CARE DECISION CONVERSATIONS

IMPROVING COMMUNICATION ABOUT TREATMENT WISHES AND LIMITATIONS: HOW TO PREPARE PATIENTS AND PHYSICIANS

Saskia Pater - Briedé

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Improving communication about treatment wishes and limitations: how to prepare patients and physicians

Praten over behandelwensen en –grenzen:

Verbeteren van gesprekken over behandelwensen en grenzen: hoe moeten we patiënten en artsen voorbereiden

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Care decision conversations: Improving communication about treatment wishes and limitations: how to prepare patients and physicians
PhD thesis, Utrecht University, the Netherlands

Cover design: Marcel Pater
Layout & Printing: Ridderprint | www.ridderprint.nl
ISBN: 978-90-393-7708-6

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(met een samenvatting in het Nederlands)

Proefschrift

ter verkrijging van de graad van doctor aan de
Universiteit Utrecht
op gezag van de rector magnificus, prof. dr. H.R.B.M. Kummeling,
ingevolge het besluit van het College voor Promoties
in het openbaar te verdedigen
op maandag 30 september 2024 des middags te 2.15 uur

door

Saskia Pater - Briedé

geboren op 29 juni 1990
te Utrecht

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You can’t cross the sea merely by standing and staring at the water.
– Rabindranath Tagore

Do as much as possible for the patient, and as little as possible to the patient.
– Dr. Bernard Lown

The secret of the care of the patient is in caring for the patient.
– Dr. Francis W. Peabody

It is more important to know what sort of person has a disease than to know what sort of disease a person has.
– Hippocrates

To cure sometimes, to relieve often, to comfort always.
– Ambroise Paré

Not everything that counts can be counted, and not everything that can be counted counts.
– William Bruce Cameron

Knowledge is proud that he has learn’d so much; Wisdom is humble that he knows no more.
– William Cowper

Family is not an important thing. It’s everything.
– Michael J. Fox

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CHAPTER 1

General introduction

"Do as much as possible for the patient, and as little as possible to the patient."
- Dr. Bernard Lown

Choosing Wisely

Healthcare costs rise every year. Discussions on this subject tend to focus on the balance between best individual patient care versus reducing the public healthcare related costs. This balancing suggests that reducing costs goes at the expense of good patient care. But more care is not always better care. Overuse of medical resources is not only a factor in health care spending, but also puts patients at risk of harm (1). It is well known that care can cause unintentional harm, such as radiation exposure, adverse drug reactions, complications or errors during procedures, unnecessary follow-up tests, and patient concern. When the care has (potential) benefit, this can outweigh the (potential) risk of harm. However, when this care is not clinically indicated, no potential benefit is present, leaving only the risks of harm. Estimates suggest that as much as 30% of all health care spending is unnecessary and does not add value in care (2–4).

Choosing Wisely is a campaign initiative to reduce potential harm and costs of care. The American Board of Internal Medicine Foundation (ABIM-F) started this campaign in partnership with Consumer Reports to stimulate a conversation between physicians and patients about avoiding wasteful, unnecessary medical tests, treatments, and procedures. The focus is on value of care and potential risks for the patient, rather than using costs as the motivating factor (5,6). Since physicians' decisions account for about 80% of health care expenditures, they need to play a leading role in reducing unnecessary tests and procedures. The Choosing Wisely campaign is now spread worldwide to more than 20 countries, including the Netherlands since 2013 (6–9).

In 2014, the Dutch Association of Internal Medicine (NIV) also committed to create a list of recommendations for internal medicine. Internal medicine is a broad and diverse specialism. In the Netherlands, the NIV has 14 subspecialties, all with their own societies. Despite this diversity, the working group for the development of the Wise Choices in Internal Medicine was able to formulate 10 evidence-based recommendations, with the support of all subspecialty societies and national patient federation. One of these 'Wise Choices' was:

"*Discuss whether treatment limitations are needed when talking to patients about treatment options*" (10).

This recommendation was one of the motivations for our research proposal.

Care Decisions – Definition – *Behandelwensen en -grenzen*

In the initial phases of this research, we deliberated to articulate an appropriate terminological framework for our objective: the alignment of treatment with the patients' preferences, desires, goals, and values, inclusive of the potential for opting out of further diagnostic or treatment interventions or put limits to this. This includes, but is not limited to, patient preferences regarding resuscitation, mechanical ventilation, Intensive Care admission (often referred to as the code status) and other possible treatment options such as hospital admission, dialysis, tube feeding, et cetera. During the discussion within the Dutch context, consensus was rapidly reached on the term '***behandelwensen en -grenzen***' (treatment wishes and boundaries), averting alternatives such as *'behandelbeperkingen'* (treatment restrictions) or *'behandelcode'* (treatment code, code status), and '*Advance Care Planning* (ACP)'. This lexical choice was informed by a desire to avoid potential negative connotations associated with *restrictions* or *limitations,* address the general population's unfamiliarity with the meaning of *code*, and disassociate from the end-of-life implications often linked with *advance care planning*. The aim was to abstain from using medical jargon, difficult words, and non-native (non-Dutch) terminology in patient communication as much as feasible.

Nonetheless, within the dominantly English-language corpus of medical-scientific literature, the term 'treatment wishes and boundaries' is notably absent and presents as a neologism derived from Dutch. Although the internationally recognized definition of ACP, as delineated by Rietjens et al., aligns closely with our interpretation of *'behandelwensen en -grenzen'* (11), ACP is predominantly linked with end-of-life contexts, a bias reinforced by the extensive research in predominantly end-of-life settings (12). To circumvent this association, we have adopted the term '***care decisions***' across our academic publications and within this thesis.

Care decisions are the alignment of treatment with the patients' desires, goals, and values, inclusive of the potential for opting out of further diagnostic or treatment interventions or put limits to this.

Relevance

Certainly, it did not occur unexpectedly that discussing care decisions became one of the ten "Wise Choices" " (10). Early and proactive conversations regarding care decisions enables the provision of care that is more closely aligned with patient preferences and is associated with reduced consumption of healthcare resources (13). Care decision conversations are crucial to ensure future healthcare decisions are aligned to a patient's wishes and have shown to reduce length of stay in the intensive care unit (ICU), ICU readmission rates and costs of healthcare, without impacting patient satisfaction (14–16). This raises the question of why these conversations are not conducted more frequently or in a timely manner.

Barriers among physicians and patients

Presumably care decision conversations are not conducted in a timely manner, because both physicians and patients avoid them due to numerous barriers. In literature, barriers to cardiopulmonary resuscitation (CPR) orders, end-of-life care and ACP in several (end-of-life) settings are identified. It is reasonable to anticipate that these barriers, though with certain subtleties, may also apply to care decision conversations. To have a good overview below are summaries of a) physician barriers to CPR decision-making and implementation, b) patient barriers to CPR decision-making and implementation, c) Physician barriers to end-of-life care and ACP, d) patient barriers to end-of-life care and ACP, and e) system barriers to end-of-life care and ACP.

a) Physician barriers to CPR decision-making and implementation (17):

- training and confidence: feeling unskilled or inadequately trained, exhibiting low confidence, inexperience, discomfort, embarrassment, difficulty in making decisions themselves, avoidance of the responsibility of decision-making
- patient factors: poor health status, fear to cause anxiety or distress, fear of harming the patient, fear of complaints and experiences with verbally or physically aggressive relatives, medical uncertainty and perceived resistance from the patient, as physicians often underestimate the number of patients willing to discuss their CPR status

b) Patient barriers to CPR decision-making and implementation (17):

- lack of understanding of CPR and its success rate; although this misunderstanding concerned physicians, they contributed to it as the information provided can vary across disciplines and contains a lot of medical jargon

c) Physician barriers to end-of-life care and ACP:

- difficult timing: poor recognition of a proper starting moment for ACP (18), the unpredictability of the prognosis and uncertain transitions toward the end of life (18–20), perceived inappropriateness of the current setting (e.g. inpatient or intensive care) to discuss ACP (18)
- unreadiness on the physicians' side: not ready to give up an aggressive approach (21,22), reluctance to discuss ACP when not all treatment options are exhausted (20,22), feeling obligated to improve patient's well-being (21), discomfort (20), avoidance of talking about end-of-life all together (21)
- patient factors: concern ACP conversations lead to anxiety, depression and take away patients' hope (18,21,22), avoidance to confront the patient with the end-of-life (19), denial on the patients side (19), the (false) beliefs that the patient is not ready to talk about the end of life (21,22), the patient does not know what (s)he wants (21), or the patient does not want treatment limitations (18)
- inadequate training and (communicational) knowledge and education (18–20)
- time constraints (18,20,21)

d) Patient barriers to end-of-life care and ACP:

- the assumption that the physician will initiate the discussion when necessary (18,20,22)
- perceived irrelevance (22–27)
    - even in a study in cancer patients with a life expectancy < 12 months, it was experienced as being too early (28)
- lack of education (18,22,27,29), poor medical literacy (18,23)
- emotions: fear of abandonment (18,23), anxiety (20), denial (20,21)
- uncertainty about what choices to make and variability of these choices (21,22)
- the perception the physician does not like to talk about it (21,22) or is too busy (23)

e) System barriers to end-of-life care and ACP:

- life-sustaining care is the default, no (support) systems for end-of-life care (20)
- poor systems for recording patient wishes (20)
- ambiguity about who is responsible (20)

As stated before, probably these barriers, though with certain subtleties, also apply to care decision conversations. The avoidance by both parties often leads to the absence of these crucial conversations. To surmount these barriers and make way for fruitful conversations regarding care decisions, both physicians and patients need tailored support.

Setting

The quality standards of the Dutch association for Internal Medicine demand that a code status is documented in every admitted patient (30). In a code status, it can be documented whether there are limitations to specific life-sustaining treatments or not. When both physicians and patients avoid talking about care decisions (because of the earlier mentioned barriers), these conversations do not take place in time (31). Consequently, the opportunity to adapt treatment to align with patient's wishes is often missed (32). As a result, care decision conversations often take place at the Emergency Department (ED) in order to document a code status. This seems a far from ideal situation, because at the ED there is limited time and sometimes an acutely ill patient (33,34). Furthermore, in such circumstances, code status (and primarily CPR status) is discussed merely to 'tick a box', fulfill a requirement on the admission note and sign out, without giving due consideration to the patient's goals and values (35). On top of that, in acute settings preexisting physician-patient relationships are rare and there is minimal time to develop familiarity with the patient, their illness and their goals of care (34).

Initiating timely conversations regarding care decision can lead to care that is more closely aligned with patient preferences and reduced consumption of healthcare resources (13). The outpatient clinic, often a setting where patients consult a physician with whom they are familiar, appears to be a more appropriate setting to such conversations (36–39). However, the care decisions conversation in the outpatient clinic is often perceived as being too soon by both the patient and the physician (32,34,40). Consequently, these conversations tend to be deferred until either the end of life, evidenced by research primarily focused on end-of-life settings (12,21,32,41,42), or in the ED during acute situations, where there is limited time for thorough discussion and consideration of the patient's preferences before a decision is made.

COVID-19

Our research project took a turn in the year 2020, when the first patient afflicted with COVID-19 was admitted in the Netherlands. This global health crisis, exerting unprecedented stress upon the healthcare system (43–45), inadvertently influenced the trajectory of our research. On the one hand, conducting scientific research was a lot more complicated, as patient contacts (especially for the purpose of doing research) had to be limited. Also the extremely high workload made physicians more hesitant to participate in research. On the other hand, it provided opportunities, as we experienced from medical practice that the high pressure context influenced the awareness for care decision conversations (46–50). This scenario presented us with an exceptional chance to explore the effects of a global pandemic on code status documentation. The research restrictions at the onset of the pandemic made it difficult to investigate the actual care decision conversations, patient satisfaction or (patient assessed) quality of communication like in our other studies. Therefore we look into code status documentation in this research period.

Shared decision-making

Over the past decades, patient-centered care and shared decision-making have become the ideal models for physician-patient decision-making (51–53). Within the framework of patient-centered care, physicians are encouraged to partner with patients to co-design and deliver personalized care (54–56). Although shared decision-making is not a central part of this thesis, it is irrevocably connected to care decisions. Throughout the project it became clear that physicians as well as patients need tailored support as part of the broader spectrum of shared decision-making.

It is surprising that despite the well acknowledged importance of patient-centered care and shared decision-making, both physicians and patients tend to avoid conversations about care decisions. How can we deliver patient-centered care and make shared decisions, if we do not talk about it?

Multiple perspectives

From the start of our research we recognized the value of integrating perspectives. This was enhanced by adding a specialist in communication and linguistics to our medical research team. This enabled us not only to juxtapose patient and physician viewpoints (as both were research subjects in our studies), but to also foster a rich, interdisciplinary dialogue among our team members. This collaborative effort, combining the clinical knowledge of physicians with the language expertise of a communication specialist, often revealed interesting insights when interpreting identical data sets. Additionally, the strong educational background of our team members allowed us to incorporate educational considerations into the development of training and interpretation of results. By merging quantitative with qualitative research methods, such as semi-structured interviews and conversation analysis, this thesis represents the convergence of these diverse viewpoints.

Intermezzos

In this thesis, we provide three Intermezzos that serve as an intermission in the main parts. In these Intermezzos the physicians' perspective will be discussed. A student's final research project provided us various interviews. The insight gained by this small interview study were highly recognizable and connected the results from our other studies. This resulted in Intermezzos like in opera: short and lighter parts that connect the major sections of the work.

Objectives of this thesis:

This thesis explores how care decision conversations can be improved. Specifically, it examines the effect of physician training and patient education in different settings: the outpatient clinic and emergency department. Besides, it provides insight in how care decision conversations are currently conducted and patients' and physicians' perspectives on care decisions. These results together learn us how best to prepare patients and physicians to talk about care decisions.

Outline of this thesis:

Part I

Part I focusses on care decision conversations at the internal medicine outpatient clinic. In **Chapter 2**, we investigate the impact of physician training and patient education (both on the topic of care decisions) on patient satisfaction and physician preparedness. **Chapter 3** provides a conversation analysis of authentic care decision conversations at the internal medicine outpatient clinic, offering insights into the communicative challenges and strategies employed by physicians and patients. In **Intermezzo 1**, we show insights in the physicians' perspective and connect these to the results of **Chapter 2** and **Chapter 3.**

Part II

In part II we focus on the patient perspective. In **Chapter 4** we explore the patient perspective on care decisions through a qualitative interview study, shedding light on patients' experiences and preferences regarding these conversations. In **Intermezzo 2**, we show parts of the physicians' perspective that relate to these topics.

Part III

In part III, we look into care decision conversations at the emergency department. In **Chapter 5**, we investigate the impact of the worldwide COVID-19 pandemic on code status documentation upon admission in a descriptive cohort study. Given the research restrictions in the beginning of the pandemic, we utilized available documentation and registration instead of focus on quality and patient satisfaction as we did in our other studies. In **Chapter 6** we evaluate a combined approach of physician training and patient education aimed at improving quality of care decision communication at the emergency department. We investigated the effect on patient-assessed quality of care decision communication. **Intermezzo 3** shows some final insights from the physicians' perspective.

Part IV

In Chapter 7, the final chapter, we will discuss the main findings of our investigations, implications for daily practice, and directions for future research, training and education.

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PART I

Discussing care decisions at the outpatient clinic

CHAPTER 2

The effect of physician training and patient education on the discussion of care decisions at the internal medicine outpatient clinic

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BMC Health Services Research (2022) 22:1569
https://doi.org/10.1186/s12913-022-08901-7

Abstract

Background: Care decision discussions are intended to align treatment with the patient's wishes, goals and values. To overcome the numerous barriers to such discussions, physicians as well as patients need tailored support. We evaluate the effect of a physicians' training and a conversation aid for patients about care decisions on patient and physician outcomes.

Methods: At the internal medicine outpatient clinic of the University Medical Centre Utrecht, a 1:1 randomized, parallel-group study (patient conversation aid) was combined with a pre-post intervention (physicians' training) design. Primary outcome was patient satisfaction, secondary outcomes were patient-doctor relationship, shared-decision-making, doctor preparedness and patient appreciation of the conversation aid.

Results: Between October 2018 and February 2020 11 physicians (36% residents, 73% female) and 185 patients (median age 58 years (interquartile range (IQR) 50-68), 60% male) participated. Only 28% of the patients reported a care decision discussion during the consultation. We found no effect of the interventions on patient satisfaction (effect sizes -0.14 (95% confidence interval (CI) -0.56-0.27) for conversation aid; 0.04 (95% CI -0.40-0.48) for physician's training), nor on the patient-doctor relationship or shared-decision-making. However, physicians felt more prepared to discuss care decisions after training (median 3 (IQR 1-4) vs 1 (IQR 0-3), p=0.015). Patients assessed the conversation aid informative and gave an overall mark of median 7 (IQR 7-8).

Conclusions: First steps towards fruitful discussions about care decisions were made: patients considered the conversation aid informative and physicians felt better prepared to discuss care decisions after training. The low number of care decision conversations patients reported shows exactly how important it is to focus on interventions that facilitate these discussions, for both the patient and physician. Further work needs to be done to establish the best way to empower patients and physicians.

Trial registration: Dutch trial register, trial 6998 (NTR 7188), registered 04/05/2018, https://www.trialregister.nl/trial/6998.

1. Background

The nationwide ‘Choosing Wisely’ campaign started in the USA in 2012 to engage physicians and patients in conversations about unnecessary tests, treatments and procedures, hereby contributing to appropriate healthcare (1). Following this, the Dutch Association of Internal Medicine published a list of 10 ‘Wise Choices’. One of these ‘Wise Choices’ is to discuss care decisions when talking to patients about their treatment (2).

We define care decisions as discussions to align treatment with the patient’s wishes, goals and values, in which the option could also be to waive treatment or further investigation or to put limits to this (e.g. mechanical ventilation, dialysis, tube feeding). This includes for instance code status discussions and advanced care planning (ACP). Although the international consensus definition of ACP as posed by Rietjens et al. corresponds greatly with our vision on care decisions (3), the term ACP is strongly associated with the end of life, mostly due to the extensive research in end-of-life settings (4). To avoid this association, we choose to use the term care decisions throughout this paper.

There are numerous barriers for both physicians and patients to discuss care decisions. Barriers for physicians described in literature are for instance: feeling unskilled or inadequately trained; discomfort and fear of complaints (5). On top of that, physicians often wrongfully assume that patients do not want to discuss care decisions (6–8). Patients face other difficulties, such as a lack of knowledge, unawareness of patients of the relevance, and the expectation that physicians will initiate the discussion when needed (4,9).

When both parties avoid talking about care decisions, these discussions do not take place in time (10). Consequently, the opportunity to adapt treatment to align with patient’s wishes is often missed (11). Also, this results in situations in which these discussions have to be conducted in far from ideal circumstances, such as in the acute setting at the emergency department with limited time and an acutely ill patient (12). To overcome these barriers and make way for fruitful discussions about care decisions, physicians as well as patients need tailored support.

For this study, we aimed to evaluate the effect of a training for physicians and a conversation aid for patients about the topic of care decisions. We measured patients' and physicians' satisfaction during the subsequent consultation at the outpatient clinic.

2. Methods

2.1 Design overview

In this study, a randomized, parallel-group study was combined with a pre-post intervention design. Participating patients were randomized in a 1:1 ratio. Randomization sequence was created using Castor EDC (electronic data capture) software and was stratified by gender in a 1:1 ratio using random block sizes of 4, 6, and 8. Participating physicians were trained halfway through the study period. This resulted in 4 groups (physicians before training and patients without conversation aid (=reference group), physicians before training and patients with conversation aid, physicians after training and patients without conversation aid, physicians after training and patients with conversation aid (=intervention group) *(Figure 1)*. The required sample size was expected to be reached after 6-9 months, based on average number of outpatient clinic consultations per physician. 42% of eligible patient population could not be reached by phone on multiple occasions and therefore could not be approached. Furthermore, a third of the approached patients refused to participate. Due to the lower-than-expected recruitment rate and the inability to further postpone physicians' training for logistical reasons, physicians' training took place 7 months after the first inclusion, before half of the intended sample size was reached. The study was terminated early after 16 months because inclusion was slowing down since an increasing part of the eligible population was already approached. At this moment 80% of the attempted sample size was reached. Besides, due to the low number of actual decisions on care decisions, one of our secondary outcomes (decisional conflict) could not be properly statistically assessed. Instead, we show number of care decision discussions and decisions made. No other changes have been made to the study protocol.

This study was performed in line with the principles of the Declaration of Helsinki and approved by the Medical Research Ethics Committee Utrecht (MREC 18-465) and prospectively registered 04/05/2018 at the Dutch trial register (http://www.trialregister.nl, NTR 7188).

2.2 Setting and participants

This study was conducted at the internal medicine outpatient clinic of the University Medical Centre Utrecht (UMCU), a tertiary care teaching medical centre in the Netherlands.

Physicians

Eligible physicians were residents and specialists working at one of the outpatient clinics in our university hospital. Specialties at this outpatient clinic are general internal medicine, endocrinology, diabetes, nephrology, infectious diseases, immunology, vascular disease and gastroenterology. Exclusion criteria were participation in the pilot test of the e-learning module (which was used in the training), and awareness of the purpose of the study (e.g. involvement in an earlier stage or research meeting). Eligible physicians were recruited by the research team and informed that the study was about patient-doctor communication, consultations would be video-taped, and they had to fill out a questionnaire for each participating patient. They were not informed that the focus of this study was the discussion of care decisions. Written informed consent was obtained, after which their schedules were screened for eligible patients.

Patients

Patients ≥18 years with a scheduled consultation with one of the participating physicians within the study period were eligible for inclusion. The time between scheduling and the actual appointment had to be ≥3 weeks to account for sufficient time for the patient to consider participation and the research team had to be available to obtain written informed consent before the appointment. Visits included routine visits and new patients at the outpatient clinic that were referred by their general practitioner. They visited the outpatient clinic for a variety of indications: renal insufficiency, diabetes mellitus, hypertension, etcetera. Exclusion criteria were insufficient command of the Dutch language (i.e. unable to read and understand the conversation aid and questionnaires), inability to give informed consent and a registered discussion on treatment limitations with their physician within 2 years before the visit. Patients could only participate once.

Patients were contacted by phone by the research team and informed that the study was about patient-doctor communication, half of the participants would receive an online conversation aid and the consultation would be video-taped. They were unaware of the topic of the conversation aid and focus of the study. After verbal informed consent was obtained, participants were randomized. Patients in the control group received an e-mail with the same information as discussed during the phone call, whilst the intervention group received an e-mail with information about the topic of the conversation aid, along with the web link to the conversation aid. Written informed consent was obtained directly before the outpatient clinic consultation by the research team.

The outpatient clinic consultations were video recorded for qualitative analyses, of which the results are reported in a separate publication (13). The video camera was visible in the consultation room and both patient and physician were aware of (and consented to) the whole consultation being video recorded.

Immediately after the consultation, both the patient and the physician received a separate questionnaire (complete questionnaires in supplementary appendix 1).

2.3 Interventions

Physicians' training

The physicians' training consisted of an e-learning module and a hands-on training with a simulated patient (i.e. an individual trained to act as a real patient). More detailed information can be found in supplementary appendix 2. After the training, physicians were aware that care decisions were the main focus of the present study. However, physicians were instructed to do their consultations with participating patients similar to those with non-participating patients (i.e. they should not discuss care decisions solely because 'the camera is on').

Patient education: conversation aid

The conversation aid for patients was an online application in which patients could find comprehensible information about why it is important to discuss care decisions, what certain treatments entail and what possible treatment limitations are. Written information was accompanied by visual material. Hyperlinks to additional information were included. The conversation aid was created in collaboration with the UMCU Patient Panel with special attention for the use of understandable language.

Due to the nature of the intervention, patients and physicians could not be blinded to their own intervention. However, both were unaware of each other's intervention.

