diseases and are familiar with the ED and the cause of their recurrent symptoms. Some of them specifically mentioned that, if they would arrive at the ED with another complaint than usual, they probably would seek reassurance.

Experiences

Many patients reported experiences as important factors for satisfaction about their ED visit and perception of health care quality. These experiences reflect all themes mentioned in the Picker Patient Experience Questionnaire[24]: coordination of care, continuity and transition, information and education, emotional support, patient preferences and family involvement. Themes mentioned most often were waiting times, followed by a kind approach of health care providers. The majority of patients expected short waiting times because they were referred to the ED, which to them implied that something was seriously wrong and that they should therefore be helped quickly. Patient 2 explained this clearly: "*I'm referred to the ED. Apparently there is a possibility that something is seriously wrong, so I expect they will help me quickly. That is why it is called Emergency Department."* If diagnostics or therapy are initiated without long waiting times, patients experience this as safe and this leads to confidence and the feeling to be in good hands. In contrast, patients who experienced long waiting times, often felt forgotten which triggered anxiousness. However, most patients could accept longer waiting times if they were informed that higher priority patients required attention prior to them. In addition, a kind approach of health care professionals is highly valued by many patients and an empathic attitude may help patients coping with their illness or stay at the ED. It may even lead to feelings of reassurance: *"I felt that I could relate to the doctor. I felt he took my problems seriously and that reassured me." (P30)*

DISCUSSION

Defining PROs for acute medical patients provides a basis for increasing patient-centeredness at the ED and reveals themes valued by patients in acute care. Although patients treated by an internist reflect a heterogeneous population, mostly not having a diagnosis when they enter the ED, we found common themes in outcomes valued by patients. These themes can be classified in 5 domains: relief of symptoms; understanding the diagnosis and cause of symptoms; the presence and understanding of a diagnostic or therapeutic plan; reassurance; and patient experiences.

The major part of the themes mentioned as important outcomes of acute care, was in fact patient experiences. However, while researchers and doctors try to distinguish Patient Reported Outcomes from Patient Reported Experiences, patients do not. In their perception of quality of care, both outcomes and experiences play an important role. Therefore, in this study, we include experiences as well as outcomes as relevant domains for evaluating the quality of acute care.

Health care leaders and many researchers have tried to improve the quality of care at the ED by incorporating the patient perspective and focusing on patient experiences and satisfaction.[19-21,25] Staff-patient communication, ED waiting times, expectations and experience of care all contribute to patient satisfaction.[26] In our study, patients reported all of these themes and even indicated an association between these experiences and feeling reassured, which is consistent with findings in the study of Body et al.[27] In addition, a positive experience is associated with superior outcomes including mortality, morbidity and length of stay.[28] This shows the importance of including patient experiences as a 5th domain in evaluating the quality of care, which is new in comparison to the study of Vaillancourt et al.[12]

We found that the domains of understanding the diagnosis and having a treatment plan are mentioned as relevant outcomes of acute care and influenced feeling reassured. We noticed that these domains influence feelings of anxiety or emotional distress and therefore could be considered as derivative outcomes of mental health. This hypothesis is supported by the findings of Body et al.,[27] who found that suffering in patients at the ED is partly due to physical symptoms, but often caused by emotional distress. Relief of mental suffering in this context can be achieved by providing information about the diagnosis and treatment plan.

In this study patients indicated that an important outcome of their ED visit was symptom relief, in particular in patients experiencing symptoms such as pain, vomiting and dyspnoea. Pain relief is a common and well-known reported outcome of patients visiting the ED.[29,30] In Dutch EDs, only pain is assessed on a structural basis using the Visual Analogue Scale or Numeric Rating Scale. It is useful therefore to pay more structural attention to other complaints such as dyspnoea and vomiting.

Understanding the diagnosis and cause of symptoms proved an important outcome for patients seeking help at the ED. A study focussing on patient needs at the ED already revealed that many patients seek emergency care to get a diagnosis.[31] However, upon closer examination patients appear to not only desire an explanation for their symptoms, but also treatment and guidance for symptoms and clear communication about testing, treatment and diagnosis, which is in line with our findings.

Our study made clear that patients would like to be well informed about the diagnostic and treatment plan, including diagnostics or treatment at the ED and thereafter. Having a plan, for example an estimation of waiting time and order of testing during the ED visit and instructions for discharge, is already part of the (Dutch) Consumer Quality Index – Emergency Department.[26] This includes questions such as: “Were you informed by your health care professional about the next steps in

your treatment?” or “Did your health care professional tell you at what moment you could restart your normal daily activities?” Although these questions are indicative of discussion of the treatment plan, it does not say much about the quality of the conversation. Attention for the quality of the conversation is important, because an association between patient-centred communication and patient satisfaction has been demonstrated.[32]

Reassurance appeared to be another relevant outcome of ED care for many patients. However, patients reporting made clear that reassurance cannot be reached in one specific manner for all patients. Some patients were already reassured by arriving at the ED, while for other patients a clear understanding of the diagnosis and treatment plan was necessary. Themes associated with reassurance were professionalism, clear communication, confidence in the staff and service, understanding the treatment plan, understanding the diagnosis, relief of symptoms and a short waiting time. These themes are congruent with the conceptual model of Togher et al.,[33] who interviewed patients on relevant outcomes of ambulance services. Clearly, there is an association between understanding the treatment plan or diagnosis, symptom relief and patient experiences, and feeling reassured, which we incorporated in our conceptual model.

We propose a conceptual model of relevant PROs for acute medical care at the ED, which shows the potential association between the different outcome domains (figure 1). It shows that among other things, understanding the diagnosis and the presence of a plan are essential themes at the ED, highly valued by patients. In the perspective of shared decision making, a first step to enable shared decision making at the ED, is to communicate the diagnosis and therapeutic or diagnostic plan in an understandable way. In addition, as patients are seeking reassurance, we believe that professionals should ask the patients what they can do to reassure them.

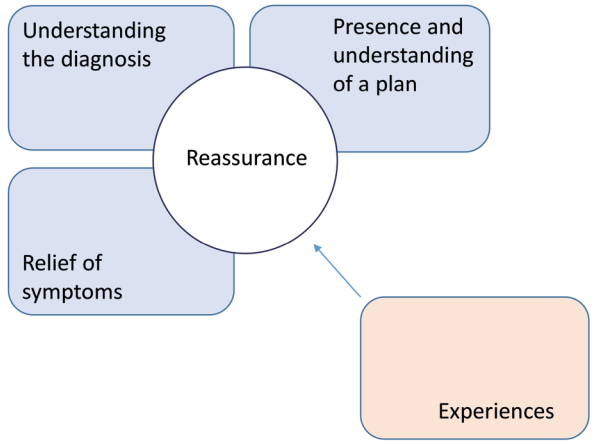

Figure 1. Proposed conceptual model of patient reported outcomes of acute care, showing the relevant domains and their mutual connection

Limitations

During the inclusion of participants, we did not register those patients who were unwilling or unable to participate in the study. We don't know if this group differs from the interviewed group, though considering the heterogeneity of the interviewed group we don't expect major differences. Of note, our study population was relatively well educated, which may have caused selection bias. Therefore, validating the conceptual model in at least a lower educated patient group would have strengthened our findings.

Due to suboptimal enrolment in focus groups, we conducted individual interviews. Although individual interviews preclude interaction between participants, we are convinced that saturation of data has been reached. Theoretically, interviews held by telephone may prevent receiving signs via facial expression or body language. However, we conducted most interviews face-to-face and taking those experiences into account, we do not think that we missed important facial expressions or expressions through body language during the interviews held by telephone.

Hypothetically, relevant outcomes of acute care may differ between admitted and discharged patients. In our study we have used a convenience sample and as a result we may have underreported discharged patients. Yet, in the study of Vaillancourt et al,[12] performed in Canada in patients treated by an ED physician, who were

immediately discharged, the same relevant outcomes were found. In addition, a meta-synthesis of Graham et al. shows that the reported relevant patient experiences in our study align with the experiences found in their study.[34] This makes it plausible that admitted and discharged patients, irrespectively of their treating specialist, value the same outcomes while being treated at the ED.

CONCLUSION

There is an increasing demand for improvement of quality of care and achieving high value for patients, taking the patient perspectives into account. However, partly due to the acute setting and heterogeneous population, development of patient-centered quality indicators at the ED has received little attention in the past. We inventoried 5 core domains representing PROs of patients who visit the ED for internal medicine in the Netherlands, which are: relief of symptoms, understanding the diagnosis, understanding treatment plan, reassurance and patient experiences. We believe that the patient perspective should be incorporated in daily practice. Doctors can use the found domains in conversations with patients to evaluate the delivered care. Furthermore, based on the findings of this study, we will develop Patient Reported Measures for acute care, with the ultimate aim of organising high-quality patient-centred care at the ED. This will encourage the conversation between patients and professionals at the ED, as a first step to shared decision making.

REFERENCES

1. Moes FB, Houwaart ES, Delnoij DMJ, et al. Stranger in the ER; Quality indicators and third party interference in Dutch emergency care. J Eval Clin Pract 2018;6:10.
2. Dijk W, van der Eijk J, Dekker M, et al. (Accessed: January 2018) Het tekort aan uitkomstindicatoren. Retrieved from: https://www.zorgvisie.nl/blog/het-tekort-aan-uitkomstindicatoren.
3. Hung KY, Jerng JS. Time to have a paradigm shift in health care quality measurement. J. Formos Med Assoc 2014;113(10):673-9.
4. Inspectie voor de Gezondheidszorg. Basisset medisch specialistische zorg kwaliteitsindicatoren 2018. August 2017
5. Lindsay P, Schull M, Bronskill S, et al. The development of indicators to measure the quality of clinical care in emergency departments following a modified-delphi approach. Acad Emerg Med 2002;9(11):1131-9.
6. Samuels-Kalow ME, Rhodes KV, Henien M, et al. Development of a patient-centered outcome measure for emergency department asthma patients. Acad Emerg Med 2017;24(5):511-522.
7. Rising KL, Carr BG, Hess EP, et al. Patient-centered outcomes research in emergency care: opportunities, challenges and future directions. Acad Emerg Med 2016;23(4):497-502.
8. Burstin HR, Conn A, Setnik G, et al. Benchmarking and quality improvement: the Harvard emergency department quality study. Am J Med 1999;107(5):437-49.
9. Porter M. What is value in health care? NEJM, 2010;363(26):2477-2481
10. Cella D, Hahn EA, Sally MA, et al. Methodological issues in the selection, administration and use of patient-reported outcomes in performance measurement in health care settings. 2012. Reached via https://www.zorginzicht.nl/kennisbank/Paginas/prom-cyclus-stap-2-selecteren-pros.aspx
11. Weldring T, Smith SMS. Patient- reported outcomes (PROs) and Patient reported outcome measures (PROMs). Health services insights 2013;6:61-68.
12. Vaillancourt A, Seaton MB, Schull MJ, et al. Patients' perspective on outcomes of care after discharge from the emergency department: a qualitative study. Ann Emerg Med 2017;70(5):648-658.
13. Van Galen LS, Van Der Schors W, Damen NL, et al. Measurement of generic patient reported outcome measures (PROMs) in an acute admission unit; a feasibility study. Acute medicine 2016;15(1):13-19.
14. Institute of Medicine. Crossing the quality chasm: a new health system for the 21ste century. Washington. National Academy Press: 2001.
15. Dawson J, DollH, Fitzpatrick R, et al. The routine use of patient reported outcome measures in healthcare settings. BMJ 2010*;18:*340.
16. Greenhalgh J, Long AF, Flynn R. The use of patient reported outcome measures in routine clinical practice: lack of impact or lack of theory*?* Soc Sci Med. 2005;60(4):833-43.
17. Terwee C, Van Der Wees PJ, Beurskens S, et al. Handreiking voor de selectie van PROs en PROMs. 2015.

18. Bos N, van Stel HF. Consumer Quality Index SEH. Bepalen van het discriminerend vermogen. 2013. Retrieved via: https://www.zorginzicht.nl/.../Spoedeisende%20hulp%20(SEH)/.../CQI%20SEH%20O
19. Bos N, Seccombe IJ, Sturms LM, et al. A comparison of the quality of care in accident and emergency departments in England and the Netherlands as experienced by patients. Health expectations. 2016;19(3):773-784
20. Male L, Noble A, Atkinson J, et al. Measuring patient experience: a systematic review to evaluate psychometric properties of patient reported experience measures (PREMs) for emergency care service provision. Int J for Quality in Health Care. 2017;29(3):314-326
21. McCusker J, Cehn-Sahin D, Cossette S, et al. How older adults experience an emergency department visit: development and validation of measures. Annals of Emergency Medicine. 2018;7(6):755-766
22. Redactie Zorgkaart Nederland. Veel onvoldoendes voor spoedzorg. (Accessed June 2018) https://www.zorgkaartnederland.nl/feiten-en-cijfers/veel-onvoldoendes-voor-spoedeisende-hulp-op-zorgkaartnederland
23. Elo S, Kyngas H. The qualitative content analysis process. *J Adv Nurs*. 2008;62(1):107-115
24. Jenkinson C, Coulter A, Bruster S, et al. The Picker patient experience questionnaire: development and validation using data from in-patient surveys in five countries. International journal for quality in health care. 2002;14(5): 353-358
25. Sonis JD, Aaronson EL, Lee RY, et al. Emergency department Patient experience: a systematic review of the literature. J of patient experience. 2018;5(2):101-106
26. Bos N, Sturms L, Schrijvers AJP, et al. The development and first use of the Consumer Quality Index for the accident and emergency department. BMC Health serv res. 2012;12:284.
27. Body R, Kaide E, Kendal S, et al. Not all suffering is pain: sources of patients' suffering in the emergency department call for improvements in communication form practitioners. Emerg Med J. 2015;32:15-20
28. Doyle C, Lennox L, Bell D. A systematic review of evidence on the links between patient experience and clinical safety and effectiveness. BMJ Open, 2013;3e001570
29. Motov SM, Khan AN. Problems and barriers of pain management in the emergency department: are we ever going to get better? J Pain Res. 2008;9(2):5-11
30. Gaakeer MI, Van Lieshout JM, Bierens JJ. Pain management in emergency departments: a review of present protocols in the Netherlands. Eur J Emerg Med. 2010;17(5):286-9.
31. Gerolamo AM, Jutel A, Kovalsky D, et al. Patient-identified needs related to seeking a diagnosis in the emergency department. Annals of Emergency Medicine. 2018;72(3): 282-288
32. Finefrock D, Patel S, Zodda D, et al. Patient-centered communication behaviours that correlate with higher patient satisfaction. J Patient exp. 2018;5(3):231-235
33. Togher FJ, O'Catharin A, Phung VH, et al. Reassurance as a key outcome valued by emergency ambulance service users: a qualitative interview study. Health expectations. 2014;18(6):2951-2961
34. Graham B, Endacott R, Smith E, et al. 'They do not care how much you know until they know how much you care': a qualitative meta-synthesis of patient experience in the emergency department. Emerg Med J. 2019;0:1-9

Appendix 1: Interview guide

Introduction questions
Why did you visit the ED? What convinced you to go there?
How did you experience your ED visit? Can you describe what happened?

Transition question
What was the purpose of your ED visit? What were you hoping to get out of the visit?
What did you expect from the ED visit?

Key questions
Looking back at your stay at the ED, which things did really matter to you? What things are important to you to happen or not to happen?
What are the things a doctor should know or ask for?
How did you feel during your stay at the ED? Did a health care professional pay attention to your feelings?
Reflecting on your experience at the ED, was there anything that didn't happen which you expected to happen?
What does the ideal ED, for you, look like?
If you had to rate your ED visit, which grade would you give and why?

Ending question
Is there anything you'd like to mention, that we didn't talk about?

QUALITY OF ACUTE CARE: A PATIENT-CENTRED APPROACH. VALIDATION AND USAGE OF THE PATIENT REPORTED MEASURE-ACUTE CARE IN THE NETHERLANDS

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ABSTRACT

Background

Providing high quality care is important and has gained more attention since the introduction of value-based healthcare. Quality of care is most meaningful when applicable to the individual patient. Therefore, patient-centeredness is one domain for quality improvement determined by the Institute of Medicine, aiming to deliver care responsive to the patient. The development and implementation of patient reported outcome- and experience measures can be used for this goal. Recently, we developed the Patient Reported Measure (PRM)-acute care, based on five relevant domains to evaluate and improve the quality of care at the Emergency Department (ED).

Objective

We aim to validate the PRM-acute care, in order to evaluate and improve patient-centred care at the ED.

Methods

We performed a prospective questionnaire-based multi-centre study. Patients ≥18 years presenting for internal medicine at the ED were eligible. The validity of the PRM-acute care was evaluated according to the COSMIN-criteria. We performed hypotheses testing to evaluate construct validity. The perceived quality of care was evaluated by statistical analysis.

Results

Face- and content validity was evaluated based on previously performed research and deemed good. Construct validity was supported by demonstrated differences between subgroups; patients with severe symptoms had a higher perceived quality of care. The correlation between overall satisfaction and the total mean score of the PRM-acute care (r=0,447, p=0.01) was significant. Overall, patients reported a mean perceived quality of care of 4.67/6.0.

Conclusion

The PRM-acute care is a valid instrument to measure the perceived quality of care in an acute setting. Additionally, patients reported a good perceived quality of care at the ED with scores ranging from moderate to well for each of the relevant domains. Therefore, we believe that the PRM-acute care can be implemented in daily practice to evaluate the perceived quality of care and to improve the quality of acute care.

INTRODUCTION

The increasing attention that providing high quality care receives since the introduction of value-based healthcare creates a need for transparency of healthcare quality.[1] The Institute of Medicine determined patient-centeredness, defined as providing care that is respectful of and responsive to individual patient preferences, needs and values, and ensuring that patients` values guide all clinical decisions, to be one of six domains for measuring and improving healthcare quality.[2]

Patient-centeredness is important for all healthcare domains, including the field of acute medicine. The emergency department (ED) is a busy environment characterised by rapid triage, acute conditions and a high turnover. As a consequence, an ED visit can be considered as a stressful life event and associated with adverse effects on the patient's emotional state.[3] It is important that patients at the ED receive high-quality care and experience it as such. A way to assess the perceived quality of care by patients is the routine use of Patient-Reported Measures (PRMs), which consist of measures of satisfaction with outcomes of care and measures of experiences of care.[4,5] So, Patient-Reported Outcomes (PROs) and patients perceptions of experiences whilst receiving care, known as Patient-Reported Experiences (PREs), are combined in PRMs. PROs and PREs are directly obtained from the patient without the interference of a clinician and pertain to the patients' health, quality of life, and functional status associated with healthcare.[6]

Commonly used outcome indicators or Patient-Reported Outcome Measures are generally disease specific and therefore not usable at the ED, since the patient population at the ED is heterogeneous and often lacks a diagnosis.[7] In particular, patients presenting for internal medicine often suffer from multiple chronic conditions and present with non-specific complaints, which may explain why commonly used indicators do not reflect relevant outcomes for this specific group of patients.[8] In a previous study, we determined the PROs relevant to internal medicine patients in an acute setting. Five core domains were identified, namely relief of symptoms, understanding the diagnosis, understanding treatment plan, reassurance and patient experiences.[8] Based on these domains, we developed a PRM-acute care in order to assess the perceived quality of acute care for internal medicine patients. In this study, we primarily aim to assess the validity of the PRM-acute care and secondly, to gain insight into the current perceived quality of acute care, with the overarching goal to use the PRM-acute care in daily practice and improve patient-centred care at the ED.

METHODS

Study design

We performed a prospective questionnaire-based multi-centre study in two hospitals in the Netherlands (Máxima MC, Veldhoven and Amsterdam UMC, location VUmc), as part of the PROMESQUE trial. Within this trial, a baseline measurement and a consecutive intervention study was planned. This study concerns the baseline measurement. The study protocol was approved by the Medical Ethics Committees of the participating hospitals.

Selection of participants

Patients were included between January 5 and March 12, 2020. Due to regulations during the COVID-19 crisis, the inclusion of patients was terminated in both hospitals. All patients ≥18 years presenting for internal medicine at the ED were eligible for inclusion. Patients were asked by their treating physician to participate in the study. Patients who were unable to participate due to a language barrier, inability to understand the questionnaire, or severity of illness, were excluded at the discretion of the treating physician. Patients willing to participate were approached by a researcher and written informed consent was obtained. The PRM-acute care was presented to participants during admission or at home by phone, 12 to 72 hours after arrival at the ED. This timeframe was selected with the planned intervention study in mind, because the presence of researchers at the ED and visible measurements might influence the daily practice at the ED (Hawthorne effect) and as a consequence the perceived quality of care.

Development of the PRM-acute care

The development of the PRM-acute care was based on the previously determined five relevant domains for patients presenting for internal medicine at the ED, namely relief of symptoms, understanding the diagnosis, understanding the therapeutic plan, reassurance, and patient experiences.[8] A concept questionnaire was developed and presented in focus groups to 16 different experts in the field of acute medicine by a trained interviewer (MK) to explore the face- and content validity. Thereafter, cognitive interviews with 15 patients were performed by a researcher trained in qualitative interviewing (MK) in order to ensure that the questions were considered relevant and understood by patients, and to determine whether each question generated the information intended by the researchers. For all interviews a topic list was established and audio records were made. As a result, the PRM-acute care was finalised and consisted of 11 questions covering the five domains (Appendix 1). Answers to questions were scored on a Likert scale with a range of 1 to 6, except questions concerning symptoms, these were scored on a Numeric Rating Scale (NRS) with a range from 0 to 10.

The scoring model for the PRM-acute care was based on qualitative interviews with 10 patients assessing the importance of the five domains, which resulted in a total score consisting of the mean of all the reported domains. A maximum of one missing domain was accepted. The domain score was calculated as the mean score of the questions of that domain. One missing score per domain was accepted. Domain scores were defined as missing when the domain had more than one missing score, or if the domain score could not be calculated (in the case of domain 'relief of symptoms'). Most domain scores were adopted from the results on the Likert-scales ranging 1-6. However, two exceptions were made. Firstly, within the domain 'understanding the diagnosis' a grade 0 was given when a patient reported not receiving any explanation about their diagnosis. Secondly, to establish the score of the domain 'symptom relief', we calculated the percentage difference between the severity of symptoms at arrival and discharge from the ED, and converted these into a 1-6 score, as is shown in appendix 2. This grading system was based on an expert discussion and on literature, which defined the minimum clinically important difference in acute pain as 30%.[9,10]

Measurements

Perceived quality of care

Participants were asked to recall their ED visit and complete the PRM-acute care. Hospitalised patients completed the PRM-acute care on paper, preferably by themselves. If necessary, caregivers or a researcher assisted without interfering in the interpretation of the patient. Patients at home received a link to the online PRM-acute care. Overall satisfaction was scored as a report mark, ranging from 1 to 10.

Visit and patient characteristics.

Destination after ED visit, arrival and discharge date and time were extracted from the electronic patient file. Length of stay at the ED (LOS-ED) was calculated. Baseline characteristics, such as gender, age, living situation and educational level were obtained from all included patients. During the first month of the study, baseline characteristics such as gender, age and destination after ED, were also collected from patients who were not included in the study. All data were stored in a web-based database (Castor EDC).

Data analysis

Validity testing

The PRM-acute care is based on a formative model, as perceived quality of care is determined by the five relevant domains.[11,12] The validation of the PRM-acute care was executed in accordance with the COSMIN-criteria applying to a formative model.[11,13-15] Firstly, face and content validity was evaluated based on our previous study and strengthened by additional cognitive interviews in this study, as mentioned

in 'development of the PRM-acute care'. Face validity is the extent to which a test is subjectively viewed as covering the concept it purports to measure. Content validity refers to the extent to which a measure represents all facets of a given construct.

Furthermore, hypotheses testing was used to assess construct validity. Construct validity refers to the degree to which a measure actually measures the theory it purports. Hypotheses were proposed with the objective to demonstrate differences in scores between subgroups, which would establish construct validity. Previous research indicates that differences related to scores regarding quality of care are present.[16] Amongst others, a positive relationship was found between patient satisfaction of care and higher age, lesser education, trust in the medical care centre and good communication between patients and healthcare professionals.[16-18] Moreover, a negative correlation between the experience of pain and patient satisfaction is demonstrated.[18,19] However, due to mandatory guidelines on pain management, early pain recognition has gained much attention in the Netherlands which leads to prompt treatment and patient satisfaction. Lastly, a negative correlation between LOS-ED and patient satisfaction, has been reported.[20-22] Considering these findings, we propose several hypotheses regarding differences in perceived quality of care between subgroups, namely: 1) Older patients perceive a higher quality of care, 2) Patients with lower education (middle-level applied education or lower) perceive a higher quality of care, 3) Patients arriving at the ED with severe complaints (graded as 8-10), will perceive higher quality of care than patients with mild complaints (graded as 0-4), 4) Patients with a LOS-ED ≥ 4 hours, perceive lower quality of care than patients with a LOS-ED <4 hours. In addition, we explored whether differences in perceived quality of care existed between hospitalised and patients discharged directly from the ED and between patients presenting during weekdays or weekends. Moreover, while the PRM-acute care is based on a formative model, we expect that differences in perceived quality in subgroups may only be present in specific domains. Therefore, statistical analysis of differences between subgroups regarding domain scores were executed.

Lastly, with the aim of strengthening the construct, we analysed whether the total score of the PRM-acute care and the individual domains correlates with the overall satisfaction of the ED-care, graded using a report mark (range 1-10).

Statistical analysis

Patient and ED characteristics were analysed using descriptive statistics. Total- and domain scores were reported using the mean, standard deviation (SD) and 95% confidence interval (CI). To asses differences in the perceived quality of care between subgroups, unpaired T-tests and linear regression tests were used. To evaluate differences between subgroups on domain scores, the Mann-Whitney U test was

used for the following domains: relief of symptoms, understanding the diagnosis, understanding the treatment plan and reassurance. An unpaired T-test was used to analyse the domain 'experiences'. A Spearman's rho was used to analyse the correlation between the overall satisfaction and relief of symptoms, understanding the diagnosis, understanding the treatment plan and reassurance. The correlation between the overall satisfaction and the domain 'experiences' was analysed using a Pearson's rho. A p-value of 0.05 was considered significant. All analyses were performed using IBM SPSS version 26.0 for Windows.

RESULTS

Patient characteristics

We included 81 patients, of which 47 were men (58%) as is shown in table 1. The mean age of the study sample was 68 years (range 26-93). All patients lived at home, 27 (33.3%) patients lived alone and 54 (66.7%) lived together. Of all patients, 57 patients (70.4%) were treated in MMC and 24 (29.6%) patients in A-UMC. Seventy patients (86.4%) were hospitalised after their ED visit and 11 patients (13.4%) were directly discharged from the ED. Seventy patients (86.4%) were seen during week-days, whereas 11 patients were seen during weekends (13.6%).

The study participants differed in gender and destination after ED visit compared to the patients who were not included. More men participated in the study (58% vs. 42%, p=0.019) and more patients were hospitalised in the study group (86.4% vs. 13.6%, p=0.000). Patients were mostly not included because they were not asked by the treating physician to participate.

Face- and content validity

Face- and content validity was partly established in our previous study.[8] In this study, professionals in acute care recognised all domains and questions as relevant. No new themes came up during the cognitive interviews with patients and all questions were deemed relevant. Minor adjustments in the questionnaire were made based on these interviews. Additionally, we observed that all five domains were equally important to patients.

Table 1. Patient characteristics

	Number of patients	Percentage (%)
Included Patients	81	
Sex		
Male	47	58.0
Female	34	42.0
Age		
18-44 years	8	9.9
45-64 years	22	27.2
65-79 years	34	42.0
≥ 80 years	17	21.0
Living situation		
Living at home, single	27	33.3
Living at home, together	54	66.7
Nursing home	0	0
Level of education		
No education	0	0
Primary education	8	9.9
Middle-High school	25	30.9
Middle level applied education	22	27.2
Higher education	24	29.6
Missing	2	2.5
Institute visited		
MMC	57	70.4
VUMC	24	29.6
Time of presentation		
Weekdays	70	86.4
Weekends	11	13.6
Length of stay		
0>4 hours	50	61.7
≥ 4 hours	31	38.3
Destination		
Discharge	11	13.6
Admission	70	86.4
Initial graded severity of complaints		
0-4	11	13.6
5-7	18	22.2
8-10	52	64.2

Construct validity

Patients experiencing severe symptoms had a higher mean total score as was shown by linear regression. The total mean score increased on average by 0.08 for each point increase in severity of symptoms (p=0.006).The associations between age, gender, educational level, LOS-ED, discharge, and day of presentation with perceived quality were not statistically significant (table 2). Subsequently, we evaluated differences between subgroups in each domain. Most differences were found among the subgroups in the domain 'understanding the diagnosis' as presented in table 2. Patients who received less education had a greater perceived understanding of the diagnosis (mean 4.94, SD 1.39) than patients with a higher education (mean 4.14, SD 1.9) as shown by a Mann-Whitney U test (p=0.01). Furthermore, patients with a LOS-ED < 4hours (mean 5.02, SD 1.41) scored on average higher in this domain than patients with a LOS-ED ≥ 4 hours (mean 4.18, SD 1.74, p= 0.003). Additionally, a linear regression model showed a significant association between the degree of understanding the diagnosis and the initial severity of symptoms (p= 0.005). Other significant differences were found in the domain 'relief of symptoms'. Patients who experienced more severe symptoms on arrival at the ED, reported the biggest relief of symptoms. The domain score for relief of symptoms increases with 0.24 with each point increase on the NRS-scale, p=0.001. Lastly, in the domain 'patient experiences' differences were found between admitted and discharged patients as admitted patients (mean 5.36, SD 0.53) reported higher scores than the discharged patients (mean 4.97, SD 0.45), p=0,02.

Table 2. Results of hypotheses testing on total score and separate domains

	Total Score			**Relief of symptoms**			**Understanding the diagnosis**		
Higher age leads to higher perceived quality of care	*R^2* 0.00	*CI* (-0.01-0.01)	*P-value* 0.891	*R^2* 0.01	*CI* (-0.01-0.03)	*P-value* 0.307	*R^2* 0.00	*CI* (-0.03-0.02)	*P-value* 0.985
Lesser education leads to higher perceived quality of care	*Mean difference* 0.26	*CI* (-0.05-0.58)	*P-value* 0.104	*Effect size* 0.04	*Mean difference* 0.11	*P-value* 0.558	*Effect size* **0.73**	*Mean difference* **-0.08**	*P-value* **0.012**
LOS >4h leads to a lower perceived quality of care	*Mean difference* 0.22	*CI* (-0.08-0.52)	*P-value* 0.15	*Effect size* 0.12	*Mean difference* -0.39	*p-value* 0.292	*Effect size* **1.00**	*Mean difference* **0.84**	*P-value* **0.003**
More complaints/ pain leads to higher perceived quality of care	*R^2* **0.09**	*CI* **(0.03-0.14)**	*P-value* **0.006**	*R^2* **0.14**	*CI* **(0.10-0.39)**	*P-value* **0.001**	*R^2* **0.10**	*CI* **(0.07-0.36)**	*P-value* **0.005**
Difference between admission and discharge	*Mean difference* 0.31	*CI* (-0.11-0.72)	*P-value* 0.150	*Effect size* 0.00	*Mean difference* 0.40	*P-value* 0.881	*Effect size* 0.15	*Mean difference* 0.29	*P-value* 0.241
Difference between weekdays and weekends	*Mean difference* -0.09	*CI* (-0.52-0.33)	*P-value* 0.661	*Effect size* 0.02	*Mean difference* 0.02	*P-value* 0.695	*Effect size* 0.00	*Mean difference* -0.35	*P-value* 0.975
Difference between men and women	*Mean difference* -0.22	*CI* (-0.54-0.04)	*P-value* 0.09	*Effect size* *0.29*	*Mean difference* *-0.49*	*P-value* *0.113*	*Effect size* ***0.95***	*Mean difference* ***-0.4***	*P-value* ***0.004***

	Understanding the treatment plan			**Experiences**			**Reassurance**		
Higher age leads to higher perceived quality of care	*R^2* 0.01	*CI* (-0.01-0.01)	*P-value* 0.946	*R^2* 0.00	*CI* (-0.01-0.01)	*P-value* 0.943	*R^2* 0.01	*CI* (0.02-0.01)	*P-value* 0.442
Lesser education leads to higher perceived quality of care	*Effect size* 0.05	*Mean difference* -0.07	*P-value* 0.496	*Mean difference* 0.13	*CI* (-0.13-0.40)	*P-value* 0.339	*Effect size* 0.24	*Mean difference* 0.53	*p-value* 0.142
LOS >4h leads to a lower perceived quality of care	*Effect size* 0.04	*Mean difference* 0.20	*P-value* 0.573	*Mean difference* 0.23	*CI* (-0.01-0.48)	*P-value* 0.057	*Effect size* 0.00	*Mean difference* 0.23	*P-value* 0.867
More complaints/ pain leads to higher perceived quality of care	*R^2* 0.00	*CI* (-0.05-0.08)	*P-value* 0.666	*R^2* 0.01	*CI* (-0.3-0.08)	*P-value* 0.314	*R^2* 0.00	*CI* (-0.08-0.14)	*P-value* 0.594
Difference between admission and discharge	*Effect size* 0.02	*Mean difference* 0.13	*P-value* 0.708	*Mean difference* **0.40**	*CI* **(0.06-0.74)**	*P-value* **0.023**	*Effect size* 0.30	*Mean difference* 0.64	*P-value* 0.100
Difference between weekdays and weekends	*Effect size* 0.16	*Mean difference* 0.06	*p-value* 0.237	*Mean difference* -0.19	*CI* (-0.54-0.16)	*P-value* 0.274	*Effect size* 0.00	*Mean difference* 0.12	*P-value* 0.853
Difference between men and women	*Effect size* *0.02*	*Mean difference* *-0.01*	*p-value* *0.711*	*Mean difference* *0.06*	*CI* *(-0.16-0.033)*	*P-value* *0.479*	*Effect size* *0.02*	*Mean difference* *-0.29*	*P-value* *0.677*

In order to strengthen the construct, the correlation between the mean total score of the perceived quality of care and the overall satisfaction of the ED-care was tested. The mean total score was correlated to the graded overall satisfaction as is shown in figure 1 (r=0.447, p =0.01). Additionally, the scores of all domains except the domain 'relief of symptoms' were correlated with the overall satisfaction of ED-care, as analysed using Spearman's rho and Pearson's rho as presented in table 3.

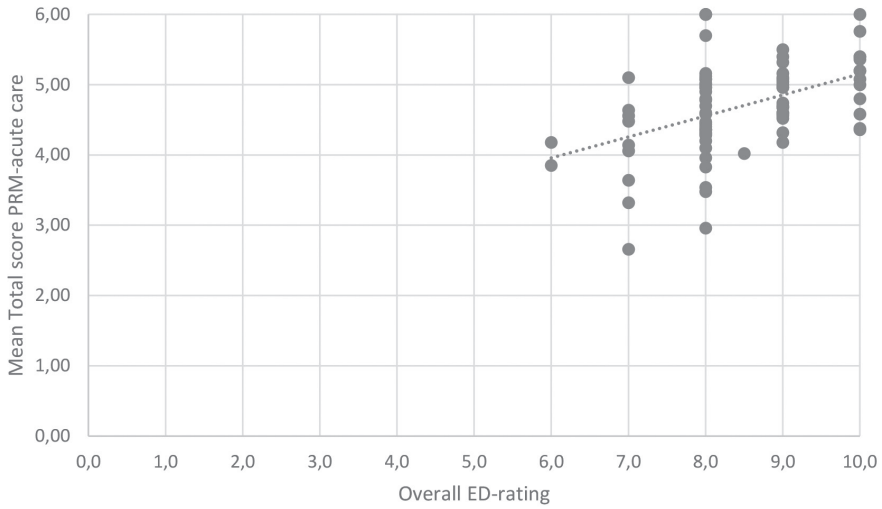


Figure 1. Correlation between total mean score and overall satisfaction at the ED

Table 3. Correlation between overall satisfaction and individual domains

Domain	Correlation co-efficient	N	P-value
Relief of symptoms	0.91	73	0.442
Understanding the diagnosis	0.32	78	0.004
Understanding the treatment plan	0.341	80	0.002
Experiences*	0.374	80	0.001
Reassurance	0.345	80	0.002

**All tests were Spearman's rho, except for the domain 'experiences'*

Perceived quality

The total score of the PRM-acute care was calculated in all patients (n=81). The mean total score for all patients was 4.67 (95% CI 4.53 – 4.82) with a range from 2.66 to 6.00 (table 4). The overall satisfaction of ED-care was 8.4/10, (range 6 to 10). Evaluation of scores per domain showed a mean score in the domain 'relief of symptoms' of 3.03 (95% CI 2.68 – 3.35) as presented in table 4. Seventy-four out of 81 patients responded to both questions within this domain. Two patients did not experience any symptoms during arrival and discharge, whereas five patients did not answer one of the two questions. These records were excluded. The domain 'understanding the diagnosis' was scored by 79 patients and had a mean score of 4.66 (95% CI 4.30 – 5.02). The domain 'understanding the treatment plan was scored with a mean of 5.33 (95% CI 5.17 – 5.49) and answered by all patients. All patients reported on the domain 'patient experiences' and revealed a mean score of 5.31 (95% CI 5.19 – 5.43). Patients graded the domain 'reassurance' (n=81) with a mean score of 4.93 (95% CI 4.67 – 5.18). A graphic overview of the distribution of scores within the domains is presented in Appendix 3.

Table 4. Mean scores per domain

Domain	n =	Mean	SD	95% CI
Relief of symptoms	74	3.03	1.40	2.70 – 3.35
Understanding the diagnosis	79	4.66	1.61	4.30 – 5.02
Understanding treatment plan	81	5.33	0.72	5.17 – 5.49
Experiences	81	5.31	0.54	5.19 – 5.43
Reassurance	81	4.93	1.16	4.67 – 5.18
Total score	**81**	**4.67**	**0.653**	**4.53 – 4.82**

DISCUSSION

This study is the first use of PRMs at the ED in the Netherlands, consisting of both outcome and experience measures. We examined the validity of the PRM-acute care following the COSMIN-criteria for a formative construct-model. Intensive previous research formed the basis of the PRM-acute care,[8] including semi-structured interviews with both healthcare professionals and patients, which was followed by cognitive testing in this study. Therefore, we deem the face- and content validity as good. Additionally, we conclude that the construct validity is adequate. This is supported by the demonstrated differences in perceived quality of care between subgroups and the correlation between the overall satisfaction of the ED-care and total score of the PRM-acute care.

The most notable difference in perceived quality of care exists between patients experiencing severe symptoms on arrival at the ED and patients with less severe symptoms. The severity of symptoms appears to be positively correlated with the total mean score of the PRM-acute care. Boudreaux et al also showed that the satisfaction level of ED-care was higher in those with serious illnesses or emergency needs.[23] We believe that our findings can be explained by the increased attention of healthcare professionals for patients who are obviously suffering and the perception of a more favourable throughput time in these patients.

Furthermore, we found differences between subgroups in specific domains of the PRM-acute care, which is important as in a formative model all domains determine the perceived quality of care. Firstly, patients who received less education did perceive a better understanding of the diagnosis. These results are in line with previous findings, showing that patients with less education tend to have a higher perceived quality of care and patient satisfaction.[24-26] Secondly, patients with a LOS-ED <4 hours had a better understanding of the diagnosis. This could be due to the complexity of the situation of patients with a LOS-ED ≥4 hours and the number of consultants involved. Research shows that the complexity of the case and the number of consultants involved are correlated with the LOS-ED.[27,28] Lastly, admitted patients were more satisfied with their ED experiences than discharged patients. This seems to be caused by a lower satisfaction with the waiting time in discharged patients. An association between perceived waiting time vs expected waiting time on patient satisfaction has been indicated previously.[29]

Moreover, we found a positive correlation between the overall satisfaction with the ED-care and the total mean score of the PRM-acute care. A positive correlation between the overall score of the ED and the domains 'understanding of the diagnosis', 'understanding of the treatment plan' and 'experiences' was also found. These correlations show that an increase in understanding the diagnosis or treatment plan, as well as better experiences, may induce an increase in overall ED-rating, which is in accordance with previous research.[25,30] The domain 'relief of symptoms' did not significantly correlate with overall satisfaction, which may be due to the selected scoring method, which was based on literature regarding only pain instead of heterogeneous symptoms. Moreover, the found correlations endorse the underlying formative model as the rated perceived quality of care increases even if only one of the domains shows an increase. However, as the correlation between overall satisfaction and the total score of the PRM-acute care knows a wide distribution, grading overall satisfaction by a report mark cannot fathom the complexity of perceived quality of care. Therefore, a more elaborate model is needed, such as the PRM-acute care model.

Due to the study design and construct model we were not able to evaluate the reliability and thus were limited to the evaluation of the face-, content- and construct validity. The validating measurements are less well-known for a formative model and therefore might seem limited. However, this does not imply that the methods we used to validate the PRM-acute care are less reliable or validating.[15]

Following a demonstrated validity of the PRM-acute care, we evaluated the perceived quality of ED-care for internal medicine patients. Overall, the perceived quality of care at the EDs was good, with a mean score of 4.67/6.0. As the Dutch healthcare system is known as outstanding in Europe, with the Netherlands being the only country consistently among the top 3 of the European Health Consumer Index,[31] these results may be an example of the high quality of care in the Netherlands. Performing this study internationally would be of interest in order to evaluate the association between the perceived quality of care and the ranking in the European Health Consumer Index.

Within the specific domains, the most remarkable findings concern the domain 'understanding the treatment plan'. In our study, patients perceive their understanding of the treatment plan good to very well. However, many studies have shown that patients regularly do not understand their treatment plan or discharge instructions.[32,33] More importantly, most patients appear to be unaware of their lack of understanding, which might be also the case in our study and an explanation for the high scores.[34,35] So, based on our results and the literature, it is important for physicians at the ED to be aware of the possible dissimilarity between perceived understanding and real understanding. The teach-back method could be used as a tool to confirm understanding and improve recall, especially in discharged patients.[36]

Evaluating the use of the PRM-acute care, we believe implementing this questionnaire into daily practice is feasible. Our study did not reveal major problems during the inclusion process, besides the challenge of reaching discharged patients. Almost all of the included patients filled out all questions and did not report any difficulties. The questionnaire is short, consisting of only 11 questions, which is not time consuming (around 10 minutes). Another study in the Netherlands also showed the feasibility of using a PROM in an acute medical unit. Patients especially appreciated the fact that their view was taken into account.[37]

LIMITATIONS

On account of the spread of COVID-19, patient based research was suspended indefinitely. Subsequently, the smaller sample size could have contributed to the inability to demonstrate differences between subgroups. One might also suggest differences are simply not there, because the healthcare system in the Netherlands is known to be outstanding for several years.[31,38] This could also be the cause for high scores of perceived quality of care among various subgroups. Especially the distribution between hospitalised and discharged patients is not optimal to identify differences between these groups, even though this distribution represents daily practice. We experienced that physicians were prone to forget to approach patients at the ED, when not reminded by a researcher. Since the admitted patients could be approached on a later moment in time, this has led to a skewed distribution between discharged and admitted patients and has contributed to selection bias.

Secondly, patients were asked to fill in the questionnaire within 12-72 hours after their ED visit, because of an intended future intervention study. This delay can affect the memory of the patient and cause recall bias.[39] To limit recall bias, patients should preferably fill out the questionnaire immediately after their ED visit.

CONCLUSION

The PRM-acute care is a valid instrument to measure the perceived quality of healthcare in an acute setting. Additionally, patients reported a good perceived quality of care at the ED and a score ranging from moderate to well was given for each of the relevant domains.

Recommendations

We recommend the use of the PRM-acute care at the ED to evaluate the perceived quality of care in order to improve the quality of care. As the PRM-acute care is able to indicate within which domain(s) improvements are needed, tailor-made adjustments can be directly implemented for every single patient and at the ED as a whole. However, when it is not possible to execute the PRM-acute care, the use of an overall satisfaction score of the ED-care can be considered as a screening tool for the perceived quality of care. We only recommend this for severely time constrained situations, as patients who perceived a low quality of care can be missed and it will remain unclear in which domain improvements could be beneficial.

REFERENCES

1. Delnoij D, Hendriks M. De CQ-index: het meten van klantervaringen in de zorg. TSG 2008;86:440-446.
2. Institute of Medicine (US) Committee on Quality of Health Care. Crossing the Quality Chasm: A New Health System for the 21st Century. Washington (DC): National Academies Press (US); 2001.
3. Faessler L, Brodbeck J, Schuetz P, et al. Medical patients' affective well-being after emergency department admission: The role of personal and social resources and health-related variables. PLoS One 2019;14(3):e0212900.
4. Crow R, Gage H, Hampson S, et al. The measurement of satisfaction with healthcare: implications for practice from a systematic review of the literature. Health Technol Assess 2002;6(32):1-244.
5. Cleary PD, Edgman-Levitan S. Health care quality. Incorporating consumer perspectives. JAMA 1997 November 19;278(19):1608-1612.
6. Weldring T, Smith SMS. Article Commentary: Patient-Reported Outcomes (PROs) and Patient-Reported Outcome Measures (PROMs). Health Services Insights 2013 Jan;6:HSI. S11093.
7. Inspectie voor de Gezondheidszorg en Jeugd. Basisset medisch specialistische zorg kwaliteitsindicatoren 2018. 2017 August.
8. Kremers MNT, Zaalberg T, van den Ende, et al. Patient's perspective on improving the quality of acute medical care: determining patient reported outcomes. BMJ Open Qual 2019 Sep 29;8(3):e000736-000736. eCollection 2019.
9. Olsen MF, Bjerre E, Hansen MD, et al. Pain relief that matters to patients: systematic review of empirical studies assessing the minimum clinically important difference in acute pain. BMC Med 2017 February 20;15(1):35-3.
10. Gridley L, van den Dolder, P A. The percentage improvement in Pain Scale as a measure of physiotherapy treatment effects. Aust J Physiother 2001;47(2):133-138.
11. de Vet, H. C. W., Terwee CB, Mokkink LB, et al. Measurement in Medicine. : Cambridge University Press; 2011.
12. Edwards JR, Bagozzi RP. On the nature and direction of relationships between constructs and measures. Psychological methods 2000 Jun;5(2):155-174.
13. Mokkink LM, Prinsen CA. COSMIN Study Design checklist for Patient-reported outcome measurement instruments. 2019 July,.
14. Mokkink LB, Bouter LM, Alonso J, et al. COSMIN Methodology for systematic reviews of Patient-Reported Outcome Measures (PROMs). Qual Life Res 2018 Feb,;27(5):1147-1157.
15. Mokkink LB, Terwee CB, Patrick DL, et al. The COSMIN checklist for assessing the methodological quality of studies on measurement properties of health status measurement instruments: an international Delphi study. Quality of life research : an international journal of quality of life aspects of treatment, care and rehabilitation 2010;19(4):539-549.
16. Sixma HJ, Kerssens JJ, Campen Cv, et al. Quality of care from the patients' perspective: from theoretical concept to a new measuring instrument. Health Expectations 1998 Nov;1(2):82-95.

17. Travaline JM, Ruchinskas R, D'Alonzo GE,Jr. Patient-Physician Communication: Why and How. J Am Osteopath Assoc 2005;105(1):13-18.
18. Otani K, Chumbler NR, Herrmann PA, et al. Impact of Pain on Patient Satisfaction Integration Process: How Patients With Pain Combine Their Health Care Attribute Reactions. Health services research and managerial epidemiology 2015;2:2333392815615103.
19. Wells N, Pasero C, McCaffery M. Improving the Quality of Care Through Pain Assessment and Management. In: Hughes RG, editor. Patient Safety and Quality: An Evidence-Based Handbook for Nurses: Rockewell MD: Agency for Healthcare Research and Quality (US); 2008. p. 469-489.
20. Nederlandse vereniging voor ziekenhuizen, NVZ, Nederlandse Federatie van Universitair Medische Centra, NFU. Vroege herkenning en behandeling van pijn. 2009.
21. Parker BT, Marco C. Emergency department length of stay: accuracy of patient estimates. The western journal of emergency medicine 2014;15(2):170-175.
22. Bos N, Sizmur S, Graham C, et al. The accident and emergency department questionnaire: a measure for patients' experiences in the accident and emergency department. BMJ Qual Saf 2013 Feb;22(2):139-146.
23. Boudreaux ED, Friedman J, Chansky ME, et al. Emergency department patient satisfaction: examining the role of acuity. Acad Emerg Med 2004 February 01;11(2):162-168.
24. Rahmqvist M. Patient satisfaction in relation to age, health status and other background factors: A model for comparisons of care units. International journal for quality in health care : journal of the International Society for Quality in Health Care / ISQua 2001;13:385-90.
25. Hall JA, Dornan MC. Patient sociodemographic characteristics as predictors of satisfaction with medical care: A meta-analysis. Social Science & Medicine 1990;30(7):811-818.
26. Alberti G. Transforming emergency care in England. Department of Health 2004 Oct 26,:1-48.
27. Brouns SH, Stassen PM, Lambooij SL, et al. Organisational Factors Induce Prolonged Emergency Department Length of Stay in Elderly Patients--A Retrospective Cohort Study. PLoS One 2015 Aug 12;10(8):e0135066.
28. Driesen, B. E. J. M., van Riet, B. H. G., Verkerk L, et al. Long length of stay at the emergency department is mostly caused by organisational factors outside the influence of the emergency department: A root cause analysis. PLoS One 2018 Sep 14;13(9):e0202751.
29. Thompson DA, Yarnold PR. Relating Patient Satisfaction to Waiting Time Perceptions and Expectations: The Disconfirmation Paradigm. Acad Emerg Med 1995;2(12):1057-1062.
30. Rapport F, Hibbert P, Baysari M, et al. What do patients really want? An in-depth examination of patient experience in four Australian hospitals. BMC health services research 2019 Jan 15,;19(1):38.
31. 2017 Euro Health Consumer Index. PharmacoEcon Outcomes News 2018 Feb;796(1):31.
32. Alberti TL, Nannini A. Patient comprehension of discharge instructions from the emergency department: a literature review. J Am Assoc Nurse Pract 2013 April 01;25(4):186-194.

33. Hoek AE, Anker SCP, van Beeck EF, et al. Patient Discharge Instructions in the Emergency Department and Their Effects on Comprehension and Recall of Discharge Instructions: A Systematic Review and Meta-analysis. Ann Emerg Med 2020 March 01;75(3):435-444.
34. Lin MJ, Tirosh AG, Landry A. Examining patient comprehension of emergency department discharge instructions: Who says they understand when they do not? Intern Emerg Med 2015 December 01;10(8):993-1002.
35. Engel KG, Heisler M, Smith DM, et al. Patient comprehension of emergency department care and instructions: are patients aware of when they do not understand? Ann Emerg Med 2009 April 01;53(4):454-461.e15.
36. Slater BA, Huang Y, Dalawari P. The Impact of Teach-Back Method on Retention of Key Domains of Emergency Department Discharge Instructions. J Emerg Med 2017 Nov;53(5):e59-e65.
37. Galen LS, der Schors W, Damen NL, et al. Measurement of generic patient reported outcome measures (PROMs) in an acute admission unit: A feasibility study. Acute Med 2016;15(1):13-19.
38. Watson R. Netherlands tops European healthcare league, with UK coming in at 12th. BMJ 2012;344:e3430.
39. Althubaiti A. Information bias in health research: definition, pitfalls, and adjustment methods. Journal of multidisciplinary healthcare 2016;9:211-217.