2.4 Data collection and outcomes

Baseline characteristics

Patient characteristics were extracted from the electronic patient records by the research team (age, gender, Charlson Comorbidity Index (CCI) (14)) and collected via the patient-questionnaires (marital status, educational level, work status, health perception, quality of life and social support). Health perception and quality of life were both measured on a 11-points Likert scale (0 to 10).Social support was measured with the Oslo-3-questionairre(15), translated into Dutch using the validated forward-backward method (16,17). Physicians' characteristics were collected in the physician-questionnaires (age, gender, resident/specialist and years of training or work experience).

Outcome measures

The primary outcome was patient satisfaction, as a mean of 2 questions of patient satisfaction on a 11-points Likert scale (0 to 10). This scale is a frequently used outcome measure for patient satisfaction in a multitude of settings and interventions (18–21). The two questions on patient satisfaction were:

- How satisfied were you with the conversation with your physician at the outpatient clinic?
- How satisfied were you with the information given before, during and after your outpatient clinic visit?

Secondary outcomes were:

- The patient-doctor relationship, evaluated using the Patient Doctor Relationship Questionnaire (PDRQ-9). 9 items are scored on a 5-point Likert scale ranging from 1 (very low quality) to 5 (very high quality). The total score consists of the sum of each of the items and ranges from 9 to 45 (22,23).

- Shared-decision-making, evaluated using the Shared Decision Making Questionaire-9 for physicians (SDM-Q9-DOC). 9 items are scored on a 6-point Likert scale ranging from 0 (totally disagree) to 5 (totally agree). Items are summed and multiplied by 20/9 to provide a score with 0 indicating the lowest and 100 the highest possible level of SDM (24–27).
- Doctor preparedness to discuss treatment wishes, evaluated through 8 questions ranging from very generic to care decision specific, and a mock question about medication to mask the focus of this study.
- Patient appreciation of the conversation aid (intervention group only), evaluated through 10 questions on aspects of the conversation aid, an overall score, and a free text space for additional suggestions.

In summary: for each patient seen by a physician, the physician needed to complete the SDM questionnaire and physician preparedness assessment, combined in one questionnaire. All patients completed the satisfaction items, and the patient-doctor relationship questionnaire. Patients in the patient intervention group additionally completed the questions on their appreciation of the conversation aid.

2.5 Statistical analysis

We performed an intention to treat analysis. Patient characteristics are shown stratified by intervention group. Physicians' characteristics were described narratively.

The primary outcome of mean patient satisfaction score was shown stratified by intervention using medians and interquartile ranges. The primary outcome in the intervention group (both patient and physician trained) was first compared to the reference group (neither patient nor physician trained) with a Mann-Whitney U test. Following a gatekeeping procedure to reduce the risk of a type I error, further statistical comparisons between the patient intervention-group and physician intervention-group versus the reference group would have been performed only if the primary outcome differed between the intervention group and the reference group (fixed sequence hierarchical testing). We used the same strategy for the patient-doctor relationship and shared-decision-making outcomes. To adjust for confounders while taking into account dependence between scores of patients within physicians, primary and secondary outcomes were analysed using a multilevel mixed model. Because patients within a physician might be more similar than patients from other physicians, (e.g. more satisfied, similar diseases) a random intercept for physician was added to the model. We hypothesized that the effect of the physicians training could be different for each physician due to differences in knowledge and experience, therefore we added a random slope for physicians training. Analyses were adjusted for patients' age, gender, CCI, quality of life, and physicians' gender and level (resident or specialist) based on previous literature (28–30). An interaction term between patient intervention and physician intervention was added to assess whether the effect of either intervention differed depending on the other intervention. The non-significant interaction term indicated that the effects of both interventions were independent. Therefore, the interaction term was subsequently removed from further analyses and, because the sample size calculated for the fixed hierarchical testing was not met, we additionally analysed the data as being a two-by-two factorial design.

To evaluate preparedness of the physician, results of physicians' questionnaires before and after training were compared and tested for statistical significance using Mann-Whitney U test. Patient appreciation of the conversation aid was described narratively.

All analyses were performed using IBM SPSS Statistics 25.0.0.2 software. P values <0.05 were considered statistically significant.

2.6 Sample size calculation

An a priori sample size calculation for the comparison of the main intervention group (physician trained, patient informed) and reference group (physician not trained, patient uninformed) on the primary outcome was performed using the statistic program G*Power. In previous studies, patient satisfaction on an 11-point Likert scale (0 to 10) was found to be between 5 and 9, with standard deviations between 1.2 and 3.2 (18–21). Hence, we assumed the mean patient satisfaction score to be 7.0 (reference group) and 8.0 (intervention group) with a standard deviation of 2 (i.e. a Cohen's effect size 0.5). To achieve a power of >80% with a (one-sided) alpha of 0.05, 51 patients per group were needed. To enable stratified analysis by gender and a loss to follow-up of 10%, the required sample size would be 232 patients.

3. Results

3.1 Study participants

Eleven physicians participated in this study, including 4 residents (educational year 3-6) and 7 specialists from different areas of specialization (nephrology, vascular medicine, immunology, endocrinology, gastroenterology). The majority were female (8/11, 73%), responsible for 71% of all consultations in this study. One physician was not able to participate due to lack of time. Between October 2018 and February 2020, a total of 185 patients participated in the study. Figure 1 shows a diagram of the patient-participant flow.

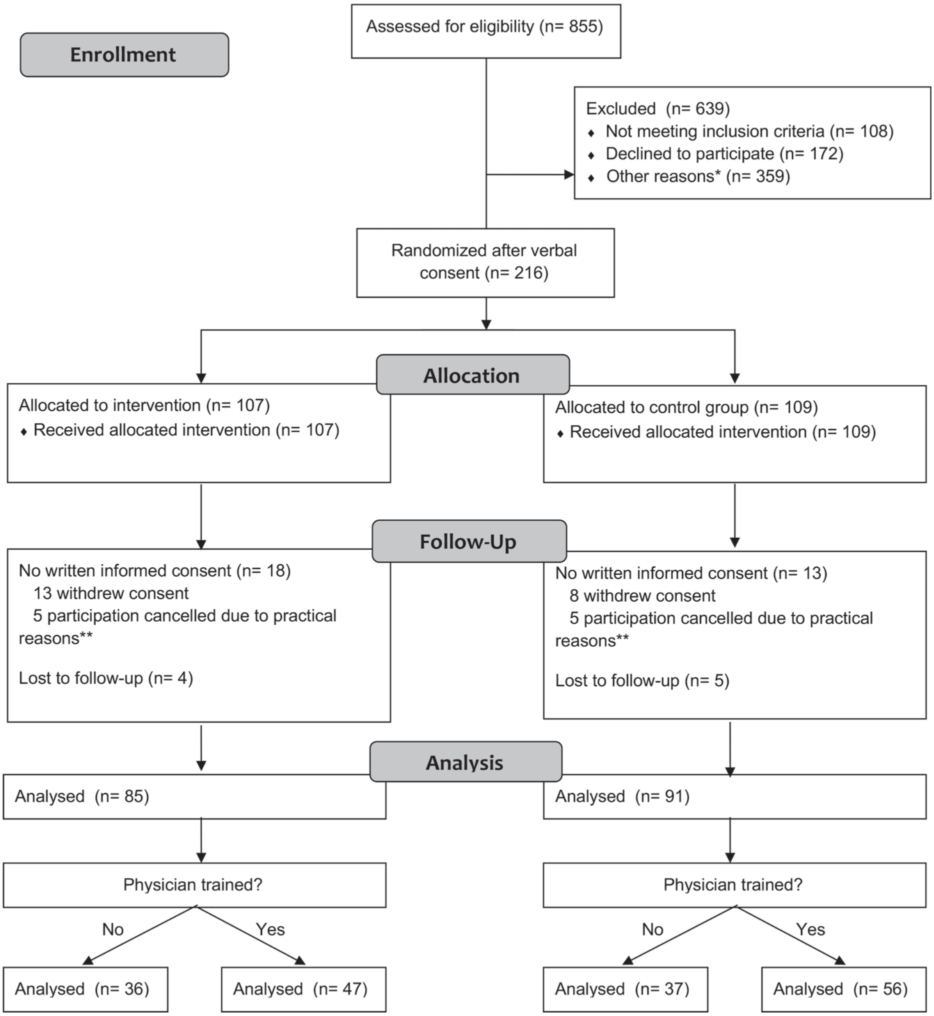
The physicians' training took place when 77 patients were included (33% of the attempted total sample size). Table 1 shows the baseline characteristics of the patients stratified by intervention group. The overall median age was 58 years (IQR 50-68), 60% were men, and the median CCI was 3.0 (IQR 1.0-5.0). A total of nine patients were lost to follow-up. These were equally divided amongst the four groups and the characteristics we had from these patients (age, gender and CCI) were similar to the overall values.

3.2 Patient satisfaction, patient-doctor relationship and shared decision making

Table 2 shows the mean patient satisfaction, patient-doctor relationship and shared-decision-making stratified by intervention group. The number of patient-reported care decision discussions during the outpatient clinic visit and in which a decision was made are shown as well. Only 45/161 (28%) patients reported to have discussed care decisions during the outpatient clinic visit, of which 25 (56%) made a decision.

After adjusting for patient-related (age, gender, quality of life, CCI) and physician-related (specialist/resident, gender) confounders, no statistically significant association between conversation aid and physician's training and mean satisfaction score was found (effect sizes -0.14 (95% CI -0.56 to 0.27) for conversation aid; -0.04 (95% CI -0.48 to 0.40) for physician's training). Similarly, for the secondary outcomes, patient-doctor relationship (effect sizes -0.45 (95% CI -2.85 to 1.95) for conversation aid; 1.28 (95% CI -1.04 to 3.60) for physician's training) and shared-decision-making (-0.01 (95% CI -5.96 to 5.94) for conversation aid; -0.23 (95% CI -8.89 to 8.42) for physician's training) no statistically significant association was found (supplementary appendix 3). When looking at the interventions separately, no significant difference in median satisfaction score with and without the intervention was observed (before physicians’ training 8.0 (IQR 8.0-9.0), after training 8.5 (IQR 8.0-9.5), p=0.476; without conversation aid 8.5 (IQR 8.0-9.25), with conversation aid 8.0 (IQR 8.0-9.0), p=0.106).

Figure 1. Diagram of the patient-participant flow



* did not answer the phone at multiple occasions

** consultation cancelled due to car traffic, car trouble, reschedule of the appointment for other reasons, sudden change to telephone consult

Table 1. Baseline characteristics of the study population

	Physician not trained, Patient uninformed *n*= **36**	**missing values** *n* (%)	**Physician not trained, Patient informed** *n*= **37**	**missing values** *n* (%)	**Physician trained, Patient uninformed** *n*= **56**	**missing values** *n* (%)	**Physician trained, Patient informed** *n*= **47**	**missing values** *n* (%)
Age (years)	61 (51-71)	0 (0)	63 (53-71)	0 (0)	57 (43-68)	0 (0)	56 (48-65)	0 (0)
Gender (male)	22 (61)	0 (0)	21 (57)	0 (0)	30 (54)	0 (0)	32 (68)	0 (0)
Charlson Comorbidity Index	3.5 (2.2-5.0)	0 (0)	3.0 (2.0-4.0)	0 (0)	2.5 (1.0-5.0)	0 (0)	2.0 (1.0-4.0)	0 (0)
Educational level		4 (11)		4 (11)		6 (11)		2 (4)
- Primary education	3 (9)		0 (0)		4 (8)		0 (0)	
- Secondary education	7 (22)		5 (15)		5 (10)		4 (9)	
- Middle education	12 (38)		7 (21)		22 (44)		15 (33)	
- Higher education	10 (31)		21 (64)		19 (38)		26 (58)	
Work status (working)	11 (34)	4 (11)	10 (30)	4 (11)	20 (40)	6 (11)	24 (53)	2 (4)
Children (yes)	21 (66)	4 (11)	28 (85)	4 (11)	35 (70)	6 (11)	32 (72)	2 (4)
Marital status		4 (11)		4 (11)		6 (11)		2 (4)
- Single	4 (13)		3 (9)		9 (18)		5 (11)	
- Married/ living with partner	24 (75)		28 (85)		33 (66)		39 (87)	
- Divorced/ widowed	4 (13)		2 (6)		8 (16)		1 (2)	
OSS-3 Confidants	3.0 (2.0-4.0)	7 (19)	3.0 (3.0-4.0)	7 (19)	3.0 (2.5-4.0)	7 (13)	3.0 (3.0-4.0)	2 (4)
OSS-3 Concern	4.0 (4.0-5.0)	8 (22)	5.0 (4.0-5.0)	7 (19)	4.0 (4.0-5.0)	7 (13)	5.0 (4.0-5.0)	2 (4)
OSS-3 Neighbour's	3.5 (2.0-5.0)	6 (17)	4.0 (3.0-5.0)	4 (11)	4.0 (3.0-5.0)	7 (13)	3.0 (3.0-4)	2 (4)
Health perception	7 (6.0-8.0)	4 (11)	6.0 (5.0-7.0)	4 (11)	7.0 (6.0-7.0)	5 (9)	7.0 (6.0-8.0)	2 (4)
Quality of life	7.5 (6.0-8.0)	4 (11)	7.0 (5.5-8.0)	4 (11)	7.0 (6.0-8.0)	6 (11)	8.0 (6.0-9.0)	2 (4)

Baseline characteristics of the patients stratified by intervention group. Data are shown as n (%) or median (IQR). For each characteristic number of missing values per intervention group are shown.
Abbreviations: OSS-3: Oslo-3-questionaire for social support

Table 2. Patient satisfaction, patient-doctor relationship, shared decision making and number of care decision discussions per group

	Physician not trained, Patient uninformed *n*= 36	Physician not trained, Patient informed *n*= 37	Physician trained, Patient uninformed *n*= 56	Physician trained, Patient informed *n*= 47	p-value*
Mean patient satisfaction[1]	8.5 (8.0-9.0)	8.0 (8.0-9.0)	9.0 (8.0-9.5)	8.0 (8.0-9.3)	0.503
Patient-doctor relationship[2]	40 (36-44)	36 (34-42)	41 (34-44)	40 (36-44)	0.963
Shared decision making[3]	67 (56-77)	58 (48-73)	64 (56-73)	67 (49-76)	0.594
Care decision discussions	8/32 (25%)	8/33 (24%)	20/51 (39%)	9/45 (20%)	**
Decision made in consultation	5/8 (63%)	4/8 (50%)	12/20 (60%)	4/9 (44%)	**

Median and interquartile range. * P-value for difference between group "Physician not trained, Patient uninformed" and "Physician trained, Patient informed" with Mann-Whitney U test. ** not statistically analysed due to sample size.

[1] scale 0-10, missing in 11/176 patients (6%)

[2] Patient Doctor Relationship Questionaire-9, scale 9-45, missing in 12/176 patients (7%)

[3] Shared Decision Making Questionnaire -9- Doctor, scale 0-100, missing in 43/176 patients (24%)

3.3 Preparedness of the physician

Physicians felt more prepared to discuss care decisions after training (median 3 (IQR 1-4) vs 1 (IQR 0-3), p=0.015). There were no differences in general aspects of the consultation (i.e. overall satisfaction and preparedness to answer questions of the patient) or factors related to discussing care decisions between before and after the training.

3.4 Patients appreciation of the conversation aid

Most patients appraised the conversation aid with an overall mark of 8 (median 7, IQR 7-8).

Most patients consider the conversation aid to be clear, informative, impartial, understandable and not too time-consuming. Most patients stated not to feel insecure or sad after reading the aid. When asked whether the conversation aid helped to form an opinion on care decisions, the majority of patients did not express a clear opinion.

In summary, neither of the interventions had a statistically significant effect on patient satisfaction, patient-doctor relationship and extend of shared-decision-making experienced by physicians. Physicians felt statistically significant more prepared to discuss care decisions after training and patients evaluated the conversation aid positively.

4. Discussion

Neither of the interventions had a statistically significant effect on patient satisfaction, patient-doctor relationship and extent of shared decision-making experienced by physicians. Patients considered the conversation aid to be informative and easy to understand without causing insecurity or anxiety. Furthermore, physicians felt better prepared to discuss treatment decisions after the training.

With the interventions under study, we aimed to stimulate patient empowerment, patient-centred care and meaningful discussions on care decisions, all hopefully resulting in more satisfied patients. We deliberately refrained from using number of care discussions as study outcome as discussing care decisions just to 'check off a box' does not improve patient-centred care and leads to frustration and pressure in physicians (31). We aimed to plant a seed, to stimulate patients to think about their preferences and to create common ground to start the conversation; not to force them to reach an immediate decision.

Although it was not the focus of our study, the low proportion of patients reporting to have discussed care decisions (28%), of which about half made a decision during the outpatient clinic visit, is remarkable. These low numbers might be explained by the perception that it is 'too soon' or 'not yet relevant' to discuss care decisions (32–34). Besides, previous research showed physicians often miss openers from patients that could have prompted these discussions (11). Our qualitative analysis shows that care decisions is a precarious topic for which there is no obvious interactional slot. Therefore, effort is needed to introduce the topic and create common ground (13).

There are several possible explanations for the absence of a statistically significant effect of the interventions on the mean patient satisfaction. First, we did not reach the intended sample size. This could have resulted in insufficient power to detect a possible effect. Another explanation may be the low number of care decision conversations, possibly diluting any effect. Furthermore, patient satisfaction is influenced by many factors (35). We tried to minimize the influence of unrelated aspects by specifically directing the two questions on patient satisfaction to the conversation with the physician and the information given rather than measuring overall satisfaction, but this does not completely exclude other influences. Moreover, patient satisfaction scores without any of the interventions were high, with a median of 8.5 (IQR 8.0-9.0). It is harder to improve satisfaction, if satisfaction is already very high (36). Finally, it could be the case that the interventions under study are not sufficient in improving care decision discussions, and therefore did not result in a statistically significant effect.

Patients' general attitude towards the conversation aid was positive. Patients considered the conversation aid informative. Yet, they did not assess it as helpful in forming an opinion about care decisions or discussing them. A potential explanation can be that processing the information and forming an opinion requires more time, in which case the conversation aid might still have planted a seed for further consideration. Physicians are often afraid that introducing the topic of care decisions makes patients anxious or insecure (5). It is reassuring that most patients reported that they did not feel insecure, sad or anxious when being provided with information about care decisions in the conversation aid.

Physicians indicated they felt more prepared to discuss care decisions after the training. The fact that this difference was not seen in separate important components of care decision discussions raises questions about whether the physicians actually *were* better prepared for these conversations, especially as it is known self-assessment has a poor agreement with externally assessed performances (37,38). However, the *feeling* of being unskilled or inadequately trained is a known barrier to discuss care decisions (5). Therefore, we consider the *feeling* of being better prepared an important step to remove this barrier and thereby improving care decision conversations.

The strength of our study lies in the outpatient clinic setting we studied. Most research on care decisions is conducted in end-of-life settings, although it is considered essential to start discussing this in an earlier stage (2).

We are aware that our research may have several limitations. The earlier termination of the study and low participation rate could have led to selection bias. The presence of the video camera in the consultation room could have influenced the conversations and thereby patient satisfaction. A sense of familiarity between the patient and physician could have influenced care decision discussions and patient satisfaction. This ‘familiarity’ might depend on many factors (e.g. number of visits, content of those visits) which makes it impossible to control or correct for. Furthermore, the conversation aid and questionnaires were in Dutch. Our results are therefore not extendable to patients with low literacy or language barriers. Finally, reasons for why neither the physician nor the patient introduced the topic of care decisions was not asked in the questionnaires. Further work needs to be done to establish the best way to remove the remaining barriers to care decision discussions and motivate physicians and patients to engage in these discussions.

5. Conclusion

Although the conversation aid for patients and training for physicians did not improve patient satisfaction in this study, these interventions can eliminate some barriers to discuss care decisions: physicians feel more prepared to discuss care decisions and patients are more informed without feeling anxious or sad. The low number of care decision discussions shows there is still a lot of work to be done. Further work needs to be done to establish the best way to remove the barriers to care decision discussions and motivate physicians and patients to engage in these discussions.

Acknowledgements

We would like to thank all physicians and patients that participated in this study. Furthermore, we would like to thank B. Silvius, I.P Klaassen and C.A.M Joosten (research nurses) and C. van Ginkel (physician) for assistance in recruiting participants and obtaining informed consents.

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CHAPTER 3

Discussing care decisions at the internal medicine outpatient clinic: a conversation analysis

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Patient Education and Counseling 105 (2022) 2045–2052
https://doi.org/10.1016/j.pec.2021.11.029

Abstract

Objective: Explore *how often, when* and *how* care decisions are discussed during consultations at an internal medicine outpatient clinic, and what we can learn from these observations.

Methods: Qualitative analysis of 150 video-taped consultations. Consultations involving a discussion of care decisions were analyzed using conversation analysis.

Results: 1) Only 21 of the 150 consultations involved a discussion of care decisions; 2) As there is no destined phase for the introduction of the topic of care decisions, the topic is most often introduced at the end of the phase 'treatment and course of the disease'; 3) A lot of interactional effort is needed to create common ground and make relevance clear with extensive justification. Hesitation markers, repairs and hypothetical talk show the precariousness of the topic.

Conclusions: Three dilemma's need to be addressed: 1) a slot has to be created to introduce the topic of care decisions; 2) common ground has to be created, possibly over time; 3) the paradox of framing the topic as relevant 'in the future' but 'needs to be discussed now' needs to be attended to.

Practice implications: We recommend that physician training should address the three dilemmas. Future research should focus on how to do so.

1. Introduction

In 2014, the Dutch Association of Internal Medicine published a list of ten 'Wise Choices' in internal medicine as part of the nationwide 'Choosing Wisely Campaign' [1–5]. One of these 'Wise Choices' is for doctors to discuss care decisions when talking to patients about their treatment [2]. Care decisions comprise a broad spectrum of topics, including discussions of code status and do-not-resuscitate orders as well as advanced care planning (ACP). In this paper, we focus on patient-physician communication about code status (patient preferences regarding resuscitation, mechanical ventilation and Intensive Care admission) and other possible treatment options such as dialysis, hospital admission and tube feeding.

Previous research has shown that both patients and physicians find care decisions a precarious topic that they tend to avoid [6]. Despite numerous barriers for physicians and patients (e.g. feeling unskilled; unawareness of the relevance[7–11]), care decisions should be a regular part of patient-physician communication [2] and patients should be engaged in the decision-making process [12,13]. It is argued that timely discussions of care decisions can lead to care that is more closely aligned with patient preferences and involves less health care consumption [14]. This topic is, however, often postponed until the end of life, reflected in the fact that research is conducted predominantly in end-of-life settings [6,11,15–17]. If such discussions are not timely, they take place in far from ideal circumstances, such as an acute setting in the emergency department when time is limited and the patient is severely ill [10]. The outpatient clinic, where patients often consult a familiar physician, seems better suited to such conversations [18]. In this paper, we examine video-taped consultations at the internal medicine outpatient clinic. We counted *how often* care decision conversations occurred within our data. Using conversation analysis (for an explanation of conversation analysis see [19]; for an example, see Erkelens et al. (2020) [20]), we then analyzed *when* (in which phase of the consultations) and *how* the topic of care decisions is introduced. Insight in these patterns could be used to guide future practices.

2. Methods

2.1 Study design

This study is part of a larger project aimed at stimulating and improving care decision conversations at the internal medicine outpatient clinic of University Medical Center Utrecht, a tertiary care teaching medical center in the Netherlands. This study was approved by the Medical Ethical Testing Committee Utrecht (MEC 18-465) and registered in the Dutch trial register (NTR 7188).

Eleven physicians (residents and staff physicians) from different specialties of the department of internal medicine participated in this study. A total of 185 of their patients agreed to participate. Randomization software was used to randomly select patients, stratified by gender, who were assigned patient education*. Physicians were trained** halfway through the study period. This resulted in four groups: 1) physicians before training and patients without patient education; 2) physicians before training and patients with patient education; 3) physicians after training and patients without patient education; 4) physicians after training and patients with patient education. This project involved both quantitative and qualitative analysis. This paper focuses on the results of the qualitative analysis.