Appendix 1a: PRM-acute care in Dutch

VRAGENLIJST: DE ERVAREN KWALITEIT VAN DE SPOED EISENDE HULP

U bent behandeld op de Spoed Eisende Hulp voor het specialisme interne geneeskunde. Wij willen graag weten hoe u de zorg ervaren heeft en of u goed geholpen bent op de Spoed Eisende Hulp.

Wilt u terugdenken aan uw bezoek aan de Spoed Eisende Hulp en onderstaande vragen beantwoorden door het meest passende cijfer te omcirkelen?

		Geen last										Zeer veel last
1.	Hoeveel last had u van uw klachten bij binnenkomst op de Spoed Eisende Hulp?	0	1	2	3	4	5	6	7	8	9	10
2.	Hoeveel last had u van uw klachten bij het verlaten van de Spoed Eisende Hulp?	0	1	2	3	4	5	6	7	8	9	10

		Helemaal niet	Vrijwel niet	Matig	Behoorlijk	Goed	Volledig
3.	Begreep u de uitleg op de Spoed Eisende Hulp over de oorzaak van uw klachten?	1	2	3	4	5	6
	◯ *Ik heb geen uitleg over de oorzaak van mijn klachten gekregen*						
4.	Wist de arts wat de oorzaak van uw klachten was op de Spoed Eisende Hulp?	1	2	3	4	5	6
5.	Begrijpt u waarom de onderzoeken en/of behandelingen op de Spoed Eisende Hulp uitgevoerd zijn? (bijv. bloed prikken, infuus)	1	2	3	4	5	6
6.	Begrijpt u wat er nog voor u (of uw klachten) gedaan moet worden tijdens opname in het ziekenhuis of thuis?	1	2	3	4	5	6
7.	Voelde u zich gerustgesteld na uw bezoek aan de Spoed Eisende Hulp?	1	2	3	4	5	6

		Helemaal niet	Vrijwel niet	Matig	Behoorlijk	Goed	Volledig
8.	Bent u tevreden over de totale duur van uw verblijf op de Spoed Eisende Hulp?	1	2	3	4	5	6
9.	Voelde u zich veilig tijdens uw verblijf op de Spoed Eisende Hulp?	1	2	3	4	5	6
10.	Werd er door de zorgverleners naar u geluisterd tijdens uw verblijf op de Spoed Eisende Hulp?	1	2	3	4	5	6
11.	Had u vertrouwen in de deskundigheid van de zorgverleners op de Spoed Eisende Hulp?	1	2	3	4	5	6

		Zeer slecht										Zeer goed
12.	Welk cijfer zou u de Spoed Eisende Hulp geven op een schaal van 0-10?	0	1	2	3	4	5	6	7	8	9	10

Om verschillen tussen patiëntengroepen te kunnen meten, willen we nog enkele persoonlijke kenmerken van u weten. Wilt u hiervoor onderstaande vragen beantwoorden?

1. Wat is uw leeftijd?

_____

2. Wat is uw geslacht?

◯ Man
◯ Vrouw

3. Wat is uw woonsituatie?

Thuiswonend
◯ Alleen
◯ Samenwonend
◯ Verblijf in verzorgingshuis
◯ Verblijf in verpleeghuis

4. Wat is uw hoogst genoten opleiding?

◯ Geen opleiding
◯ Lagere school / basisschool
◯ Lager beroepsonderwijs / MAVO/ VMBO
◯ HAVO / VWO
◯ Middelbaar beroepsonderwijs (MBO)
◯ Hoger beroepsonderwijs (HBO)
◯ Wetenschappelijk onderwijs (WO)

Appendix 1a: PRM-acute care in English

You are treated in the Emergency Department for the specialty of internal medicine. We would like to know how you perceived the delivered care and if you feel you are treated well in our Emergency Department.

Could you please recall your Emergency Department visit and answer the following questions?

		No complaints										**Very severe complaints**
1.	What was the severity of your complaints on arrival at the Emergency Department?	0	1	2	3	4	5	6	7	8	9	10
2.	What was the severity of your complaints on departure from the Emergency Department?	0	1	2	3	4	5	6	7	8	9	10

		Not at all	**Barely**	**Moderate**	**Fairly**	**Good**	**Completely**
3.	Did you understand the explanation in the Emergency Department about the cause of your complaints?	1	2	3	4	5	6
	◯ *I did not get an explanation about the cause of my complaints*						
4.	Do you understand why additional diagnostics and treatments were executed in the Emergency Department?	1	2	3	4	5	6
5.	Do you understand the next steps in the treatment of your condition, during admission or at home?	1	2	3	4	5	6
6.	Did you feel reassured after your visit of the Emergency Department?	1	2	3	4	5	6
7.	Are you satisfied with the total length of stay in the Emergency Department?	1	2	3	4	5	6

		Not at all	Barely	Moderate	Fairly	Good	Completely
8.	Did you feel safe during your visit in the Emergency Department?	1	2	3	4	5	6
9.	Did the healthcare professionals listen attentively to you, during your stay in the Emergency Department?	1	2	3	4	5	6
10.	Did you have trust in the expertise of the healthcare professionals in the Emergency Department?	1	2	3	4	5	6

Additional questions

		Very poor										Very good
11.	How would you grade the Emergency Department in general? (on a scale form zero tot ten)	0	1	2	3	4	5	6	7	8	9	10

Patient characteristics

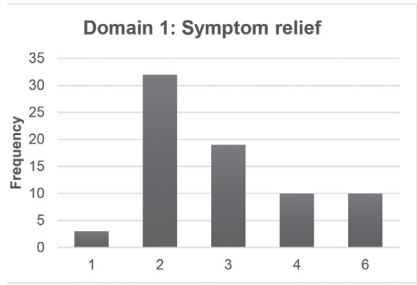
1. Gender
2. Age
3. Living situation
4. Educational level

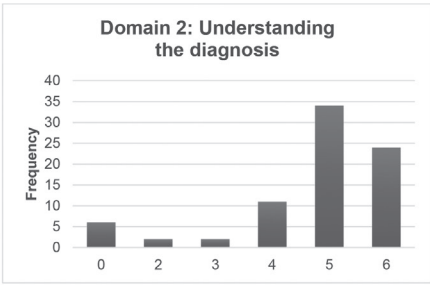
Appendix 2: scoring 'relief of symptoms'

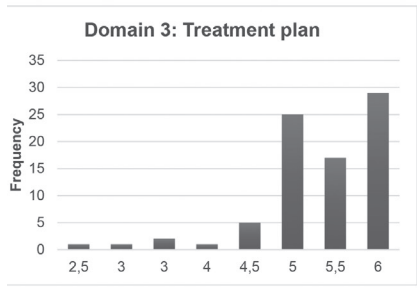
Table. scoring of the domain 'relief of symptoms'

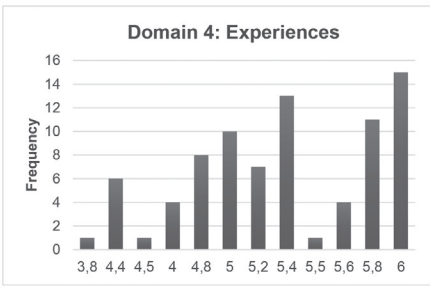
Scoring domain 1: Symptom relief	Difference (%)
1	< 0%
2	0%
3	0-30%
4	30-50%
5	50-80%
6	> 80%

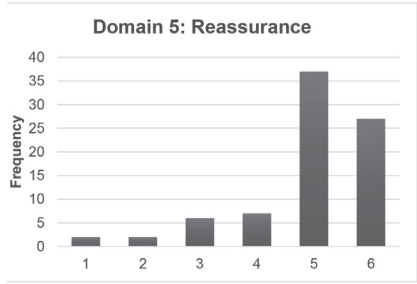
Appendix 3: graphic overview of the distribution of scores per domain











UNDERSTANDING WHAT MATTERS MOST TO PATIENTS IN ACUTE CARE IN SEVEN COUNTRIES, USING THE FLASH MOB STUDY DESIGN

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ABSTRACT

Background

Truly patient-centred care needs to be aligned with what patients consider important and is highly desirable in the first 24 hours of an acute admission, as many decisions are made during this period. However, there is limited knowledge on what matters most to patients in this phase of their hospital stay. The objective of this study was to identify what mattered most to patients in acute care and to assess the patient perspective as to whether their treating doctors were aware of this.

Methods

This was a large-scale, qualitative, flash mob study, conducted simultaneously in sixty-six hospitals in seven countries, starting November 14th 2018, ending 50 hours later. 1850 adults in the first 24 hours of an acute medical admission were interviewed on what mattered most to them, why this mattered and whether they felt the treating doctor was aware of this.

Results

The most reported answers to "*what* matters most (and why)?" were *'getting better or being in good health'* (why: to be with family/friends or pick-up life again)*, 'getting home'* (why: more comfortable at home or to take care of someone) and *'having a diagnosis'* (why: to feel less anxious or insecure). Of all patients, 51.9% felt the treating doctor did not know what mattered most to them.

Conclusions

The priorities for acutely admitted patients were ostensibly disease- and care-oriented and thus in line with the hospitals' own priorities. However, answers to why these were important were diverse, more personal, and often related to psychological well-being and relations. A large group of patients felt their treating doctor did not know what mattered most to them. Explicitly asking patients what is important and why, could help healthcare professionals to get to know the person behind the patient, which is essential in delivering patient-centred care.

Key points

- To deliver patient-centred care, it is important to know what matters to every patient. Nevertheless, our study showed that a large group of patients felt that their treating physician did not know what mattered most to them at that moment.
- Although the majority of patients initially indicated disease- and care-related matters to be most important, they shared diverse personal stories when asked about their motivations and why these were important. These stories show the person behind the patient.
- The questions "What matters most to you?" and especially "why does this matters most?" are questions that can provide healthcare workers with personal information about the patients' preferences, needs, goals, values and emotions, necessary to deliver patient-centred care.

INTRODUCTION

Effective patient-doctor communication and patient involvement can lead to increased patient satisfaction, better health outcomes, and is essential to the delivery of patient-centred care.[1,2] However, with growing worldwide pressure on acute healthcare systems and the resultant limited time available per patient,[3,4] it is increasingly challenging for healthcare providers to have comprehensive conversations with patients. As a result, they may not have adequate psychological and emotional insights into the patients' priorities.[5,6] Research shows that many clinicians' conversations are *about* patients and not *with* them,[7] and that patients are seen as their disease(s) rather than as individuals.[6]

The goal of patient-centred care is to customize care to the individual patient, taking into consideration their preferences, needs and values. To achieve this, Barry and Edgman-Levitan (2012) proposed asking the patient "what matters to you?", in addition to "what is the matter?".[8] This topic has received increasing attention over the years, and an annual international "What Matters to you?" day was launched in 2016 to promote meaningful conversations between healthcare providers and patients.[9] The Institute for Healthcare Improvement (IHI) states that the "what matters to you?" question is a quick, simple, but yet profound way to start deep and personal conversations with patients.[10] It encompasses discussing the patients' priorities and values alongside potentially revealing unanswered questions, which could provide input for a personalized care plan.[11]

Much research has been conducted to investigate the priorities and preferences of patients with specific diagnoses,[12-14] treated in the Emergency Department or in chronic disease programs,[15-20] which has resulted in the development of multiple frameworks (e.g. Lim[21] and Picker experience[22]). However, little is known about what is most important to the heterogeneous group of patients (with regards to morbidity, basic characteristics, culture, health and socio-economic status) during the acute phase of a hospital admission. The first 24 hours of an acute admission will often determine the course of the hospital stay. In this phase many diagnostic tests are carried out, care plans are created, and key decisions made. It is crucial that during this time-period the priorities of the patient are clear to the healthcare team.[12] Therefore, the primary objective of this study was to identify and categorize what matters most to the diverse group of patients in the first 24 hours of an admission.

Not only must doctors converse with patients, it is important that patients feel that they have been listened to, have been understood, and that their concerns will be considered and addressed.[5,8,23] As such, the secondary objective of this study was to

assess the patient perspective on whether they felt their doctor knew what mattered most to them.

METHODS

Study design and setting

A large-scale qualitative international study was conducted using the flash mob design.[24,25] The flash mob research design is based on the concept of flash mobs, where groups of people suddenly meet in a public place, briefly perform a specific act and then quickly disappear. This allowed us to collect structured qualitative data from a large number of patients within a short time-period. To get an overview of what matters most to patients in a wider socio-cultural context, the study was conducted across a wide range of countries, regions and cultures.

The study started on November 14th, 2018 at 10 AM local time, and ended 50 hours later on November 16th, 12 PM local time. Patients in 66 hospitals were recruited simultaneously in The Netherlands, United Kingdom, Ireland, Denmark, Switzerland, Hong Kong and Singapore. Data were collected in acute medical units (AMUs, short stay departments[26]) and other medical wards (i.e. observation units, cardiology, geriatrics, gastroenterology, haematology, internal medicine, nephrology, neurology, oncology, pulmonary medicine and rheumatology).

The Executive Committee of the Medical Ethics Review Committee of VU University Medical Center (IRB00002991) reviewed the research proposal, approved the project and decided that the Medical Research involving Human Subjects Act did not apply (reference No. 2018.318). In all other countries, approval of national ethics committees and executive boards was sought in line with local research policies.

The acute medicine research team of Amsterdam University Medical Center (located at VUmc, the Netherlands) coordinated the project. Collaborators from the Safer@ Home research consortium were involved in the design of the study and acted as coordinating researchers, responsible for the recruitment of hospitals in their country.[27]

Research team and responsibilities

The coordinating investigator in each country was responsible for translating the English datasheet into the local language (using forward- and backward translation, according to the ISPOR guidelines[28]) and translating the open text answers to English (with a forward- and backward translation of a 10% convenience sample).

Every hospital had one ambassador responsible for appointing interviewers for data collection, recruitment of patients and entering the data into the digitalized secured database (Castor EDC). Interviewers were physicians, (research)nurses, medical students, or psychologists, all trained in communication skills.

Recruitment of patients

Consecutive sampling was used to recruit a broad range of participants which would be largely representative of the acute patient population. All patients were 18 years or older, were unplanned admitted to hospital in the previous 24 hours and able to give informed consent. Patients presenting with surgical, trauma and obstetric conditions and patients unable to give informed consent, as judged by the medical team, were excluded. Patients were asked for oral or written informed consent, depending on national research policies. Patients were approached face-to-face and assured that their decision to participate or not participate would have no consequences for their care.

Questionnaire

In the questionnaire we used the classic 'what matters to you?' question.[8,10,29,30] After a pilot study in ten patients, we found that adding a probing question ('why is this important to you?') was necessary to grasp the full concept. The data from these patients were used purely for the purpose of pilot testing the questionnaire, and not included in the data analysis.

The question 'does your treating doctor in the hospital know what matters to you most?' was added to find out about the patients' perception regarding this subject. The questionnaire was complemented by questions concerning basic characteristics, living conditions, social and work situation. To find out how patients interpreted all questions, we used a cognitive interviewing style during the pilot (e.g. by asking their opinion about the content and relevance of questions).[31]

All questionnaires were available in each country's local language.

Data collection and privacy

Interviewers solely introduced themselves by name and had no prior relationship with the patients. Each interview took approximately five minutes. Data were collected at the bedside, and either entered directly into the digital database or transcribed from a paper datasheet, without the use of audio or visual recordings. Patients' responses were not recorded verbatim, but paraphrased by the interviewer. Paraphrased answers were not returned to patients for review.

All interviewers had their own personal Castor EDC account for data input and were trained by both video tutorials and written instructions. Measures and warnings were built into the database to minimize the potential for errors. Interviewers transcribed the patient's answers into the Castor EDC database. All records were labelled with an individual number. The key list with record numbers could only be accessed by the local coordinating researcher. No directly identifiable data were entered into the database.

Data translation and development of the conceptual coding framework for content analysis

Danish, Swiss and Dutch data were translated to English; back-translation was conducted on 10% convenience samples and checked by independent assessors. No essential differences between the original data and back-translations were found.

To analyse the large number of open-text answers, a framework needed to be developed that could be used for coding both the answers to the 'what matters most?' and 'why?' questions.

An inductive approach of content analysis was used to identify categories and sub-categories in the data, leading to the development of a conceptual framework on what matters most to acutely admitted patients and why.[32] This framework was developed through five phases (using open coding, grouping, categorization and abstraction throughout each phase)[32], by four researchers (two medical doctors and two psychologists). A detailed description of the process can be found in Figure S1 in the Supplementary Material.

Coding and data analysis

All 3700 answers (100% of data) to the 'what matters most?' and 'why?' questions were independently coded by both a medical doctor (EE or MK) and a psychologist (BS or HM), using the developed framework. Multiple categories could be assigned to one answer, without hierarchy. When there were discrepancies in assigned categories, an extensive consensus procedure followed (resulting in 100% agreement regarding the final categories). Composition of teams rotated to account for differences in interpretation (i.e. EE+BS, EE+HM, MK+BS, MK+HM).

As the qualitative data were large-scale, the frequency of categories was analysed and visualized in word clouds. Moreover, we analysed the combined occurrence of answers to the 'what matters most to you?' and 'why?' questions to identify patterns. We did this by counting which combinations of categories occurred most between the 'what matters most?' and 'why?' question (for example; patients often wanted

to go home because they missed family members). Finally, we performed multiple subgroup analyses.

Coding was performed in Excel (Microsoft Office Professional Plus 2016). Word counts and word clouds were generated using Atlas.ti8 (Atlas.ti Scientific Software GmbH). Descriptive statistics were performed with SPSS for Windows, version 24 (SPSS Inc).

RESULTS

During the inclusion period, 2798 patients had been admitted to the participating units for 24 hours or less, and were therefore eligible for inclusion. However, 866 (31%) patients were excluded because they were not able to give informed consent or were unwilling or unable to participate (Figure 1). Eighty-two patients were interviewed but later excluded because they had been admitted for more than 24 hours prior to their questionnaire. Therefore, the interviews of 1850 (66%) acutely admitted patients were analysed. Figure 1 provides an overview of the inclusion process and numbers of included patients per country. Table 1 shows the patient characteristics of the included patients.

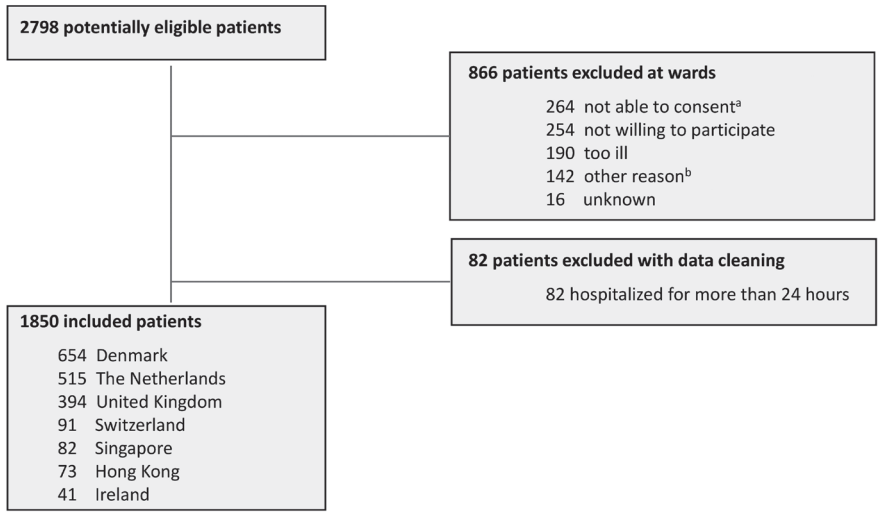

Figure 1. Patients Included and Excluded in Analysis

[a] i.e. sleeping, patient not present, already discharged, unable to read, language barrier, advise nurse

Table 1. Characteristics of 1850 included patients

Characteristics [a]	No. (%) [b]
Sex (n=1836, 14 missing)	
Male	918 (50.0)
Female	918 (50.0)
Age in 5 year intervals, median (IQR)	66-70 (51-55 - 76-80)
Patient had children (n=1843, 7 missing)	
Yes	1466 (79.2)
No	366 (19.9)
I prefer not to tell	11 (0.6)
Patient had pets (n=1838, 12 missing)	
Yes	559 (30.4)
No	1279 (69.6)
Work situation (n=1850, 0 missing) [c]	
Retired	1083 (58.5)
Employed by a company	378 (20.4)
Unemployed but not retired	253 (13.7)
Self employed	100 (5.4)
Studying	36 (0.2)
Living condition (n=1840, 10 missing) [c]	
With partner or family	1181 (64.2)
Alone	578 (31.4)
Healthcare facility, of which	81 (4.4)
Retirement home	43 (53.1)
Nursing home	18 (22.2)
Rehabilitation centre	2 (2.5)
Other	18 (22.2)
Help at home (n=1761, 89 missing)	
No	1248 (70.9)
Yes, of which	513 (29.1)
Domestic assistance	289 (56.8)
Domestic assistance and personal care	161 (31.6)
Personal care	59 (11.6)
Patient was an informal caregiver (n=1842, 8 missing)	
No	1325 (71.9)
Yes [d]	505 (27.4)
Does not know	12 (0.7)

[a] All patients answered the 'What matters most' and 'Why it matters' questions. Demographic data on some patients were missing as can be seen in the table.

[b] Unless otherwise indicated, data are presented as No. (%) of patients.

[c] 1 month before admission.

[d] Informal caregiver for child(ren), partner, parent(s), friend(s), acquaintance(s), animal(s).

What matters most to patients and why?

The coding framework included twelve categories (*health, getting home, symptom relief, functioning, medical issues, hospital experience, patient values, reassurance, possessions, emotions, urgency,* and *other)*. These categories were divided into 38 sub-categories (e.g. 'symptom relief' was divided into pain, dyspnoea, fatigue, nausea). Table S1 in the Supplementary Material shows the categories and sub-categories, illustrated by explanations and quotes.

To most answers, two to four categories were assigned. Of all patients, 29.6% answered that being in *good health* or *getting better* was most important at that moment, 17.4% said they wanted to *go home* and 16.1% considered *knowing the diagnosis* was most important. These categories were assigned notably more often than others (see Figure 2 and Table S2 in the Supplementary Material).

Compared to the answers to the 'what matters most?' question, the answers to 'why this matters most?' showed a broader range of categories, with no clear top three (see Figure 3). *Health* was mentioned less often as an underlying reason compared to the 'what matters' question (Supplementary Material: Table S3). Many issues were mentioned by comparable numbers of patients (e.g. *family and friends (11.8%), psychological functioning (11.2%), fear, anxiety* and *insecurity (10.4%))*.

Figure 2. Word cloud of 'what matters most'

Figure 3. Word cloud of 'why is this important'

Combined occurrence of what matters and why

Underlying reasons for 'what mattered most?' were given when asked 'why this mattered most?'. Analysis of answers to the 'what matters most?' and 'why?' questions, revealed combinations of answers that occurred frequently together. Illustrations of apparent combinations observed in the top three 'what matters most?' categories are shown below.

Getting better

Most patients wanted to get better *to be reunited with their loved ones* (usually partner or children, sometimes friends or other family members): "I miss my two-year-old son and sense that he is missing me a lot too. I want to get better so I can take care of my son and to have the energy to do fun things with him." (Female, age-group 31-35 years, The Netherlands), "To get rid of my alcohol problem. It is important because it is destroying me and my family." (F, 56-60Y, Denmark), "It's important for me to recover as my children and grandchildren depend on me for money." (M, 61-65Y, United Kingdom) Other patients wanted to get better *to get back to their normal life*: "That I will be able to do everything I feel like again." (M, 71-75Y, The Netherlands)

Getting home

Most patients mention the *familiarity of the home situation*, their role as an *informal caregiver* or *relationships* as the main reason to strive for a return to home. Examples

include: “I feel better at home, having your own stuff around.” (M, 71-75Y, The Netherlands), “At home I feel most comfortable, they have no dark beer here.” (M, 86-90Y, The Netherlands), “To get home to my wife and our 3-year old daughter. My wife is expecting, I just cannot bear the thought of her giving birth without me.” (M, 41-45Y, Denmark), “My husband is 80. It is more difficult for him to visit me in hospital now.” (F, 67-80Y, United kingdom), “Wish to get home to my daughter- in-law’s 50th birthday on Friday.” (M, 66-70Y, Denmark).

Getting a diagnosis

The wish for an established *diagnosis* was most often expressed in combination with *fear and insecurity*. Patients wanted *reassurance* and felt having a diagnosis would make them *function better psychologically*. “To know what is wrong for peace of mind.” (M, 46-50Y, The Netherlands), “I want to be able to do my own research or reading about the diagnosis.” (F, 66-70Y, United Kingdom), “It is unsafe to be sent home without clarification.” (F, 31-35Y, Denmark), “That I get my diabetes management optimised, even though I’m admitted with a COPD exacerbation. I’m scared that my legs will need amputating and then I can’t live in my apartment and keep my 11-year-old dog anymore.” (M, 51-55Y, Denmark), “To find peace of mind and closure. I’m afraid of Alzheimer’s and aging, it is affecting work.” (F, 56-60Y, Ireland).

Patient perspective: does your doctor know?

More than half of all patients (51.9%) felt their treating doctor did not know what mattered to them most. Of this group, some patients (21.3%) reported to not have seen a doctor yet. Other reasons included “it did not come up in the conversation”, “the doctor does not need to know”, “there was no chance or no reason to tell”, or “the doctor did not listen” *(Table 2)*.

Subgroup analysis

Women more frequently considered the way that they were *approached* by healthcare staff (e.g. a kind approach, personal attention, honesty, openness, feeling supported, being treated with respect and dignity) as most important (12.2% of women, 5.6% of men). We found no major differences in both ‘*what* matters most?’ and ‘*why?*’ between different age groups (18-40, 41-70, 71+), patients with different length of stay (≤6 and >6 hours), and those who felt that the doctor knew (or not) (Supplementary Material: Table S4). In Asian countries we found a relatively high percentage of patients mentioning *getting better/ good health* as being most important (47.8% - 65.8% in Asian countries, 18.3% - 39.0% in Western countries). Patients in Singapore mentioned their *work* as the reason *why* things mattered more often than patients in other countries (17.1% and ≤7.2% respectively) (Supplementary Material: Table S5).

Table 2. Patient perspective: does your doctor know what matters most to you?

Does your doctor know what matters most?	No	(%)
Yes	886	(48.1)
No[a]	861	(46.7)
No, but someone else from the health care professional team knows[a,b]	96	(5.2)
Did not speak to the doctor yet	202	(21.3)
Doctor does not need to know	165	(17.4)
The doctor did not listen	45	(4.7)
Other reason	538	(56.6)
Did not talk about it[c]	219	
No reason to tell[d]	67	
No chance to tell[e]	53	
Other reason[f]	44	
Unknown	162	

[a] *When patient felt the doctor did not know, a follow-up question was asked.*
[b] *(e.g. nurse, physiotherapist, etc.)*
[c] *I.e. doctor did not ask (78), patient did not tell (40), not covered in conversation (101)*
[d] *I.e. assuming the doctor knows (29), expectations already met (7), not relevant (19), too early to get answers (5), a nurse knows (7)*
[e] *I.e. insufficient continuity of care (7), doctor was too busy (28), do not know who my doctor is (8), afraid to tell (5), doctor did not care (5)*
[f] *I.e. does not remember (4), other reason (35), does not know (5)*

DISCUSSION

In this study 1850 patients admitted acutely to sixty-six hospitals in seven countries were asked what mattered most to them and why. Irrespective of the country, disease- and care-related issues were predominant in reply to the ‘what matters most?’ question: getting better, knowing the diagnosis and being able to go home. This is in line with the main function of an acute hospital admission and the motivation and focus of clinicians: diagnosing, treating and timely discharge.[33] However, when asked why they answered the way they did, patients provided more personal answers, often mentioning relationships and psychological well-being. Whereas many patients mentioned the same issues to the question ‘what matters most to you?’, the underlying reasons as to ‘why is this important?’ differed significantly. This probably reflects the heterogeneity of acutely admitted patients with regards to morbidity, baseline characteristics, culture, health, socio-economic

status and phases of their lives. It demonstrates the challenges of providing patient-centred care without discussing what is most important with each individual patient.

Although certain combinations of *what matters?* and *why?* were more common than others, and some categories were mentioned more frequently within certain subgroups of patients, individual priorities are not predictable. Knowing what matters to each individual patient is key because, as our data shows, it is a reflection of personal goals and preferences.[34-36]

A large group of patients felt the treating doctor was unaware of what mattered most to them, partly because it did not come up during the consultation. Doctor-patient communication is crucial to the doctor-patient relationship,[37] and essential in delivering high quality care, since the priorities of doctors and patients can differ.[38] It is conceivable that doctors focus mainly on diagnosing and treating the underlying medical condition. However, since the data represents the perception of patients, it is also possible that doctors do know what matters most, without the patient consciously realizing this. As the feeling of being heard and understood is essential in the process of patient-centred decision-making,[39] it is recommended to have explicit conversations about what matters most and why, even if the doctor believes they already know this. Feeling heard and understood is known to alleviate suffering,[40,41] reinforce dignity and is one of the key factors in patient reported quality of care.[42-45] It could help making patients feel that doctors see them as a person instead of a disease to be treated.

In healthcare settings with limited time per patient, these two simple questions ('what matters most to you?' and 'why?') may be a feasible way to quickly get to know the person behind the patient. The conversation will give insight into the personal situation of the patient, stimulate patient involvement and ultimately could facilitate more patient-centred care.[46] Having these conversations early in the admission will help set the agenda and design a tailored care plan.[8,47,48]

Strengths and Limitations

The flash mob research design enabled us to include many patients within a short timeframe in seven different countries and 66 hospitals, across cities, towns and rural areas. It provided data from a large heterogeneous patient population representative of the wide diversity of acutely admitted patients. There were no missing data in the main questions. The scale of the study has enabled us to create awareness among many healthcare providers and patients. Lastly, we developed a new conceptual framework based on multiple perspectives using an iterative process. Answers were coded by both a medical doctor and psychologist, which ensured capturing the medical as well as the psychological component. The framework is comprehensive

and suitable for the broad concept of 'what matters most?' and 'why?'. Therefore, we believe the framework will be suitable for use in other patient groups and settings as well.

The results of our study need to be interpreted in the light of a few limitations. Firstly, answers from patients might have been paraphrased, which may have simplified patient answers. Secondly, due to the large number of interviewers, it is possible that there were differences in interview styles. However, as there were only two, highly standardized main questions, we believe this would not have a significant influence on our results.

Future research might focus on how 'what matters most' to patients might change over the course of a hospital admission. Although no large differences were found between patients that had only spent up to six hours in hospital and those in hospital from six to 24 hours, we do not know whether the findings are representative for what matters most to patients in later phases of their admission. Furthermore, it would be interesting to conduct a study where both the patient, the doctor and all other professionals in the healthcare team are interviewed about what matters most to the patient in order to compare and align their views.

CONCLUSIONS

Patients most frequently mentioned the importance of getting better, having a diagnosis and going home in the first 24 hours of an admission. 'Why' this matters is strongly determined by each individual patient and often goes well beyond the medical targets of healthcare professionals. When asking for the patient perspective, a large group of patients felt the treating doctor did not know what mattered to them. Explicitly asking 'what matters most?' and especially 'why?', may help the healthcare team to obtain a more holistic picture and to see the person behind the patient. Having conversations regarding what is important to the patient should assist with the design of a personalized care plan and will help the patient to feel heard, which positively effects the patient satisfaction, health outcomes and the overall quality of care.

REFERENCES

1. Kebede S. Ask patients "What matters to you?" rather than "What's the matter?". BMJ. 2016;354:i4045.
2. Wilson SR, Strub P, Buist AS, Knowles SB, Lavori PW, Lapidus J, et al. Shared treatment decision making improves adherence and outcomes in poorly controlled asthma. Am J Respir Crit Care Med. 2010;181(6):566-77.
3. Simmons S, Sharp B, Fowler J, Fowkes H, Paz-Arabo P, Dilt-Skaggs MK, et al. Mind the (knowledge) gap: the effect of a communication instrument on emergency department patients' comprehension of and satisfaction with care. Patient education and counseling. 2015;98(2):257-62.
4. Sustersic M, Gauchet A, Kernou A, Gibert C, Foote A, Vermorel C, et al. A scale assessing doctor-patient communication in a context of acute conditions based on a systematic review. PloS one. 2018;13(2):e0192306.
5. Shachak A, Reis S. The impact of electronic medical records on patient–doctor communication during consultation: a narrative literature review. Journal of Evaluation in Clinical Practice. 2009;15(4):641-9.
6. Muntlin A, Carlsson M, Gunningberg L. Barriers to change hindering quality improvement: the reality of emergency care. Journal of emergency nursing. 2010;36(4):317-23.
7. Marvel MK, Epstein RM, Flowers K, Beckman HB. Soliciting the patient's agenda: have we improved? Jama. 1999;281(3):283-7.
8. Barry MJ, Edgman-Levitan S. Shared decision making--pinnacle of patient-centered care. The New England journal of medicine. 2012;366(9):780-1.
9. website what matters to you [cited 2019 12-07]. Available from: https://www.whatmatterstoyou.scot/.
10. Improvement IfH. The Power of Four Words: "What Matters to You?" [Available from: http://www.ihi.org/Topics/WhatMatters/Pages/default.aspx.
11. Rutherford PA. Reliably Addressing "What Matters" Through a Quality Improvement Process. Clinical journal of oncology nursing. 2016;20(1):20-2.
12. Osborne TR, Ramsenthaler C, de Wolf-Linder S, Schey SA, Siegert RJ, Edmonds PM, et al. Understanding what matters most to people with multiple myeloma: a qualitative study of views on quality of life. BMC Cancer. 2014;14:496.
13. Guzman J, Gomez-Ramirez O, Jurencak R, Shiff NJ, Berard RA, Duffy CM, et al. What matters most for patients, parents, and clinicians in the course of juvenile idiopathic arthritis? A qualitative study. J Rheumatol. 2014;41(11):2260-9.
14. Karel MJ, Mulligan EA, Walder A, Martin LA, Moye J, Naik AD. Valued life abilities among veteran cancer survivors. Health expectations : an international journal of public participation in health care and health policy. 2016;19(3):679-90.
15. Kremers MNT, Zaalberg T, van den Ende ES, van Beneden M, Holleman F, Nanayakkara PWB, et al. Patient's perspective on improving the quality of acute medical care: determining patient reported outcomes. BMJ open quality. 2019;8(3):e000736.

16. Bos N, Sturms LM, Stellato RK, Schrijvers AJ, van Stel HF. The Consumer Quality Index in an accident and emergency department: internal consistency, validity and discriminative capacity. Health expectations : an international journal of public participation in health care and health policy. 2015;18(5):1426-38.
17. Jonathan D. Sonis ELA, Allison Castagna, and Benjamin White. A Conceptual Model for Emergency Department Patient Experience. Journal of Patient Experience. 2018.
18. Male L, Noble A, Atkinson J, Marson T. Measuring patient experience: a systematic review to evaluate psychometric properties of patient reported experience measures (PREMs) for emergency care service provision. International journal for quality in health care : journal of the International Society for Quality in Health Care. 2017;29(3):314-26.
19. Vaillancourt S, Seaton MB, Schull MJ, Cheng AHY, Beaton DE, Laupacis A, et al. Patients' Perspectives on Outcomes of Care After Discharge From the Emergency Department: A Qualitative Study. Annals of emergency medicine. 2017;70(5):648-58.e2.
20. Olthuis G, Prins C, Smits MJ, van de Pas H, Bierens J, Baart A. Matters of concern: a qualitative study of emergency care from the perspective of patients. Annals of emergency medicine. 2014;63(3):311-9.e2.
21. Lim CY, Berry ABL, Hirsch T, Hartzler AL, Wagner EH, Ludman EJ, et al. Understanding What Is Most Important to Individuals with Multiple Chronic Conditions: A Qualitative Study of Patients' Perspectives. Journal of general internal medicine. 2017;32(12):1278-84.
22. Jenkinson C, Coulter A, Bruster S, Richards N, Chandola T. Patients' experiences and satisfaction with health care: results of a questionnaire study of specific aspects of care. Quality & safety in health care. 2002;11(4):335-9.
23. Ha JF, Longnecker N. Doctor-patient communication: a review. Ochsner J. 2010;10(1):38-43.
24. Wesselius HM, van den Ende ES, Alsma J, Ter Maaten JC, Schuit SCE, Stassen PM, et al. Quality and Quantity of Sleep and Factors Associated With Sleep Disturbance in Hospitalized Patients. JAMA internal medicine. 2018;178(9):1201-8.
25. Alsma J, van Saase J, Nanayakkara PWB, Schouten W, Baten A, Bauer MP, et al. The Power of Flash Mob Research: Conducting a Nationwide Observational Clinical Study on Capillary Refill Time in a Single Day. Chest. 2017;151(5):1106-13.
26. Atkin C, Knight T, Subbe C, Holland M, Cooksley T, Lasserson D. Acute care service performance during winter: report from the winter SAMBA 2020 national audit of acute care. Acute Med. 2020;19(4):220-9.
27. Website Safer@Home [Available from: http://www.saferathome.org/.
28. Wild D, Grove A, Martin M, Eremenco S, McElroy S, Verjee-Lorenz A, et al. Principles of Good Practice for the Translation and Cultural Adaptation Process for Patient-Reported Outcomes (PRO) Measures: report of the ISPOR Task Force for Translation and Cultural Adaptation. Value in health : the journal of the International Society for Pharmacoeconomics and Outcomes Research. 2005;8(2):94-104.
29. Lang D, Hoey C, Whelan M, Price G. The introduction of "What Matters to You": a quality improvement initiative to enhance compassionate person-centered care in hospitals in Ireland. Int J Integr Care. 2017;17(5):445.
30. Doyle C, Reed J, Woodcock T, Bell D. Understanding what matters to patients - identifying key patients' perceptions of quality. JRSM short reports. 2010;1(1):3.

31. Aschermann E, Mantwill M, Köhnken G. An independent replication of the effectiveness of the cognitive interview. Applied Cognitive Psychology. 1991;5(6):489-95.
32. Elo S, Kyngas H. The qualitative content analysis process. J Adv Nurs. 2008;62(1):107-15.
33. Deruaz-Luyet A, N'Goran AA, Pasquier J, Burnand B, Bodenmann P, Zechmann S, et al. Multimorbidity: can general practitioners identify the health conditions most important to their patients? Results from a national cross-sectional study in Switzerland. BMC family practice. 2018;19(1):66.
34. Naik AD. On the road to patient centeredness. JAMA internal medicine. 2013;173(3):218-9.
35. Epstein RM, Street RL, Jr. The values and value of patient-centered care. Ann Fam Med. 2011;9(2):100-3.
36. Hanyok LA, Hellmann DB, Rand C, Ziegelstein RC. Practicing patient-centered care: the questions clinically excellent physicians use to get to know their patients as individuals. Patient. 2012;5(3):141-5.
37. Emanuel EJ, Emanuel LL. Four models of the physician-patient relationship. Jama. 1992;267(16):2221-6.
38. Lee CN, Hultman CS, Sepucha K. Do patients and providers agree about the most important facts and goals for breast reconstruction decisions? Annals of plastic surgery. 2010;64(5):563-6.
39. Elwyn G, Lloyd A, May C, van der Weijden T, Stiggelbout A, Edwards A, et al. Collaborative deliberation: a model for patient care. Patient education and counseling. 2014;97(2):158-64.
40. Cassell EJ. Diagnosing suffering: a perspective. Ann Intern Med. 1999;131(7):531-4.
41. Cassel EJ. The nature of suffering and the goals of medicine. The New England journal of medicine. 1982;306(11):639-45.
42. Houmann LJ, Chochinov HM, Kristjanson LJ, Petersen MA, Groenvold M. A prospective evaluation of Dignity Therapy in advanced cancer patients admitted to palliative care. Palliat Med. 2014;28(5):448-58.
43. Chochinov HM, McClement S, Hack T, Thompson G, Dufault B, Harlos M. Eliciting Personhood Within Clinical Practice: Effects on Patients, Families, and Health Care Providers. J Pain Symptom Manage. 2015;49(6):974-80 e2.
44. Ingersoll LT, Saeed F, Ladwig S, Norton SA, Anderson W, Alexander SC, et al. Feeling Heard and Understood in the Hospital Environment: Benchmarking Communication Quality Among Patients With Advanced Cancer Before and After Palliative Care Consultation. J Pain Symptom Manage. 2018;56(2):239-44.
45. Gramling R, Stanek S, Ladwig S, Gajary-Coots E, Cimino J, Anderson W, et al. Feeling Heard and Understood: A Patient-Reported Quality Measure for the Inpatient Palliative Care Setting. J Pain Symptom Manage. 2016;51(2):150-4.
46. Leavitt M. Medscape's response to the Institute of Medicine Report: Crossing the quality chasm: a new health system for the 21st century. MedGenMed. 2001;3(2):2.
47. CCI. the New Agenda: Patient-Centered Strategies for the Exam Room. 2016.
48. Elwyn G, Frosch D, Thomson R, Joseph-Williams N, Lloyd A, Kinnersley P, et al. Shared decision making: a model for clinical practice. Journal of general internal medicine. 2012;27(10):1361-7.
49. Flash mob website SAFER@HOME [Available from: http://www.flashmobsite.com/.

Supplementary materials

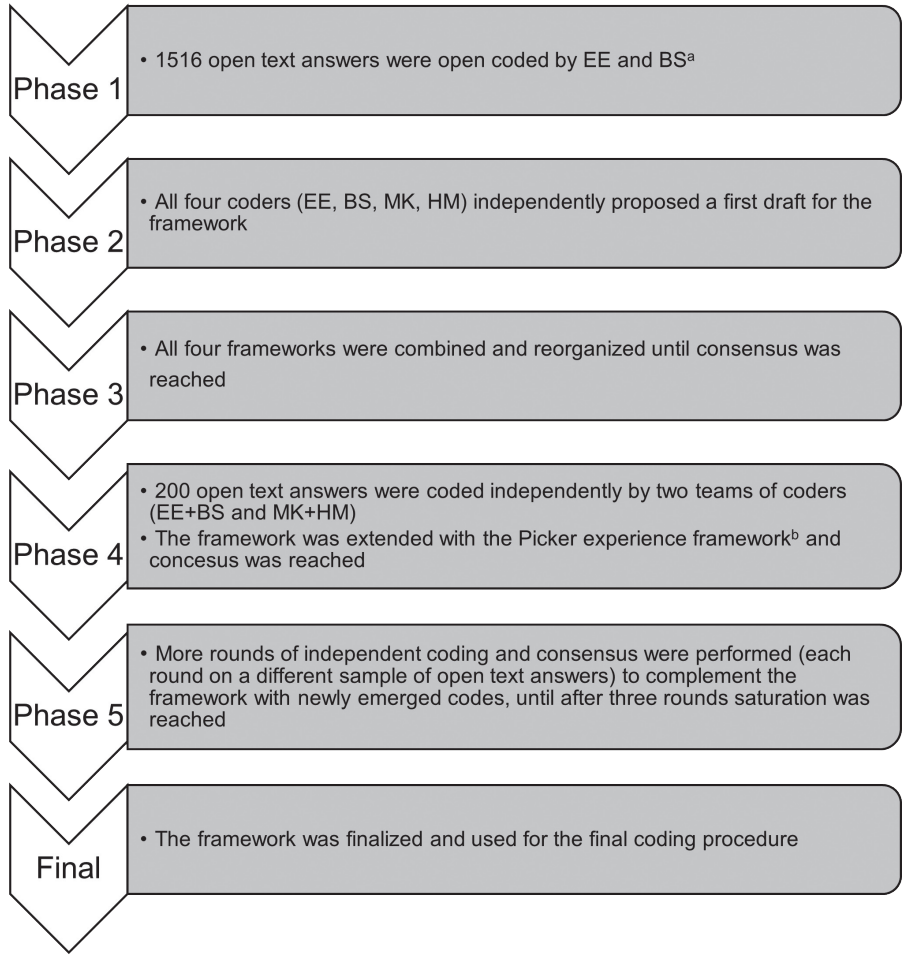

Figure S1. Developmental process of framework

[a] EE, MK (medical doctors) and BS, HM (psychologists)

[b] Jenkinson C, Coulter A, Bruster S, Richards N, Chandola T. Patients' experiences and satisfaction with health care: results of a questionnaire study of specific aspects of care. Quality & safety in health care. 2002;11(4):335-9.

Table S1. Framework for coding

MAIN THEME	SUB-THEME	EXPLANATION	QUOTES
HEALTH	Getting better / good health	Getting well, general concept of health	*"My health", "To get better", "To recover from what has happened", "Health improvement", "To be as healthy as possible and to stay heathy", "To get healthier: I suffer from pneumonia, and something in my lungs that is not right", "Being healthy and a healthy life", "That the blood pressure goes down".*
	Stability	Health remains stable, not to deteriorate	*"No further decline of heart and kidneys", "To maintain a reasonable standard of health", "I'm not going to be cured but…."*
	Surviving	Not dying, continue living, to be able to live	*"Just to continue living", "I want to survive", "To stay alive"*
GETTING HOME	Getting home	To go home and/or to be discharged and leave the hospital	*"To be allowed to go home", "Return to residence and workplace (Paris)", "To be discharged as soon as possible. Did not wanted to be admitted and wants to go home at least before noon".*
	Familiarity of the home situation	Wanting to be at home, feeling better at home, having your own stuff around	*"I prefer to be at home", "Home feels more pleasant", "At home it is nicer than in the hospital", "I want my own things around me", "I like it way better at home, familiar situation. There I have my medication in my own management, so I know I take them correctly. Also, I have privacy at home (alone instead of a room for four people)."*
	Future living condition	Help at home, having a place to go to, moving to a different place, a roof over your head	*"To get the needed care at home or at the nursing home", "A new home, shelter. I have no roof over my head", "That the home caregivers are at home with me for almost the entire day, help me with everything", "I want to stay out of prison longer".*
SYMPTOM RELIEF	Pain	Being pain-free	*"Living without pain", "The pain is not bearable right now", "When you have been in pain a long time it grows on you. Feels it's important for no one to be in pain if possible".*
	Nausea	Relief of nausea	*"I have a gastric carcinoma, want to get rid of de nausea", "That I get rid of the nausea and can eat again".*
	Dyspnoea	Relief of shortness of breath	*"To breath more easily", "I am worried about breathing and not being able to breath"*
	Fatigue	Rest, sleep quality	*"To be able to sleep again", "Fatigue is very annoying and because of this I cannot do much", "Just to lie down and rest".*

Table S1. (Continued)

MAIN THEME	SUB-THEME	EXPLANATION	QUOTES
	Other	Relief of all other symptoms, complaints and discomfort	*"I am hungry and would like to eat something", "Getting rid of my atrial flutter", "That my complaints and fever are taken care of", "Not being thirsty anymore", "My vertigo to pass", "Getting my symptoms managed", "To make me comfortable".*
FUNCTIONING	Social & hobbies	I.e. religious activities, cycling, playing cards, vacation	*"I love gardening", "I want to be able to go to football match", "I still want to do a lot in life", "I want to be able to go bicycling with my wife again. I had a bicycle shop previously. Bicycling is my hobby and life's work", "I want to have the energy for activities, like reading, shopping groceries and go to concerts".*
	Psychological	LONG TERM behaviour, coping skills, and overall mental health	*"I want peace and clarity on what the future will look like", "Happiness", "To become the old me again, that I used to be", "I wish I never had COPD a self-made disease. Feels it is my fault, caused by being selfish", "To have a healthy mind".*
	Physical	I.e. regaining strength, Gaining weight, Physical condition, walking, be able to move arm/ legs again, physical capabilities, physical appearance	*"To sit up for another twenty minutes", "To be able to walk again", "To be able to see with both eyes", "To recuperate and regain strength", "To be able to speak clearly again. Admitted after rehabilitation. Since yesterday difficulties to speak".*
	Informal caregiving	Patient takes care of people or animals (NOT if patient HAS an informal caregiver)	*"My younger brother has low IQ and unable to take care of himself", "That I can't be there for my kids right now and make them anxious", "That someone takes care of my husband while I'm in hospital", "It's important for me to recover as my children and grandchildren depend on me for money and help with 'do it yourself', advice etc.", "That someone can take care of the dog at home".*
	Activities of daily living	Activities/skills performed on a daily basis fundamental for basic needs, i.e. household chores, personal hygiene, etc.	*"That I can get out of bed independently and do things myself again", "I'd like to restart activities at home", "To be able to function at home", "I want to do the grocery shopping and housekeeping".*
	Work	I.e. study, have to get back to work	*"A lot of problems, but the main one is that I can't work currently", "School/career", "I'm missing time at work due to recent admission".*

Table S1. (Continued)

MAIN THEME	SUB-THEME	EXPLANATION	QUOTES
	Back to normal life	Return to (parts of) their normal life, i.e. their life as it was before the acute hospital admission	*"I want to live a normal life, without my abdomen bothering me", "That I can continue driving the car", "To be able to continue living like I used to do".*
MEDICAL ISSUES	Diagnosis	ASSUMING THIS IS STILL UNKNOWN BY HEALTHCARE TEAM: Diagnosis, prognosis, finding out what patient is suffering from	*"Clarity about what is wrong and what the consequences of the disease are for the chemotherapy treatment", "That they find what is wrong with me".*
	Testing (diagnostics)	Test result, getting medical test, physical examination (if NO MORE tests: also add "other")	*"I want proper diagnostics", "Even if it's not sure, I would like to know what my complaints may indicate and what the diagnosis might be", "I want the cause of symptoms being examined".*
	Treatment	Getting the right treatment, treatment plan, results of treatment or procedures, timing of treatment (if STOP treatment: also add "other")	*"The removal of my kidney drain and right kidney", "I want non-invasive treatment", "To have better blood pressure control", "I came here for my bladder problem, maybe to take out my prostate; to get treated".*
	Prevention	to prevent a similar health condition and/ or deterioration in the future	*"I want to know how to prevent these symptoms in the future", "I want to prevent amputation as that would impede my abilities to take care of household".*
HOSPITAL EXPERIENCE	Receiving information	ASSUMING THIS DIAGNOSIS IS KNOWN BY HEALTHCARE TEAM: Getting clear information, getting explanation about diagnosis, being well informed	*"Communication is key. When in hospital you in-trust other people to make the best decision on your behalf, therefore being kept in the loop reduces worry", "To be shown what will be the next step", "I want to know how long I'll have to stay here", "To find out what possibilities there are for recovery".*
	Coordination of hospital care	I.e. COMMUNICATION BETWEEN PROFESSIONALS, waiting times, hospital processes, familiar physician, teamwork of staff	*"It means a lot to me that it is easy to transfer information from general practitioner to the hospital", "Less waiting time", "I would like to have the same physician throughout. I keep seeing different ones. I'd like to have a contact person".*