2.2 Video recordings

The outpatient clinic visits were video recorded for purposes of qualitative analysis. Since the consultation rooms had different set-ups, the extent to which both participants were visible varied. Figure 1 shows that we set out to record 185 consultations. Thirty-five recordings failed for various reasons, for example camera malfunction, last-minute location change, or camera inadvertently_not switched on. This means that the resulting dataset consists of 150 recordings.

2.3 Analysis

All video recordings were assessed by one of the authors (SB) to determine whether or not the consultations involved a discussion of care decisions (see our description in section 1). The recordings in which care decisions were discussed were transcribed verbatim. To identify *when* care decisions were discussed, we used Heritage & Clayman’s (2010) framework of phases in physician-patient conversations in acute primary care visits [21], as this institutional context is most closely related to our data. We first identified the phases in our data using a similar bottom-up approach. We identified moments in which the physician and patient themselves make a new phase relevant in the interaction. Two of the authors (SB & TvC) identified these phases independently and then discussed their findings.

To analyze *how* the topic of care decisions was introduced, we analyzed the parts of the consultation involving a discussion of care decisions. Here we used Jeffersonian transcription conventions to show phonetic information and pacing (see *Appendix A*) [22]. We also described notable non-verbal information (e.g., looking at the computer, typing, or handing over forms).

We began our analysis at the point when either the physician or the patient introduced the topic of care decisions and then looked at the previous and subsequent turns until the topic was concluded. We focused on the introduction of the topic to gain insight into the interactional implications of certain care decision introductions.

To describe the discussion of care decisions in greater detail, we organized a data session, a common practice in conversation analytic studies. Six conversation analysts analyzed specific fragments using the video recordings and transcripts [19].

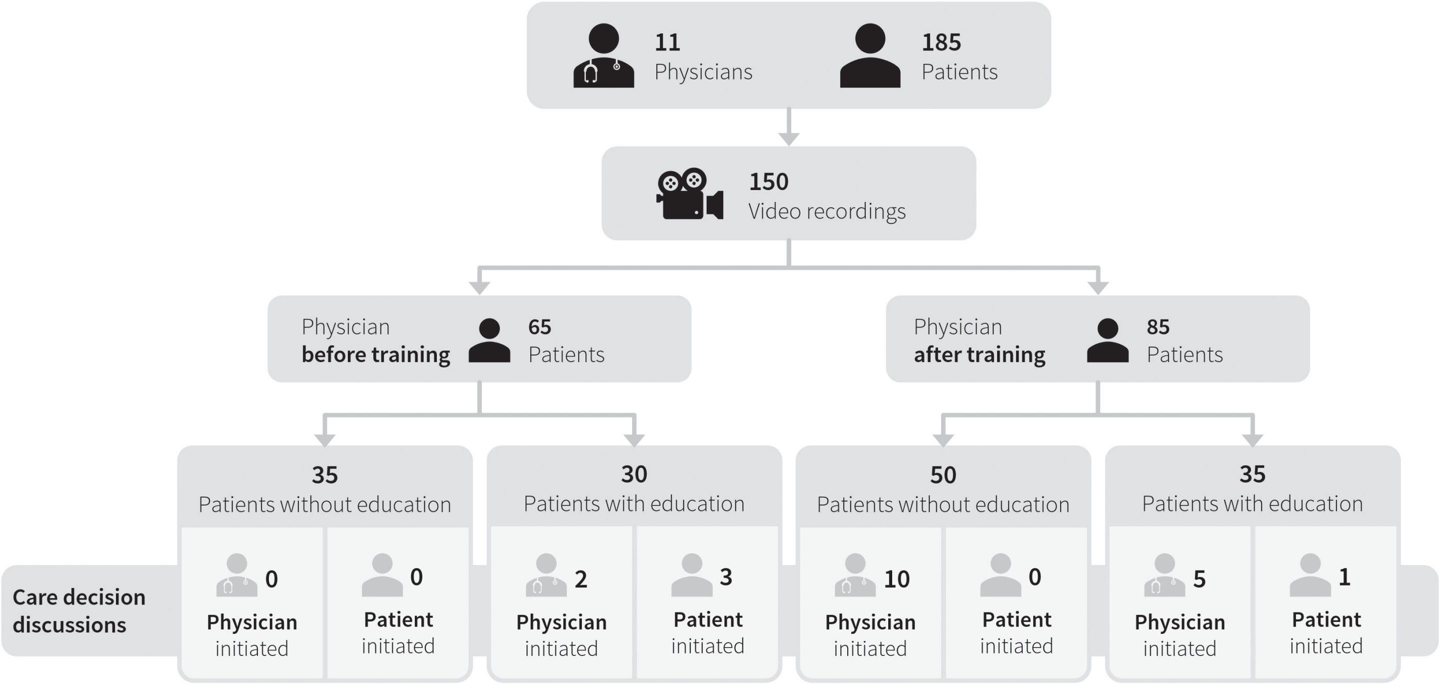
3. Results

In this section, we show *how often* care decisions were discussed (section 3.1), *when* -or in which phase of the consultations- care decisions were discussed (section 3.2) and *how* the topic of care decisions was introduced (section 3.3).

3.1 How often are care decisions discussed?

Care decisions were discussed in 21 of these consultations, conducted by six different physicians. Figure 1 shows the distribution of these conversations over the four groups and who initiated the topic. Physicians initiated the topic of care decisions in two of the 65 (3.1%) consultations before their training and 15 of the 85 (17.6%) consultations after their training. Of the 85 patients who had not received patient education, none introduced the topic, whilst four of the 65 (6.2%) patients who had received the patient education did.

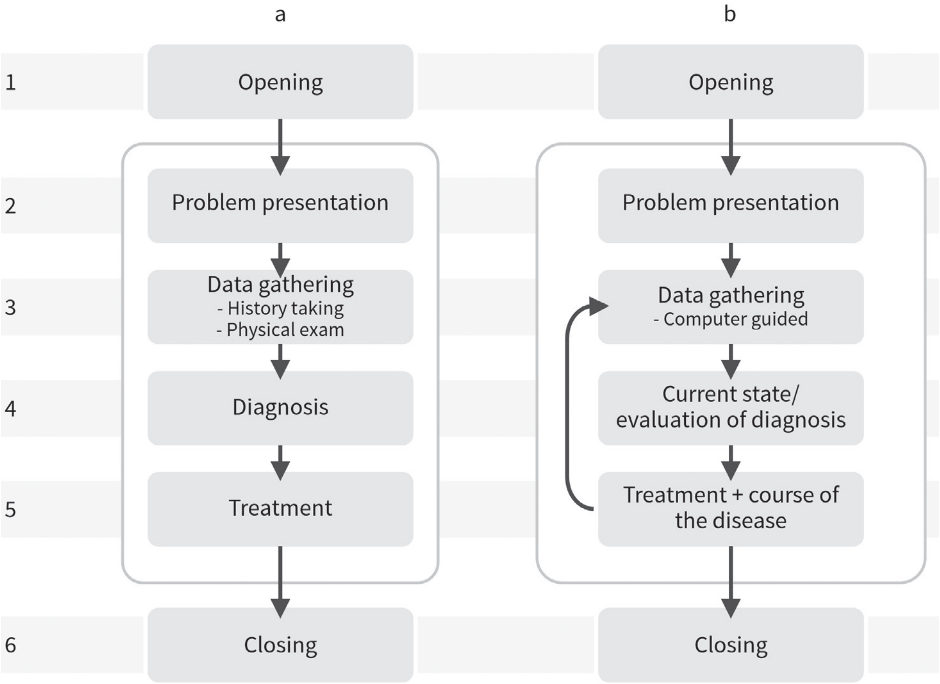
Figure 1. Diagram of the study



3.2 When are care decisions discussed?

The conversations in our data take place in an institutional setting: during consultations at the internal medicine outpatient clinic. Unlike acute primary care visits, which formed the basis for Heritage & Clayman's (2010) [21] framework of phases in physician-patient conversations, our data consists of scheduled (follow-up) visits. Most of our patients therefore had a known diagnosis, for instance chronic kidney failure or diabetes. In our data we identified roughly the same phases as Heritage & Clayman (see Figures 2a and 2b), although we also found differences.

Figure 2. Phases of the consultation



a. phases in physician-patient conversations in acute primary care visits identified by Heritage & Clayman, 2010[1].

b. phases in physician-patient conversations in scheduled (follow-up) visits at the outpatient clinic of internal medicine.

In Heritage and Clayman's model the 'problem presentation' (phase 2) is patient-directed, whereas in our data, phase 2 is physician-directed: the physician states the reason for the consultation ('*You are here for your three-month check-up on your diabetes*) and sets the agenda from that point on until the pre-closing/closing phase (phase 6).

Another difference is that 'data gathering' (phase 3) in our data involves little in the way of history taking/ physical examination; instead, it consists mainly of computer-guided data collection, for instance lab results or blood pressure.

As most patients have already been diagnosed, phase 4 involves evaluating the current state of the patient's condition: is it stable, improving or deteriorating? This is followed by an 'evaluation of the treatment' (continue, start, stop or change). On top of that, in this fifth phase the physician often outlines the 'course of the disease': how he or she expects the disease to unfold (improvement, deterioration or stability, and what consequences will this have for the future?). Phases 3 to 5 are usually iterative: the physician evaluates different aspects of the diagnosis one after another, including their consequences for treatment and the future.

After discussing all the various aspects of the diagnosis, the physician generally initiates a pre-closing by asking whether the patient has any questions ('*That was all I wanted to discuss, do you have any questions?*'). At this stage of the consultation, the patient can take the lead. If the patient does not, this phase is followed by the closing.

As can be seen, there is no phase destined for care decision conversations and hence there is no natural slot available for the introduction of this topic within the event.

In the instances in our data, the topic of care decisions is introduced most often at the end of the phase 'treatment and course of the disease'. This was the case in 11 out of the 17 cases in which the physician initiated the topic. In two consultations, the physician introduced the topic even later, in the pre-closing stage or even after the closing and the physician had said, '*hey that's it for now, thanks for coming'.* Patients, in their turn, also introduced the topic near the end of the consultation in two out of four patient-initiated cases. In only five out of 21 consultations care decisions were discussed early on in the consultation; four of these were physician-initiated.

3.3 How the topic of care decisions is initiated

Because most care decision conversations were physician-initiated (17 out of 21), we focus on the physician-initiated conversations in this section. We provide two illustrative examples from our data. Throughout our data a problem is visible with creating relevance for the introduction of the care decision conversation. Physicians provide several justifications or accounts [23] for this introduction, although– in the institutional context of a consultation – they have privileged opportunities to ask a patient health-related questions [24]. Physicians use two distinct strategies: external accountability or patient-related accountability. In external accountability, the physician uses sources outside of the patient's health domain as justification. Most frequently used is participation in this study/presence of the camera in the consultation room (10 out of 17 consultations). Other examples are that information about care decisions is currently missing in the system/electronic health record (EHR) or referral to hospital policy on discussing and documenting agreements on care decisions. In patient-related accountability, physicians provide justifications connected directly to the specific patient (e.g. a reference to something the patient has said before, the patient's impaired physical condition or a recent event such as surgery). An example of this is '*some people have - because you have also had a heart surgery - have ideas about whether or not they want this*'. In the first example, the topic of care decisions is introduced in the 'treatment and course of disease' phase with use of external accountability.

Example 1: A typical physician-initiated care decision discussion (external accountability)

The patient (P) is a 64-year-old female with a history of glomerulonephritis and thyroid dysfunction. She is attending her (annual) follow-up appointment with her regular (experienced, male) nephrologist (D). The excerpt starts at the end of the treatment and course of disease phase. Previously in the consultation, the physician and patient discussed kidney function (stable), thyroid function (good), an episode of inflamed molar and urinary tract infection in the past year, and when the patient should contact the physician in between scheduled appointments. Just before this excerpt starts, the physician measured the patient's blood pressure (good to a bit low) and they discussed possible side effects, such as dizziness.

```
406   D:    I I have now something (.) this already is a fantastic blood
407         pressure,
408         if if >I measure him a few times again< then it is perhaps a
409         bit lo↑wer.
410         but if this works [for you?
411   P:                           [yes.
412   D:    then,
413   P:    yes.
414   D:    then I do not need to know that necessarily,=
415   P:    =no.
416   D:    U:hm (.) the interesting thing about that ca↑mera project is
417         also that the idea is that you-
418         that we also talk about care decisions?=
419         =not that it is an obligatory subject.=
420   P:    =no.
421   D:    but if the opportunity arises.
422         and I was↑ (.) when we were- when I was preparing this
423         consultation realizing that we indeed really have >nothing at
424         all< [written up about it,
425   P:                 [no.                  no.
426   D:    and I find that (.) in itself a bit unfortunate
427         =cause what if you enter the emergency department and
428         something serious has happened,
429         then <we do not know at a:ll> [if you have=
430   P:                                  [no.
431   D:    =an opinion about that.
432         and of course it could be the case that you (.) have already
433         thought about that very carefully.
434         and I would find that <really unfortunate>,
```

Hereafter, the patient responds that she had not thought about care decisions regarding herself, because she feels very healthy, but did so regarding her sick mother. The physician confirms this "makes sense", but it would still be good to know and document her opinion. The patient states she does not want any treatment limitation at this moment, again confirmed by the physician as "making sense", but she states that this might change over time, especially when her physical condition would detoriate. This is documented in the EHR, after which the consultation is closed.

In example 1, the physician initiates a topic change after closing the topic of 'blood pressure' in line 414. After the patient's negatively formulated agreement *'no'* (no need for further information) in line 415, the physician changes the topic with the hesitation marker '*uhm'* in line 416. This turn-initial 'uhm' seems to be marking the physician's editing of the utterance-in-progress [25,26].

The physician now begins an elaborate multi-unit turn [27] (lines 416-434) and produces three accounts for the nomination of the topic: the camera project (lines 416-417), the realization that this information was missing in the system (lines 422-424), and the possibility the patient might have her own ideas (lines 430-434). The multi-unit turn is marked by the aid of various 'rush throughs': 'a practice in which a speaker, approaching a possible completion of a turn-constructional unit, speeds up the talk, withholds a dropping pitch or the intake of breath, and phrases the talk to bridge what would otherwise be the juncture at the end of a unit' [27] (e.g. lines 418-419 and 426-427). The patient uses various 'continuers' (see 'no's' in lines 420, 425 and 430), thereby claiming understanding and encouraging the physician to continue [27].

Besides the hesitation marker and multiple accounts the physician provides for introducing the topic of care decisions, there are also repairs noticeable in lines 417-418 ('*that you- that we')* and line 422 ('*and I was↑ (.) when we were- when I was'*). Repairs are generally preceded by a 'trouble source', i.e. something apprehended as a problem [28], and are observed in talk about 'sensitive' issues [16,29]. Furthermore, in line 427, the physician uses hypothetical talk (*what if*). In our data, hypothetical future scenarios are sketched to explore the patient's thoughts and wishes in particular scenarios, such as '*imagine you come to the hospital and are very ill'* or '*what if there is an emergency, let's say, something happens to your heart'.* Across several settings, hypothetical questions have shown to be effective in encouraging patients to engage with difficult issues but at the same time show the 'serious and sensitive' nature of these topics [16].

In the multi-unit turn, the physician does not ask the patient a direct question. He uses declarative utterances designed as 'my side' tellings [30] in lines 423-424 and 429. In a 'my side' telling, the speaker has less access to information than the recipient does. That is the case here because the patient's thoughts and wishes are in the patient's epistemic domain [31,32]. The physician requests information by these my-side telling declaratives [30], after which the patient responds. Her decision (no limitations) is documented in the EHR, and the consultation is closed.

Example 1 is typical of the exchanges in our data. Care decisions are introduced in the 'treatment and course of disease' phase as a final point on the agenda. While the 'last topic' is made explicit in some of the examples in our data (e.g. *one last thing*, *one more point*, *I had one last (little/ silly) question*), example 1 demonstrates a more implicit instance of 'last topic to be discussed'.

Example 2. Topic of care decisions introduced in the data gathering phase patient-related accountability).

This is a consultation between an 81-year-old male patient (P) with chronic kidney damage and his experienced female nephrologist (D). The patient’s partner (F) also takes part in the conversation.

```
87   D:   ((uses blood pressure meter on patient))
88   D:   here it comes,
89   P:   yes.
90   D:   I am ac↑tua↓lly very happy with these results↑
91        it looks proper,
92        uhm (.)
93        it is also (.) so hi, -or so good, actually,
94   P:   yes?
95   D:   that I am no:t (.) going to give you the information about what
96        if the kidneys stop working,
97   P:   ((nods yes))
98   D:   that chance will <in the end> come up at some point,
99   P:   yes,
100  D:   uh(.) and then you would have to go on <dialysis>,
101       I don’t know if you know what that is?
102  P:   no,
          ((8 lines omitted))
110  D:   and u:hm (.) with these values it is definitely not relevant,
111  P:   no.
112  D:   but if it comes- becomes worse,
113       and often is that number; right, that 27 is going towards the:
114  P:   [yes?
115  D:   [let’s <goes towards> say 15, then-
116  D:   ->°I am going to do it gain okay°<
117       ((turns on blood pressure meter again))
118  D:   then it can be. that the dialysis, right, comes in sight.
119       and then of course you should have in ample time, you should
120       get some information about that,
121       what is it exactly, and what does that mean:?
122       [and-uh
123  P:   [yes I have seen that before you see.
124  D:   well I think that that information (start) is really not
125       relevant yet,
126       uhm but it is [already a good,
127  F:                 [-i was already afraid of that earlier before we
128       came h[ere
129  D:         [yes.
130  F:   (than I thought like) well↑ (.) hey↑
131  D:   yes.
132       and if we then eh: right,
133       if that <will co:me> in sight,
134       then we should also elaborately discuss,
135       at your age (0.3) if you would want that. (0.3)
136       right, because you can also say with that bad kidney
137       functioning,
138       then I will actually try with >pills< (0.5) to keep it
139       functioning as long as pos[sible.
140  P:                             [yes.
          and that you then say that the dialysis that you say of that-
141  D:   that it might be a a bridge too far:,
142       and that–that–there is something to say [for that
143                                               [yes::, that is not
144  P:   pleasant of course.
145
```

After line 145 the patient and physician continue to talk about various options and their consequences considering the patient’s age (>80) and clinical condition (good). The actual decision on whether or not to opt for dialysis is deliberately postponed and they continue the consultation with evaluation of the blood pressure, fluid status, and increasing the diuretics, etcetera.

The second example shows an example of patient-related accountability to introduce the topic of care decisions.

In this example, the physician moves from evaluating the good blood results (lines 90-91) to stating it is *not* necessary to give the patient information about care decisions (line 95). The physician uses the 'good' or 'high' blood levels as a way to make the transition to the possibility that the kidney might stop working. In this transition (lines 92-93), we see that the physician edits her speech in progress [26] after a short 'uhm'. This all takes place while the physician is measuring the patient's blood pressure. After a minimal agreement with rising intonation by the patient in line 94, the physician refers to a (possible) future scenario ('about what if') in lines 95-96. By presenting the information about this particular care decision (dialysis) as something that needs not to be discussed right now, the physician attends to two underlying dilemmas: 1) this could have been an appropriate slot to introduce care decisions, but since the blood result is fine it is no longer appropriate; 2) the topic of care decisions is only relevant in the future when things get worse, but, at the same time we should not wait until it is too late. The patient demonstrates understanding with a nodding agreement (line 97), and the physician responds to this by indeed providing further information about future care decisions (until line 143).

The patient's minimal responses throughout this elaborate stretch of talk solicits continued information-giving from the physician, noticeable throughout the entire excerpt. Although the physician introduces all sorts of topics and points for consideration (age, type of medication, hassle), she presents them in an information-giving format, rather than as items for that discussion at that point in time. The physician emphasizes multiple times that at *this* point, no decision has to be made, and that it is in fact unnecessary to have the information at all (lines 110, 124-125). However, she does provide some information about what dialysis entails (omitted lines), when a decision should be made (not in actual 'time' but in 'lab value') (lines 112-118), that the patient needs to be well-informed before that moment arrives (lines 119-120), that they should *elaborately* discuss the care options (131-139), and that it is a legitimate choice *not* to opt for dialysis (141-143). By presenting all this information - even though she said she did not have to (lines 95-96) – the physician solves two dilemmas: she has created a slot in which to initiate the topic and she prepares the patient for the ‘what if’ scenario: what if it gets worse. We can also see this as creating common ground: the physician shares the information that matters in making care decisions from a physician perspective [33].

A paradox, however, still remains. The topic is framed as ‘relevant in the future’ but ‘needs to be discussed now’. Elsewhere in our data we also see that the care decisions are framed as not yet relevant (e.g., we see references to it being ‘logical’ not to have discussed this thus far because of the patient’s young age). Although the care decisions become (more) relevant when things get worse, by that point it could also be too late to make certain decisions. At the same time, patients might feel anxious when the topic is brought up in the routine consultation. We call this the relevance paradox. Because the topic is introduced as ‘not yet relevant’ in this example, postponing the actual decision is a logical consequence. In example 1, a logical consequence of the physician introducing care decisions as ‘missing information in the EHR’ is to document the decision in the EHR.

4. Discussion and conclusion

4.1 Discussion

After counting in our data *how often* care decisions were discussed during consultations at the internal medicine outpatient clinic, we used conversation analysis to explore *when* and *how* they are discussed. It is striking how few discussions of care decisions took place: the topic was introduced in only 21 of the 150 video-taped consultations. We established there is no destined phase and therefore no interactional slot for the introduction of the topic of care decisions. Because there is no obvious slot, a lot of interactional effort is needed to introduce the topic. Common ground needs to be created and relevance needs to be accounted for. Hesitation markers, repairs and hypothetical talk furthermore show the precariousness of the topic, as confirmed by previous literature.

Extensive accounts are provided by both physicians and patients to introduce the topic of care decisions. We have noted a difference in implication between external and patient-related accountability.

The data show that there seems to be a dilemma with relevance. General perception is that the care decision conversation becomes relevant when the treatment that is discussed is just around the corner (e.g., an end-of-life setting or acute/severe medical illness). This results in statements like ‘it is actually not yet relevant’, it is discussed ‘just to fill the EHR’, or it is discussed ‘because of study participation’, with diverse consequences. Such statements all attempt to create relevance while contradictory sustaining the ‘not actually relevant yet’ perception. In order for the patient to make a considered decision, it is relevant to have these conversations at an earlier moment during regular consultations. *Discussing* care decisions is relevant far before a decision is made. Therefore, physicians have a difficult task in negotiating the conflicting demands of addressing a precarious topic at a time it is not perceived necessary yet.

In 2014, Parry et al. published a systematic review synthesizing observational evidence about patients-physician communication about future illness progression and end-of-life, summarized as ‘sensitive future matters’ [16]. Although our research takes place in a different context, i.e. a general internal medicine outpatient clinic and not an end-of-life setting, some observations are similar. Parry et al. also observed the occurrence of delays, hesitations, and repeats and the use of “hypothetical questions and talk”. In addition, their “framing of the difficult issue as universal or general rather than individual to this patient” corresponds to the use of external accountability in our study (participation in the study or ‘the system’), and their “linking questions and proposals to what the patient had said or not said” corresponds to the use of patient-related accountability in our study. Indirectness, allusive talk, euphemisms, fishing questions and shifting to the positive [16] were less common in our data, probably because of the different setting.

This study has various strengths and limitations. One of its major strengths is that we focused on care decision conversations in a general outpatient clinic. So far, most research on this topic has been conducted in end-of-life settings [6,11,15–17] despite calls to conduct these conversations at an earlier stage [2,10,18]. Furthermore, we not only assessed whether a conversation about care decisions in fact occurred but explored *when* and *how* these conversations were conducted in this population. Our analysis revealed practices and dilemma’s common in our data and their implications, which will be useful in future training.

The low frequency of consultations involving a discussion of care decisions shows the importance of this study and the need for further training and education, but it also limited the number of consultations we were able to analyze. Furthermore, the conversations were not evenly distributed over the participating physicians: some had not a single conversation about care decisions while one physician introduced the topic of care decisions in ten consultations. This may have influenced our observations: this physician's personal preference about how to discuss care decisions could have been interpreted as a common practice simply because we observed it with more frequency. However, because we saw different patterns in this physician's consultations and similar patterns in the conversations of the other physicians, we do not believe this impacted our analysis.

Because of the small number of patient-initiated care decision conversations, it was difficult to draw conclusions about how patients introduce the topic. It is, however, remarkable that patients almost never do so, perhaps because they believe the physician will take the initiative if and when the topic becomes relevant [11].

4.2 Conclusion

We observed that care decisions are rarely discussed during consultations at a general internal medicine outpatient clinic. There is no destined phase in the consultation to initiate this topic, and it involves considerable effort and (external) accountability to create common ground and to solve the relevance paradox. The topic is often framed as an alien, administrative matter.

4.3 Practice implications

Although the importance of discussing care decisions has been recognized [2], our study shows that the frequency of these discussions in our dataset of 150 video recordings at the internal medicine outpatient clinic is low. Education and training are therefore needed. Our physician training and patient education program, which focused mainly on emphasizing the importance of care decision conversations, improved the frequency of care decision conversations.

Our analysis illustrates the need to devote more attention to three problems: 1) an interactional slot has to be created to introduce the care decision topic; 2) common ground has to be created and found; 3) the paradox of the topic as 'relevant in the future' but 'needs to be discussed now' needs to be overcome.

Although our study shows no definite solution, we would like to share ideas to address these problems. A slot can be created by putting care decisions on the agenda at the beginning of the consultation. Furthermore, preparation of the patient can be helpful. All four patient-initiations in our data were by patients that received the patient education. This indicates that these patients considered the topic relevant to bring up. Understanding of the relevance and background information (i.e., what are the treatment options and what choices do patients have with what types of consequences), can be seen as first steps in creating common ground. As discussed before, more common ground needs to be created. Regular discussion of care decisions during outpatient clinic visits could create more common ground over time.

Finally, we recommend incorporating these dilemmas in physicians' training. This creates awareness among physicians that they should address these dilemmas when discussing care decisions. Future action-oriented research should focus on the best way to do so.

Appendix A

Transcription symbols used in the examples. The symbols are based on Jefferson's glossary of transcript symbols, which are routinely used in conversation analytic research.

Symbol	Definition and use
(.)	Brief interval < 0.2 seconds
.,?	Markers of final pitch direction at turn construction unit boundary: Final falling intonation (.) Slight rising intonation (,) Sharp rising intonation (?)
=	End of one turn construction unit and beginning of next begin with no gap/pause in between
↑ ↓	Marked shift in pitch, up (↑) or down (↓)
.hhh	Inbreath. Three letters indicate 'normal' duration. Longer or shorter inbreaths indicated with fewer or more letters.
hhh	Outbreath. Three letters indicate 'normal' duration. Longer or shorter inbreaths indicated with fewer or more letters.
Emphasis	Underlining indicates emphasis. Placement indicates which syllable(s) are emphasized.
word-	A dash indicates a cut-off
<slower>	Decreased speaking rate than surrounding speech by the same speaker
>faster<	Increased speaking rate than surrounding speech by the same speaker
°quieter°	Degree sign indicate syllables or words quieter than surrounding speech by the same speaker
pro::longed	Colon indicates prolonged vowel or consonant, one or two colons common, three or more colons only in extreme cases
[overlap] [overlap]	Overlapping talk
((description))	Double parentheses contain descriptions of non-verbal actions

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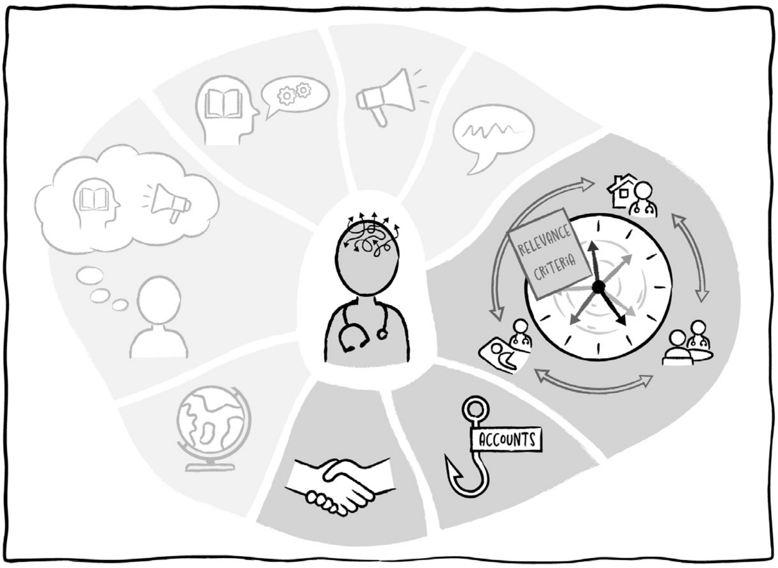
Intermezzo 1



The figure above shows topics that emerged in an interview study with physicians. On the right sight of this intermezzo, we clarify the topics tinted dark gray in the figure. These topics relate to the previous chapters. The light gray tinted topics will be discussed in intermezzos elsewhere in this thesis. Participating physicians were residents and specialists of the internal medicine department, who worked at the outpatient clinic. All participating physicians also performed (supervision) duties at the emergency department.

The topics that emerged are:

1. Time and place, which encompass several aspects: setting, time, timing (emphasis on relevance) and exchanging medical information between caregivers
2. Hooks: justifications to introduce the topic. In conversation analytic terms: accounts
3. Physician-patient relationship
4. Cultural differences
5. Prepared and aware patient
6. Competence and skills
7. Awareness
8. Physician initiative

Intermezzo 1 focuses on topics 1, 2 and 3.

Physicians say that…

Time and place: Setting

- care decisions are not discussed regularly at the outpatient clinic
- their main experience with care decisions is at the emergency department or during an intensive care internship

- the best time and place for care decision conversations is debatable (they had different opinions)
- the outpatient clinic is the best place for care decision conversations *when relevant* (more on *relevance* in Intermezzo 2)

- the general practitioner is responsible for care decision conversations since (s)he knows the patient best (mentioned by a few)

Time and place: Time

- lack of time is the biggest barrier to care decision conservations
  - *“because it is a difficult subject, you can only bring it up if you can take the time for it”*

- they experience lack of control and the required time is unpredictable
  - “*because you have no idea how the patient will respond*”
- they misuse time as an easy excuse as well
  - *“because it is a difficult topic, so we rather talk about lab results and avoid conversations about care decision”*

Hooks (accounts)

- it is difficult to bring up the topic of care decisions if there is no *“direct cause”*

- they search for a “*hook*” to initiate the conversation
- they feel the need to justify the introduction of the topic of care decisions

Physician-patient relationship

- the established physician-patient relationship at the outpatient clinic enables care decision conversations, although not every physician had long-term physician-patient relationships

- they sometimes feared to negatively impact the relationship through care decision conversations, when the patient became overwhelmed or anxious
- care decision conversations positively impact the physician-patient relationship due to more profound conversations and free expression of emotions

PART II

Patients perspective on discussing care decisions

CHAPTER 4

A patient's perspective on care decisions: a qualitative interview study

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BMC Health Services Research (2023) 23:1335
https://doi.org/10.1186/s12913-023-10342-9

Abstract

Background and objectives: Discussing treatment wishes and limitations during medical consultations aims to enable patients to define goals and preferences for future care. Patients and physicians, however, face multiple barriers, resulting in postponing or avoiding the conversation. The aim of this study was to explore an internal medicine outpatient clinic population's perception on (discussing) treatment wishes and limitations.

Methods: Semi-structured interviews were conducted in two rounds with 44 internal medicine outpatient clinic patients at the University Medical Centre Utrecht, a tertiary care teaching medical centre in the Netherlands. Interviews were transcribed verbatim and thematically analysed with a phenomenological approach and inductive, data-driven coding.

Results: Four themes were identified, two (1-2) represent a deep conviction, two (3-4) are practically oriented: 1) patients associate treatment wishes and limitations with the end-of-life, making it sensitive and currently irrelevant, 2) patients assume this process leads to fixed choices, whilst their wishes might be situation dependent, 3) treatment wishes and limitations are about balancing whether a treatment 'is worth it', in which several subthemes carry weight, 4) the physician is assigned a key role.

Conclusion and practice implications: The themes provide starting points for future interventions. It should be emphasized that care decisions are a continuous, dynamic process, relevant at any time in any circumstance and the physician should be aware of his/her key role.

Key points: Four themes were identified in the perception of an internal medicine outpatient clinic population's on (discussing) treatment wishes and limitations. The themes provide starting points for future interventions. It should be emphasized that care decisions are a continuous, dynamic process, relevant at any time in any circumstance and the physician should be aware of his/her key role.

1. Introduction

"Discuss care decisions when discussing treatment with patients." This is one of the ten Wise Choices compiled by the Dutch Association of Internal Medicine [1], to improve the quality and efficiency of healthcare in the spirit of the global Choosing Wisely campaign [2, 3]. Care decision discussions comprise a broad spectrum of topics, all with the purpose to align treatment with the preferences of the patient. This includes code status documentation (i.e. whether limitations to specific life-sustaining treatments are in place) and all forms of advance care planning.

Although the Wise Choice above implies care decisions discussions should be a regular part of the medical consultation [1], both physicians and patients face multiple barriers in doing so [4–9]. Patients face difficulties such as lack of knowledge, passivity and refusing to think about the end-of-life [5]. Maybe even more important is the patient's unawareness of the relevance of care decisions and the expectation that physicians will initiate the discussion when needed [8]. Avoidance by both parties results in care decision discussions not taking place [9], and therefore an opportunity to improve the efficiency and quality of healthcare is missed.

Patients and physicians often perceive the care decisions discussion in the outpatient clinic as being too soon [4, 5, 10]. However, the quality standards of the Dutch association for Internal Medicine demand a code status is documented in every admitted patient [11]. Therefore, when discussions about care decisions are postponed, it could be the case that code status suddenly has to be discussed in acute settings (e.g. at the emergency department), when there is less time for discussion and thoughtful consideration of the patients preferences before making a decision. Besides, in acute settings preexisting physician-patient relationships are rare [5]. Therefore, the outpatient clinic setting would be a better option [12, 13].

There are some subtle differences in the Netherlands between hospitals and settings in how one refers to care decisions. Terms that are for instance used are: treatment restrictions, code status discussions, advance care planning (often associated with end-of-life) [4] and treatment instructions. In the communication with patients we used the term 'treatment wishes and limitations', as this makes clear that the discussion about care decisions is not just about a code status or treatment restriction, but about patient preferences and aligning treatment with these preferences, in which refraining from a treatment is also a possibility.

To stimulate and improve care decision conversations at the internal medicine outpatient clinic, we previously conducted a study in which internal medicine physicians were trained on the topic of care decisions and patients were computer-randomized to receive a patient education on this topic [14]. Care decisions were not specifically related to current treatment of these patient, because the intention was to improve timely care decision discussions in all patients. This patient education was constructed based on expert opinions and in collaboration with a patient panel. The patient education is an online web page that emphasizes the relevance of discussing care decisions and provides background information, for instance about who can initiate the discussion (patient or physician), who can decide on treatment limitations, how this is documented/ for whom this information is available. Examples included treatment wishes for patients for ventilation at the intensive care unit or blood transfusion. Additional information, for instance about certain treatments and its consequences, is accessible through hyperlinks. Remarkably, patients assessed the patient education as informative and with good overall marks (median 7 out of 10), while at the same time not valuing it as helpful in forming an opinion about care decisions or discussing them [14]. To clarify this contradiction and gain insight in what would be more helpful for patients to aid them in care decision conversations, we conducted the current study.

Most research on treatment wishes and limitations and advance care planning is conducted in end-of-life settings [8]. On the other hand Harris et al. conducted a qualitative interview study on goals of care discussions in acute hospital admissions in Australia [15]. Knowledge about the perceptions of a relatively healthy outpatient clinic population towards this subject is lacking.

We used semi-structured interviews to (1) further evaluate our patient education, (2) gain in-depth insight in patient’s perspective on the topic of care decisions, and (3) gain insight in necessities (from the patients’ view) for discussing care decisions. In this article we focus on the results of the last two, as these insights are most relevant for a wide audience. Our results should enable us to improve patient education and discussion of care decisions.

2. Methodology

2.1 Study design

This study is part of a larger project, aimed at stimulating and improving care decision conversations at the internal medicine outpatient clinic of the University Medical Centre Utrecht, a tertiary care teaching medical centre in the Netherlands. We conducted a descriptive qualitative study with a phenomenological approach to explore patient's perspective on the topic of care decisions and the patient education.

This study was approved by the Medical Ethical Committee of the University Medical Centre Utrecht (MEC 18-465). The study procedures comply with the Declaration of Helsinki. The study was reported using the consolidated criteria for reporting qualitative studies (COREQ) (see supplementary appendix 1) [16].

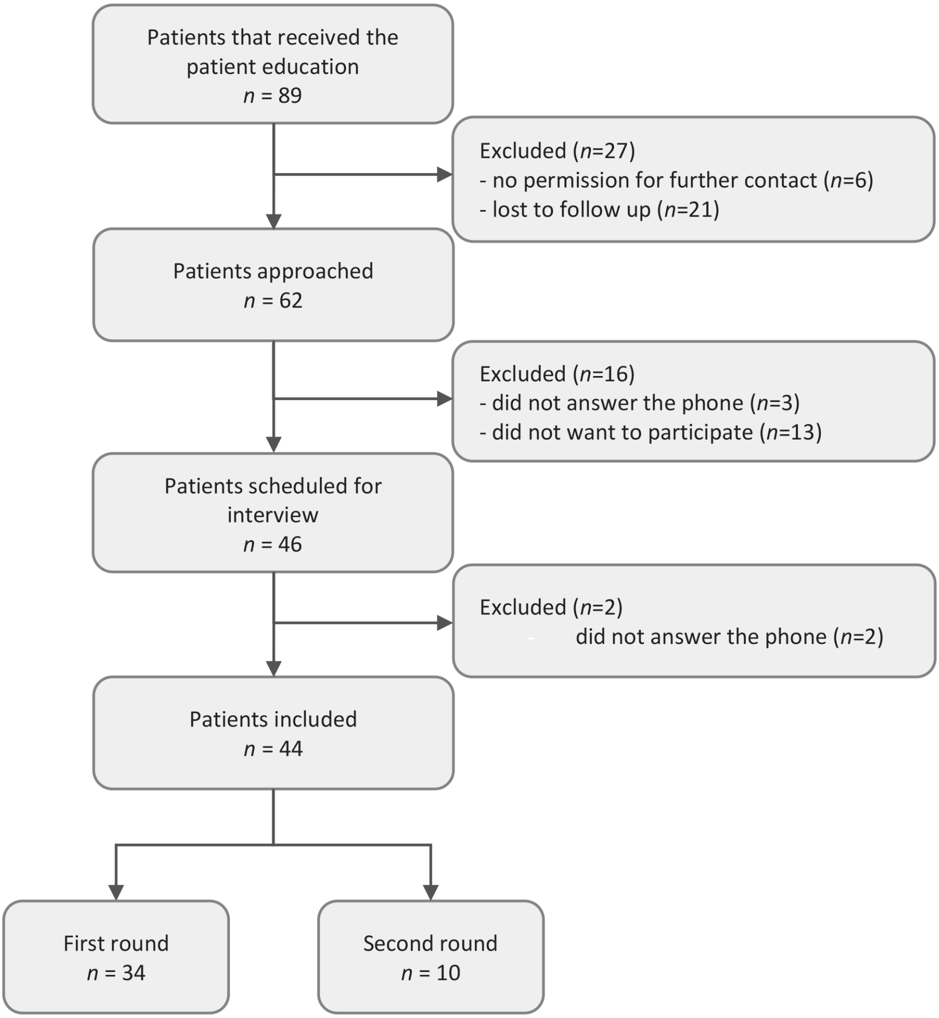
2.2 Participants

We used convenience sampling to select participants that had received the patient education in a clinical setting (i.e. the intervention group of the previous study). In this previous study, patients over the age of 18 with a scheduled outpatient visit with a participating physician, were eligible for inclusion. Physicians belonged to the department of internal medicine, nephrology, gastroenterology, endocrinology, immunology or vascular medicine. Exclusion criteria were: inability to read Dutch, inability to give informed consent, or recently (<2 years) documented treatment limitation discussion. All patients that gave permission to be approached for further researchquestions, were contacted for this particular study. They were informed about this subsequent interview-study by phone, and asked for verbal informed consent. When verbal informed consent was given, interviews were planned and executed by phone.

Figure 1 shows the inclusion of patients. In two rounds, a total of 44 patients were interviewed, 34 patients in the first round and 10 in the second round. Interviews were conducted in two rounds for both practical and methodological reasons: the former study was not ended yet during the first round of interviews, so new eligible patients were available after the first round, and this gave us the opportunity to adjust our interview guide in-between the rounds based on our first analysis. One interview was only partly recorded due to a technical issue. Of the 44 patients, 25 were male (56,8%) and 19 female

(43,2%). The median age was 57,5 years (interquartile range 53–67,5) and they had a median Charlson Comorbidity Index of 2,5 (interquartile range 1–4) [17].

Figure 1. Diagram of the participant flow



2.3 Data collection

The semi-structured interviews were conducted for the purpose of this study in two rounds, January 2020 and June/ July 2020, by two medical students (AB and NB respectively) after training. The interviewers did not have a former relationship with the participants and were not involved in the recruitment of patients in the previous study or the distribution of the patient education, to ensure patients could be as honest as possible in their evaluation. The interview guide contained straightforward questions about the content of patient education and open and flexible topics regarding feelings and expectations, allowing new or unexpected responses to be introduced (see supplementary appendix 2). In between the two rounds, the first set of interviews was analysed and the interview guide was adjusted according to these results. Main adjustments were removal of design-related questions (as we had sufficient input on that topic) and additional questions regarding patient perspective on the topic of care decisions, to explore this further. Interviews were conducted by phone to minimize burden for the participants and audio-recorded.

2.4 Data analysis

All interviews were transcribed verbatim, anonymised and coded using NVivo 12 software. Collected data were analysed using reflexive thematic analysis with an inductive approach, meaning that the process of coding was data-driven [18–20]. Two authors (SB & NB) independently familiarised themselves with the data by reading and re-reading all transcripts. We used an iterative and flexible coding process. SB and NB identified, discussed, refined and revised codes regularly and when necessary a third author (TvC) was consulted until full agreement was reached. First theme development took place in multiple sessions with SB, NB and TvC with use of visual mapping to aid pattern formation and identification. In additional sessions with all four authors, themes were reviewed and refined. Throughout the process, we operated within a qualitative paradigm, corresponding to the “Big Q thematic analysis” described by Terry et al. [19] and kept the research questions in mind. Opposed to “small q thematic analysis”, often used in positivist research, “big Q thematic analysis” is characterised by theoretical independence and flexibility, and organic processes of coding and theme development. “*The researcher is more like a sculptor, chipping away at a block of marble. The sculpture is the product of an interaction between the sculptor, their skills and the raw materials. Analysis becomes a creative rather than technical process, a result of the researcher’s engagement with the dataset and the application of their analytic skills and experiences, and personal* *and conceptual standpoints*" [19]. In the later stages of theme development, we moved to an interpretative orientation and used thematic maps to gain a deep understanding of the dataset to identify and understand potential themes in relation to each other and the overall dataset. In the final stages of the analysis, after data sessions with all authors, we constructed our final model, that captures the relations and connections within our dataset and provides an answer to our research questions.

3. Results

In this section, we show our thematic map, followed by a narrative clarification of this map, a table with examples from the interviews and a description of the themes and how they relate to one another.

Figure 2. Thematic map of patient perspective on care decisions

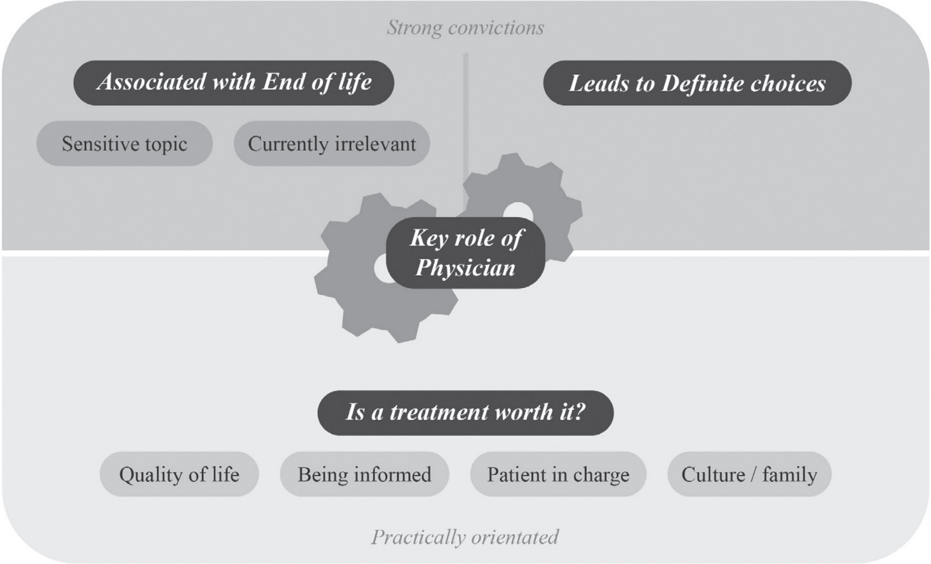


Figure 2 shows our thematic map. It is important to point out that two themes at the top layer in Fig. 2 represent strong convictions of what patients associate with care decisions, whilst the other two themes are more practically oriented. The two strong convictions are: (1) that discussing care decisions is about the end-of-life phase and (2) discussing care decisions leads to fixed choices. The end-of-life association results in the perception that care decisions are a sensitive topic, and irrelevant for the patient at *this moment in time*. The perceived 'definiteness' makes some patients hesitant towards discussing the subject. One of the more practically orientated themes is: (3) (when relevant) care decisions are about balancing whether a treatment is 'worth it', in which several subthemes carry weight: quality of life, culture/ family, being informed and patient in charge. The final (also more practically orientated) theme is (4) the physician. Patients assign the physician a key role in the care decision process. To show this important position we visualized the physician as the wheel that moves the process along.

Table 1 shows illustrative quotes for each (sub)theme taken from the interviews. We dig deeper into these themes and the connected subthemes in the following paragraphs.

Table 1. Quotations illustrative for the theme's

End of life	*"Oofh (laughter) yes then I think about the last phase (...) suppose you are terminally ill or there is no more treatment possible, then you start thinking about this stuff (...) Yeah (laughter) I- you don't start thinking about this stuff when you're healthy and when there's nothing wrong" (37)*
Sensitive topic	*"I walk away from that kind of sensitive subjects" (12)* *"otherwise I think people feel like oh why do I receive this, why does he say that, ouch" (40)* "*Because it's about a precarious thing, you can die or not, do you want to be resuscitated or not." (39)*
Currently irrelevant	*"it was not really relevant, it did not come up, because I visited for a silly cholesterol-story and there was nothing life-threatening about that (...) I can imagine if I ever get a diagnosis like madam you have cancer and it can take a few more years but, etcetera. That then I would think about things like that" (36)*
Definite choices	*"it depends on many factors and how you are at that moment and what happens, to record this now already I think noh"(40) ** *"I would not want to have answers to this recorded in my medical file because you can absolutely not oversee how you would react in certain circumstances or would like to react" (5)*
Is a treatment worth it?	*"you state your own boundaries for whether you want to be treated and what is acceptable concerning side effects and what not" (43)* *"it depends on many factors and how you are at that moment and what happens, to record this now already I think noh"(40) **
Quality of life	"*but if the quality of life is so low then I think you should have the right to say well until here, no further" (42)*
Being informed	*"Of course I am unaware of what all possibilities are and what its limitations are"(28)* *"But I think it is nice to be able to put the possibilities in context" (1)* *"I think that it starts with such a patient education, through which eh based on the information you receive eh yes actually get the knowledge to first check for yourself, gosh what is my point of view, how do I think about that" (41)*

Table 1. Continued

Patient in charge	*-) "I think anyway regardless of the disease also diabetes or other diseases it is important to think about what you want for yourself and what you do not want and make that a topic of discussion" (26)*
Culture/ family and loved ones	*"But if it is that moment, and maybe you are too late, then my husband should decide (...) he knows very well what I want and what I don't want" (7)* *"it is something you together, if you make a decision your family has consequences of that as well (...) see my father is a kidney-patient and he dialyses three times a week (...) so, he has a do not attempt resuscitation. He did discussed that with us and we respect that"(18)* *Because unexpectedly you can get into an accident resulting in being unconscious and then somebody else should know how you want it"(33)*
Physician	
Open and sensitive communication	*"In -if possible but yeah those doctors are not all equally empathic and you name it- but in a friendly, calm and clear way" (23)*
Physician initiates	*"what comes to my mind is that it is well how should I say it a necessary topic could be what comes up in the conversation with a physician the moment there is a reason for it eh yeah given the disease development of the patient" (41)* *"because then the physician makes it discussable, because probably a lot of patients are not thinking about this yet"(15)*
Discuss	*"I think that is important I think you have to know what the options are but also that the doctor knows how you feel about it"(1)*
Knowledge deficit	*"You really need the doctor for that (...) I have no idea about that and I don't know what the costs of that are, the costs in pain and in discomfort it gives the patient for example" (28)*

* Some quotes relate to more than one (sub)theme, as for example the quote marked with an Asterix from interview 40 relates to both definite choices and is a treatment worth it?