Table S1. (Continued)

MAIN THEME	SUB-THEME	EXPLANATION	QUOTES
	Approach by healthcare staff	I.e. COMMUNICATION WITH PATIENT. (Kind) approach, personal attention, patient centeredness, honesty, openness, feeling supported, professional listens, has time, treated with respect and dignity.	*"Empathy, I have been in hospital before and remember the empathy of the staff", "To feel recognized and noticed", "A secure and safe stay, with mutual respect", "That the staff recognizes and respects my boundaries", "It is important that I'm taken seriously, in what I say", "A good welcome".*
	Attention for preferences	RELATED TO TREATMENT: shared decision making, Involvement in decisions about treatment and care.	*"I am plagued by old injuries, so I know best how my body works. To talk openly is important", "I have chosen to do without the treatment because of side effects", "I do not worry because I feel involved".*
	Involvement of family and friends	Information and decision-making in presence of family	*"I want to be able to clearly explain to my family what is wrong and my treatment plan. I don't want to seem 'dumb'", "It's important to me that my family don't needlessly worry. I don't want them in emotional distress and would prefer they knew what to expect in terms of outcome"," The care is important both to me and my relatives".*
	Facilities	I.e. hospital beds, -rooms, -food, coffee, tranquillity, privacy, circumstances stay, visiting hours, eating, smoking, hospital environment	*"Getting an appropriate mattress (in hospital), making it very soar for back", "That I am allowed to have my good friend by my side", "I have not slept all night because of the noise from appliances", "Good food and quietness to get sleep", "That there is good coffee", "It's too hot, can someone cool down the place?".*
	Being cared for / good care	I.e. getting the help that is needed, not being discharged too soon, getting better before discharge, hospital admission, trust in professionals, receiving good care and treatment, adequacy, competence, expertise, care at the ED, trust.	*"It is degrading to be as vulnerable as you are when you are ill. Therefore, it is important to me to be cared for", "That I'm being taken care of", "That somebody takes care of me and my problem", "The care at the ED", "To receive good hospital care, even if it is busy".*

Table S1. (Continued)

MAIN THEME	SUB-THEME	EXPLANATION	QUOTES
PATIENT VALUES	Family and/or friends	I.e. partner, family, friends, pets	*"Family, Child, Son and Daughters. I'd rather be in a different hospital. I don't know anyone here", "What's extremely important to me is visiting my family in a different canton on Thursday", "Lost my partner. Childhood dreams are gone. To experience more love".*
	Independence	I.e. being independent from others, freedom	*"Want to keep my independence", "Regain autonomy", "I feel a bit trapped, my freedom is limited", "Do not like to be dependent on others to be taken to the hospital, as I do not live nearby".*
	Carer burden	The potential burden the patient and the health condition could put on the carers (i.e. family, friends, etc.)	*"I want to go come Saturday early noon because my kids will pick me up. At night it will be inconvenient for them", "I don't want to put too much carer burden on my partner. To give her the least possible burden".*
	Quality of life	I.e. enjoying life,, end of life care, expectations about the future, wanting to die	*"To improve quality of life. Now I have no quality of life", "I would like the optimal quality of life that can be reached for my age (the level of a couple of months ago, before the complaints started)".*
	Religion & spirituality	Religious and spiritual beliefs	*"Receiving the right care in the spiritual field", "God, I'm a pastor in Pakistan", "That god helps me with this".*
REASSURANCE		Desire to be reassured by professionals, i.e. wanting clarity, certainty, feeling ensured that everything will be fine	*"Older people need safety to function", "That everything is going to be fine", "Being kept in the loop, I am an ex-military, it's the way I was trained and it gives me reassurance".*
POSSESSIONS		I.e. finances, hospital bills, daily expenditure, personal belongings	*"I have been admitted yesterday, still waiting. I think it is a loss of money, as I'm only here for examinations that have a longer waiting time at the outpatient clinic", "I worry making too little money and not being able to take care of the family", "Money - hospital bills and daily expenditure"*

Table S1. (Continued)

MAIN THEME	SUB-THEME	EXPLANATION	QUOTES
EMOTIONS	Negative	SHORT TERM expression of mood and/or feelings, i.e. fear, anxiety, insecurity, anger, disappointment, frustration, sadness, despair	*"Medication being changed on me for no real reason. It's uncomfortable and unfamiliar to me, especially since medication prescribed by GP who has cared for me for 4 years", "Because the staff react right away I become insecure because I sense that I am an acute patient", "I'm nervous that my cancer operation will be postponed", "Anxiety since the cancer diagnosis". "I am just waiting for nothing to happen. Because one can get the feeling of being put on a shelf and just wait for information about ones' course if no one speaks to you", "I was very angry with the nurse", "Very sad to hear the diagnosis", "I want to know the future for my wife. She is from Thailand, and if I die, she has to leave the country within three months. I feel sorry for her".*
	Positive	SHORT TERM expression of mood and/or feelings, i.e. joy	*"I love to enjoy a cup of good coffee", "So happy to finally have a diagnosis".*
HAVING THINGS DONE QUICKLY		Quickly, immediate	*"To be discharged as soon as possible. Did not wanted to be admitted and wants to go home at least before noon", "Being assessed quickly, that my treatment starts immediately".*
OTHER		Politics, etc.	*"To allow others to get access to treatment", "Nothing really truly matters to me anymore. I have lived for many years almost 90", "Politics", "The Brexit and remaining in Europe".*

Table S2. Ten most frequent answers to the question 'what matters most'

What matters most to you at the moment? - Top 10 answers	n	%
Getting better / good health[a]	547	29.6%
Getting home	322	17.4%
Knowing the diagnosis	298	16.1%
Treatment	192	10.4%
Having things done quickly	185	10.0%
Being cared for / receiving good care	184	9.9%
Receiving information	179	9.7%
Approach (attitude of healthcare staff)	169	9.1%
Coordination of hospital care	127	6.9%
Reassurance	101	5.5%

n = number of patients
%= percentage of all included patients (N=1850)
[a] obtaining good health or staying in good health

Table S3. Ten most frequent answers to the question 'why is this important'

Why it matters - Top 10 answers	n	%
Family and/or friends	218	11.8%
Psychological functioning[a]	208	11.2%
Fear/ anxiety/ insecurity	192	10.4%
Reassurance	173	9.4%
Back to normal life	150	8.1%
Social activities / hobbies	132	7.1%
Getting better / general health	104	5.6%
Familiarity of home situation[b]	101	5.5%
Getting home	98	5.3%
Role as an informal caregiver	95	5.1%
Work	92	5.0%

n = number of patients
%= percentage of all included patients (N=1850)
[a] e.g. coping skills, and overall mental health
[b] e.g. Wanting to be at home, feeling better at home, having your own stuff around

Table S4. Differences in what matters most and why between: sex, age groups, length of stay and if patients feel the doctor knows what matters or not.
WHAT matters most

	DOCTOR DOES KNOW (N=886)	DOCTOR DOES NOT KNOW (N=957)
1	Getting better / good health n=258 (29.1%)	Getting better / good health n=290 (30.3%)
2	Getting home n=157 (17.7%)	Getting home n=163 (17.0%)
3	Knowing the diagnosis n=154 (17.4%)	Knowing the diagnosis n=143 (14.9%)
4	Treatment n=108 (12.2%)	Receiving information n=103 (10.7%)
5	Being cared for / good care n=89 (10.0%)	Having things done quickly n=102 (10.7%)

	MALE (N=918)	FEMALE (N=918)
1	Getting better / good health n=282 (30.7%)	Getting better / good health n=264 (28.8%)
2	Getting home n=163 (17.8%)	Getting home n=157 (17.1%)
3	Knowing the diagnosis n=157 (17.1%)	Knowing the diagnosis n=141 (15.4%)
4	Having things done quickly n=103 (11.2%)	Approach n=112 (12.2%)
5	Treatment n=101 (11.0%)	Receiving information n=97 (10.6%)

	<6 HOURS AFTER ADMISSION (N=688)	≥6 HOURS AFTER ADMISSION (N=1152)
1	Getting better / good health n=189 (27.5%)	Getting better / good health n=357 (31.0%)
2	Knowing the diagnosis n=133 (19.3%)	Getting home n=227 (19.7%)
3	Getting home n=94 (13.7%)	Knowing the diagnosis n=166 (14.4%)
4	Approach n=76 (10.9%)	Receiving information n=119 (10.3%)
5	Treatment n=76 (10.9%)	Treatment n=118 (10.2%)

	18-40 YEARS (N=195)	41-70 YEARS (N=799)	71+ YEARS (N=811)
1	Getting better / good health n=59 (30.3%)	Getting better / good health n=209 (26.2%)	Getting better / good health n=269 (33.2%)
2	Getting home n=40 (20.5%)	Knowing the diagnosis n=156 (19.5%)	Getting home n=151 (18.6%)
3	Knowing the diagnosis n=33 (16.9%)	Getting home n=126 (15.8%)	Knowing the diagnosis n=104 (12.8%)
4	Receiving information n=27 (13.8%)	Treatment n=99 (12.4%)	Being cared for / good care n=77 (9.5%)
5	Coordination of care n=25 (12.8%)	Having things done quickly n=93 (11.6%)	Treatment n=69 (8.5%)

WHY does this matter most

	DOCTOR DOES KNOW (N=886)	DOCTOR DOES NOT KNOW (N=957)
1	Fear / anxiety / insecurity n=91 (10.3%)	Family and/or friends n=136 (14.2%)
2	Psychological functioning n=91 (10.3%)	Psychological functioning n=116 (12.1%)
3	Family and/or friends n=81 (9.1%)	Fear / anxiety / insecurity n=100 (10.5%)
4	Reassurance n=78 (8.8%)	Reassurance n=94 (9.8%)
5	Back to normal life n=75 (8.5%)	Back to normal life n=75 (7.8%)

	MAN (N=918)	FEMALE (N=918)
1	Family and/or friends n=110 (12.0%)	Family and/or friends n=108 (11.8%)
2	Psychological functioning n=99 (10.8%)	Psychological functioning n=107 (11.7%)
3	Fear / anxiety / insecurity n=93 (10.1%)	Fear / anxiety / insecurity n=98 (10.7%)
4	Reassurance n=82 (8.9%)	Reassurance n=91 (9.9%)
5	Social activities & hobbies n=80 (8.7%)	Back to normal life n=73 (8.0%)

	<6 HOURS AFTER ADMISSION (N=688)	≥6 HOURS AFTER ADMISSION (N=1152)
1	Reassurance n=69 (10.0%)	Family and/or friends n=155 (13.5%)
2	Fear / anxiety / insecurity n=66 (9.6%)	Psychological functioning n=142 (12.3%)
3	Psychological functioning n=65 (9.4%)	Fear / anxiety / insecurity n=126 (10.9%)
4	Family and/or friends n=62 (9.0%)	Reassurance n=103 (8.9%)
5	Getting home n=48 (7.0%)	Back to normal life n=103 (8.9%)

	18-40 YEARS (N=195)	41-70 YEARS (N=799)	71+ YEARS (N=811)
1	Psychological functioning n=28 (14.4%)	Psychological functioning n=96 (12.0%)	Family and/or friends n=104 (12.8%)
2	Reassurance n=28 (14.4%)	Family and/or friends n=95 (11.9%)	Psychological functioning n=78 (9.6%)
3	Fear / anxiety / insecurity n=26 (13.3%)	Fear / anxiety / insecurity n=90 (11.3%)	Social activities & hobbies n=72 (8.9%)
4	Work n= 26 (13.3%)	Reassurance n=90 (11.3%)	Fear / anxiety / insecurity n=71 (8.8%)
5	Role as an informal care giver n=25 (12.8%)	Back to normal life n=75 (9.4%)	Back to normal life n=65 (8.0%)

Table S5. Differences in what matters and why to patients between countries

Top 5 what matters most

	DENMARK (N=654)	NETHERLANDS (N=515)	UK (N=394)	SINGAPORE (N=82)	SWITZERLAND (N=91)	IRELAND (N=41)	HONG KONG (N=73)
1	Knowing the diagnosis n=140 (21.4%)	Getting better / good health n=164 (31.8%)	Getting better / good health n=121 (30.7%)	Getting better / good health n=44 (47.8%)	Getting better / good health n=31 (34.1%)	Getting better / good health n=16 (39.0%)	Getting better / good health n=48 (65.8%)
2	Getting better / good health n=123 (18.3%)	Getting home n=105 (20.4%)	Getting home n=94 (23.9%)	Getting home n=11 (13.4%)	Getting home n=22 (24.2%)	Getting home n=8 (19.5%)	Getting home n=7 (9.6%)
3	Treatment n=97 (14.8%)	Knowing the diagnosis n=75 (14.6%)	Knowing the diagnosis n=55 (14.0%)	Having things done quickly n=7 (8.5%)	Knowing the diagnosis n=14 (15.4%)	Family and/ or friends n=7 (17.1%)	Family and/ or friends n=6 (8.2%)
4	Approach n=97 (14.8%)	Having things done quickly n=66 (12.8%)	Receiving information n=37 (9.4%)	Pain relief n=7 (8.5%)	Family and/ or friends n=12 (13.2%)	Being cared for / quality of care n=5 (12.2%)	Knowing the diagnosis n=5 (6.8%)
5	Being cared for / quality of care n=93 (14.2%)	Treatment n=46 (8.9%)	Being cared for / quality of care n=36 (9.1%)	Treatment n=7 (8.5%)	Having things done quickly n=12 (13.2%)	Knowing the diagnosis n=5 (12.2%)	Familiarity home situation n=2 (2.7%)

Top 5 why is this important

	DENMARK (N=654)	NETHERLANDS (N=515)	UK (N=394)	SINGAPORE (N=82)	SWITZERLAND (N=91)	IRELAND (N=41)	HONG KONG (N=73)
1	Reassurance n=103 (15.7%)	Family and/ or friends n=89 (17.3%)	Family and/or friends n=58 (14.7%)	Work n=14 (17.1%)	Social activities & Hobbies n=13 (14.3%)	Independence n=7 (17.1%)	Symptom relief other n=9 (12.3%)
2	Psychological functioning n=85 (13.0%)	Psychological functioning n=71 (13.8%)	Psychological functioning n=40 (10.2%)	Activities of daily living n=12 (14.6%)	Family and/or friends n=11 (12.1%)	Family and/ or friends n=6 (14.6%)	Family and/ or friends n=6 (8.2%)
3	Fear / anxiety / insecurity n=76 (11.6%)	Social activities & Hobbies n=66 (12.8%)	Fear / anxiety / insecurity n=37 (9.4%)	Role as an informal care giver n=11 (13.4%)	Getting home n=10 (11.0%)	Getting better / good health n=4 (9.8%)	Social and hobbies n=6 (8.2%)
4	Getting better / good health n=44 (6.7%)	Back to normal life n=59 (11.5%)	Back to normal life n=34 (8.6%)	Independence n=9 (11.0%)	Familiarity home situation n=9 (9.9%)	Quality of life n=4 (9.8%)	Back to normal life n=5 (6.8%)
5	Family and/or friends n=40 (6.1%)	Fear / anxiety / insecurity n=57 (11.1%)	Work n=28 (7.1%)	Symptom relief other n=9 (11.0%)	Having things done quickly n=8 (8.8%)	Reassurance n=4 (9.8%)	Getting home n=5 (6.8%)

PART III

ASSESSING THE QUALITY OF ACUTE CARE NATIONALLY

INTRODUCING A QUALITY REGISTRY ON ACUTE INTERNAL MEDICINE: METHOD OF DEVELOPMENT AND OPPORTUNITIES OF USE

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DISCUSSION, FUTURE DIRECTIONS AND SUMMARY

GENERAL DISCUSSION

In July 2020 the Dutch Ministry of Health published the so-called "charcoal sketch" about the future organisation of acute care, with the aim of preserving quality and accessibility and reduce costs.[1] Prior to this sketch, a nationwide discussion about the optimisation of the emergency care landscape has been conducted over the years and several reports on this topic has been published.[2-5] Given the variety of conflicting comments on this charcoal sketch and level of disagreement between health care professionals on the one hand and policymakers on the other, the (re)organisation of acute care in The Netherlands remains a subject for debate. The availability of more scientific research on this topic can lead to a more balanced and informed debate, aiming to organise acute care in a more evidence-based way in the future. Therefore, some important topics need to be explored and evaluated profoundly.

Firstly, there are known differences in the organisation of acute care on international, national, regional and local levels.[6-8] For instance, in the Netherlands, the organisation of the Emergency Departments (ED) are heterogeneous and no uniform criteria or guidelines exist. Only recently, minimal standards for acute care were established containing some ED-specific requirements.[4] In contrast to, for example, the United Kingdom where uniform quality standards are in place, measured and also insightful for several years.[9] Comparing the similarities and differences in the organisation and outcomes of acute care chain internationally on one hand and identification of regional differences in the organisational characteristics of acute medical care in the Dutch regions on the other, may lead to a better understanding of acute care models and thereby provide a foundation for a futureproof optimisation of the organisation of acute care.

Secondly, the quality of the Dutch acute medical care is not measured structurally. Therefore, the effect of the local choices made in the organisation of acute care (such as working agreements, number of staff and ED treatment bays) on the quality of acute medical care is unknown. Given the heterogeneity of the organisational characteristics in acute care, studying the effect of differences in organisational characteristics on the quality of acute medical care would be necessary to optimise the local or regional organisation of acute care. Also, best practices may be detected and broadly implemented.

Lastly, a recent report of the Council for Health and Society indicated that local inhabitants and patients should be involved in decision making processes about the organisation of acute care to include their values and perspectives in the debate.[10] Additionally, the increasing attention for Value Based Health Care (VBHC) requires insight in patients values and evaluation of the perceived quality of care, also in acute care.[11,12]

Given the knowledge gaps in these topics in acute care and consequences for the future acute care landscape, with this thesis we aim to provide knowledge, insight and inspiration for the future organisation of acute medical care by studying:

1) the current organisation of the acute medical care in the Netherlands compared to the British organisational model and learning lessons;

2) the patient's perspective on the quality of acute medical care;

3) the quality of acute medical care and the influence of the local organisation on this quality.

In this chapter we provide an overview of the main findings of this thesis, discuss these findings and provide future directions for research and policy development in acute medical care.

MAIN FINDINGS

The organisation of acute medical care in the Netherlands

Acute medical care in the Netherlands is mainly provided in EDs and by General Practitioners (GPs) in primary care. The Dutch ED landscape is diverse with differences in the organisation and number of treatment bays, nurse staffing levels, presence of Emergency Physicians (EPs), number of hospital beds and whether collaboration with GP cooperatives exist.[13] Over the last years more and more EDs have been closed, mostly due to mergers of hospital organisations.[8] Gaakeer et al. demonstrated associations between patient and hospitalisation volumes on the one side, and nurse workforce capacity, the number of treatment bays and hospital beds on the other.[14] The authors suggest to use these findings as input for a future ED resource allocation framework. However, all of these studies focused on the ED in the widest sense, providing acute care for a very heterogeneous patient group, including trauma, surgical and medical patients. One could argue that acute medical care may require specific organisational characteristics to deliver optimal quality.

Therefore, in the **first part of this thesis,** we focused on the organisation of acute medical care, starting with a nationwide inventory of organisational details of the Dutch acute care for internal medicine patients. Internal medicine patients are more and more characterised by an increasing case complexity due to multi-morbidity, polypharmacy, disability and/or frailty.[15] These patients often present themselves with varying critical conditions or undefined diagnosis.[16] Given the demographic changes and increasingly complex cases presenting at the ED presently and the

expected increase in the future, the organisation of acute care for internal medicine patients may require fundamental changes to what is in place at the moment. As a response to these (expected) changes and following the example of the UK, in 2012 acute medicine was recognised as a subspecialty of internal medicine in the Netherlands.[17] The so-called acute internists, i.e. acute physicians, are generalists with specific knowledge of acute presentations of diseases, diagnostic possibilities in acute care and treatment options for the most common acute internal medical presentations. In addition, acute physicians have specific knowledge of the organisation of acute care for internal medicine patients and are able to take a leading role in the organisation and coordination of acute care for these patients.[18]

In **chapter 2** we inventoried the organisational characteristics of acute care for internal medicine patients in the Netherlands, which showed variation between hospitals. We demonstrated many notable differences, which concerned patient numbers, the staffing and roles and responsibilities. Firstly, the total number of patients and the number of internal medicine patients presenting at the ED per year differed greatly between centres. Overall, over the years there was a trend towards decreasing total numbers of patients visiting the ED while there was an increase in the numbers of patients ≥65 years, which was in line with national reports.[2,3] Secondly, the presence of EPs and internists at the ED varied greatly. In fact, at 14 EDs an internist was not physically present but only available on call. Lastly, working agreements between internists and EPs regarding supervision of residents and providing initial care in hemodynamically unstable patients showed differences between referred and not-referred patients. In general, EPs take care and provide supervision for not-referred patients whereas internists primarily take care for referred patients. However, EPs are not present in every hospital (i.e present in 79% of the hospitals) and only present in 42.1% of the hospitals 24/7.

Based on these findings, we concluded that heterogeneity exists regarding presence of internists and EPs, roles and responsibilities of internists and working agreements between EPs and internists. Coppes et al. also demonstrated that a high degree of heterogeneity exists in the Netherlands with regard to the roles and responsibilities of EPs at EDs, for example in the responsibilities in direct patient care, supervision of residents and performing specific procedures such as procedural sedation and analgesia. In their opinion, 24/7 presence of EPs at all EDs, functioning as the main consultant for all patients at EDs and recognition of Emergency Medicine as an independent specialty should be the way forward.[19] Of note, 3 of the authors were board members or members of the advisory board of the Dutch Society of Emergency Physicians. On the other hand, the Netherlands Association of Internal Medicine states in their current strategic vision that internists should be the central contact for acute medical patients with multi-morbidity and polypharmacy, which

is in contrast with an EP acting as the main consultant for all patients at the ED.[20] In addition, some internists participating in our study experienced that there was limited knowledge amongst EPs concerning internal medicine related problems. Thereby, we identified signs of suboptimal interprofessional collaboration, reported as a conflict of domains, which is strengthened by the contrary views reported above.

Due to demographic changes and improved treatment possibilities, most patients presenting for internal medicine at the ED will be older and often have multi-morbidity or polypharmacy. These patients will mostly suffer from an acute deterioration of a chronic disease. Therefore, knowledge of the disease course prior to the ED visit, diagnostic and treatment possibilities considering comorbidities and medication use, and coordination of follow-up is essential. In general, internists are specialised and experienced in taking care for these types of patients. However, EPs are well trained in taking initial care of acute patients and co-ordinate the patient flow at the ED, which is of major importance to maintain performance. Therefore, we believe that EPs and internist can be complementary to each other while working in the ED. The presence of internists in the ED and their influence on the quality of care for acute internal medicine patients and ED-performance, should be investigated further in order to select the most optimal organizational model and staffing policy.

Emergency and acute care is provided internationally, but differences exist in organisational structures. Therefore, we hypothesised that lessons could be learned by comparing the organisational characteristics of the English and Dutch acute care chains as described in **chapter 3**. Based on similarities and differences in the organisation of acute care in both countries, we distilled potential lessons for the organisation of acute care. In our opinion, the main strength of the Dutch organisational structure of acute care is the 24/7 accessibility of GPs in so-called GP-posts (or GP co-operatives), where they serve as gatekeepers. Compared to England, corrected for the population, less patients are seen at the EDs and the admission rate is higher, which indicate a better triage of patients. This strength has been recognised internationally in various reports and research.[21,22] For example, the Monitor, presently called NHS Improvement, indicated that the GP-cooperatives in the UK may also lead to reduced ED-visits, an improved accessibility and good workforce outcomes.[23] In addition, the Emergency Care Access Point (ECAP) model, a collaboration between GP-cooperative and EDs using the same entrance and joint triage, has shown to triage self-referred patients efficiently either to the GP or ED.[24] A strength of the British model might be the availability of ambulatory emergency care. Ambulatory emergency care can provide an appropriate support to primary care when escalation is needed, and reduce the use of the inpatient bed base, thereby facilitating more treatment of acute illnesses from a community setting. The Netherlands may benefit from this example, as the Dutch traditional out-patient

care is not focussed on acute illnesses and lacks an adequate availability of 'acute generalists' as well as infrastructure facilitating not only a diagnostic, but also a therapeutic response to acutely unwell patients.