3.1 End of life

Most patients shared a deep conviction that care decisions are about the end-of-life. They associated it with 'a certain age', 'a bit older', 'terminal cancer', 'terminal illness', 'your last phase', 'the end-of-life', 'a severe illness', '*very* sick', 'dying', 'life-threatening', a bad diagnosis or prognosis', 'people who are worse', and so on. As can be seen in these examples, some patients explicitly connected care decisions to the 'last phase' of life, or a certain illness. Others described it more vaguely as 'something for later', without being able to exactly indicate when 'later' will be. This basic attitude towards care decisions, i.e. it belonging to the end-of-life, results in two subthemes: sensitive topic and currently irrelevant.

Sensitive topic

Patients described the topic of care decisions as a sensitive topic. Because they associated the topic with the end-of-life and dying, they characterized it as ‘difficult’, ‘not a fun topic’, ‘precarious’, ‘a tricky subject’, ‘sensitive’, ‘heavy’, ‘loaded’, ‘confronting’ or ‘threatening’, and articulated feeling hesitant to talk about it. Patients expressed this is especially the case when it is unclear to them why the subject is discussed, or why they received the patient education. This makes sense in the light of the end-of-life association: when the topic is brought up, the patient thinks this implies they are at the end-of-life. In this way it might give the impression of being sicker than expected or getting an unfavourable test result, which can make them anxious. A few patients assumed discussing care decisions was (mainly) about whether or not to resuscitate, which could be contributing to the sensitivity of the topic.

Currently irrelevant

Patients perceived care decisions as a ‘far-flung’ event. The majority of patients identified care decisions as not relevant for themselves, at least not at *this* moment in time, because they did not consider themselves in that phase of life. They described it as ‘not really necessary yet’, ‘just not relevant’, ‘does not apply’, ‘ it is not on the agenda at the moment’, ‘too early’, ‘don’t really care too much about it yet’. The exact moment they believed it does become personally relevant varied. This is best summarised as: ‘when it gets a little closer’, and can be explained by the fact they related it to the end-of-life. This perceived current irrelevance is reflected in the evaluation of the patient education: patients assessed it as unhelpful in forming an opinion or discussing care decisions, because they felt they did not *need* to form an opinion or discuss care decisions yet.

3.2 Definite choices

The second theme that represents a deep conviction is definite choices. Thinking about care decisions, discussing and talking about it and making choices seems to be irrevocably linked to the definite documentation of these choices in the electronic health record. Some patients saw this as an advantage: the physician is aware of the patient’s point of view in case of an unexpected situation in which the patient cannot express his opinion. On the other hand, however, several patients were hesitant towards discussing care decisions with the physician, because they were afraid this resulted in a fixed, documented decision. How you make up the balance might be situation dependent and varies over time. They expressed that ‘you push your limits’, and felt unable to decide now what they would like in the future: ‘how your condition is at that time and what happens’. This altogether made patients feel hesitant towards making decisions, and discussing the subject now.

3.3 Is a treatment worth it?

The bottom layer in Fig. 2 is the patient’s consideration whether a treatment is worth it or not. This is the more practical perspective on care decisions that patients expressed. They mentioned care decisions is about the ‘balance between side effects and benefits of a treatment’, ‘to put the possibilities in context’, ‘to what extent you want to be treated and when you no longer want that’. It comprised thinking about whether something is worthwhile, and indicating boundaries if a treatment is not worthwhile. Several subthemes play a role in this balancing act, as will be described below.

Quality of life

Patients stated quality of life as an important factor in care decisions and the choice to limit treatments or not. Patients (or their relatives they use as an example) did not want ‘agony’, ‘a very heavy treatment process’ or to be treated when ‘it is hopeless’. They were afraid to become ‘a vegetable’ or were ‘reluctant to lose quality of life’. Life ‘should still be liveable’. They considered whether a treatment (and its side effects) is worse than the disease, ‘maybe live a little shorter but then you don’t have any misery because of the side effects’. Some stated to treat only if there is ‘hope’ for the future.

Being informed

Patients discussed that being informed of options and possibilities concerning care decisions is needed to be able to make decisions whether care is worthwhile or not. Currently they experienced a knowledge deficit, although the patient education did contribute to being informed. Especially the idea that care decisions include more than resuscitation and the background information given about other choices was mentioned as informative by many patients. Some stated being informed as a general benefit of the patient education, others mentioned specific positive consequences. For example, when one is aware of the options, one can form their own opinion and become enabled to make choices. One patient mentioned being less overwhelmed when a critical situation occurs if you have thought about care decisions in advance.

Patient in charge

Numerous patients indicated the importance of thinking about your own wishes. Some viewed thinking about care decisions as beneficial, because it empowers a patient to take control rather than depending on the input of the physician. Patients named 'being in charge', 'taking responsibility' and 'being aware of your own wishes' both as a benefit from the patient education and as a necessity to be able to discuss care decisions. To be able to be in charge, the patient must be informed, as can be seen by the quote of patient 41 in Table 1. Some patients stated they had to be 'forced' to take responsibility for their treatment and think about care decisions and said the patient education was beneficial in doing so.

Culture, family and loved ones

Patients mentioned two more important factors in care decision discussions and decisions: culture and family and loved ones. One patient, from a non-western culture, pointed out differences in directness and openness in communication and the role culture plays in care decisions. Some other patients mentioned the position of family and loved ones in care decision discussions, either as a reason not to make decisions beforehand (because a family member can fulfil this duty when necessary), or as a reason to indeed make decisions beforehand and discuss these with family (so they are aware of your opinion and not burdened with this task). Some stated it was something you should decide together with you family, as it concerns them as well.

3.4 Physician

The final theme we identified is the physician. As is visualized in Fig. 2 by the wheels, the physician plays a key role in care decisions according to patients.

When we asked patients openly what they perceived as necessary or helpful in discussing care decisions, many patients mentioned factors related to the physician, and more specifically the physician's communication. Words patient used to describe the desired communication style are for instance 'honest', ‘sensitive’, ‘clear’, ‘open’, ‘trustworthy’, ‘attention for the person’, ‘treating the patient as an equal’ or just ‘good communication’. This demonstrates the need for a sensitive and empathic communicative approach: physicians should take into account their communication style.

Another common opinion amongst patients is that the physician should initiate the care decision discussion. This was most often mentioned in relation to the question what would be necessary or helpful to discuss care decisions. Patients related this to the sensitivity of the topic, for instance, ‘because people are hesitant to think about it, it would be better if someone else starts talking about it’, or to the perceived current irrelevance, for instance ‘because people are not thinking about that yet’, ‘if the physician makes the assessment it is relevant for this person, then the physician should also take initiative’.

The physician is also assigned a task in informing the patient and resolving the knowledge deficit: ‘as a patient you don’t think of all the things that the physician can think of’. A minority of the patients fully trusted their physician’s expertise and preferred to leave the decisionmaking up to the physician. Most stated that the physician should inform them about treatment options, pros and cons, risks and chances of recovery: ‘if you choose not to do this, this is what it means, and also what it means if you choose to indeed do so’. The physicians role is not limited to informing. Patients also stated the physician should ‘make you really consider so really ask the questions’, in order to help the patient make up the balance. The physician can/ should enable the patient to take charge: ‘the patient should feel they have a choice (…) and they are free to make choices’, ‘the physician might know better, but the patient should know what he wishes’, ‘that the patient is made to think about it and that he dares to speak’. Finally, patients stated it is important that the physician is aware of their patient’s opinion, and is assigned the role as registrar of this opinion.

Because the physician is connected to almost all other (sub)themes, we visualised the physician as a wheel at the centre of Fig. 2, able to initiate and generate discussions, taking into account all themes perceived as relevant by the patients.

4. Discussion

We aimed to gain deeper insight in patient’s perspective on the topic of care decisions. Most patients considered care decisions as belonging to the end-of-life, and therefore currently irrelevant. Consistent with other research, reading, talking or deciding about care decisions is perceived as unnecessary at this moment in time, because patients feel relatively healthy [15, 21–25].

There seems to be a vicious circle: literature about and research on care decisions is predominantly conducted in end-of-life settings. Furthermore, patients associate care decisions with the end-of-life. And in a previous study we showed that doctors frame the topic often as ‘relevant in the future’ as well [26]. Altogether, this results in postponement of the discussion of care decisions, and consequently research can only be conducted in the end-of-life phase. As is recognised by the Dutch Association of Internal Medicine by incorporating it in the Choosing Wisely campaign, this cycle should be broken, otherwise care decision conversations keep being assessed as being too soon, until it is too late [1].

We attempted to address this perceived irrelevance in our current patient education by emphasizing the current importance of care decision conversations. However, our study shows this attempt was insufficient. Several behavioural models have described differences in information processing and likelihood of persuasion depending on motivation [27, 28]. Probably, the relevance and thereby motivation to process information about care decisions should be even further emphasized. In order to break the vicious cycle, we might need to do more than patient education alone.

Another important connection patients made with the topic of care decisions was the need to make definite, binding decisions. This created a barrier, because patients expressed that the balance whether a treatment is ‘worth it’ depends on the situation. This barrier corresponds with previous research [29, 30]. Care decision discussions should not focus on fixed decisions, but on goals of care and the regular discussion of treatment options and preferences, as it better fits patient’s changing needs [30]. Our research shows patients should be aware of that as well.

Very recently, Harris et al. conducted a qualitative interview study on goals of care discussions in acute hospital admissions in Australia [15]. Although their study population differed from ours (experiences of acute hospitalized patients with goals of care discussions versus the perspective of an outpatient population), we found many similarities. Both patient populations perceived care discussion irrelevant at this moment in time. Also, they described the connection to dying and death, a focus on resuscitation, a knowledge deficit, and the need for involvement of family.

There are several strengths and limitations to our study. The qualitative approach and semi-structured interviews provided us the ability and flexibility to get in-depth information about aspects of patients' perspective on the topic of care decisions. In line with the growing awareness that care decision discussions should take place 'earlier', we investigated the perspective of the, relatively healthy, internal medicine outpatient clinic population. In this study, the median age was 57,5 years (interquartile range 53–67,5) and the patients had a median Charlson Comorbidity Index of 2,5 (interquartile range 1–4), which means they were relatively healthy and not in the end of life. This adds to existing research which mostly revolves around patients with severe chronic diseases, elderly patients or patients with a terminal illness [8, 15]. We are aware that in an interview-study the ways in which questions are asked have an effect on the patient responses and can thus have an effect on the themes that are identified. To minimize this risk, we mostly asked open questions. For instance, all physician-related factors patients mentioned, were an answer to "what is necessary/ helpful in care decision discussions". We did not ask "what should the physician do" or "what is the role of the physician" (which inevitably would have resulted in a theme physician).

Another potential limitation arises from the notable amount of eligible patients that did not answer the phone or did not want to participate in the interviews, as this might originate from a certain perspective or emotional response to the topic of care decisions. However, numerous participants expressed hesitance regarding the topic, which pleads against this group being underrepresented. Furthermore, patients with insufficient command of the Dutch language could not participate in this study. One patient (from a non-western culture), pointed out some cultural differences, but we have too little data to draw conclusions on cultural differences. Lastly, the amount of time between reading the patient education and the interview varied between patients, and some were unable to remember the content very well. However, in a normal clinical setting, patients would not read a patient education on a daily basis either, and their perspective on care decisions was still insightful.

5. Conclusion

This study showed that patients' perception of the topic of care decisions is overshadowed by two (wrongful) convictions: the perception that it belongs to the end-of-life and therefore is not relevant for them at this moment in time, and the belief that care decision discussions leads to fixed decisions. This resulted in assessing our patient education as informative, but not helpful at this moment in time and no desire to discuss care decisions yet.

Future perspective Our research shows some opportunities to improve care decision discussions. The top layer in Fig. 2 shows two deep convictions patients have, that prevents them from going to the actual, more practically orientated, balancing whether a treatment is 'worth it'. These two associations, with the end-of-life and need for binding decisions, should be addressed first. These convictions seem persistent and call for a change of the care decision narrative. We propose care decisions should be a normal, regular, recurring part of the medical consultation. This "new" narrative, of care decision conversations as a continuous, dynamic process, relevant at any given time and circumstance, should be disseminated. Framing it as "a plan" could possibly be helpful in seeing it as currently relevant and flexible, rather than fixed. To accomplish this, both patient, physicians, and perhaps even society should be informed and engaged. One might think of patient education, a short informative movie in the waiting room, or even a national campaign. Patients assign the physician a key role in this process, so the physician should pick up the gauntlet and take this role. Physicians should be educated in this role, and specifically in the expectation of patients that the physician initiates this conversation, informs them, and does so with sensitive communication skills. As a regular part of the medical consultation.

Acknowledgements

We would like to thank all participants for their time and openness. We would like to thank A. Belt, medical student, for conducting the first round of interviews.

Supplementary appendix. COREQ checklist

No	Item	Response
Domain 1: Research team and reflexivity		
Personal Characteristics		
1.	Interviewer/ facilitator	The interviews were conducted by AB and NB after training and under supervision of SB.
2.	Credentials	SB: medical doctor; NB: medical student; TvC: PhD, assistant professor language and communication; KK: medical doctor, professor of Acute Internal Medicine; AB: medical student.
3.	Occupation	SB is a resident in internal medicine at the University Medical Centre Utrecht and PhD student at Utrecht University. TvC is assistant professor language and communication at the department of Languages, Literature and Communication at Utrecht University. KK is professor of Acute Internal Medicine at Utrecht University. NB and AB were medical students at Utrecht University during the conduct of the study, currently NB is a medical doctor.
4.	Gender	All researchers were female.
5.	Experience and training	SB is a PhD student and therefore received formal education in research and medical ethics. KK is professor of acute internal medicine with research experience mainly in quantitative research. TC is assistant professor language and communication. Her research is mostly concerned with talk in interaction. She focuses mainly on talk in the health domain. SB and KK are both BROK certified (Basic course on Regulations and Organisation for clinical investigators). Before this project, SB was trained in qualitative research and especially interview studies by dr. A Oerlemans, assistant professor IQ Healthcare at Radboud university medical centre. NB and AB followed a Good Clinical Practice course and works under supervision of SB.
Relationship with participants		
6.	Relationship established	The interviewers did not have a prior relationship with the participants. The interviewers were not involved in the recruitment of patients in the previous study or the distribution of the patient education.
7.	Participant knowledge of the interviewer	Participants were aware the interviewers and other researchers were conducting a research project with the aim to understand more about the participants perspective on treatment wishes and limitations and the assessment of the patient education.
8.	Interviewer characteristics	The participants were aware the interviewers were medical students during a research internship and the aim of the research team was to publish this research data.
Domain 2: study design		
Theoretical framework		
9.	Methodological orientation and Theory	Collected data was analysed using reflexive thematic analysis with an inductive approach. Throughout the process, we operated within a qualitative paradigm, corresponding to the “Big Q thematic analysis” described by Terry et al. [17]

No	Item	Response
Participant selection		
10.	Sampling	Participants were selected using convenience sampling. Participants that had received the patient education in a clinical setting (i.e. the intervention group of the previous study) were approached for participation.
11.	Method of approach	Participants were approached by telephone.
12.	Sample size	44 participants (34 in the first round, 10 in the second round)
13.	Non-participation	Of the 62 patients that were approached for this study, 13 did not want to participate, 3 could not be reached, and 2 did not answer the telephone at the scheduled interview time. (See figure 1).
Setting		
14.	Setting of data collection	Data was collected by telephone.
15.	Presence of non-participants	No non-participants were present.
16.	Description of sample	Of the 44 patients, 25 were male (56,8%) and 19 female (43,2%). The median age was 57,5 years (interquartile range 53-67,5) and they had a median Charlson Comorbidity Index of 2,5 (interquartile range 1-4)
17.	Interview guide	We provided the interview guides (appendix 2)
Data collection		
18.	Repeat interviews	No repeat interviews were carried out.
19.	Audio/visual recording	Interviews were audio-recorded, downloaded onto a secure folder at the UMC Utrecht network, and subsequently deleted from the recording device. The interviews were transcribed by NB and AB and checked by SB for accuracy.
20.	Field notes	No field noted were collected.
21.	Duration	Interview duration was on average 15-20 minutes.
22.	Data saturation	Not applicable.
23.	Transcripts returned	Transcripts were not returned to participants.
Domain 3: analysis and findings		
Data analysis		
24.	Number of data coders	Two of the researchers (SB and NB) coded the data.
25.	Description of the coding tree	No coding tree was used as subthemes and themes were inductively derived from the data.
26.	Derivation of themes	Themes were derived from the data.
27.	Software	NVivo 12 software
28.	Participant checking	Participants did not provide feedback on the findings.

No	Item	Response
Reporting		
29.	Quotations presented	Table 1 shows illustrative quotations for each theme with unique study numbers for participant identification. Besides, in the text short quotes are shown for additional illustration.
30.	Data and findings consistent	According to the research team data presented and findings are consistent.
31.	Clarity of major themes	We identified 4 themes and 10 subthemes. Figure 1 shows the relationship between the themes.
32.	Clarity of minor themes	Not applicable

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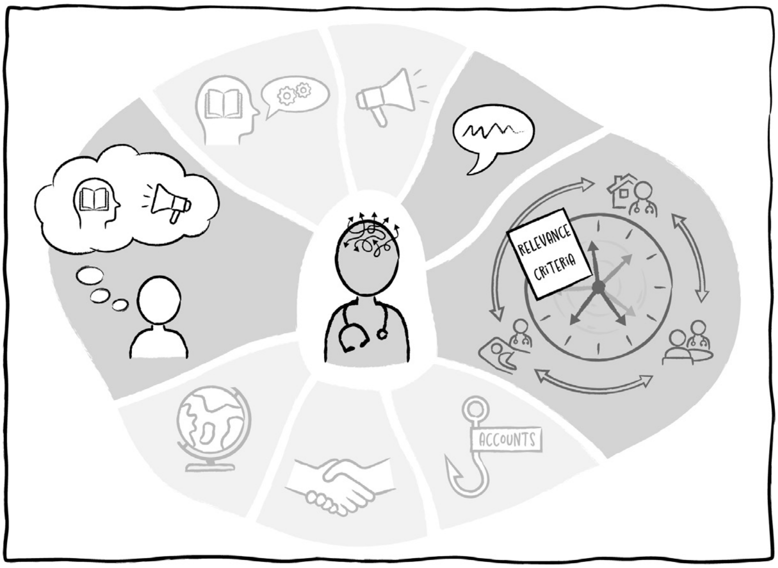
Intermezzo 2



The figure above shows topics that emerged in an interview study with physicians. On the right sight of this intermezzo, we clarify the topics tinted dark gray in the figure. These topics relate to the previous chapters. The light gray tinted topics will be discussed in intermezzos elsewhere in this thesis. Participating physicians were residents and specialists of the internal medicine department, who worked at the outpatient clinic. All participating physicians also performed (supervision) duties at the emergency department.

The topics that emerged are:

1. Time and place, which encompass several aspects: setting, time, timing (emphasis on relevance) and exchanging medical information between caregivers
2. Hooks: justifications to introduce the topic. In conversation analytic terms: accounts
3. Physician-patient relationship
4. Cultural differences
5. Prepared and aware patient
6. Competence and skills
7. Awareness
8. Physician initiative

Intermezzo 2 focuses on topics 1, 5 and 8.

Physicians say that ...

Time and place: Timing

- they do not know exactly what the appropriate timing or place is (and opinions differed between physicians)
  - *" it sometimes feels 'random' to discuss it"*
  - *"it is not exact science, it is not that simple that you could say, we discuss this with everybody above 70 years old or something"*
  - *"I prefer when it is discussed with all patients, so I can say: I'm not only discussing this with you, but we discuss this with all our patients"*
- the formulation of general criteria could facilitate care decision conversations and serve as a "*hook*"

Prepared and aware patient

- it is helpful if the patient is informed and aware of the topic of care decisions (preferably in advance)

Physician initiative

- the physician should initiate the conversation
  - *"It is your responsibility, as a doctor."*
  - *"You need to support and facilitate the patient. And that means you need to ask the question."*

PART III

Discussing care decisions at the emergency department

CHAPTER 5

Code status documentation at admission in COVID-19 patients: a descriptive cohort study

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BMJ Open, 2021;11:e050268.
https://doi.org/doi:10.1136/bmjopen-2021-050268

Abstract

Objectives: The COVID-19 pandemic pressurized healthcare with increased shortage of care. This resulted in an increase of awareness for code status documentation (i.e., whether limitations to specific life-sustaining treatments are in place), both in the medical field and in public media. However, it is unknown whether the increased awareness changed the prevalence and content of code status documentation for COVID-19 patients. We aim to describe differences in code status documentation between infectious patients before the pandemic and COVID-19 patients.

Setting: University Medical Centre of Utrecht, a tertiary care teaching academic hospital in the Netherlands.

Participants: A total of 1715 patients were included, 129 in the COVID-19 cohort (a cohort of COVID-19 patients, admitted from March 2020 to June 2020) and 1586 in the pre-COVID-19 cohort (a cohort of patients with (suspected) infections admitted between September 2016 to September 2018).

Primary and secondary outcome measures: We described frequency of code status documentation, frequency of discussion of this code status with patient and/or family, and content of code status.

Results: Frequencies of code status documentation (69.8% vs 72.7%, respectively) and discussion (75.6% vs 73.3%, respectively) were similar in both cohorts. More patients in the COVID-19 cohort than in the before COVID-19 cohort had any treatment limitation as opposed to full code (40% vs 25%). Within the treatment limitations, ‘no intensive care admission’ (81% vs 51%) and ‘no intubation’ (69% vs 40%) were more frequently documented in the COVID-19 cohort. A smaller difference was seen in ‘other limitation’ (17% vs 9%), while ‘no resuscitation’ (96% vs 92%) was comparable between both periods.

Conclusion: We observed no difference in the frequency of code status documentation or discussion in COVID-19 patients opposed to a pre-COVID-19 cohort. However, treatment limitations were more prevalent in patients with COVID-19, especially ‘no intubation’ and ‘no intensive care admission’.

Strengths and limitations of this study

The effect of the pandemic on code status discussion and documentation is largely unknown. This is the first study to compare code status documentation of patients admitted with COVID-19 and patients before the COVID-19 pandemic in the Netherlands. Results can be useful for improving code status documentation and discussion.

This study had few missing values, improving the accuracy and reliability of our results.

Due to differences between the cohorts, statistical comparison was not appropriate and results are therefore descriptive.

1. Introduction

Code status discussions are crucial to ensure future healthcare decisions are aligned to a patient's wishes. In a code status, it can be documented whether there are limitations to specific life-sustaining treatments or not. Code status discussion has shown to reduce length of stay in the intensive care unit (ICU), ICU readmission rates and costs of healthcare, without impacting patient satisfaction.[1–3] Discussing code status in time is essential to prevent unnecessary or undesirable care in acute settings.[1 3] Therefore, it is recommended in the Netherlands to discuss code status with every patient on admission. This can be documented in the electronic health record (EHR).

In March 2020, the COVID-19 pandemic reached in the Netherlands, putting tremendous pressure on patient care and hospital capacity, especially on the ICU.[4–6] We received signals from the professional field that code status documentation and discussion increased as a result of the awareness to the possible shortage of care, inside and outside the ICU,[7–9] and attention that was raised to the considerable risks and disadvantages of long-term intubation and ICU admission after infection with COVID-19.[7–11] This increased awareness was not only in the medical world, also in the media there was a lot of attention for disadvantages of intubation and ICU admission, which might have stimulated patients to broach the topic when the physician did not. Conversely, a well-known argument not to discuss code status is lack of time.[12–15] Hence, code status documentation could be negatively affected by the pandemic as workload for clinicians rapidly increased along with the psychological burden.[16–18]Unequivocal code status documentation is of utmost importance to prevent undesirable treatment, especially in a pandemic setting with high pressure on healthcare resources. Therefore, we aimed to describe how this pandemic has impacted the occurrence of code status documentation and discussion. In this study, we describe code status documentation, discussion and frequency of treatment limitations documented in two cohorts: patients admitted with COVID-19 during the first wave of the pandemic, and a previous cohort of patients admitted with (suspected) infection. The results might help us to guide future practice regarding code status discussion.

2. Methods

2.2 Study context

This descriptive, retrospective study was conducted in the University Medical Centre of Utrecht (UMCU), a tertiary care teaching medical centre in the Netherlands. The UMCU has 1042 hospital beds, over 11 000 employees, and in 2019, a total of 29 000 admissions. All patient information is documented in the EHR. The EHR includes a form for code status. The quality standards of the Dutch association for Internal Medicine demand a code status is documented in every admitted patient.[19] To complete a code status form, mandatory questions are if and which treatment limitations are in place and whether this is discussed with the patient and/or family. Treatment limitations are divided in ‘no resuscitation’, ‘no intubation’, ‘no ICU admission’ and ‘other limitation’, the last one accompanied by a free form question for specification.

2.3 Patient and public involvement statement

It was not applicable or possible to involve patients or the public in the design, or conduct, or reporting, or dissemination plans of our research.

2.4 Study population

For this study, we combined data from two existing databases.[20] Data from COVID-19 patients were extracted from the COVPACH cohort, which consists of all patients >18 years old admitted to the UMCU through the emergency department (ED) or directly on the ward with a positive COVID-19 PCR test from March 2020 to June 2020. Patients immediately transferred from an ICU of another hospital to our ICU were excluded for our analysis. Patients transferred from the general ward or ED of another hospital to our general ward or ED were not excluded.

Data of patients admitted before COVID-19 were extracted from the SPACE cohort, which consists of patients above 18 years old with a suspected infection at the ED. The SPACE database has been described in more detail previously.[21] For the current analysis, we included only unique patients that were admitted in the hospital, defined as the first presentation with admission. Patients were admitted between September 2016 and September 2018.

For both databases, patients were offered a general opt-out for data collection, according to hospital policy. This option is taken by 1.7% of the patients.

2.5 Data collection

Baseline characteristics

For both cohorts, age and gender were automatically extracted from the EHR along with the first measured clinical parameters necessary to calculate the Modified Early Warning Score (MEWS).[22] If the Glasgow Coma Scale was missing, the ED documentation was analysed for information on mental state and manually added accordingly. Manually extracted baseline characteristics were transfer from other hospital, living situation before admission, malignancy and dementia. The other comorbidities needed to calculate the updated Charlson Comorbidity Index (CCI) were also added manually.[23]

For the 'before COVID-19' (SPACE) cohort, type of infection was extracted manually and divided in five groups (respiratory, gastrointestinal, urinary tract, skin and other infections). Classification was based on the ED primary discharge diagnosis. For patients from the 'COVID-19' (COVPACH) cohort, type of infection was a COVID-19 infection.

Code status

The date of code status documentation, presence of any and which treatment limitations and discussion with patient or family were automatically extracted from the EHR. Code status documented on admission was defined as documentation entered in the EHR between 24 hours before and after the date of admission. Earlier or later documentation of code status was regarded as not documented on admission.

2.6 Analysis

Baseline characteristics

Patient characteristics were described using counts and percentages for categorical variables and median with IQR for continuous variables.

Code status

We used descriptive statistics using counts and percentages. First, we described how many patients in both cohorts had a code status documented on admission. Within the documented code status, we compared whether these were discussed with patients and/or family or not, and the proportion of any treatment limitation as opposed to full code. Lastly, we described which treatment limitations were documented in case any treatment limitation was in place. As a COVID-19 infection often presents as respiratory infection, we hypothesized this could influence the types of treatment limitations. Therefore, we also described types of treatment limitations in only patients admitted with respiratory infections from the before COVID-19 cohort. Since the two existing cohorts are essentially different, no additional statistical analysis was performed.

3. Results

The COVPACH cohort consisted of 190 patients. Sixty-one patients were transferred from the ICU of another hospital to the ICU of our hospital, and therefore, excluded from our analysis. The SPACE cohort consisted of 3178 patient-visits at the ED, 2056 of which were followed by an admission. A total of 470 of these were recurrent visits/admissions and therefore excluded from our analysis. This resulted in a total of 1715 patients included for analysis, 129 patients from the COVID-19 (COVPACH) cohort and 1586 patients from the before COVID-19 (SPACE) cohort.

3.1 Patient characteristics

Table 1 shows the patient characteristics in both groups.

3.2 Code status documentation and discussion

In 90 out of 129 patients (69.8%) in the COVID-19 cohort and in 1153 out of 1586 patients (72.7%) in the before COVID-19 cohort, a code status was documented. These documented code status were discussed in 75.6% (68/90) of the COVID-19 cohort and 73.3% (845/1153) of the before COVID-19 cohort.

Table 1 Characteristics of patients admitted before the COVID-19 pandemic and admitted with COVID-19.

	COVID-19 (N= 129)	Before COVID-19 (N= 1586)
Age (median (IQR))	66 (55-76)	64 (52-72)
Male (N(%))	71 (55%)	873 (55%)
Dementia (N(%))	6 (5%)	26 (2%)
Malignancy (N(%))	12 (9%)	665 (42%)
Charlson comorbidity index (median (IQR))	1 (0-2)	2 (1-4)
Modified early warning score[a] (median (IQR))	3 (1-4)	3 (1-4)
Housing situation (N (%))		
Own house	118 (92%)	1484 (94%)
Nursing home or long term facility	6 (5%)	88 (6%)
Other/unknown	5 (4%)	14 (1%)
Transferred from other hospital (N (%))	32 (25%)	13 (1%)
Type of infection (N(%))		
Respiratory	-	555 (35%)
Gastrointestinal	-	240 (15%)
Urinary tract	-	285 (18%)
Skin	-	115 (7%)
COVID-19	129 (100%)	-
Other	-	391 (25%)

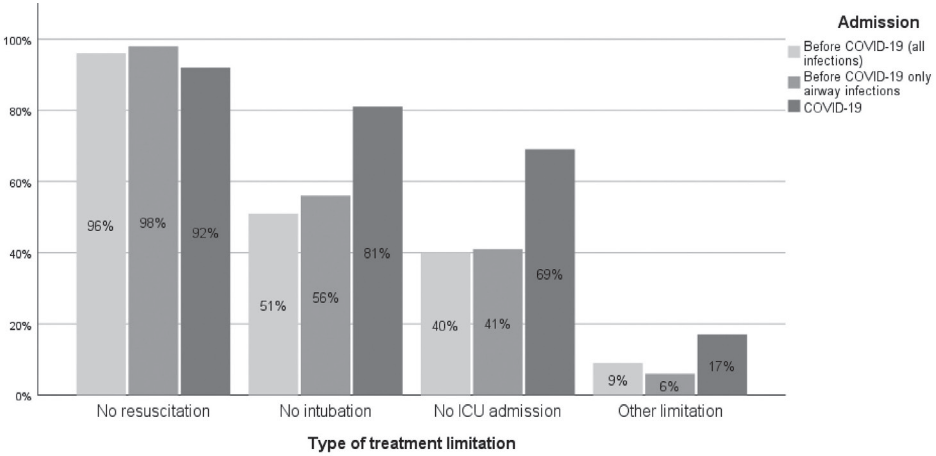
All variables had <1% missing values, except for MEWS (12% missing values). Patients admitted with COVID-19 had a notably lower prevalence of malignancy (9% vs 42%) and more were transferred from another hospital (25% vs 1%). Additionally, patients with COVID-19 were slightly older, had more dementia, lower CCI scores and in more people housing situation was unknown. No difference was found for gender and MEWS score between both groups. The most prevalent type of infection of admitted patients in the SPACE cohort was respiratory (35%).

3.3 Code status content

Subsequently to comparing the documentation and discussion of code status, we compared the content of these code status in both patient groups on limitations or not and type of limitations. In the COVID-19 cohort, there was a higher frequency of any treatment limitation than in the before COVID-19 cohort (40% (36/90) vs 25% (283/1153) of patients with documented code status, respectively).

Figure 1 shows the types of limitations in patients with any limitation in both cohorts. Patients in the COVID-19 cohort had a higher frequency of ‘no intubation’ (81% vs 51%),‘no ICU admission’ (69% vs 40%) and, to a lesser extent, ‘other limitation’ (17% vs 9%) compared with patients in the before COVID-19 cohort. The frequency of ‘no resuscitation’ was comparable in both cohorts (96% vs 92%). The difference in limitations remained when comparing the COVID-19 patients with only patients with respiratory infections from the before COVID-19 cohort.

Figure 1 Prevalence of types of limitations in patients with any limitation admitted before the COVID-19 pandemic and admitted with COVID-19. ICU, intensive care unit.



4. Discussion

To broaden our knowledge on code status decision-making in the impactful COVID-19 period, we described code status documentation, discussion and content of code status in a cohort of COVID-19 patients and a cohort of patients prior to the pandemic. Surprisingly, we found similar frequencies of code status documentation on admission in the COVID-19 and the before COVID-19 cohort (69.8% vs 72.7%, respectively). We had expected an increase given the raised attention to disadvantages of ICU admission and shortage of care during the pandemic.[4 5 24] Reassuringly, code status documentation did not decrease either, indicating the higher workload during COVID-19 did not reduce the attention to code status documentation. The equal frequency of discussion of code status in the COVID-19 cohort compared with the before COVID-19 cohort (75.6% and 73.3%, respectively, discussed of all documented code status) supports this as well.

COVID-19 appears to have led to a more limitation-directed approach: substantially more patients had treatment limitations during the COVID-19 pandemic (40% vs 24% of all documented code status). Both are relatively high compared with earlier research, which show treatment limitation frequencies ranging from 9% to 23%.[25–29] Since hospital type is known to influence code status documentation, the already high frequency before the COVID-19 pandemic seems appropriate given our academic tertiary centre patient population.[28 29] The increase of treatment limitations during the COVID-19 pandemic might even be underestimated, as patient characteristics known to increase do-not-resuscitate documentation (e.g., malignancy and CCI) were lower during the COVID-19 pandemic, possibly as a result of the transfers from non-tertiary hospitals.[30] The distribution of limitations also shows an increased limitation-directed tendency: 'no intubation' and 'no ICU admission' were substantially more prevalent in COVID-19 patients than before the COVID-19 pandemic (81% vs 51% resp. 69% vs 40%).

To our knowledge, only one other study thus far compared code status documentation before and during the COVID-19 pandemic, a single centre study by Coleman *et al* in the UK. In contrast to our study, they reported a substantially increased documentation of code status during the COVID-19 pandemic (from 20% before COVID-19% to 50% during COVID-19).[7] However, in their hospital, there was a change of policy at the start of the pandemic to expand code status documentation to all inpatients, which was already standardly instructed in our medical centre before the pandemic.[7] This is also reflected in our remarkably higher code status documentation even before the pandemic of 73%, as compared with 20% in their study population before the pandemic, presumably leaving less space for improvement. Earlier studies on non-mandatory code status documentation reported a wide range of documentations from 3% to 61%(1, 7–9). Furthermore, Coleman *et al* report more patients with full active treatment during the COVID-19 pandemic,[7] while we see more treatment limitations. However, the earlier mentioned increase in code status documentation in their study might have influenced the proportion of full code versus treatment limitations, thus no definite conclusion was drawn by Coleman *et al* about the precise influence of the pandemic on treatment limitations.[7]

To explore whether the increase in 'no intubation' and 'no ICU admission' was due to the nature of the COVID-19 disease, or other factors as increased awareness during the pandemic, we additionally compared the COVID-19 patients to only the patients with respiratory infections. Since similar differences were found when comparing COVID-19 patients to the patients with respiratory infections, we believe other factors during the pandemic than type of infection alone play a role in this increase. However, early reports of the risk during a COVID-19 infection on severe symptoms necessitating long intensive care admissions[10 11] might have led to more restrained physicians in COVID-19 infections. Other possible explanations are increased awareness in patients and physicians to the harms of intubation and ICU admission along with raised attention to ICU shortages.[7–9] Our study was not designed to differentiate between these explanations.

One of the major strengths of this study is the unique comparison between code status documentation of patients admitted with COVID-19 and patients before the COVID-19 pandemic. To our knowledge, only Coleman *et al* analysed this before.[7] Another strength is the few missing values (all <1% except for the MEWS scores, in which it was 12%), improving the accuracy and reliability of our results.

There are some limitations to our study, the primary being that we cannot distillate what caused the differences we found: the type of infection (COVID-19), factors associated with being in a worldwide pandemic (shortage of care, awareness in physicians, awareness in patients) or differences in the patients. We chose to use two existing databases, to be able to have results as early as possible to guide practice in the developing pandemic. Our goal was to describe code status documentation during COVID-19, rather than calculate an effect size. Because we compared two existing cohorts that were essentially different, we used descriptive statistics instead of performing statistical tests for significance.

Another potential limitation is that we could not assess the quality of the code status. In our opinion, discussing the code status with the patient is of utmost importance for its quality; this was done equally in the cohorts. Code status in COVID-19 patients contained more often limitations, what could suggest code status is considered more thoughtful (one could say it is easier to check the box ‘full code’ than a treatment limitation). However, measuring the actual quality of the code status (discussion) is difficult and was not possible with our data.

Next to this, we did not know if patients had former documented code status before admission, which could influence code status documentation.[29] However, this effect applied to both cohorts and we regarded an important difference in predocumented code status between both periods unlikely.

We believe our results are an important first step to understand the how the COVID-19 pandemic impacted code status documentation, discussion and content. Future research should focus on further distinguishing what might explain the increase in limitations and especially ‘no intubation’ and ‘no ICU admission’. This might also help us how to improve code status documentation and discussion.

5. Conclusion and recommendation

We have seen that frequency of code status documentation or discussion did not differ between patients with infections prior to the pandemic and COVID-19 patients. Yet, in COVID-19 patients treatment limitations were more prevalent and within these limitations, ‘no intubation’ and ‘no ICU admission’ were more often reported. This suggest a more limitation-directed approach during the COVID-19 pandemic. Our results support the notion that the COVID-19 pandemic influenced code status, although more extensive research is needed to verify these changes and to determine what causes this effect.

Acknowledgments

We would like to thank Dr. CH van Werkhoven, assistant professor at the Department of Epidemiology of the Julius Centre (Research Programme Infectious Diseases), for his advice on the design and methodology of our study.

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CHAPTER 6

Physicians' training and patient education initiative to improve quality of care decision communication at the emergency department

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Submitted

Abstract

Background: Discussions about care decisions, including code status documentation and advance care planning, are crucial components of patient-centered care. However, due to numerous barriers these discussions are often avoided by both physicians and patients. As a result, these discussion often take place at the emergency department (ED). We aimed to improve the quality of care decision conversations in the internal medicine ED.

Methods: This pre-post intervention study was conducted at the internal medicine ED of a tertiary hospital in the Netherlands. Two interventions were implemented simultaneously: physician training and patient education. Physician training included an e-learning module and simulated patient sessions. Patients received a leaflet providing information about care decisions. Primary outcome was patient satisfaction with the care decision discussions, assessed using the Quality of Communication questionnaire. Secondary outcomes included the percentage of patients recalling a care decision discussion, initiator of the discussion, leaflet recall, leaflet evaluation, prior care decision discussions, and perceived appropriate timing for discussions.

Results: 333 patients participated, 149 before and 184 after the interventions. Post-intervention, there were significant improvements in patient-reported quality of care decision communication ($p < 0.001$) and more patients recalled having care decision discussions (63.7% vs. 45.9%, $p = 0.001$). However, only 12% of patients recalled receiving the leaflet.

Conclusions: Implementation of physician training and patient education significantly improved the quality of care decision conversations in our internal medicine ED. Despite low leaflet recall, the interventions demonstrated a notable impact on patient satisfaction with care decision discussions. Future research could explore alternative patient education methods and involve other healthcare professionals in initiating discussions. These findings underscore the importance of ongoing efforts to enhance communication in healthcare settings, particularly in emergency care.

Key Messages:

What is already known on this topic:

- Care decision discussions are vital for patient-centered care but often avoided due to barriers faced by physicians and patients.

What this study adds:

- Implementation of physician training and patient education significantly improved the quality of care decision conversations in the internal medicine emergency department, even though only a limited number of patients received the education.

How this study might affect research, practice, or policy:

- Policymakers and healthcare institutions may consider integrating similar interventions into standard practice to enhance the quality of care decision conversations.
- Future research could explore alternative patient education methods and involve other healthcare professionals in initiating care decision discussions.

1. Introduction

Care decisions comprise a broad spectrum of topics, all with the purpose to align treatment with the preferences of the patient. This includes code status documentation (i.e. whether limitations to specific life-sustaining treatments are in place) and all forms of advance care planning. In 2014, the Dutch association for Internal Medicine compiled a list of ten Wise Choices to improve the quality and efficiency of healthcare in the spirit of the nationwide Choosing Wisely Campaign.[1–5] One of these is to discuss care decisions when discussing treatment with patients.[2] Although this implies care decision discussions should be a regular part of the medical consultation, both physicians and patients face multiple barriers in doing so, leading to avoidance of the topic. [6–12] Besides, the care decisions discussion in the outpatient clinic is often perceived as being too soon.[9–11] This results in postponing care decision discussions until the end of life, which is reflected in research conducted mostly in these end-of-life settings.[12]

Over the past decades, patient centered care and shared decision making has become the ideal model for doctor-patient decision making.[13–15] Within the framework of patient centered care, physicians are encouraged to partner with patients to co-design and deliver personalized care.[16] It is surprising that despite the well-acknowledged importance of patient centered care and shared decision-making, both physicians and patients tend to avoid conversations about care decisions, a topic in which patient centered care and shared decision making are particularly important.

The quality standards of the Dutch association for Internal Medicine demand a code status is documented in every admitted patient.[17] In a code status, it can be documented whether there are limitations to specific life-sustaining treatments or not. As a result from the avoidance and postponement of care decision discussions earlier in life, care decision discussions often take place at the ED to document a code status. This documentation, or registration, is only a small part of what we attempt to accomplish with improving care decision discussions. In a previous study, we saw the registration of a code status in hospitalized patients in our hospital is quite good (70%-73%).[18] However, we are unaware of the *quality* of care decision discussions at the emergency department.

A study from Schluep et al. in some other hospitals in the Netherlands showed a discrepancy between the documented code status, and patients memory of what was discussed and registered.[19] Besides, an interview study with internal medicine outpatient clinic patients we performed, showed several misconceptions regarding the topic of care decisions, and necessities in the patients view for a proper care decision discussion.[20]

We used the lessons we learned from these previous studies to develop two interventions, one for physicians and one for patients, to improve care decision discussions at the emergency department. Because research shows educating both physicians' and patients simultaneously is more effective in improving shared decision making than either of them alone [21], we decided to implement both interventions at the same moment in time, and evaluate the effect of this combined intervention.

2. Methods

2.1 Setting and context

This study was set at the internal medicine emergency department (ED) of the University Medical Centre Utrecht, a tertiary teaching hospital in the Netherlands. Patients were included between October–December 2020 (before-group) and January–April 2021 (after-group). This study was performed in accordance with Dutch and European guidelines for medical research and ethical review was waived by the Medical Research Ethics Committee Utrecht (MREC 20-539). The study was reported using the SQUIRE-2.0-checklist for reporting quality improvement studies.[22]

2.2 Participants and procedures

Patients aged > 18 years that were hospitalized following an ED visit for internal medicine (and related specialisms: endocrinology, hematology, gastroenterology, geriatrics, immunology, infectious disease, nephrology, oncology, rheumatology and vascular diseases) were eligible for inclusion. Exclusion criteria were refusal to participate or a condition that limited their ability to answer the survey (e.g. language barrier, decreased cognitive function, too critically ill, dementia or delirium). A patient was eligible to participate with every distinctive admission to the ED and could therefore be included multiple times.

We assessed potential admissions the adjacent business day. After review of eligibility by the researcher, we contacted the responsible nurse to ascertain exclusion criteria. Subsequently, we informed the eligible patients about the study. Surveys were handed out on paper to each participant to collect data, and obtaining informed consent. Surveys were anonymous, we did not collect names, birth dates or other patient-identifiers. At the request of the patient, sometimes the survey was conducted orally. All data was entered manually into Castor electronic data capture system. A second researcher double-checked 10% for error interception, in which no discrepancies were found.

The inclusions of the before-group coincided with the second wave in the Netherlands in the context of the COVID-19 pandemic. Due to upscaling of cohort divisions and high risk of infection by cause of immunocompromised status, COVID-19 and hematology patients were not included for a few weeks. Subsequently, we established a protocol to resume inclusions in a safe way. We arranged that the resident or nurse of the corresponding department approached the patient with the survey instead of the researcher.

2.3 Interventions

Physicians' Training

Internal Medicine residents were approached through mail to participate in a training program. The program was comprised out of an e-learning module regarding communication on care decisions in conjunction with a hand-on training with simulated patients. The e-learning was established using expert opinions. The e-learning module was developed based on expert opinions and comprised written text and videos to emphasize the significance of the topic. It provided background information, discussed common pitfalls, and offered valuable tips. The module concluded with example cases featuring simulated patients. As for the hands-on training, qualitative analysis of authentic conversations in the outpatient clinics of our hospital was used as input.[23] Trainees reflected on commonly used sentences and various strategies in care decision conversations. Afterwards, they practiced care decision conversations with simulated patients. We organized five sessions to maximize attendance from December through February. From that moment on, the training became a permanent part of the introduction program for internal medicine residents at the UMC Utrecht.

Patient leaflet

From December 2020 onwards, all patients at the internal medicine ED received a patient leaflet on care decisions at the ED. We chose to distribute the leaflet to all patients, because the information might be useful for all patients, not just those who will be admitted. Besides, it is not always clear right away whether a patient is admitted or not. This was a quality improvement intervention, the leaflet was distributed to aid care decision discussions at the ED, thereby improving shared-decision-making, patient-centered-care, and complying with the Wise Choice of the Dutch association for Internal Medicine. Patients may use the information to feel better informed, feel more clear about what is of importance to them and gain accurate expectations of the choices to be made.[21,24] The leaflet was developed by the research team using an earlier developed patient information webpage on this subject (developed with the aid of the UMC Utrecht patient panel) and data from the previously mentioned interview-study.[20] The research team consisted of an (acute) internal medicine resident/ PhD student (SB), a language and communication scientist (TvC) and a professor of acute internal medicine and program director of the internal medicine residency (HHK), thereby leading to an interdisciplinary approach with a focus on education. The written language was adjusted to Dutch B1 level. The residents at the ED distributed the leaflet, and received weekly reminders by mail to do so.

2.4 Study of the interventions

We chose to conduct a before-after intervention study to evaluate the effect of both interventions combined. Because research shows educating both physicians' and patients simultaneously is more effective in improving shared decision making than either of them alone,[21] and for practical reasons, we decided to implement the training and leaflet at the same moment in time, and evaluate the effect of this combined intervention.