One of the challenges in the Dutch system is the heterogeneously organised emergency care, which makes it hard to establish uniform quality standards for acute care. The British organisational model knows a more uniform structure, especially concerning staffing of EDs and Acute Medical Units (AMUs). In general, Emergency Physicians are 24/7 present at most EDs. Consultants of all medical specialties are available on-call to treat high-complex patients, particularly those needing in-hospital treatment. Acute medical patients needing admission are mostly seen at the AMU by one of the acute physicians. This uniformity in staffing and pathways for medical patients, creates easier comparable acute care systems and might be one of the reasons that quality assessment in acute medical care is more developed in the UK compared to the Netherlands.[9,25] In addition, a bundle of quality indicators is part of the NHS Constitution, consisting of amongst others the percentage of ambulance handovers within 15 minutes, percentage of patients being initially assessed within 15 minutes and number of patients spending more than 12 hours in the ED.[26]

In the Netherlands, a quality framework for acute care has been established over the last years with the aim of delivering high quality care for each individual acute patient. This quality framework contents minimal standards for the (regional) organisation of acute care and was established by 11 parties involved in the organisation of acute care. Due to lack of consensus on two standards, the Quality Board of the National Health Care Institute took over the coordination of the process to determine the final quality framework. This lack of consensus might be a sign of contrasting interests of the involved parties, or unclear effects of the proposed standards on quality. Remarkably, most of the required standards in the quality framework are not evidence based, but based on previous reports or opinions.[27] Given the differences in organisational structure of acute care, it might not be desirable to pursue uniform standards as it may interfere with the flexibility and resilience of a system. Despite that the quality framework acute care aims to set minimal standards for regional organisation of acute care, the standards seem to mostly affect the small, general hospitals. It is doubtful whether consequences of these standards were foreseen for these hospitals, which often are essential for providing accessible and timely acute care in those specific regions. The question rises whether parties involved in the quality framework are pre-sorting on centralisation of acute care, as at this point evidence is lacking for beneficial effects of centralisation on all types of acute care.

We believe that comparing acute care systems may highlight important lessons and best practices for the organisation of acute care. However, the regional context

should be taken into account, as it is known that external factors such as socio-demographic characteristics among others, affect the medical service use and quality.[28-30] Therefore, regional acute care networks should have the freedom and possibility to make its own choices to organise care in order to pursue optimal quality of care, according to its regional context.

Quality of acute medical care – the patient's perspective

Healthcare is more valuable when its quality is secured. However, defining quality is a challenge. In 2001 the Institute of Medicine defined six aims for improvement of healthcare quality as a response to the existing discrepancy between the ideal of good healthcare and the actual delivered healthcare in the U.S.A. These six domains include safety, effectiveness, patient-centeredness, timeliness, efficiency and equity and are generally accepted worldwide.[31]

The domain patient-centeredness specifically aims to deliver care with respect to the individual patient's culture, social context, and specific needs. Additionally, the patient should play an active role in making decisions about her own care. A relatively similar view is proposed by Michael Porter while introducing Value Based Health Care (VBHC), stating that value should be defined around the patient and measured by health outcomes. Though, this value should be relative to the inputs (or cost) required, and as such it encompasses efficiency and induces competition between health care providers in order to attract patients.[32] Possibly most importantly, Porter recommends providers to start measuring and reporting outcome data on each of the medical conditions they treat. A method to evaluate patients' value is assessing Patient Reported Outcomes (PROs) using Patient Reported Outcomes Measures (PROMs).

In **chapter 4**, we provide an overview of PROMs used in acute care settings. We showed that the use of PROMs in acute care settings currently is limited. Despite Porter's recommendation, in acute care many medical conditions are not systematically being measured and evaluated. In general, barriers to implement PROMs at the patient level are, time restrictions, inadequate capacity or difficulty using electronic devices to complete PROMs. At the health professional level, major barriers include lack of time and knowledge to meaningfully interpret and integrate PRO data into clinical practice and the inability to act upon findings from PROMs. Prominent barriers at the service level include difficulties integrating PROMs into clinical workflows and inadequate information technology infrastructures for PRO collection.[33,34] Possible reasons for limited availability of PROMs in acute care are the time-constrained setting in which care is provided, the heterogeneity of the target population and the difficulty to interpret outcomes as acute care is provided in several settings, all potentially influencing outcomes.

Additionally, only the generic PROMs in acute care as identified in our study meet the standards regarding validity and reliability. Reliability analyses are usually focused on consistency, stability and repeatability of the outcome of the assessment method, which might be a challenge in acute care as health outcomes can change rapidly which may hamper the results of test-retesting as patients are not stable over time. Intriguingly, many PROMs lack reporting on content validity and as a consequence it is unclear if patients were involved during the development of the PROM and if the PROM actually measures the concept of interest which it intends to measure.

Aiming to fill this gap, in **chapter 5**, we determined outcomes of acute care that are relevant for internal medicine patients. We divided these outcomes into five domains: relief of symptoms, understanding the diagnosis, presence and understanding of the diagnostic and/or therapeutic plan, reassurance and patient experiences. These findings are in line with a similar research of Vaillancourt et al. performed in Canada amongst patients being immediately discharged after an ED visit and therefore the determined domains may be valid in different patient populations presenting in the ED.[35] However, a few remarks can be made. Firstly, patient experiences and patient outcomes are different concepts in scientific research and are recommended to be measured separately, using respectively Patient Reported Experience Measures and Patient Reported Outcome Measures.[36,37] Though, during the interviews in our study it became clear that patient experiences, such as waiting time, influence outcomes and hence are important to evaluate integrative. Additionally, despite that researchers try to distinguish experiences from outcomes, patient do not. Secondly, the results are based on responses from mainly highly educated patients with predominantly a Dutch background. Given the multi-cultural characteristics of the Netherlands, it would be of interest to evaluate if the same results will be found in patients with a lower educational level or different cultural background. Finally, the identified relevant domains focus on the perceived quality of care in the ED rather than on functional outcomes or quality of life after the ED visit. It therefore can be used to improve healthcare delivery. This is in line with the Professionalism discourse on VBHC in the Netherlands, in which VBHC is predominantly construed as a methodology for the organisation and improvement of health care delivery.[38] However, another important discourse is Patient Empowerment, using VBHC as a framework for strengthening the position of patients regarding their medical decisions. In this light, functional outcomes or outcomes on quality of life are important to be used in shared decision making. Though, it may be questionable to what extend interventions in the ED influence outcomes in the long term.

Based on the determined relevant domains for internal medicine patients in acute care, in **chapter 6**, we developed the Patient Reported Measure-acute care and assessed its validity. Given the formative construct model, we analysed face -, content-

and construct validity which were all deemed good. In addition, the correlation between overall satisfaction and the total mean score of the PRM-acute care was significant, which endorses the underlying formative model. Patients reported a good perceived quality of care at the ED with scores ranging from moderate to well for each of the relevant domains and the overall perceived quality was judged as good with a mean of 4.67/6.0.

The use of a formative model is not very common in the use of PROMs, as the classical test theory is most frequently the followed concept. This theory assumes that each observable item can be viewed as a reflection of the underlying latent construct.[39] In a formative model however, the items or indicators, are combinations that form the composite latent variable.[40] Formative scales are valuable to model and to quantify the impact of multiple dimensions on a latent variable.[40,41] In our construct model, the five relevant domains all have an impact on the perceived quality of care independently and therefore the formative model suits best. As a consequence, the reported scores on the individual domains are as important as the calculated total score to evaluate and improve the quality of acute care.

In our study, we found scores ranging from moderate to well on each domain suggesting that patients are quite satisfied with the provided care. A challenge when assessing perceived quality of care is that there is always the risk of receiving socially desirable answers as patients depend on the care provided. Aiming to limit this risk, the researchers were not involved in the care process of the patient. Additionally, it has been shown that cultural differences exist in reporting experiences, both in health care as in marketing research.[42,43] One could hypothesise that Dutch patients in general tend to report satisfying scores, however our findings are in line with the evaluation of patient experiences in one large Dutch ED by Bos et al.[44]

A strength of the PRM-acute care compared to for example the CQI Accident&Emergency is that the results of the PRM-acute care can be interpreted real time, which gives the health care provider the opportunity to improve the care for the individual patient.[44] For example, when scores on specific domains are reported as insufficient, an effort can be made immediately by the health care professional to provide information on diagnosis or treatment again in a more understandable manner. In this way, patients can take advantage of filling out the questionnaire. In our opinion, this increase the chance of to implementing and use the PRM-acute care in daily practice.

In **chapter 7** we studied internationally “what matters most” to patients who are acutely admitted, aiming to incorporate patient’s perspectives in the daily practice of acute care. We found that the priorities for acutely admitted patients were ostensibly

disease- and care-oriented and thus in line with the hospitals' own priorities. For instance, 'getting better', 'getting home' or 'having a diagnosis' were frequently mentioned. However, answers to why these were important were diverse, more personal, and were often related to psychological well-being and relations. Examples are: "I Wish to get home to my daughter- in-law's 50th birthday on Friday" or "It is unsafe to be sent home without clarification."

Since several years a paradigm shift in healthcare is pursued, aiming to get to the essence of patient centred care. Instead of asking 'what is the matter?' healthcare professionals should rather ask 'what matters to you?'.[45] This question allows patients to disclose their interests, values, and preferences, and it gives the clinical team a chance to appreciate patients as human beings and not just as recipients of care.

In the process of shared decision making, exploring what matters to patients with regard to their health decisions, is referred to as values clarification.[46] Rocque et al. showed that values can be distinguished in five categories in primary care, namely: 1) preferences, 2) concerns, 3) treatment-specific values, 4) life goals and philosophies, or 5) broader contextual or sociocultural values. They also identified that the categories preferences and concerns are raised most frequently during conversations between doctor and patient.[47] When comparing these categories to the framework we created during our study, all of the above-mentioned categories are represented. The most frequent mentioned categories in our study are getting better and getting home, which correlates with the value of preferences. This was followed by the category 'knowing the diagnosis', often driven by concerns of patients. Therefore, asking "what matters most and why does this matter" appears to be a relevant step in value clarification in acute care and can serve as a basis towards shared decision making and delivering patient-centred care.

Interesting, perhaps alarming, a large group of patients felt their treating doctor did not know what mattered most to them. Underlying causes can be diverse. Firstly, a previous study investigating patients' perspectives of communicating with providers suggested that patients set boundaries for the type of information they broach in the consultation based on what they perceive is proper to discuss in medical appointments (e.g., patients may have avoided talking about religion and cultural beliefs).[48] These findings are strengthened by a systematic review, indicating that because of the dominance of biomedical culture, discussions were oriented toward medical information. Although patients wished to discuss psychosocial information, most patients did not feel confident in initiating these broader discussions.[49] Furthermore, because of the growing pressure on acute healthcare systems and limited time available per patient as a consequence, it is very challenging to have comprehensive conversations with patients in the ED.[50,51] However, in our study we

showed that asking "what matters to you and why?" only takes a few minutes and therefore it is assumed to be feasible in acute care settings.

Recapitulatory, asking patients "what matters to you and why" is a good way to clarify patient values, provides a basis for shared decision making and therewith strengthens patient empowerment and is feasible in acute care settings. Therefore, we recommend to use these questions in daily practice, also in acute care.

Developing a national quality registry on acute care

Given the increased pressure on emergency care services internationally and also in the Netherlands, quality assurance and improvement is of major importance in order to provide care of good quality and identify opportunities to improve quality.[2,52,53] Additionally, the heterogenous organisation of acute care for internal medicine patients in EDs and nationwide discussion on minimal standards of ED organisation, provides further arguments for the need of evaluating the quality of acute medical care.[4,54] In the Netherlands, a nationwide registry of trauma patients is established in 2007 with the aim of evaluating the quality of trauma care by benchmarking and performing scientific research. All hospitals with an ED and some ambulance services are participating in this registry.[55] In contrast, a quality registry for acute medical patients, and internal medicine patients in particular, is lacking despite their significant contribution on the ED workload.[54] In order to ensure the best outcomes and care practices for acute internal medicine patients, we initiated the development of a quality registry on acute internal medicine.

In **chapter 8**, we describe the creation of the Dutch Registry for Acute and Internal Medicine (DRAIM) and illustrate opportunities of use, based on data collected before and during the first Covid-19 wave in the Netherlands in one hospital (Máxima MC). Potential benefits of our registry are numerous. Firstly, ED-performance can be evaluated, taking organisational characteristics into account and correct for patient characteristics. Secondly, changes can be objectified after implementation of quality-improvement initiatives. Lastly, comparison of outcomes between EDs with a different organisation, may contribute to the identification of bottlenecks in the local organisation and provides space to learn and improve.

The completeness of the collected variables in our registry was fair. Missing variables were most distinct in the variables 'respiratory rate' (27.4%), 'level of consciousness' (96.8%) and specific laboratory results. The type of missing variables should be evaluated further and acted upon when performing research including these variables.[56] However, previous research showed that an unregistered respiratory rate is a favourable prognostic and therefore can be assumed as missing not at random.[57] An important limitation is the questionable validity of diagnosis, as financial data

are used and the diagnosis of the underlying chronic disease may be reported instead of the acute problem a patient presents with in the ED. A uniform manner of registration of the diagnosis at presentation in the EHR may increase its validity. It is recommendable to pursue a nationwide standard for registration of data in the EHR to improve the quality and validity of data, as also suggested by Nictiz, the Dutch organisation for digital information-exchange in healthcare.[58]

We showed that this registry can provide substantial insights into the characteristics and outcomes of acute internal medicine patients. For example, we identified an ED-revisit rate of 16.3%. When analysing this specific group of patients, a significant difference between patients directly discharged from the ED and admitted patients was identified, to the disadvantage of discharged patients. For the purpose of quality improvement, one may suggest to start a quality improvement project on patients being directly discharged from the ED and evaluate whether ED-revisits will decrease post implementation.

We believe that the development of this quality registry, can be an important tool to influence the course in the nationwide debate on minimal requirements for EDs and hospitals providing acute care. Historically, EDs are focussed on - and organised to deliver trauma care.[59] Nowadays, the proportion of medical patients is increasing and therefore the organisation of EDs should also be focussed on these type of patients.[2,54] In the Netherlands, concentrating emergency care for trauma patients, myocardial infarction and cerebrovascular accidents has become a standard.[60] The benefits of centralisation seem to be extrapolated to all so-called high-complex acute patients, despite that scientific evidence is lacking for acute internal medicine patients.[1] To date, the organisation of EDs for internal medicine patients is heterogeneous and no quality standard exists.[54] Our quality registry can provide insight in the quality of care delivered for this group of patients and can be used to assess the influence of organisation and patient characteristics on the quality. In order to organise acute care for internal medicine patients in the best way, the following topics need to be addressed:

Quality of care knows six dimensions as stated by the Institute of Medicine.[31] Most reports and guidelines on (the organisation of) acute care, such as the most recent quality standard acute care, are focussed on the domains safety and accessibility to a lesser extent.[27] A profound debate on defining quality for acute internal medicine needs to be held amongst healthcare providers, managers, healthcare insurance companies, patients and citizens as different perspectives are necessary to reach consensus on determining quality.

Regional differences in organisation of acute care can exist, as long as quality is preserved. Therefore, our quality registry can be used to demonstrate persistence of quality within a specific organisation or region.

A research agenda on acute internal medicine needs to be established concerning the improvement of quality of care and optimising the organisation of acute care; not only in the ED but also in AMUs. Our quality registry can provide data collected in several type of hospitals in different regions and be used for quality improvement projects and research.

For future benefits, nationwide participation of all hospitals with an ED will strengthen the project. Also, a more profound debate on and evaluation of the minimal dataset necessary to evaluate quality (i.e. selection of variables) may be valuable. Lessons may be learned from the ZIRE project on Dutch ICUs in order to register meaningful indicators only and therewith diminish the administrative burden.[61] Furthermore, pursuing real-time insight in data may increase the usage of this registry in regard to organisational consequences.

Overall, our quality registry provides insight in characteristics and outcomes of internal medicine patients presenting in the ED, reflecting ED-performance. Knowledge of acute internal medicine patients can be obtained as well as related outcomes. Therefore, we believe that our registry is a valuable source for future quality improvement projects and research.

FUTURE DIRECTIONS

Policy

Quality of care is a main driver for health care professionals, as well as for managers and politicians to create guidelines, develop minimal standards and change the organisation of care. The domain safety is the main driver, followed by effectivity.[62] However, it is often unclear how quality improvement strategies fit within a given health system as many guidelines are developed based on evidence gained in another setting. This is probably also the case in the recent approved national quality standard for acute care.[4] The report 'no evidence without context' of the Council for Public Health and Society also indicated this deficiency of evidence-based practice and calls professionals to embrace the uncertainty in the argumentation when performing research and put the focus on the context of their patients. For the scientists, it means acknowledging that scientific evidence is never complete and must always be subject to new insights and experiences. For health insurers, authorities and supervisory bodies, it means that the frameworks they define must give scope for

an experimental approach to care practice and that they must prioritise the capacity of care professionals and care organisations to learn from this and to improve.[63]

Furthermore, experts in healthcare quality, Koksma and Kremer, state that the currently dominant concept of quality has reductionist tendencies and is at odds with the dynamic complexity of today's health care. Too often, quality tools have become disconnected from the real world of people.[64] Therefore, they favour a new concept of quality that is dynamic, pluralistic, and moral. *The* quality does not exist; rather, quality differs according to the context and perspectives of the people involved. The crucial concept to grasp is that quality has a *moral* nature. The way to go is not to update the protocol but, rather, to embrace the new concept of quality— that is, to start learning.

Based on our findings, we believe that it is possible to measure quality of acute care and this can be used to optimise the organisation of care. However, we strongly recommend continuous evaluation of the delivered quality in an open atmosphere, in order to start learning. Therefore, healthcare professionals, managers and patients should work together and discuss the findings retrieved from quality measurement. Local and regional characteristics and the patients' perspective are important subjects in order to include context in evidence. Policymakers should provide space to experiment and learn.

Clinical practice

This thesis provides starting points to improve acute care for internal medicine patients. Firstly, we believe that the developed and validated PRM-acute care can be implemented in daily practice in order to improve the perceived quality of care by patients. Barriers for implementation such as a time-constraints can be minimised by using the hospital's patient portal to fill in the questionnaires by patients themselves. Secondly, every doctor who aims to deliver patient-centred care in an acute setting, can ask the question: what matters to you and why? When this question becomes common practice, the person behind the patient will be seen and acknowledged. Personal values and beliefs can be taken into account in the shared decision making process. As a consequence, treatment goals and plans can be personalised. Lastly, we believe that acute physicians should take a leading role in the evaluation of the delivered quality of acute care. This can be achieved by participating in our quality registry, but also by structural collection of performance data locally. These data can form the basis for local or regional discussions between healthcare professionals and managers on quality, aiming to learn from each other, to start an inventory for quality improvement projects and to optimise organisation and outcomes in acute care.

Research

This thesis creates a basis for future research on organisation and quality of acute care, and acute internal medicine in particular. Several themes deserve a closer look and progression of already started research.

First, the organisation of acute care for internal medicine patients has been assessed and showed to be organised in a heterogeneous way. Since 2016, an acute internist is present in more and more hospitals. This may lead to different working agreements and staffing. It would be of interest to assess the impact of the presence of an acute internist on the quality of care for acutely presenting internal medicine patients. Additionally, identification of organisational factors influencing patient or process outcomes in a positive way are of major importance to optimise acute care. Furthermore, a qualitative analysis of the collaboration between EPs and (acute) internists needs further attention given the identified various appreciation of this collaboration and the known association between quality of care and interprofessional collaboration.[65,66] Internationally, the organisation of acute medical care knows various models, which may influence the quality. We showed that lessons can be learned from different perspectives and models. It may be of interest to structurally measure acute care quality in different organisational models internationally, to learn even more and improve the quality of acute care by adapting organisations.

Second, we introduced and validated Patient Reported Measures in acute care for internal medicine patients. However, due to Covid-19 some aspects in the validation process are postponed: for instance, the cross-cultural validation needs to be executed to optimise external validation. Also, one may suggest to validate these PRMs for all ED-patients because the determined outcomes seem to be quite general and appropriate for patients presenting for other specialties than internal medicine.[35,67] Moreover, using PRMs in evaluating the quality of care might be optimised by connecting organisational characteristics, patient characteristics and medical outcomes to PRMs. In that way, most quality domains can be assessed and evaluated integrally. When assessing the literature regarding PROMs, functional status or health related quality of life on the long term are outcomes used to evaluate the quality of care or even more the effect of treatment. From a patient perspective, those outcomes are important and valuable. However, in the acute setting and from a researcher perspective, it may be hard to differentiate whether or to what extent the care delivered affects outcomes on the long term. This may be possible for specific acute diseases such as fractures,[68] but may become very complex for patients with multimorbidity and multiple problems at once. On the other hand, when striving for optimal patient-centred care, it is worthwhile to assess whether generic PROMs

measuring functional decline or health related quality of life, can be used in an acute setting for shared decision making.

Third, the creation of the quality registry in acute internal medicine offers many opportunities for future research. Data from the registry can be directly used for amongst others risk prediction or stratification within specific patient groups, assessing ED-performance and identifying subjects for quality improvement or efficiency studies. An open debate on quality in acute care for internal medicine patients amongst patients, healthcare professionals and managers may help to prioritise knowledge gaps in quality evaluation and judging on quality. In order to reach a next step in quality research and evaluation, studies to the optimal way of using the quality registry to create a learning atmosphere, may help patients, healthcare professionals and policymakers even more.

CONCLUSION

The organisation of acute care for internal medicine patients in the Netherlands is heterogeneous. Its influence on the quality of care has not been determined yet. Opportunities for improvement of the organisational structure can, for instance, be found by learning from the British system, with ambulatory emergency care as an example.

In order to improve patient-centredness in acute care and assess the perceived quality of care, the Patient Reported Measure-acute care is a valid tool and can be implemented in daily practice, covering the domains understanding the diagnosis and treatment plan, relief of symptoms, reassurance and experiences. Asking patients 'what matters most and why' is an easy way to learn about the person behind the patient and provide personalised care, also in an acute setting.

The quality of acute care for internal medicine patients can be structurally evaluated by using a quality registry, providing room for a learning environment and optimise the organisation and quality of acute care.

REFERENCES

1. Ministerie van Volksgezondheid Welzijn en Sport. Houtskoolschets acute zorg. https://www.rijksoverheid.nl/documenten/rapporten/2020/07/03/houtskoolschets-acute-zorg: Rijksoverheid; 2020.
2. Nederlandse Zorgautoriteit. Monitor acute zorg 2018. https://puc.overheid.nl/nza/doc/PUC_260889_22/1/: NZa; 2018.
3. Nederlandse zorgautoriteit. Marktscan acute zorg 2017. https://puc.overheid.nl/nza/doc/PUC_3650_22/1/; 2017. Contract No.: PUC_3650_22.
4. LNAZ, FMS, NVSHA, Patiëntenfederatie Nederland, Ineen, NVZ. Kwaliteitskader spoedzorgketen. https://www.zorginstituutnederland.nl/publicaties/publicatie/2020/02/19/kwaliteitskader-spoedzorgketen: Zorginstituut Nederland; 2019.
5. Nederlandse Vereniging van Ziekenhuizen. Acute zorg, er zit meer aan vast dan u denkt! : NVZ; 2013.
6. International comparisons of selected service lines in seven health systsems. https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment_data/file/382847/Annex_5_AandE.pdf; 2014.
7. Baier N, Geissler A, Bech M, Bernstein D, Cowling TE, Jackson T, et al. Emergency and urgent care systems in Australia, Denmark, England, France, Germany and the Netherlands – Analyzing organization, payment and reforms. Health Policy. 2019;123(1):1-10.
8. Gaakeer MI, van den Brand CL, Gips E, van Lieshout JM, Huijsman R, Veugelers R, et al. [National developments in Emergency Departments in the Netherlands: numbers and origins of patients in the period from 2012 to 2015]. Ned Tijdschr Geneeskd. 2016;160:D970.
9. National Health Service England. Provisional accident and emergency quality indicators for England, October 2021, by provider. https://digital.nhs.uk/data-and-information/publications/statistical/accident-and-emergency-quality-indicators: NHS; 2021.
10. Raad voor Volksgezondheid en Samenleving. Van deelbelang naar gedeeld belang. Een handreiking voor regie op toegankelijke acute zorg. https://www.raadrvs.nl/documenten/publicaties/2020/06/17/van-deelbelangen-naar-gedeeld-belang: RVS; 2020.
11. Steinmann G, Delnoij D, van de Bovenkamp H, Groote R, Ahaus K. Expert consensus on moving towards a value-based healthcare system in the Netherlands: a Delphi study. BMJ Open. 2021;11(4):e043367.
12. BCG. How Dutch hospitals make value-based health care work https://www.bcg.com/publications/2018/how-dutch-hospitals-make-value-based-health-care-work2018 [
13. Thijssen WA, Giesen PH, Wensing M. Emergency departments in The Netherlands. Emerg Med J. 2012;29(1):6-9.
14. Gaakeer MI, Veugelers R, van Lieshout JM, Patka P, Huijsman R. The emergency department landscape in The Netherlands: an exploration of characteristics and hypothesized relationships. Int J Emerg Med. 2018;11(1):35.
15. Nardi R, Scanelli G, Corrao S, Iori I, Mathieu G, Cataldi Amatrian R. Co-morbidity does not reflect complexity in internal medicine patients. Eur J Intern Med. 2007;18(5):359-68.