Measures

Our primary outcome is the patient satisfaction with the care decision discussion at the emergency department. We used the validated Quality of Communication (QOC) questionnaire,[25] which we translated to Dutch using the validated forward-backward method.[26] We handled the questionnaires in accordance with Engelberg: substituting sample median values for responses of “don’t know” or “no response”; and imputing a value of 0 for “doctor didn’t do this”. Engelberg et al. chose for the imputation of a 0 for “doctor didn’t do this” based on the assumption that all of the items identified important aspects of end-of-life communication, and therefore the failure to complete or address an item warranted a low score.[25] However, our patient population was not (necessarily) at the end-of-life and therefore we deemed it inappropriate for two of the items (“Talking about how long you have to live” and “ Talking about what dying might be like”) to impute a 0 for “doctor didn’t do this”. Instead, we treated it as “no response”. We summarized scores in accordance with Engelberg to a median score for general communication (QOC-gen) and median score for care decision communication (QOC-CD).[25]

To adjust for potential confounders, we assessed the following baseline characteristics: age, gender, educational level, health perception and presence of a family member. To take into account the possibility of other factors that improve care decision discussions over time, we also explored the effect of time.

Secondary outcomes are: 1) how many patients recall a care decision discussion, 2) who initiated this discussion, 3) how many patients recall to have received the leaflet, 4) their evaluation of this leaflet, 5) whether they had a previous care decision discussion and with whom, and 6) what they perceive to be an appropriate moment for care decision discussions.

Originally, we planned to evaluate the physicians preparedness for care decision discussion as well, using a questionnaire inspired by the one used by Smith et al. to evaluate residents approaches to advance care planning. [27] We intended to compare these before the implementation and 3 months after implementation. However, because of the extremely low response rate before implementation (<20%), possible due to extensive workload due to the COVID-19 pandemic, we dropped this analysis.

2.5 Statistics

We compared baseline characteristics between the two groups with Chi-square test for nominal data and Mann Whitney U for ordinal data. Primary outcome (care decision communication, QOC-CD) was first compared using univariate analysis (students T-test or Mann Whitney U test depending on distribution) and then analysed using a multiple linear regression model to adjust for potential confounders (age, gender, educational level, health perception and presence of a family member) using forced entry. The effect of time on quality of care decision communication was explored using linear regression. Dummy variables were made for categorical variables. Secondary outcomes 1 (how many patients recall a care decision discussion) and 2 (who initiated this discussion) are compared with Chi-square test. The other secondary outcomes are descriptive.

3. Results

A total of 333 patients were included in this study, 149 before and 184 after the interventions. Figure 1 shows the patient flow. Table 1 shows the baseline patient characteristics of the patient population before and after the interventions. Missing values were <5% for all items. The populations were quite similar.

Figure 1. Patient flow

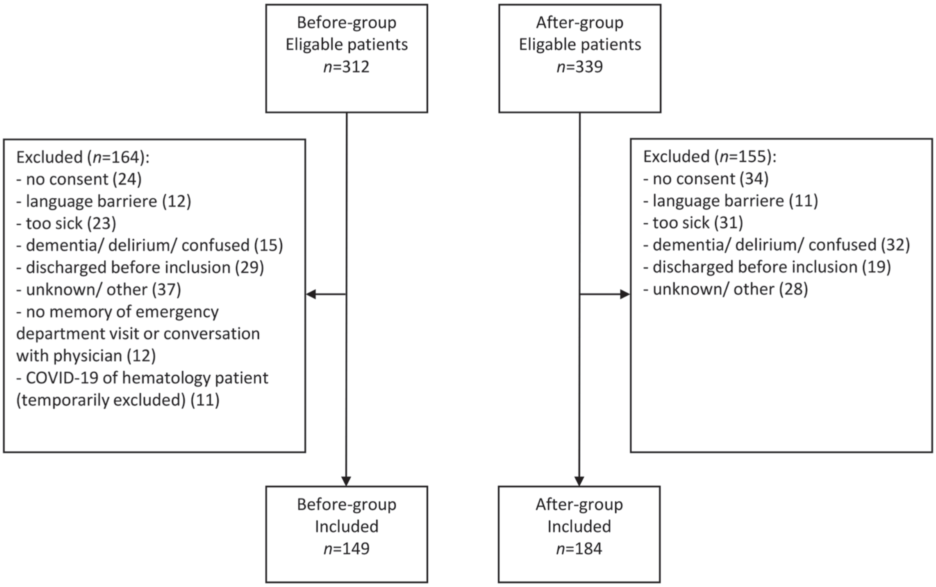


Table 1. Baseline patient characteristics of the patient populations

	Before interventions *n*= 149	**After interventions *n*= 184**	**Statistical comparison**
Age			p= 0.107
- ≤44 years	31 (21.1%)	27 (14.8%)	
- 45-64 years	55 (37.4%)	72 (39.6%)	
- 65-74 years	44 (29.9%)	45 (24.7%)	
- 75-84 years	12 (8.2%)	33 (18.1%)	
- ≥85 years	5 (3.4%)	5 (2.7%)	
Gender (male (%))	82 (56.2%)	106 (58.6%)	p= 0.663
Educational level			p= 0.082
- Primary education	10 (7.0%)	7 (3.9%)	
- Secondary education	32 (22.5%)	65 (36.3%)	
- Middle education	50 (35.2%)	58 (32.4%)	
- Higher education	50 (35.2%)	49 (27.4%)	
Health perception			p= 0.174
- Poor	26 (17.9%)	38 (20.9%)	
- Average	57 (39.3%)	81 (44.5%)	
- Good	52 (35.9%)	52 (28.6%)	
- Very good	7 (4.8%)	9 (4.9%)	
- Excellent	3 (2.1%)	2 (1.1%)	
Family member present at ED (yes (%))	119 (81%)	144 (79.1%)	p= 0.680

Chi-square test was used for nominal data and Mann Whitney U for ordinal data. <5% missing values.
ED = emergency department

First, we handled the Quality of Communication questionnaire in accordance with Engelberg: substituting sample median values for responses of "don't know" or "no response"; and imputing a value of 0 for "doctor didn't do this"[25], except for the items "talking about how long you have to live" and " talking about what dying might be like". Although we anticipated these two items to be less applicable and therefore discussed less often (which is why we did not intend to impute "doctor didn't do this" with a zero, but with the sample median instead) we did not expect to only have a grade in 21/333 (6.3%) questionnaires for "talking about how long you have to live" and 13/333 (3.9%) for "talking about what dying might be like". We therefore omitted these two items. Then, we calculated the median score on the 5 remaining items for care decision communication, the median score for the 6 items for general communication, and the total median quality of communication score. Table 2 shows the results of the univariate comparison of these scores between the groups before and after the interventions. As they were not normally distributed, we used Mann Whitney U to test for statistical significance. As can be seen in table 2, both care decision communication and total quality of communication improved significantly after the interventions, as opposed to general communication.

Table 2. Quality of communication scores before and after implementation of the interventions.

	Before interventions ***n*= 149**	**After interventions** ***n*= 184**	**Statistical comparison (p-value)**
Care decision communication, median (IQR)	0.0 (0.0-7.0)	6.0 (0.0-8.0)	<0.001
General communication, median (IQR)	8.0 (7.5-9.0)	8.0 (8.0-9.0)	0.126
Total Quality of Communication, median (IQR)	8.0 (7.0-8.0)	8.0 (7.0-9.0)	0.003

Univariate analysis. Mann Whitney U was used to test for statistical significance. IQR = Interquartile range.

Next, we aimed to adjust for potential confounders with a multiple linear regression model. First, we inspected the Pearson correlations amongst all variables (supplementary appendix 1). All correlations were well below 0.8, so we continued with the model. In supplementary appendix 2, the complete results from our multiple linear regression model to adjust for potential confounders can be found. Both before and after addition of potential confounders to the model, there was a significant difference for the interventions. After adjustment for confounders, the quality of care decision communication was 1.753 (95% CI [0.906, 2.599]) higher in the after-group compared to the before-group ($p<0.001$).

Next, we explored the effect of time. Table 3 shows the results from linear regression in the before- and after-group. Both before and after the interventions, there was no significant effect of time on quality of care decision communication, which makes it likely that the increase in quality of care decision communication after the interventions (1.753 higher after the interventions, see above) is due to the interventions and not simply an effect of increase over time.

After the interventions, significantly more patients recalled a care decision conversation at the emergency department (63.7% after vs 45.9% before, p=0.001). Both before and after the interventions, most conversations were initiated by the physician (86.6 before vs 86.9% after).

Table 3. The effect of time on quality of care decision communication using linear regression in the before- and after-group

Variable	B	95% CI for B	β	t	p
Before interventions					
Constant	3.344	[2.205, 4.483]		5.803	**<0.001**
Time	0.014	[-0.019, 0.046]	0.069	0.833	0.406
After interventions					
Constant	5.111	[3.018, 7.205]		4.817	**<0.001**
Time	-0.006	[-0.035, 0.023]	-0.029	-0.391	0.696

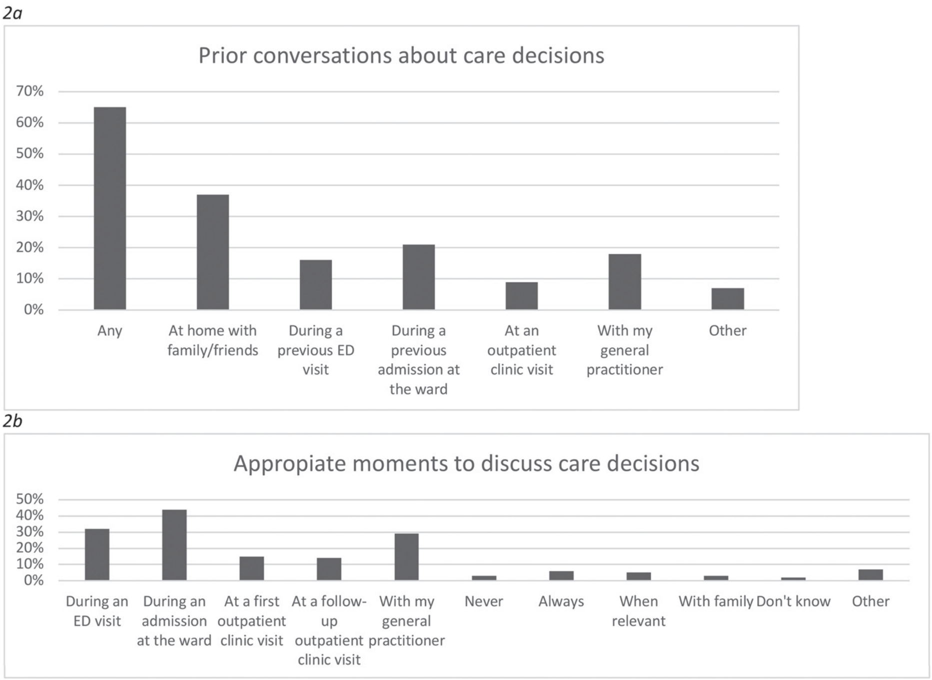
Dependent variable: Quality of care decision communication. Time is the number of days after the first training (so value is negative in the before group and positive in the after group).

Unfortunately, only 22 of the 184 patients in the after-group recalled to have received the leaflet, of which 6 stated to have not read it because there was insufficient time (1), they felt too sick (2), thought it was not important (1), lost the leaflet (1) or forgot (1). None stated being scared by the subject. 14 patients rated the folder, they scored the folder a median of 8 (IQR 6-8,25) on an 11-point Likert scale (0-10).

Figure 2a shows whether patients have had conversations about care decisions prior to current ED visit and with whom. In the ‘other’ group they mentioned various things, such as nursing home, districts nurse, palliative team, ambulance, pre-operative screening, or they couldn’t recall with whom exactly. Of the 106 patients that never discussed care decisions prior to the current ED visit, 71 (67%) did never think about it either.

Figure 2b shows what appropriate moments to discuss care decisions are according to patients. In the open field answers of the original ‘other’ group, 4 answers were frequently given (“always”, “when relevant”, “with family” and “don’t know”), which is why we recoded these into 4 new categories and a new “other” for the residual answers.

Figure 2. Prior conversations about care decisions and appropriate moments to discuss care decisions according to patients



2a. Patients were asked whether they had prior talks about care decisions and with whom. They could give multiple answers

2b. Patients were asked what they perceive appropriate moments to discuss care decisions. They could give multiple answers

ED = emergency department

4. Discussion

The objective of our study was to develop an intervention targeted to improve the quality of care decision conversations between physicians and emergency department patients through a pre-post intervention study. Quality of care decision communication demonstrated a significant improvement after the implementation of physician training and patient education, as compared to the period before intervention.

A similar approach was observed in an oncology outpatient department study, wherein a comprehensive strategy involving the Serious Illness Conversation Guide,[28] provision of patient and family information materials pre and post-conversation, clinician training, and system changes resulted in increased, earlier, and superior documented serious illness conversations.[29] The intervention, with slight modifications, was later applied in a study involving patients hospitalized for at least 48 hours, yielding comparable outcomes.[30] Another study also indicated that physician training increased care decisions in the electronic medical record (EMR).[31] While these last two studies align closely with our study in terms of population and intervention, they didn't measure for patient satisfaction or quality of communication. One of our secondary endpoints, the number of (patient-reported) code status discussions, indicated that prior to the intervention, code status was discussed in 46% of patients, compared to 64% after the implementation of the intervention. Noteworthy, in a previous study we observed that the *registration* of a code status in hospitalized patients in our hospital was 70%-73% [18], which is more than the 46%-64% of (patient-reported) code status discussions. This discrepancy between the documented code status, and patients memory of what was discussed and registered, was found in other Dutch hospitals as well.[19] This could either mean code statuses are registered without discussion, or the patient does not recall the discussion. Ma et al. demonstrated that code status documentation (DNR) did not increase post-intervention (76% versus 71%). However, choices regarding life-sustaining treatments in general were noted much more frequently (67% versus 32%).[30]

High health literacy emerged as an important factor in achieving high-quality care decisions. However, the optimal means of achieving this remains uncertain. Some studies have looked into video-assisted interventions, which proved to be a viable option.[32] In our study, we chose to provide an information letter because of practical reasons in the emergency department. Remarkably, our study uncovered that a mere 12% of patients reported receiving the information letter. One plausible explanation could be the heightened workload experienced by physicians during our study period due to the COVID-19 pandemic, rendering it a low priority.

4.1 Strengths and limitations

One strength of our study lies in the comprehensive examination of the intervention's impact on all types of admitted patients, as opposed to exclusively focusing on critically ill individuals. This approach enhances the generalizability of our data. Moreover, our investigation delved into patient satisfaction rather than the sheer quantity of conversations, providing a nuanced perspective on the intervention's outcomes. Our study is susceptible to recall bias due to its post-experience interview nature. However, we prioritized the patient's recollection of the conversation over the specific details discussed. Additionally, almost half of the patients were excluded due to critical illness, cognitive impairment, or language barriers, precluding conclusions about these groups. COVID-19 restrictions limited family presence, hindering their role as proxies for patients. There may also be selection bias as critically ill patients unable to respond to the questionnaire were excluded from care decision conversations. The pre-post intervention study design may introduce effects from unexamined factors, however we explored the effect of time on our outcome, which showed to be insignificant. Because of the decision to implement both interventions at the same moment in time, we are unable to distinct which intervention (the patient leaflet or the physician training) is more effective. However, as mentioned before, only 12% of patients recalled receiving the leaflet. This suggest that the physician training contributed more to the significant improvement in patient-reported quality of communication than the patient leaflet. We did not separately evaluate the effect of different parts of the training either. However, in a previous study at the outpatient clinic, a physician training without this basis on care decision conversations showed to be ineffective in improving patient satisfaction.[24] Although that study differed in terms of setting and outcome measurements from the current study, it indicates that the adjustments we made based on conversation analysis of authentic care decision conversations[23] contributed to the effectiveness. This could be explained by an increased perceived relevance for the physician when authentic, recognizable sentences are provided and the interactional implications are discussed. Increasing the perceived relevance stimulates the retention of the gained knowledge/ skills.[25-34]

4.2 Future perspectives

Various studies have explored alternative approaches to care decision conversations, such as those conducted by social workers or nurses.[33,34] These studies indicated that such conversations need not be exclusively conducted by physicians, with high patient satisfaction observed. The emotional proximity that social workers and nurses establish with patients may render them particularly well-suited for initiating these conversations. Additionally, nurses may face fewer time constraints, increasing the likelihood of these discussions, particularly during challenging periods such as the COVID-19 pandemic.

An ongoing study by Prachanukool investigates the impact of a priming conversation by a nurse in the emergency room on subsequent care decisions.[35] Another approach involves a brief negotiated interview conducted by a different physician, which has proven effective in increasing the number of care decision conversations and subsequent self-reported care decisions.[36] However, this method is time-consuming and may not be feasible in an emergency department setting. Further research could explore the most suitable individuals for conducting care decision conversations. Although our data suggests the physicians' training probably contributed most to the effectiveness of the interventions, we recognize the potential of patient education materials. Further research could explore optimal approaches to patient education and increasing the distribution of the patient educational materials., the most suitable individuals for conducting care decision conversations, and the organization of professional training. These areas warrant further investigation to enhance our understanding and inform best practices in healthcare communication.

We based part of our hand-on training on our prior study, in which we used conversation analysis of authentic care decision conversations in our hospital.[23] The examples that we use in our training might be generalizable to other settings, especially in the Netherlands and countries comparable to the Netherlands in communication strategies. However, to adjust the training to another setting, especially were communication strategies are quite different from the Netherlands, we would suggest to video-tape several care decision conversations in that setting and discuss the interactional implication of strategies and words physicians use with an communication expert. In this way, the training can be adapted to other settings as well.

5. Conclusion

To conclude, our study successfully achieved its objective of enhancing the quality of care decision conversations in the emergency department, revealing a substantial improvement following the implementation of physician training and brief patient education.

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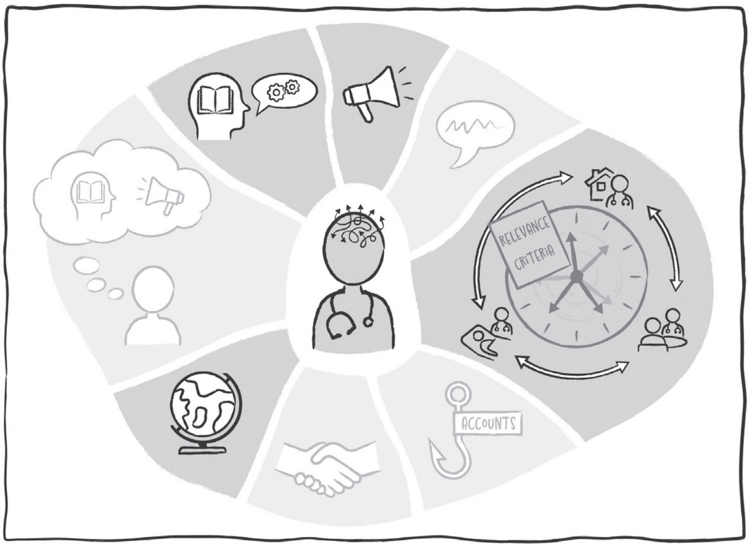
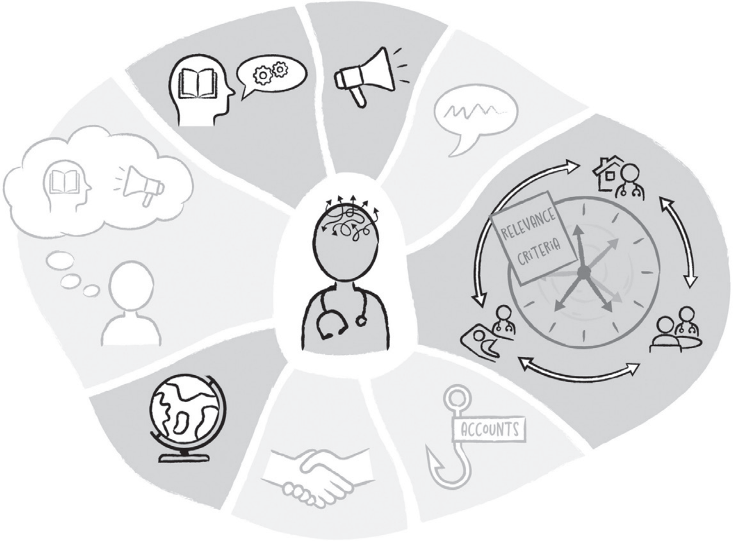
Intermezzo 3





The figure above shows topics that emerged in an interview study with physicians. On the right sight of this intermezzo, we clarify the topics tinted dark gray in the figure. These topics relate to the previous chapters. The light gray tinted topics will be discussed in intermezzos elsewhere in this thesis. Participating physicians were residents and specialists of the internal medicine department, who worked at the outpatient clinic. All participating physicians also performed (supervision) duties at the emergency department.

The topics that emerged are:

1. Time and place, which encompass several aspects: setting, time, timing (emphasis on relevance) and exchanging medical information between caregivers
2. Hooks: justifications to introduce the topic. In conversation analytic terms: accounts
3. Physician-patient relationship
4. Cultural differences
5. Prepared and aware patient
6. Competence and skills
7. Awareness
8. Physician initiative

Intermezzo 3 focuses on topics 1, 4, 6 and 7.

Physicians say that...

Time and place: exchanging medical information

- the exchange of information between general practitioners and hospital physicians is insufficient

Cultural differences

- care decisions conversations are more difficult with patients from another cultural background

Competence and skills

- being and feeling competent and skilled is necessary to discuss care decisions
- they themselves felt competent and skilled
    - but they did not receive formal training besides general communication training in medical school, nor were they specifically observed or received feedback on these kind of conversations: they taught themselves by just doing it
- they think especially unexperienced residents could benefit from formal training
    - although they perceived themselves as already experienced, they thought it was still valuable to receive feedback from colleagues and find recognition in the same struggles during the training

Awareness

- awareness is necessary:
    - physicians, themselves, should be aware so they remember to initiate the topic
    - patients should be aware, so they know the topic can be brought up and are not scared by it
    - general awareness should be created, as a way to achieve awareness amongst patients

PART IV

General discussion and Summary

CHAPTER 7

General discussion and summary

"Not everything that counts can be counted, and not everything that can be counted counts."
- William Bruce Cameron

In this thesis, we investigated how care decision conversations can be improved. For this purpose we developed a training for physicians and educational materials for patients. Both items were implemented and evaluated in different settings: the outpatient clinic (**chapter 2**) and emergency department (**chapter 6**). We used conversation analysis to gain insight in how authentic care decision conversations are currently conducted (**chapter 3**) and what we can learn from this. Furthermore, using semi-structured interviews we explored patients' (**chapter 4**) and physicians' (**intermezzos**) perspective towards care decisions. This provides further insights into possible targets to improve care decision conversations. During our research, we had to cope with the COVID-19 pandemic, which affected our research as it has affected virtually everything and everyone. This provided the unique opportunity to describe the effect of an extremely high pressure situation on code status documentation (**chapter 5**). Before the study at the emergency department, we adapted the physician training and patient educational materials. We made adaptations based on the results of the prior studies as well as to fit the different setting. To summarize, we attempted to answer the question "*how can care decision conversations be improved?*" by answering several subquestions: "*how are care decision conversations currently conducted?*", "*What are patients' and physicians' perspectives towards care decisions and care decision conversations?*" and "*what is the effect of physicians' training and patient education on care decision conversations* in different settings*: the outpatient clinic and the emergency department?*". In this chapter, we will first discuss our main findings in relation to our study questions. Subsequently, we discuss some limitations to this research. This is followed by three overarching learning points. Then, we summarize all the necessities for a care decision conversation using a metaphor of a dance between patient and physician. We conclude with future perspectives for research and clinical practice: how to reach that perfect dance.

What is the effect of physicians' training and patient education on care decision conversations at the outpatient clinic?