16. Nardi R, Scanelli G. Multimorbidity and complexity: a current research priority not only int he UK and primary care, but all over the world and in every care setting. BMJ. 2007;17(334):1016.
17. Centraal College Medische Specialismen. Besluit interne geneeskunde. Netherlands: https://www.knmg.nl; 2010.
18. Nederlandse Vereniging voor Internisten Acute Geneeskunde. Visie https://www.acuteinternisten.nl/visiedocument/#: NVIAG; 2019
19. Coppes S, Veugelers R, Hessels R, van den Brand CL, Gaakeer MI. Position within the hospital and role in the emergency department of emergency physicians in the Netherlands: a national survey. Int J Emerg Med. 2020;13(1):8.
20. Nederlandse Internisten Vereniging. Strategische visie 2018-2022: cruciale schakel in de zorg. De internist als regiebehandelaar, nu en in de toekomst. www.internisten.nl: NIV; 2018.
21. England NHS. International comparisons of selected service lines in seven health systems. https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment_data/file/382853/Annex_11_GP_Posts_in_the_Netherlands.pdf; 2014.
22. van der Straten LM, van Stel HF, Spee FJ, Vreeburg ME, Schrijvers AJ, Sturms LM. Safety and efficiency of triaging low urgent self-referred patients to a general practitioner at an acute care post: an observational study. Emerg Med J. 2012;29(11):877-81.
23. National Health Service England. High quality care for all, now and for future generations: Transforming urgent and emergency care services in England - Urgent and Emergency Care Review. https://www.nhs.uk/NHSEngland/keogh-review/documents/UECR.Ph1Report.Appendix%201.EvBase.FV.pdf: NHS; 2013.
24. Smits M, Rutten M, Schepers L, Giesen P. Self-referrals at Emergency Care Access Points and triage by General Practitioner Cooperatives. Ned Tijdschr Geneeskd. 2017;161:D1601.
25. Atkin C, Knight T, Subbe C, Holland M, Cooksley T, Lasserson D. Acute care service performance during winter: report from the winter SAMBA 2020 national audit of acute care. Acute Med. 2020;19(4):220-9.
26. NHS. Clinically led review of urgent and emergency care standards. Measuring performance in a transformed system. https://www.england.nhs.uk/wp-content/uploads/2021/05/B0546-clinically-led-review-of-urgent-and-emergency-care-standards.pdf: NHS; 2021.
27. van der Wilden G, Sandkuyl R, Kremers M. Kwaliteitskader spoedzorgketen: Gaat het echt om kwaliteit? : TIAS; 2020.
28. Doheny M, Agerholm J, Orsini N, Schön P, Burström B. Socio-demographic differences in the frequent use of emergency department care by older persons: a population-based study in Stockholm County. BMC Health Serv Res. 2019;19(1):202.
29. Fisher KA, Griffith LE, Gruneir A, Upshur R, Perez R, Favotto L, et al. Effect of socio-demographic and health factors on the association between multimorbidity and acute care service use: population-based survey linked to health administrative data.
30. Wachelder JJH, van Drunen I, Stassen PM, Brouns SHA, Lambooij SLE, Aarts MJ, et al. Association of socioeconomic status with outcomes in older adult community-dwelling patients after visiting the emergency department: a retrospective cohort study. BMJ Open. 2017;7(12):e019318.

31. Institute of Medicine. Crossing the Quality Chasm: A New Health System for the 21st Century. Washington (DC)2001.
32. Porter ME, Teisberg EO. Redefining health care: creating value-based competition on results: Harvard business press; 2006.
33. Foster A, Croot L, Brazier J, Harris J, O'Cathain A. The facilitators and barriers to implementing patient reported outcome measures in organisations delivering health related services: a systematic review of reviews. J Patient Rep Outcomes. 2018;2:46.
34. Nguyen H, Butow P, Dhillon H, Morris L, Brown A, West K, et al. Using patient-reported outcomes (PROs) and patient-reported outcome measures (PROMs) in routine head and neck cancer care: What do health professionals perceive as barriers and facilitators? J Med Imaging Radiat Oncol. 2020;64(5):704-10.
35. Vaillancourt S, Seaton MB, Schull MJ, Cheng AHY, Beaton DE, Laupacis A, et al. Patients' Perspectives on Outcomes of Care After Discharge From the Emergency Department: A Qualitative Study. Ann Emerg Med. 2017;70(5):648-58 e2.
36. Desomer A, Heede K, Triemstra M, Paget J, de Boer D. Het gebruik van patiëntenuitkomsten en -ervaringen (PROMS/PREMS) voor klinische en beleidsdoeleinden. https://www.nivel.nl/nl/publicatie/het-gebruik-van-patientenuitkomsten-en-ervaringen-promsprems-voor-klinische-en: Nivel; 2018.
37. Weldring T, Smith SM. Patient-Reported Outcomes (PROs) and Patient-Reported Outcome Measures (PROMs). Health Serv Insights. 2013;6:61-8.
38. Steinmann G, van de Bovenkamp H, de Bont A, Delnoij D. Redefining value: a discourse analysis on value-based health care. BMC Health Serv Res. 2020;20(1):862.
39. Conventional wisdom on measurement: A structural equation perspective, (1991).
40. Jarvis CB, MacKenzie SB, Podsakoff PM. A Critical Review of Construct Indicators and Measurement Model Misspecification in Marketing and Consumer Research. Journal of Consumer Research. 2003;30(2):199-218.
41. MacKenzie SB, Podsakoff PM, Jarvis CB. The Problem of Measurement Model Misspecification in Behavioral and Organizational Research and Some Recommended Solutions. Journal of Applied Psychology,. 2005;90(4):710-30.
42. Satmetrix. Satmetrix Reveals Findings on Cultural Differences in Customer Loyalty Surveys and Net Promoter Scores, https://www.businesswire.com/news/home/20070222005121/en/Satmetrix-Reveals-Findings-Cultural-Differences-Customer-Loyalty2007
43. Hasnain M, Schwartz A, Girotti J, Bixby A, Rivera L. Differences in patient-reported experiences of care by race and acculturation status. J Immigr Minor Health. 2013;15(3):517-24.
44. Bos N, Sturms LM, Schrijvers AJ, van Stel HF. The Consumer Quality index (CQ-index) in an accident and emergency department: development and first evaluation. BMC Health Serv Res. 2012;12:284.
45. Kebede S. Ask patients "What matters to you?" rather than "What's the matter?". BMJ. 2016;354:i4045.
46. Fagerlin A, Pignone M, Abhyankar P, Col N, Feldman-Stewart D, Gavaruzzi T, et al. Clarifying values: an updated review. BMC Med Inform Decis Mak. 2013;13 Suppl 2(Suppl 2):S8.

47. Rocque R, Chipenda Dansokho S, Grad R, Witteman HO. What Matters to Patients and Families: A Content and Process Framework for Clarifying Preferences, Concerns, and Values. Medical Decision Making. 2020;40(6):722-34.
48. Lim C, Berry ABL, Hirsch T, Hartzler AL, Wagner EH, Ludman E, et al. "It just seems outside my health": How Patients with Chronic Conditions Perceive Communication Boundaries with Providers. DIS (Des Interact Syst Conf). 2016;2016:1172-84.
49. Rocque R, Leanza Y. A Systematic Review of Patients' Experiences in Communicating with Primary Care Physicians: Intercultural Encounters and a Balance between Vulnerability and Integrity. PLoS One. 2015;10(10):e0139577.
50. Marvel MK, Epstein RM, Flowers K, Beckman HB, Singh Ospina N, Phillips KA, et al. Soliciting the patient's agenda: have we improved? Eliciting the Patient's Agenda-Secondary Analysis of Recorded Clinical Encounters. JAMA. 1999;281(3):283-7.
51. Singh Ospina N, Phillips KA, Rodriguez-Gutierrez R, Castaneda-Guarderas A, Gionfriddo MR, Branda ME, et al. Eliciting the Patient's Agenda- Secondary Analysis of Recorded Clinical Encounters. J Gen Intern Med. 2019;34(1):36-40.
52. Di Somma S, Paladino L, Vaughan L, Lalle I, Magrini L, Magnanti M. Overcrowding in emergency department: an international issue. Intern Emerg Med. 2015;10(2):171-5.
53. Morley C, Unwin M, Peterson GM, Stankovich J, Kinsman L. Emergency department crowding: A systematic review of causes, consequences and solutions. PLoS One. 2018;13(8):e0203316.
54. Kremers MNT, Wachelder JJH, Nanayakkara PWB, Haak On Behalf Of The Orca Onderzoeks Consortium Acute Geneeskunde Acute Medicine Research Consortium HR. Organisation of internal medicine in acute care in the Netherlands: a detailed overview. Neth J Med. 2020;78(5):251-60.
55. Kuipers EJ, Leenen LPH. Landelijke Traumaregistratie 2015-2019. https://www.lnaz.nl/cms/files/rapportage_landelijk_2020_-_v2.pdf: LNAZ; 2020.
56. Lang KM, Little TD. Principled Missing Data Treatments. Prev Sci. 2018;19(3):284-94.
57. Newman DA. Missing Data: Five Practical Guidelines. Organizational Research Methods. 2014;17(4):372-411.
58. Van Gool CH, Volkert PA, Savelkoul M, Schoemaker C, Melse J, van Sonderen JF, et al. Eenheid van taal in de Nederlandse zorg. https://www.rivm.nl/bibliotheek/rapporten/2018-0081.pdf: RIVM; 2018. Contract No.: RIVM-2018-0081.
59. Sakr M, Wardrope J. Casualty, accident and emergency, or emergency medicine, the evolution. Journal of Accident & Emergency Medicine. 2000;17(5):314.
60. Federatie Medisch Specialisten. Kwaliteitsstandaard Intramurale Spoedzorg. https://richtlijnendatabase.nl/richtlijn/kwaliteitsstandaard_intramurale_spoedzorg/basiseisen.html: Federatie Medisch Specialisten,; 2019.
61. Zegers M., Gerritsen G., Welker G. Experiment Zinvolle Registratie (ZIRE). Van Wantrouwen naar vertrouwen. https://nfukwaliteit.nl/pdf/Eindrapportage_ExperimentZIRE_DEF_1.pdf: NFU; 2021.
62. Busse R, Klazinga N, Panteli D, Quentin W. Improving healthcare quality in Europe. https://apps.who.int/iris/bitstream/handle/10665/327356/9789289051750-eng.pdf; 2019.
63. Raad voor Volksgezondheid en Samenleving. Zonder context geen bewijs. https://www.raadrvs.nl/documenten/publicaties/2017/06/19/zonder-context-geen-bewijs: RVS; 2017.

64. Koksma JJ, Kremer JAM. Beyond the Quality Illusion: The Learning Era. Acad Med. 2019;94(2):166-9.
65. Reeves S, Pelone F, Harrison R, Goldman J, Zwarenstein M. Interprofessional collaboration to improve professional practice and healthcare outcomes. Cochrane Database Syst Rev. 2017;6(6):CD000072.
66. Pedersen AHM, Rasmussen K, Grytnes R, Nielsen KJ. Collaboration and patient safety at an emergency department - a qualitative case study. J Health Organ Manag. 2018;32(1):25-38.
67. Vaillancourt S, Cullen JD, Dainty KN, Inrig T, Laupacis A, Linton D, et al. PROM-ED: Development and Testing of a Patient-Reported Outcome Measure for Emergency Department Patients Who Are Discharged Home. Ann Emerg Med. 2020;76(2):219-29.
68. Vestergaard V, Schrøder HM, Hare KB, Toquer P, Troelsen A, Pedersen AB. Patient-reported outcomes of 7133 distal femoral, patellar, and proximal tibial fracture patients: A national cross-sectional study with one-, three-, and five-year follow-up. Knee. 2020;27(5):1310-24.

SUMMARY

SUMMARY

This thesis focused on the organisation and quality of acute medical care, primarily in the Netherlands, with a specific interest for the patient perspective in acute care.

The first part of this thesis, consisting of **chapter 2 and 3**, includes studies on the organisation of acute medical care in the Netherlands and also the United Kingdom.

In **chapter 2** we performed a nationwide questionnaire based study to investigate the organisation of the Dutch acute medical care in detail. In addition, we explored the roles and responsibilities of acute physicians and Emergency Physicians (EPs) in the participating hospitals. We found differences in staffing, the presence of EPs and internists at the Emergency Department (ED) and working agreements. For instance, a registered acute internist was present at 62% of the locations and an EP at 79% of the EDs. Internists reported not being physically present at the ED in 13.8% of the EDs. Furthermore, we found a variety of roles reported by internists, with roles as practitioner and consultant mentioned by the majority. Reported roles as manager or coordinator were associated with the presence of an acute internist. In addition, we evaluated the collaboration between EPs and internists which was graded with a mean of 7.4/10. Based on these results, we recommended future research on the influence of the various organisational structures of the EDs on quality of acute care in order to provide a more evidence based policy in the organisation of acute care.

In **chapter 3** we studied the organisation of acute care in the United Kingdom and The Netherlands using national reports, literature and expert experiences, aiming to learn from each other's experiences and improve the quality of acute care. Over the last years, both countries faced an increased demand on acute care services, resulting in crowding and queing. Despite the similarities in the healthcare systems, such as universal health coverage, the British and Dutch EDs differ in the number of patients presenting at the ED and the burden of crowding. In the Netherlands, less patients are seen at the ED and the admission rate is higher than in England. General Practitioners (GPs) serve 24/7 as gatekeepers in acute care, but EDs are heterogeneously organised. In the UK, the acute care system has many different access points and the accessibility of GPs seems to be suboptimal. Acute ambulatory care may relieve the pressure from EDs and Acute Medical Units. We noticed that in both countries the population is ageing, which leads to a changing case mix at the ED with an increased amount of multimorbid patients with polypharmacy, requiring generalistic and multidisciplinary care. We suggest that The Netherlands may benefit from an acute ambulatory care system and the UK by optimising the accessibility of GPs 24/7 and improving signposting for urgent care services. In both countries the changing case mix at the ED needs doctors who are superspecialists instead of

subspecialists. Finally, to improve the organisation of health care, we concluded that doctors need to be visible medical leaders and participate in the organisation of care.

In the second part of this thesis, including **chapter 4 to 7**, we present studies concerning the quality of acute care within the domain patient-centeredness.

In **chapter 4** we executed a scoping review to provide an overview of Patient Reported Outcome Measures (PROMs) in acute care settings and assess their psychometric properties according to the COSMIN criteria. We found 1407 publications and included 14 articles, describing 15 measures. The identified PROMs are generic, disease specific or symptom specific. Most publications provided limited information on psychometric properties. Three generic PROMs were deemed of adequate quality for use in acute care. By chance, these were only generic PROM and all had evaluative purposes. Content validity often could not be assessed, while no information concerning the relevance, comprehensiveness and comprehensibility for patients and healthcare professionals was described. Additionally, reliability testing lacked reporting, which may be due to the fact that health outcomes can change rapidly, especially in acute care, which may hamper the results of test-retesting as patients are not stable over time. We recommend future development and evaluation of PROMs focussing on acute care to further evaluate and improve the quality of acute care.

In **chapter 5** we performed a qualitative interview study to identify relevant outcomes of acute care for internal medicine patients presenting at the ED, with the overarching goal of improving patient-centred care at the ED. Determining Patient Reported Outcomes (PROs) is one way to find out which outcomes are valued by the patient. PROs are defined as 'any report from patients about their own health, quality of life, or functional status associated with the health care or treatment they have received'. Based on these PROs, PROMs can be developed and used for routinely assessment of the quality of care in a patient-centred manner. Thirty patients were interviewed between March and July 2018. Five relevant domains were identified, namely: 1) relief of symptoms, 2) understanding the diagnosis and cause of symptoms, 3) presence and understanding of the diagnostic or therapeutic plan, 4) reassurance and 5) patient experiences. These domains were incorporated in a conceptual model, showing the potential association between the different domains. The major part of the themes mentioned as important outcomes of acute care, was in fact patient experiences. However, while researchers and doctors try to distinguish Patient Reported Outcomes from Patient Reported Experiences, patients do not. In their perception of quality of care, both outcomes and experiences play an important role. Therefore, we included experiences as well as outcomes as relevant domains for evaluating the quality of acute care from a patient perspective.

Based on the results presented in chapter 4, we developed a Patient Reported Measure (PRM) of acute medical care, with the ultimate aim of improving acute medical care from a patient's perspective. In **chapter 6** we describe the validation of the PRM-acute care and the results of the perceived quality of acute care in 82 patients. Unfortunately, this study was early terminated due to the regulations during Covid-19. A good face- and content validity was achieved by the semi-structured interviews performed in our previous study, complemented with cognitive interview testing of the PRM-acute care in 15 patients. Construct validity was assessed by hypotheses testing, which was deemed adequate as differences in the perceived quality of care between patients with severe and less symptoms could be demonstrated. In addition, a significant correlation between overall patient satisfaction and the total mean score of the PRM-acute care supported our construct. Therefore, we concluded that the PRM-acute care is a valid measurement instrument for the perceived quality of acute care in internal medicine patients. Overall, patients reported a good perceived quality of acute care with a mean of 4.67/6 and a score ranging from moderate to well was given for each of the relevant domains. Patients did not encounter difficulties with completing the questionnaire. Therefore, we believe that the PRM-acute care can be implemented in daily practice to evaluate the perceived quality of care by internal medicine patients. Based on the scorings in the different domains, tailor-made and patient-centred improvements can be initiated.

In **chapter 7** we used a specific method of research, called Flash Mob research, to inventory what matters most to acutely admitted patients internationally. We aimed to discover shared values between patients in order to improve the acute care in a patient-centred way worldwide. We performed an international, multicentre, 50 hours lasting, qualitative interview based study in 66 hospitals including 1850 patients. All patients were asked what matters most to them and why. In addition, we evaluated whether patients felt their treating physician was aware of this. The most reported answers to the question '*what* matters most to you at the moment?' were '*getting better or being in good health' (29.6%), 'getting home' (17.4%)* and *'having a diagnosis' (16.1%).* However, answers on the question *why* this matters differed greatly between individuals. Remarkably, over 50% of all patients felt the treating physician did not know what mattered to them, which may suggest there is a need for more explicit conversations about *what* is important to patients, and especially *why* this matters. These simple questions may guide physicians in providing personalised and patient-centred care, also in an acute setting.

The third part of this thesis, consisting of **chapter 8**, contains a study on assessing the quality of acute care nationally.

In **chapter 8** we evaluated the first results of an aimed nationwide quality registry for acute internal medicine. We started this project with the primary aim to assess the quality of acute care in the Netherlands for internal medicine patients on a regular basis, in order to improve the quality of care for these patients. Therefore we created a quality registry, called Dutch Registry for Acute and Internal Medicine (DRAIM), in which during the starting phase six hospitals participated. The results of the pilot study in one participating hospital, including 1729 internal medicine patients, showed that 61.4% was admitted and 16% revisited the ED within 30 days. Furthermore, during the first Covid-19 wave there was a decrease in the number of internal medicine patients visiting the ED and an increase of patients in triage-category U1. Completeness of data used in the quality registry was deemed good. We concluded that the quality registry provides insight in the characteristics and outcomes of internal medicine patients presenting in the ED, reflecting the ED-performance. Therefore, it can be a valuable source for quality improvement projects, bench marks and research.

Chapter 9 contained a general discussion on our findings, conclusions per part of this thesis and provided future directions for research and policy in acute care. In **chapter 10** we presented a summary in English and Dutch.

SAMENVATTING

Dit proefschrift focust zich op de organisatie en kwaliteit van de acute zorg, voornamelijk gericht op de Nederlandse situatie, met specifieke aandacht voor het patiënten perspectief in de acute zorg.

Het eerste gedeelte van dit proefschrift, bestaand uit **hoofdstuk 2** en **3**, bevat studies over de organisatie van de acute, niet-trauma zorg in Nederland en het Verenigd Koninkrijk.

In **hoofdstuk 2** voerden we een landelijke enquête uit om de organisatie van de acute interne zorg in detail te onderzoeken. Daarnaast exploreerden we de rollen en verantwoordelijkheden van internisten (acute geneeskunde) en Spoed Eisende Hulp (SEH)-artsen in de deelnemende ziekenhuizen. Wij vonden verschillen in personele bezetting, aanwezigheid van SEH-artsen en internisten op de SEH en werkafspraken. Zo is op 62% van de deelnemende locaties een geregistreerd internist-acute geneeskunde aanwezig op de SEH en op 79% van de locaties een SEH-arts. Op 13.8% van de deelnemende SEH's is de internist niet fysiek aanwezig. Daarnaast werden er verschillende rollen door internisten gerapporteerd, waarbij behandelaar en consulent door de meerderheid genoemd werd. Rollen als manager of coördinator bleken geassocieerd met de aanwezigheid van een internist-acute geneeskunde. Verder evalueerden we ook de samenwerking tussen SEH-artsen en internisten, welke gemiddeld met een 7.4/10 beoordeeld werd. Op basis van deze resultaten adviseren wij om meer onderzoek uit te voeren naar de invloed van de organisatiestructuur van de SEH op de kwaliteit van zorg, met als doel een beleid gebaseerd op meer wetenschappelijk bewijs ten aanzien van de organisatie van de acute zorg te kunnen voeren.

In **hoofdstuk 3** onderzochten wij de organisatie van acute zorg in het Verenigd Koninkrijk en Nederland, gebruik makend van nationale rapporten, wetenschappelijke literatuur en ervaringen van experts, met als doel te kunnen leren van elkaars ervaringen en zo de kwaliteit van de acute zorg te kunnen verbeteren. De afgelopen jaren hebben beide landen te maken gehad met een toegenomen zorgvraag in de acute keten, wat resulteerde in het zogenaamde 'crowding' op SEH's en toegenomen wachttijden. Ondanks de overeenkomsten van beide zorgsystemen, zoals een universele zorgverzekering, zijn er toch verschillen tussen beide landen in het aantal patiënten dat zich presenteert op de SEH en de mate van 'crowding'. In Nederland worden minder patiënten gezien op de SEH, maar het percentages opnames na SEH-bezoek is hoger in vergelijking met Engeland. Ook kent Nederland 24/7 beschikbaarheid van huisartsen als poortwachter in de acute zorg, maar SEH's zijn heterogeen georganiseerd. In het Verenigd Koninkrijk kent het acute zorg

systeem veel verschillende toegangen, maar de toegankelijkheid van huisartsen lijkt daar suboptimaal. Acute poliklinische zorg zou de druk van SEH's en acute opname afdelingen kunnen verminderen. In beide landen veroudert de populatie, wat leidt tot een veranderende casemix op de SEH met een toegenomen aantal patiënten met multimorbiditeit en polyfarmacie. Dit vraagt generalistische en multidisciplinaire zorg. We suggereren dat Nederland baat kan hebben bij het verbeteren van de acuut poliklinische zorg en het Verenigd Koninkrijk bij optimalisatie van de 24/7 toegankelijkheid van huisartsen en het verbeteren van de bewegwijzering tussen alle acute zorg faciliteiten. Voor beide landen geldt dat de veranderende patiënten populatie op de SEH dokters nodig heeft die superspecialist zijn in plaats van subspecialist. Tot slot, om de organisatie van gezondheidszorg te verbeteren, concludeerden wij dat dokters zichtbaar leiderschap moeten tonen en zich actief moeten mengen in de organisatie van zorg.

In het tweede deel van dit proefschrift, bestaand uit **hoofdstuk 4 tot 7**, presenteren we studies over de kwaliteit van de acute zorg binnen het domein patiëntgerichtheid.

In **hoofdstuk 4** voerden wij een literatuurstudie uit met als doel een overzicht te creëren van vragenlijsten gericht op door patiënten gerapporteerde uitkomsten (Patient Reported Outcome Measures, PROMs) in de acute zorg. We evalueerden de psychometrische eigenschappen van deze PROMs volgens de COSMIN criteria. We vonden 1407 publicaties en includeerden 14 artikelen, welke 15 vragenlijsten beschreven. Deze geïdentificeerde PROMS bleken algemeen, ziekte specifiek of symptoom specifiek van aard. De meeste publicaties voorzagen slechts beperkt in informatie betreffende de psychometrische eigenschappen. Drie algemene PROMs bleken kwalitatief adequaat genoeg voor gebruik in de acute zorg. Toevallig waren al deze PROMs algemeen van aard en waren ze evaluatief van opzet. Evaluatie van de inhoudsvaliditeit was regelmatig niet mogelijk, omdat er geen informatie beschikbaar was met betrekking tot de relevantie, begrijpelijkheid en volledigheid van de vragenlijsten voor patiënten en zorgverleners. Ook werd het testen van de betrouwbaarheid van de vragenlijsten zelden gerapporteerd. Dit kan te maken hebben met het feit dat gezondheidsuitkomsten in de acute zorg snel veranderen, waardoor de zogeheten *test-hertest* lastig kan zijn, aangezien patiënten niet stabiel zijn over tijd. We raden aan om PROMs in de acute zorg verder te ontwikkelen en te evalueren om daarmee de kwaliteit van de acute zorg te kunnen verbeteren.

In **hoofdstuk 5** voerden wij een kwalitatieve studie uit, gebaseerd op interviews, om relevante uitkomsten van acute zorg voor interne patiënten op de SEH te identificeren, met als onderliggend doel patiëntgerichte zorg op de SEH te kunnen verbeteren. Het vaststellen van door patiënten gerapporteerde uitkomsten (Patient Reported Outcomes, PROs) is een methode om te bepalen welke uitkomsten relevant

en belangrijk zijn voor patiënten. PROs zijn gedefinieerd als 'elke rapportage van patiënten over hun eigen gezondheid, kwaliteit van leven of functionele status die verband houdt met de zorg of behandeling die ze hebben ontvangen'. Vervolgens kunnen op basis van deze PROs PROMs ontwikkeld worden en gebruikt voor routinematige evaluatie van de kwaliteit van zorg waarbij de patiënt centraal staat. Wij interviewden 30 patiënten tussen maart en juli 2018. Vijf relevante domeinen werden geïdentificeerd, namelijk: 1) verbetering van symptomen, 2) begrip van de diagnose en oorzaak van symptomen, 3) de aanwezigheid en begrip van het diagnostisch en behandelplan, 4) geruststelling en 5) patiënt ervaringen. Deze domeinen werden geïncorporeerd in een conceptueel model, welke de mogelijke associaties tussen de verschillende domeinen weergeeft. Het grootste deel van de thema's die genoemd werden als belangrijke uitkomsten van acute zorg bleken feitelijk patiënt ervaringen. Hoewel dokters en onderzoekers proberen door patiënten gerapporteerde uitkomsten (PROs) te onderscheiden van ervaringen (Patient Reported Experiences), doen patiënten dat niet. In hun perceptie van kwaliteit van zorg, spelen zowel uitkomsten als ervaringen een belangrijke rol. Daarom includeerden wij zowel ervaringen als uitkomsten als relevante domeinen om de kwaliteit van acute zorg vanuit het patiënten perspectief te evalueren.

Gebaseerd op de resultaten van hoofdstuk 5, ontwikkelden wij een vragenlijst acute zorg, gericht op patiënt gerapporteerde uitkomsten (Patient Reported Measure, PRM) met als doel de acute zorg te verbeteren vanuit patiënten perspectief. In **hoofdstuk 6** beschrijven wij de validatie van de PRM-acute zorg en de resultaten van de ervaren kwaliteit van zorg van 82 patiënten. Helaas moest deze studie vroegtijdig gestopt worden in verband met de Covid-19 maatregelen. We bereikten een goede face- en inhoudsvaliditeit met behulp van de semigestructureerde interviews uitgevoerd in onze vorige studie, aangevuld met cognitief testen van de PRM-acute zorg bij 15 patiënten. Construct validiteit werd geëvalueerd met behulp van hypothese testen, welke wij beschouwden als adequaat omdat wij verschillen in ervaren kwaliteit van zorg tussen patiënten met ernstige en weinig symptomen aantoonden. Verder werd ons construct ondersteund door een significante correlatie tussen de algemene patiënttevredenheid en de gemiddelde score van de PRM-acute zorg. Wij concludeerden dat de PRM-acute zorg een valide meetinstrument is voor de ervaren kwaliteit van acute zorg bij interne patiënten op de SEH. In het algemeen waardeerden patiënten de kwaliteit van de acute zorg met een gemiddelde van 4.7/6 en een score variërend van redelijk tot goed om ieder separaat domein. Patiënten ervaarden geen moeilijkheden bij het invullen van de vragenlijst. Daarom denken wij dat de PRM-acute zorg geïmplementeerd kan worden in de dagelijkse praktijk om daarmee de ervaren kwaliteit van zorg bij interne patiënten op de SEH te kunnen evalueren. Gebaseerd op de scores in de verschillende domeinen kunnen op maat gemaakte en patiëntgerichte verbeteringen geïnitieerd worden.

In **hoofdstuk 7** gebruikten we een unieke onderzoeksmethode, genaamd Flash Mob onderzoek, om internationaal te inventariseren wat acuut opgenomen patiënten echt belangrijk vinden. We probeerden gedeelde waarden tussen patiënten te ontdekken om daarmee de acute zorg wereldwijd op een patiëntgerichte manier te verbeteren. We verrichtten een internationaal, multicenter, vijftig uur durend onderzoek, gebaseerd op interviews in 66 ziekenhuizen waarbij 1850 patiënten werden geïncludeerd. Alle patiënten werd gevraagd wat echt belangrijk voor hen was en waarom. Daarnaast evalueerden we of patiënten dachten dat hun behandelend arts hiervan op de hoogte was. De antwoorden die het vaakst gegeven warden op de vraag 'wat is voor u op dit moment het belangrijkst?' waren 'beter worden of gezond zijn' (29.6%), 'naar huis kunnen' (17.4%) en 'een diagnose hebben' (16.1%). De antwoorden op de vraag waarom dit het belangrijkst was, varieerden echter behoorlijk tussen individuen. Opmerkelijk genoeg dacht meer dan 50% van alle patiënten dat hun behandelend arts niet op de hoogte was van wat het meest belangrijk was voor hen, wat kan suggereren dat meer expliciete gesprekken gevoerd moeten worden over wat belangrijk is voor patiënten, maar zeker ook waarom. Deze simpele vragen kunnen artsen helpen om gepersonaliseerde en patiëntgerichte zorg te verlenen, ook in een acute setting.

Het derde deel van dit proefschrift, bestaand uit hoofdstuk 8, bestaat uit een studie over een nationale kwaliteitsevaluatie van de acute zorg.

In **hoofdstuk 8** evalueerden wij de eerste resultaten van een beoogde nationale kwaliteitsregistratie gericht op de acute internistische zorg. Wij startten dit project met als doel de kwaliteit van de acute zorg in Nederland voor patiënten zich presenterend voor de interne geneeskunde op een structurele basis te evalueren en daarmee de kwaliteit van zorg voor deze patiëntengroep te verbeteren. Met deze reden creëerden wij een kwaliteitsregistratie, genaamd Dutch Registry for Acute and Internal Medicine (DRAIM) waaraan tijdens de startfase 6 ziekenhuizen deelnamen. De resultaten van de pilot studie waaraan één ziekenhuis deelnam en 1729 patiënten zich presenterend op de SEH voor de interne geneeskunde werden geïncludeerd, liet zien dat 61.4% aansluitend werd opgenomen en 16% opnieuw de SEH bezocht binnen 30 dagen. Verder zagen we dat tijdens de eerste Covid-19 golf er een afname was van het totale aantal patiënten zich presenterend voor de interne geneeskunde en er een toename was van patiënten getrieerd in urgentiecategorie 1. De compleetheid van data in de kwaliteitsregistratie beschouwden wij als goed. We concludeerden dat de kwaliteitsregistratie inzicht geeft in de karakteristieken en uitkomsten van patiënten presenterend voor de interne geneeskunde op de SEH. Daardoor kan de registratie een belangrijke bron zijn voor kwaliteitsverbeteringsprojecten, bench marks en onderzoek.

Hoofdstuk 9 bevat een algemene discussie over onze bevindingen, conclusies per onderdeel van dit proefschrift en geeft richting voor toekomstig onderzoek en beleid in acute zorg. In **hoofdstuk 10** presenteren we een samenvatting in het Engels en het Nederlands.

IMPACT, LIST OF ABBREVIATIONS, DANKWOORD, ABOUT THE AUTHOR

IMPACT

This chapter reflects on the primary objective of this dissertation, the societal and scientific relevance, the dissemination of the findings and the future use of the results.

Objective and Main Findings

The primary objective of this dissertation is to identify the organizational structure of acute care in the Netherlands, particularly regarding internal medicine patients; to evaluate the perceived quality of care by patients and to systematically assess outcomes of acute care for internal medicine patients in order to optimise the organisation and quality of acute care.

The main findings can be divided in three categories:

1. Organisation
   This dissertation shows that the organisation of acute care for internal medicine patients in the Netherlands is heterogeneous. Physical presence of internists in the ED differs as well as their roles and working agreements with Emergency Physicians. Lessons can be learned from comparing the Dutch organization of acute care to the British model. For instance, ambulatory emergency care is barely implemented in the Netherlands, but may help to diverge patients to outpatient departments and relieve pressure on EDs.

2. Perceived quality
   We describe the process of development of the Patient Reported Measure-acute care for internal medicine patient. This PRM is established based on five relevant domains, namely relief of symptoms, understanding the diagnosis, having and understanding the treatment plan, reassurance and experiences. All domains were graded equally important. Additionally, the PRM-acute care was validated in Dutch internal medicine patients presenting in two Dutch EDs. Furthermore, we demonstrated that asking patients "what matters most and why?" is feasible in acute settings and this provide information about the person behind the patient, which can be used in shared decision making.

3. Quality registry
   We created a quality registry on internal medicine patients presenting in Dutch EDs. The initial data were collected in one hospital and the completeness of data was deemed adequate. In addition, the real-time performance of the ED was insightful via an online dashboard.

Scientific Impact

Acute internal medicine is a relatively new speciality in the Netherlands. As a consequence, to date, research in this area is rather comprehensive. The studies in this dissertation have added to the scientific knowledge about acute care for internal medicine patients in several ways. First, we provided a detailed overview of the organisation of care for these patients, which has never been assessed before. This knowledge is important in the light of evaluating the quality of care and more specifically, the impact of the various organisational models on quality or ED-performance. We showed that the organisational structure in acute care for internal medicine patients in The Netherlands is heterogeneous. When assessing the quality of acute care or the impact of quality improvement projects, our work can be used as a reference.

Second, we are the first research group developing Patient Reported Measures for internal medicine patients in acute care and thereby providing a basis to evaluate patients' values in acute care and the perceived quality of the care delivered. As Value Based Health Care is becoming more and more important in the Netherlands, the PRM-acute care can serve as a measurement instrument to improve the value of acute care for patients. Moreover, we provided the basis to start more profound research on outcomes incorporating the patient's perspective in acute care. Additionally, we evaluated internationally what matters most to acutely admitted patients, resulting in a broad insight in patients' values during an acute admission such as getting home or getting better. More importantly a deeper understanding was achieved by questioning "why" these categories mattered. Therefore, we recommend to ask every single admitted patient the question *what matters to you and why*, aiming to get to know the person behind the patient and deliver patient-centered care. This type of qualitative research added another perspective on quality in acute care and contributes to a more divers palette of research subjects in acute care.

Third, we created a quality registry on internal medicine patients presenting in Dutch EDs which was the first attempt to assess the quality of care for acute internal medicine patients on a regular basis in the Netherlands. The first results provided insight in the ability to use Electronic Health Record data for quality assessment as well as its restrictions. Furthermore, the ED performance was made insightful via an online dashboard, which could be used to identify the impact of quality improvement projects. For instance, the number of revisits to the ED in recently discharged patients was identified as a possible subject for quality improvement. Near upon, when several hospitals participate, this registry will primarily be used to compare ED performance. Furthermore, scientific questions may also be answered using the collected data of all participating hospitals.

Societal Impact

This dissertation has provided an overview of the organisational structure of acute care for internal medicine patients. This overview can be used in nationwide discussions about organizing acute care. In our opinion it highlights that regional differences exists, plausibly for a reason, and therefore striving for 'one size fits all' model in the organization of acute care may not be optimal. Given that some policymakers in the Netherlands call for centralisation and uniformation of the EDs, this dissertation shows another perspective which can contribute to a discussion incorporating local and regional differences regarding the organization of acute care.

Furthermore, we introduced a new method to evaluate and improve the patient's value in acute care, namely the PRM-acute care. When implementing this measurement instrument on a structural basis in acute care, the patient's perspective will play a central role in evaluating and improving acute care for internal medicine patients. Additionally, the PRM-acute care provides physicians the opportunity to directly intervene and optimize care for patients who are unsatisfied with the care received. For instance, explaining the diagnosis in another way or using the teach-back method when the understanding of the diagnosis was scored as inadequate.[1] Therefore, the PRM-acute care may lead to improvement of the quality of care on an organizational level, but also on a personal level.

Our international study on "what matters most" in acutely admitted patients, emphasized the need to get to know the person behind the patients instead of treating the disease alone. It made doctors aware that solely diagnosing and treating the disease is not sufficient to achieve patient-centred care. This study showed that two simple questions can help to start a conversation about the patient's values and wishes. We believe that the use of these questions in acute care can help to provide the care tailored to the unique patient in front of you, guiding the shared decision making process and therewith ultimately serving as a cornerstone to provide care and treatment meaningful to patients.

Finally, the creation of a quality registry will contribute to a structural evaluation of the quality of acute care for internal medicine patients. Using the data and outcomes in this registry will lead to optimalisation of the delivery of acute care for this growing number of patients. For instance, identifying patients who revisit the ED may lead to an increased attention for this patient group, leading to the start of quality improvement projects aiming to decrease of the number of revisits, which will be beneficial to all patients. Moreover, our registry can create insight which patients benefit the most from an ED-visit, or identify those who are most at risk of adverse outcomes and improve the care for these patients.

Dissemination of Findings

Several channels have been used to share the findings of this research with researchers, (acute) internists, scientific associations, policy makers and other relevant stakeholders. Of the seven articles in this dissertation, six have been published in international, peer-reviewed journals and the seventh article has been submitted for publication as well. Five articles have been published open-access, which means that they are accessible free-of-charge. Furthermore, the main findings of the performed studies have been presented at various national and international conferences, amongst others twice at the international conference of the Society of Acute Medicine (SAM), the national conference of the Netherlands Association of Internal Medicine (NIV) and Dutch Association of Internists Acute Medicine (NVIAG).

Also, the main findings and some study protocols have been discussed within the Dutch Acute Medicine Research Consortium (ORCA). All of the above mentioned channels are used to reach researchers and internists (acute medicine) in particular.

Aiming to reach policymakers, the majority of findings regarding the organizational structure of acute care were spread amongst acute care committees within the Netherlands Association of Internal Medicine, Dutch Association of Internists Acute Medicine and the Dutch Federation of Medical Specialists. Additionally, this input has served as a basis for the implementation of the strategic vision regarding acute care within the Netherlands Association of Internal Medicine and was taken into account in the discussion regarding the quality standard of the Dutch acute care chain.

The dissemination of findings concerning the PRM-acute care took place internationally by conferences and in online meetings with interested researchers, including members of the Quality Improvement committee of SAM. Nationally, implementation of the PRM-acute care is being established, aiming to connect with the Value Based Health Care project of the Dutch Foundation of University Medical Centres (NFU). Also, the PRM-acute care has been shared with the Netherlands Patients Federation.

Additionally, the results of the quality registry project will be shared via several routes. First, this project is coordinated by a project group and supervised by a steering committee. The steering committee consists of internists acute medicine, an internist elderly care, a consultant of the Netherlands Patients Federation, consultants of the Netherlands Association of Internal Medicine and delegates of MRDM. This composition serves a broad supported decision making process and a wide dissemination of findings. Furthermore, the participating hospitals gain insight in their ED-performance via an online dashboard and are able to compare these results to a benchmark, based on data from all participating hospitals. Also, we are

aiming to organise meetings with health care professionals and/or quality officers from all participating hospitals to evaluate and interpret the results, discuss possible quality improvement projects and learn from each other. Potentially, these meetings can also be organised for board members of the Netherland Association of Internal Medicine and the Dutch Association of Internists Acute Medicine, with the aim of using the results of ED-performance in their policy regarding acute care. Lastly, meetings with Emergency Physicians representing the "Netherlands Emergency department Evaluating Database" are still taking place, in order to combine forces by connecting databases and working together in the evaluation and optimisation of acute care in the Netherlands.

The organisation and the quality of acute care in the future

The results of the studies in this dissertation have provided a foundation for future research in acute care for internal medicine patients, specifically regarding the organization and quality of this care. We highlighted that the organization of acute care for internal medicine patients is heterogeneous, the incorporation of the patient's perspective evaluating quality is possible and we started a structural evaluation of the quality of care for internal medicine patients.

At this point, several plans are made to ensure continuation within this specific field of research. First, it would be of interest to evaluate the interprofessional collaboration between EPs and internists as we showed that working agreements and the evaluation of Emergency Physicians (EPs) by internists differ between hospitals. It is known that interprofessional collaboration affects the delivery of health services, patient care and safety and therewith the quality of care.[2-4] Additionally, it is worthy to evaluate the influence of the presence of an internist acute medicine on this interprofessional collaboration.

Second, aiming to incorporate the patient's voice in acute care and its daily practice, we plan to continue with the PRM-acute care research, starting with a feasibility study. During the validation study, students and researchers were needed to introduce the questionnaire. However, for implementation of the PRM-acute care in daily practice, it is necessary that the healthcare staff is able to provide the questionnaire to the patient at the ED. Thereafter, validation of the PRM-acute care in a bigger cohort is planned given the relatively small cohort in our first study, which was due to the Covid-19 pandemic. Finally, we plan to validate the PRM-acute care cross-cultural, which creates possibilities for international use of the PRM-acute care and therewith evaluate and compare the perceived quality of acute care on an international level. Additionally, we think about validating the PRM-acute care in other patient groups, for instance all patients at the ED or AMU, after potential adjustments of the questionnaire.

Lastly, the quality registry for acute and internal medicine, will be continued and data of several hospitals will be collected. We aim to compare ED-performance between these hospitals, incorporating patient characteristics and organisational characteristics. This information will be used to optimise acute care for internal medicine patients in general, but also for specific patient groups within this cohort. For instance, it would be possible to identify patients most at risk for adverse outcomes or revisits. Furthermore, we hope to connect medical outcomes and patient reported outcomes in our registry, so that it will be possible to evaluate the quality of care from multiple perspectives.

We believe that this thesis is a solid foundation for future research in acute care for internal medicine patients, and can inspire researchers to expand knowledge in this specific patient group. Collaborating with other specialties present in the acute care is highly recommended, as acute care is delivered in a chain and most optimal when working together.

REFERENCES

1. Mahajan, M., Hogewoning, J.A., Zewald, J.J.A. *et al.* The impact of teach-back on patient recall and understanding of discharge information in the emergency department: the Emergency Teach-Back (EM-TeBa) study. Int J Emerg Med 2020;13**,**49
2. Reeves S, Pelone F, Harrison R, Goldman J, Zwarenstein M. Interprofessional collaboration to improve professional practice and healthcare outcomes. Cochrane Database Syst Rev 2017 Jun 22;6:CD000072.
3. van Leijen-Zeelenberg JE, van Raak AJ, Duimel-Peeters IG, Kroese ME, Brink PR, Vrijhoef HJ. Interprofessional communication failures in acute care chains: How can we identify the causes? J Interprof Care 2015;29(4):320-330.
4. Lillebo B, Faxvaag A. Continuous interprofessional coordination in perioperative work: an exploratory study. Journal of Interprofessional Care 2015;29(2):125-130.

LIST OF ABBREVIATIONS

AMU	Acute Medical Unit
A-UMC	Amsterdam University Medical Center
AVPU scale	Alert, Verbal, Pain, Unconscious scale
CCI	Charlson Comorbidity Index
CI	Confidence Interval
COSMIN	COnsensus-based Standards for the selection of health Measurement INstruments
COVID-19	Coronavirus disease
CQI	Consumer and Quality Index
DRAIM	Dutch Registry for Acute and Internal Medicine
ED	Emergence Department
ECAP	Emergency Care Access Point
EHR	Electronic Health Record
EP	Emergency Physician
GDP	Gross Domestic Product
GP	General Practitioner
GPC	General Practitioner Cooperative
ICU	Intensive Care Unit
IHI	Institute of Healthcare Improvement
LCPS	National Coordinating Centre for Patient Distribution
LOS-ED	Length of Stay in the Emergency Department
MEWS	Modified Early Warning Score
MIU	Minor Injury Unit
MMC	Máxima Medical Center
MRDM	Medical Research Data Management
NAM	National Academy of Medicine
NFU	Dutch Foundation of University Medical Centres
NHS	National Health Service
NIV	Netherlands Association of Internal Medicine
NRS	Numeric Rating Scale
NTR	Netherlands Trial Registry
NVIAG	Dutch Association of Internists Acute Medicine
ORCA	Dutch Acute Medicine Research Consortium
PREM	Patient Reported Experience Measure
PRM	Patient Reported Measure
PRO	Patient Reported Outcome
PROM	Patient Reported Outcome Measure
ROAZ	Regional Consultation Acute Care Chain
SAM	Society of Acute Medicine
SD	Standard Deviation
TTP	Trusted Third Party
UCC	Urgent Care Centre
UK	United Kingdom
WiC	Walk in Centre

DANKWOORD (ACKNOWLEDGMENTS)

'Perseverance is not a long race; it is many short races, one after the other.' – Walter Elliot

In september 2017 besloot ik mijn opleiding tot internist acute geneeskunde te onderbreken om promotieonderzoek te gaan verrichten. Enigszins een bijzondere stap omdat ik er lang van overtuigd was dat onderzoek doen niet bij mij paste. Het onderwerp was me echter zo op mijn lijf geschreven, dat ik niet anders kon dan vol enthousiasme deze kans te grijpen en gelukkig werd deze me ook gegund. Met gepaste trots kijk ik terug op het afgelegde traject, waar ik met veel plezier en soms ook enige tegenslag aan gewerkt heb. En nu is mijn proefschrift klaar!

Dit proefschrift was er nooit gekomen zonder hulp van collega's, vrienden en familie. Er zijn veel mensen op één of andere manier belangrijk geweest en ik hoop dat ik aan iedereen heb gedacht. Mocht ik je toch vergeten zijn te noemen, sorry daarvoor.

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Elsemieke, als student koos jij om je wetenschappelijke stage in de acute onderzoeksgroep in het Máxima MC te verrichten. Jouw enthousiasme en tomeloze inzet werkte aanstekelijk en heeft er zeker voor gezorgd dat de PRM-acute care ontwikkeld heeft kunnen worden. Jij leerde mij veel bij over statistiek en SPSS, en ik ben blij dat ik jou nu mag begeleiden in jouw promotietraject. Met jouw werklust en enthousiasme zal jouw proefschrift zeker slagen. Dat we in de tussentijd maar regelmatig bij de stadsbrouwerij mogen belanden voor onderzoeksbesprekingen, maar zeker ook een dosis gezelligheid.

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Yvonne en Tessel, ook jullie hebben je enorm ingezet tijdens je stage en een belangrijke bijdrage geleverd aan het ontwikkelen van de PRM-acute care. Zonder jullie was dit nooit gelukt!

Ook studenten van de VU: Lara, Myriam, Sani, Eva, Kathy en Eline, dank voor jullie inzet om patiënten te includeren. Veel succes met jullie verdere carrière.

Een van mijn onderzoeken betreft de kwaliteitsregistratie acute geneeskunde, die nooit tot stand had kunnen komen zonder de steun en medewerking van de NIV. Robin, dank voor je inzet ten behoeve van de toekomstbestendigheid van deze registratie. Gertjan, dank voor jouw altijd goede voorbereiding voor overleggen, het bruggen slaan tussen verschillende relevante partijen en het oneindig herschrijven van aanvragen en rapporten. Hoewel we maar kort in dezelfde straat hebben gewoond in de voor mij grote stad Utrecht, was het fijn te weten dat je om de hoek woonde en heb ik met veel plezier met jou verschillende terrassen verkend. Samara, dank voor jouw tomeloze inzet voor de acute zorg en de rol van de internist hierin. Ik waardeer je doelgerichtheid, fanatisme en scherpte. Ik hoop dat we samen nog veel doelen mogen bereiken in het acute zorglandschap.

Met mijn onderzoek probeer ik de kwaliteit van de acute interne geneeskunde te verbeteren en dit doel wordt ook binnen de werkgroep spoedzorg van de NIV nagestreefd. Jan, Douwe, Karin, Charlotte, Simon, Eveline en Samara, dank voor jullie voortdurende inzet om zowel binnen als buiten de internisten vereniging de kwaliteit van de acute zorg voor de interne patiënt te verbeteren. We hebben mooie stappen gemaakt en zullen dat zeker blijven doen.

Ook binnen de NVIAG wordt er hard gewerkt aan het verbeteren van de kwaliteit van zorg in de kwaliteitscommissie. Frederiek, Tycho, Hilde, Suzanne, Dirk, Karin en Sanne, ook al zetten we voor mijn gevoel soms maar kleine stapjes, jullie laten me zien hoe waardevol die zijn. Dank voor de prettige overleggen en kennis die we delen.

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Dear friends of the Safer@home group. Thank you for your inspirational thoughts and enthusiasm to collaborate in international studies, specifically in the GPS flashmob study. I am very grateful to be a part of this unique, multidisciplinary group characterised by its sense of humour, fun and always full of new ideas. I am looking forward to meet again in person, discuss new ideas and have a lot of fun during and after the scientific meeting.

Dan, Tom and Cat, dear friends from Birmingham. Thanks for welcoming me and showing the organisation of acute care in and around Birmingham. I am still inspired by your views on and execution of same day emergency care and hospital at home.

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Rebecca, we leerden elkaar kennen tijdens het eerste jaar geneeskunde in Nijmegen. Je leerde mij het studentenleven kennen en hoewel onze muziekstijlen niet helemaal overeen kwamen, hebben we toch veel lol gehad in het nachtleven. Na in verschillende ziekenhuizen werkzaam te zijn geweest, kruisten onze paden weer in het Radboudumc. Wat was het fijn een maatje te hebben, ook in opleiding tot internist. Ik hoop oprecht dat we ooit in dezelfde vakgroep zullen belanden! Tot die tijd kom ik regelmatig bij je langs, geniet ik van je warme gezinnetje, de speciaal biertjes die Rik me enthousiast aanbiedt en onze fijne gesprekken.

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ABOUT THE AUTHOR

Marjolein Kremers was born on the 23th of April 1986, in Venray. In 2004 Marjolein graduated from the St.-Willibrord Gymnasium in Deurne and started studying medicine at the Radboud University in Nijmegen. After finishing medical school in 2011 she started working as a resident internal medicine (non-trainee) at the Jeroen Bosch Ziekenhuis in 's-Hertogenbosch. Since March 2012, Marjolein started her training becoming an internist in the Jeroen Bosch Ziekenhuis and continued this training in the Radboudumc. During her residency, she was also a board member of the national association of residents 'De Jonge Specialist' and finally chairwoman between 2016 and 2018.

Twice, Marjolein chose to interrupt her training program. First, she worked as a Medical Doctor for Doctors without Borders in the refugeecamp Kule, Ethiopia from February 2015 until August 2015. Secondly, from September 2017 until September 2020 she performed her PhD-project in acute medicine supervised by Prof. dr. Haak and Prof. dr. Nanayakkara at the Maastricht University, in collaboration with the Máxima MC, Veldhoven and Amsterdam UMC, location VUmc.

Since September 2020 Marjolein restarted her training program in acute internal medicine at the UMC Utrecht and finished her specialisation in August 2021. Thereafter, Marjolein started working at the Sint Jans Gasthuis in Weert. She combines working at the Emergency Department and the internal medicine ward with managerial tasks in acute care.

Furthermore, she supervises two PhD-students at the Máxima MC/Maastricht University.

Besides her work and PhD-project, Marjolein is chairwoman of the working group 'acute care' of the Netherlands Association of Internal Medicine.