Inspired by the Wise Choice of the Dutch Association of Internal Medicine (NIV) (1), we set up a study to investigate the effect of physician training and patient education on care decision conversations at the outpatient clinic. In this study, we trained physicians with an e-learning module and small group hands-on training with simulated patients. Patients received an email with a weblink to a web page with information about care decisions, why it is important to discuss them, how a decision is made and background information about several treatments (accessible though hyperlinks). Unfortunately, we saw no effect on our primary outcome: patient satisfaction with the outpatient clinic visit. Remarkable was the already very high satisfaction of patients before the interventions. Even though there was no effect on our primary outcome, we learned valuable lessons from this study. In the first place, overall patient satisfaction might not be the best outcome to measure the effect of interventions to improve care decision conversations. In addition, in the study design we combined this quantitative study (**chapter 2**) with conversation analysis of video-recording of authentic consultations (**chapter 3**). The inclusion rate was much lower than expected. In contact with the researcher many patients expressed they did not want to participate because of the video-recordings. This is something to take into account when you set up a study like this. Nevertheless, this study showed us that our specific training made physicians feel more prepared to discuss care decisions. Not to mention, most patients expressed that they did not feel insecure, sad or anxious when being provided with information about care decisions in the patient education, a commonly heard fear amongst physicians (2). It is noteworthy, however, that, although patients assessed the education as informative and with quite high marks (median 8), they were neutral about whether it helped them form an opinion about care decisions or helped the discussion. This raised the question "*why was the patient education assessed as not helpful, if it indeed was informative?*". Last, but definitely not least, this study showed that care decisions were barely discussed at the outpatient clinic, even after our interventions. This brought up the questions: "*How are care decisions discussed and what can we learn from that?*" and *"Why are care decision conversations not conducted more often at the outpatient clinic?"*.

How are care decision conversations currently conducted?

In **chapter 3**, we used conversation analysis to study video-recordings of authentic conversations at the outpatient clinic to investigate *how often*, *when* and *how care decision conversations are currently conducted*. Strikingly, the number of care decision conversations we observed (21/150, 14%)(**chapter 3**) is even lower than the number of patient reported care decision conversations (45/161, 28%)(**chapter 2**). This discrepancy cannot be explained by the number of failed video-recordings. A possible explanation might be that care decisions are discussed in another visit, despite the instruction given to patients that the questionnaire was about the last video-recorded visit. Conversation analysis of these real care decision conversations at the outpatient clinic, showed us how hard it was to introduce the topic of care decisions. Hesitation markers, repairs and hypothetical talk characterized the care decisions conversation, showing the precariousness of the topic. Furthermore, there is no destined phase or interactional slot for the introduction of the topic of care decisions. In addition, common ground needs to be created and relevance needs to be accounted for. Physicians often use several accounts to justify the introduction of the topic, some external (e.g. “the hospital wants it”), some patient-related (e.g. “because of your current physical condition”). There is a relevance paradox: the topic is being framed as ‘relevant in the future’ but ‘needs to be discussed now’. All this leads to the fact that a lot of interactional effort is needed to introduce the topic of care decisions. This study led to three targets to improve care decision discussions 1) an interactional slot has to be created to introduce the care decision topic; 2) common ground has to be created and found; 3) the paradox of the topic as ‘relevant in the future’ but ‘needs to be discussed now’ needs to be overcome.

What is patients’ perspective towards care decisions and care decision conversations?

The trigger for our qualitative interview study with patients (**chapter 4**) was the discrepancy in the assessment of the patient education (informative, good overall marks, but at the same time neutral towards its helpfulness). However, the insight into the patients’ perspective towards care decisions provided much more information. The most likely explanation for the discrepancy, is the deep conviction of patients that care decisions are associated with the end of life. Therefore, they thought the information was indeed useful, but not for *them* at *this moment in time*. Furthermore, this association with the end of life made the topic sensitive. Another deep conviction this study revealed, was the (mis) conception that care decision conversations lead to definite, fixed choices, which made some patients hesitant towards discussing the topic. It also revealed the key role patients assign to the physician, namely that physicians should determine when it is relevant, initiate the conversation, provide information, explore patients' thoughts and communicate in an empathetic and sensitive manner. More practically orientated, patients stated that care decisions were about whether a treatment is worth it, a balancing scale in which several elements carry weight. Our patient education provided information on the relevance of care decision conversations, that the conversation is more than the resuscitation question and that the decisions are not fixed and can be adjusted over time. This study taught us that just providing information in a patient education is insufficient to eradicate the deep convictions of patients that care decisions conversations belong to the end of life and leads to fixed choices. Though, it is precisely these convictions that must be overcome in order to engage patients in care decision conversations. This study also partly answers the question: *"Why are care decision conversations not conducted more often at the outpatient clinic?"*. Patients do not frequently initiate the conversation because they believe the physician should. Furthermore, there is a persistent belief that it is (apparently) irrelevant if the physician does not initiate the conversation.

What is the physicians' perspective towards care decisions and care decision conversations?

In three **intermezzos**, running throughout this thesis, we showed the findings of a qualitative study using semi-structured interviews with physicians. This study, despite limitations such as a small sample size and convenience sampling, provided insights that were very recognizable and triangulated the results from our other studies, described in the main chapters. Physicians themselves also stated care decisions were not discussed regularly at the outpatient clinic, as we detected in **chapter 2** and **3**. Furthermore, similar to the findings of our conversation analysis in **chapter 3**, physicians indicated that they must exert considerable interactional effort and provide justifications for introducing the topic of care decisions. Although they call it different. Physicians express the difficulty to bring up the topic if there is no 'direct cause', and search for a 'hook' to start the conversation. These 'hooks' (e.g. study participation, a recent event, patients condition) are exactly the same as what is called accounts in conversational analytic terms. Physicians agree with patients that the physician should initiate the conversation, but whilst patients assume the physicians knows best when it is ‘relevant’ to start the conversation, physicians state they do not know what the appropriate timing and place is either (**chapter 4**, **intermezzos**). They struggle with relevance and express the lack of general criteria, national or hospital guidelines on when to discuss the topic. This relevance paradox was seen in the video-recorded consultations as well (**chapter 3**).

Physicians expressed other difficulties as well. They perceive it is a sensitive topic and they feel a lack of control in not knowing how the patient will respond. Besides, cultural differences complicate care decision conversations. It is striking that time is a barrier, but on the other hand sometimes misused as an ‘easy excuse’ not to discuss care decisions. On top of that, some argued the responsibility for care decision conversations should be with the general practitioner. Related to this, the insufficient exchange of information between general practitioners and hospital physicians was pointed out as well. All these barriers further explain why physicians do not initiate care decision conversations more often at the outpatient clinic. This completes the answer to the question “*Why are care decision conversations not conducted more often at the outpatient clinic?”.* Physicians named some facilitators to care decision conversations as well namely feeling competent and skilled, an informed patient, and awareness amongst themselves, the patients and the public in general. These insights in the physicians perspective towards care decisions reaffirmed targets to improve care decision conversations and brought up new areas to study.

What is the effect of a high-pressure situation on care decisions?

In March 2020, the COVID-19 pandemic reached the Netherlands. Since this affected pretty much everything and everyone, so did it affect our research. The pandemic put tremendous pressure on patient care and hospital capacity, especially on the ICU. Reports from the frontline indicated an uptick in discussions surrounding ‘code status’. To objectify these rumblings of more attention to code status, we compared code status documentation in a cohort of COVID-19 patients to code status documentation in a cohort of infectious patients before the COVID-19 pandemic in **chapter 5**. Since the two existing cohorts were essentially different, we compared them descriptively and no statistical analysis was performed. We found similar frequencies of code status documentation and (documented) code status discussion. However, in the COVID-19 cohort more patients had treatment limitations and within the limitations, ‘no intubation’ and ‘no ICU admission’ were substantially more prevalent. Although our study was not designed to differentiate between possible explanations for this difference, baseline characteristics and subcomparisons indicated that it was not (just) patient or disease related factors (e.g. clinical severity, age, comorbidity, type of infection), so other forces were at play. We assume awareness played a huge role in this. Awareness amongst physicians, in a time with high pressure, tasked with the judicious allocation of limited resources to those patients most likely to benefit. This might have made the physicians take a more restrictive stance or elaborate more extensively on the negative impact of certain treatments. But we assume awareness amongst patients and the public contributed as well. There was a lot of attention on media platforms showing the realities of invasive procedures such as intubation and intensive care, thereby showing the potential severity of their implications. The quality of the conducted conservations and attention to other aspects of care decision discussions, like goals and values of the patient remain unclear. However, the higher frequency of treatment limitations might indicate a more considered decision-making process. Previous research shows that a well-informed patient often results in a more restrictive policy (3–6). Altogether, the results of this study suggest that creating (public) awareness for care decisions could improve care decision conversations, something that can be implemented and contained in the post pandemic setting as well.

Adaptations to the physicians’ training and patient education

Within this project we adopted the lessons we learned from our previous studies, and adjusted the physicians’ training and patient education. Main adjustments to the physicians’ training were more emphasis on the relevance of care decision conversations and the wide range it comprehends (i.e. it is about more than the resuscitation question, attention to the goals and values of the patient). Another add was to highlight the key role the physician plays in the patients point of view. Furthermore, we incorporated learning points acquired from the conversation analytic study. We included some example utterances and discussed the interactional implications of these utterances.

Thereby, we addressed the creation of an interactional slot, common ground, use of different kind of accounts, and the paradox of the topic as 'relevant in the future' but 'needs to be discussed now' (the relevance paradox). Main adjustments to the patient education were 'patient experiences': short statements of patients derived from our interviews (**chapter 4**) and open fields in the questionnaire at the outpatient clinic (**chapter 2**), to emphasize the relevance and broad spectrum it comprehends. Thereby attempting to disconnect the topic from the end of life and make the relevance more clear. Besides, we shortened the extensive information on various treatments, to be able to pay more attention to the possibility to change one decisions. Finally, we paid extra attention to the language level and created a matching information leaflet. An information leaflet seemed more appropriate to use on the emergency department, the setting of our next study.

What is the effect of physicians' training and patient education on care decision conversations at the emergency department?

In **chapter 6** we investigated the effect of our adjusted interventions on care decision conversations at the emergency department. Next to this, we applied the learned lessons from previous research to the methodology of this study. As primary outcome measurement, we used a Quality of Communication questionnaire. Thereby keeping the focus on patient-experienced quality, but more specifically than overall satisfaction. The ambition to investigate both interventions separately made the design of our study at the outpatient clinic more complicated and the attempted sample size larger. Besides, research shows educating physicians and patients simultaneously is more effective than either one of them (7). Therefore, we choose to implement the two interventions simultaneously in our study at the emergency department. In **chapter 6**, we found that the quality of care decision communication improved significantly after our interventions. The number of patient reported care decisions conversations improved as well. This can be the result of more conducted conversations or a higher recall rate of these conversations, both being a valuable effect. A mere 12% of the patients (recalled to have) received the information leaflet, what suggests the physicians' training had the largest share in these effects. Another noteworthy result we found in this study is that patients are quite divided about what they perceive an appropriate moment to discuss care decisions. Although only 32% appointed the emergency department, this was even more than the 29% that appointed the general practitioner and 15% and 14% that appointed the outpatient clinic (first and follow-up visit respectively). The most appointed moment was during an admission at the ward (44%). Noticeable was a reasonable amount of patients (5%) that used the 'other, namely' option to express their opinion 'when relevant'. This study showed us that physicians' training and patient education can improve care decision conversations at the emergency department.

Limitations

In addition to specific limitations in the various chapters, there are some limitations to the research in this thesis in general. We would like to point out two of them.

First, the patient education, research questionnaires and interviews were all in Dutch. This hindered the participation of patients with insufficient command of the Dutch language. Therefore, the results cannot be extended to these patient groups. This is unfortunate, as it is presumable that these patients more often have a different cultural background and physician named that as a complicating factor in care decision conversations.

Second, it can be debated why our interventions showed a significant improvement at the emergency department, but did not at the outpatient clinic. We made several adaptions to the interventions and used a more specific outcome measurement. Therefore, we cannot conclude whether the adaptations made the interventions more effective, interventions are more useful at the emergency department than at the outpatient clinic, or we were able to measure the effect at the emergency department because of the more specific outcome measurement. Possibly the interventions did have an effect at the outpatient clinic as well, but we were unable to measure it in overall satisfaction. Despite this limitation, we underline the decision to make the adaptations, because the implementation of the lessons we learned helped us to answer our research question.

It is always too soon, until it is too late

Relevance – end of life association

One of the main themes throughout our research is (perceived) (ir)relevance and the association with the end of life. Two items that are inextricably linked. The expectation that care decision conversations belong to the end of life and focus on resuscitation seem quite persistent. From the beginning of our research we defined care decisions as the alignment of treatment with the patients' preferences, desires, goals, and values. Inclusive of the potential for opting out of further diagnostic or treatment interventions or put limits to this, which is far broader than 'do you want to be resuscitated'. Besides, we attempted to refrain from the end of life association by purposefully not using the term advance care planning and not selecting specific patients that are 'more at the end of life' (e.g. based on age, disease, or the in ACP commonly used 'surprise question' (i.e. Would you be surprised if this patient died within the next 12 months?).

Despite our efforts, perceived irrelevance and the end of life association played a role in all our studies. In **chapter 2**, the perceived irrelevance at this moment in time explains the low number of care decision discussion. As well as naming that the patient education is informative, but not helpful in forming an opinion or talk about care decisions. Also in **chapter 3**, we observed the perceived irrelevance in the low number of care decision discussions, the extensive use of accounts to create common ground, and the relevance paradox of the topic being framed as 'relevant in the future', but 'needs to be discussed now'. Furthermore, the end of life association makes it a sensitive topic, which is seen by the use of hesitations, repairs and restarts by physicians when introducing the topic of care decisions. However, at the same time all efforts by the physician (e.g. hesitations, accounts) and the relevance paradox sustain the image of the topic of care decisions belonging to the end of life, sensitive and irrelevant at this moment in time. In **chapter 4**, we discovered patients are deeply convinced that care decisions are associated with the end of life, and therefore irrelevant at this moment in time and a sensitive topic, explaining part of our results in **chapter 2**. The physicians' perspective we explored further declared this problem in the **intermezzos**. There was no consensus amongst physicians on what an appropriate time is for conducting care decision conversations, and when it was deemed relevant. The lack of criteria for them to aid the decision of introducing the topic of care decisions further troubled care decision conversations. In **chapter 5**, we observed the effect of a high pressure situation on increased awareness and therefore probably more perceived relevance. Before our study at the emergency department, we adjusted the interventions for both physicians and patients to emphasize the relevance more and further disconnect the topic of care decisions from the end of life. Despite these adaptations, still 5% of the patients used the ‘other namely’ option to express their feeling an appropriate moment to discuss care decisions was ‘when relevant’. This implies they did not perceive it as relevant now. Remarkable is that literature shows that even patients who are indeed closer to the end of life than the population we studied, still believe they are not there yet and it is too soon (8).

It might be discouraging to see that despite several interventions, we were still unable to completely eliminate the end of life association and therefore perceived irrelevance of the topic of care decisions. This is an important challenge. Several behavioral models have described differences in information processing and likelihood of persuasion depending on motivation and perceived relevance (9–18). In order for all information provision and training to be meaningful and to stick, first both patients and physicians must see the relevance. We will further elaborate in this challenge in the future perspectives section.

Setting

There is a lot of debate about the appropriate setting to discuss care decisions (19–26). At the start of this research, we assumed that the outpatient clinic was a more suitable setting for care decision conversations than the emergency department. An assumption quite common in the medical world and underlined in previous research (20–23,26). Although some advantages of the outpatient clinic are quite obvious (a preexisting physician-patient relationship, calmer environment, ‘time’ as in less pressure to come to an immediate decision), this setting provides multiple challenges as well. In **chapter 2** and **3**, we showed the number of care decision conversations in the general internal medicine outpatient clinic population is low. Presumably, the dilemma of the perceived irrelevance, that resonates in all our studies, contributes to this low frequency. Surprising to some extent the topic of care decisions is discussed more frequently at the emergency department, as was observed in **chapter 5** and **6**. These findings are consistent with physicians statements that the topic is barely discussed at the outpatient clinic and that they mainly have experience with care decision conversations at the emergency department (**intermezzos**). An explanation for the higher frequency of these conversations at the emergency department could be that the quality standards of the Dutch Association of Internal Medicine (NIV) demand a code status is documented at admission (27). In case the topic was not discussed at the outpatient clinic, these conversations took place at the emergency department. However, a risk of demanded documentation is that the topic is discussed 'because it had to be registered' – to 'tick a box' on the admission note and sign out – without proper attention to goals and values of the patient (28).

Recently, the Dutch Federation of Medical Specialists published a guidance document on when to conduct care decision conversations at the emergency department. It is stated that in the decision to start this conversation, the physician should weight the chance of an acute cardiac arrest and medical meaningfulness of resuscitation. Besides, at least resuscitation should be discussed (29). In this guidance document, as is a common believe in the medical world, the emergency department is often pointed out as the worst place to discuss care decisions, with doom scenarios of seriously ill patients, unable to think clearly, who are overwhelmed by the question whether they want to be resuscitated. We take a more nuanced view. Obviously, a patient can be shocked if the physician suddenly asks "*do you want to be resuscitated?*", and purely the resuscitation question may not be relevant and for every patient. However, the broader spectrum care decisions comprehends is relevant. Patients' goals and values matter – regardless of their risk of a cardiac arrest – and discussing the potential for opting out of further diagnostic or treatment interventions is always appropriate. If this potential is discussed more frequently, this might also reduce the sensitivity of the topic and create common ground over time. In the secondary outcomes of our study at the emergency department (as we discussed in **chapter 6**) we asked patients what they deemed an appropriate moment to discuss care decisions. Although merely 32% of the patients appointed the emergency department as an appropriate moment, this was still more often than the general practitioner (29%) or an first (15%) of follow-up (14%) outpatient clinic visit. The most appointed appropriate moment was during an admission at the ward (44%) (**chapter 6**), which would endorse the recommendation in the guidance document that this conversation can sometimes be postponed to hospital admission.

Limited time is a complicating factor in both settings. In the emergency department, time is limited because the patient can be acutely ill, but also because of overcrowding and the need to keep turnaround times as short as possible. At the outpatient clinic, time (per consultation/ patient) is limited as well, which results in physicians' prioritizing other conversation topics over care decision discussions (**intermezzos**).

Multiple perspectives

Our final overarching learning point is not so much about the content of care decisions or the answer to our research question, but about the way in which we attempted to answer our research question. Bringing together multiple perspectives, both in the research population (patients and physicians), research methods (quantitative and qualitative: interviews and conversation analysis) and research team (physicians, a language and communication scientist, educator) proved to be very valuable. We found many similarities and themes that recurred in the different studies, which triangulated the results. It also contributes to determine which targets are most important for future interventions and research. The fact that 'relevance' resonates in all studies, regardless of the population, setting or method, shows the importance of addressing this relevance. Bringing together multiple perspectives showed that different 'glasses' might use different words to describe the same phenomenon, and to look through these other 'glasses' and the implications of these other words can be very insightful. For example, in the adjusted physicians' training, we showed physicians that the 'hooks' to introduce the topic of care decisions that physicians searched for (**intermezzos**), were the same as 'accounts' that conversation analysis of real outpatient clinic conversations revealed (**chapter 3**). The accounts are used as a justification, and we found several accounts, patient related and external. This insight made the physicians aware of why they were searching for a 'hook', and that different accounts can have different implications.

"Dancing is the world's favorite metaphor."
– Kristy Nilsson

It takes two to tango

Dance is used as a metaphor all over the world. As Herbert H. Clark, a psycholinguist known for his theory of "common ground" (individuals engaged in conversation must share knowledge in order to be understood and have a meaningful conversation (30,31)) wrote: *"It takes two people working together to play a duet, shake hands, play chess, waltz, teach, or make love."*(32).

Our main question in this thesis was "*how can care decision conversations be improved?*". We will use the metaphor of a ballroom dance to cover all necessities for care decision conversations. This provides targets for improving care decision conversations, which we will further elaborate on in the future perspectives section.

A ballroom dance is danced with two partners together, just as you need (at least) two people for a conversation. Both with their own individual style and rhythm. Both partners need to be willing to dance (be aware of the relevance of care decision conversations) and know the dancing steps (knowledge on what the conversation comprehends, goal of the care decision conversation): they need common ground. Then, someone has to ask the other one to dance, either verbally or nonverbally (one needs to take the initiative for the care decision conversation, either explicitly or implicitly). Timing is important in this initiative, when your partner is just holding a full glass, it might be better to wait a few minutes until it is empty.

In dance, one of the partners is the leader and the other one is the follower. Although these are different roles, both are equal. One cannot dance without the other, they need each other and both play their part in performing the dance. In a care decision conversation, the physician and patient have different roles as well, but on order to come to a meaningful conversation, they have to be equal and both contribute to the conversation. Whilst the physician contributes medical knowledge, the patients contributes goals and values, as these are in their epistemic domain. And also in a conversation it is useful if someone takes the lead and structures the conversation, a task that most logically lies with the physician.

An excellent leader in dancing leads while following. The leader will set in a movement, ‘read’ the steps of the follower and adjust the movement accordingly. This can be seen as the exchange of information in the care decision conversation. The physicians shares knowledge on treatments and outcomes, the patient shares knowledge on goals and values, the physician adjusts the information to the patient. During the conversation, you constantly have to stay connected to the other one, find out where they stand, whether they come along. Whether you stick with the basic steps, or continue with more advanced dance moves (which treatments you discuss, but also whether you stay in the information provision and exchange phase or whether a decision can or should be made).

Without practice, you cannot learn to dance properly, and you need to dance to practice it. You can look in a book to study the dancing steps (gain knowledge on treatments and outcomes, read about communication skills), you can watch other people dance (watch how a role model, colleague, supervisor, etc. conducts a care decision conversation), but eventually you really have to start dancing and practice to become better at it, preferably with a teacher that can provide you with personal feedback (you have to start talking about it, and receive feedback on your conversations to become better at it). Finally, if you never dance it can feel ‘awkward’ to start dancing (use of hesitations, repairs, accounts), but when you do it more often you will probably feel more comfortable. Because the physician is the professional in this setting, the responsibility for the conduct of the conversation (learning how to dance) lies most with the physician.

It might seem that’s it, all necessities for two partners to perform a perfect ballroom dance. But we are not there yet, there are some surroundings that are necessary as well. It is pretty hard to dance without music (awareness; if you hear music you know you can dance; you have to be aware of the topic of care decisions in order to start a conversation about it) and if there is a dance floor this invites you to dance more. The ‘dance floor’ in care decision conversations are all practical necessities: time, physical space (e.g. in an admitted patient a private family room instead of a room with four other patients), a supporting system/ electronic health record, etc. Finally, when you see other people dancing, this stimulates others to start dancing as well. Lead by example.

Future perspectives – Research

There are some areas still open for future research. Many physicians mentioned it was more difficult to discuss care decisions with patients from another cultural background. In a diverse society, it is important to develop cultural sensitivity and connect with people from different backgrounds as well. In a topic such as care decision conversations, in which communication plays a key role, it is important to further explore the best way to involve patients with different backgrounds. These can be different cultural backgrounds, but also (health)literacy or a language barrier influences how best to involve the patient in care decision conversations.

We focused our research on two settings, the outpatient clinic and emergency department. The recently published guidance document from the Dutch Federation of Medical Specialists on when to discuss care decisions in acutely ill patients, provides room to postpone the care decision conversation to during admission at the ward. How desirable this is, is a question still open. In our opinion, future research should not focus on whether one setting is ‘*better’* than the other setting, but on how we achieve to engage patients and physicians in these conversations in *every* setting.

Next to the individual patient educations we studied, future research could focus on ways to create and maintain public awareness. The increased awareness during the COVID-19 pandemic suggests this could enable care decision conversations. However this increased awareness seems to be waning. One could think of several ways to create public awareness (media attention, a public campaign), more focused on individuals (a letter on your x^{th} birthday, as with the donation register) or directed to patient populations (poster or video in waiting rooms, information on websites), the possibilities are almost endless. The most important challenge for these interventions is to emphasis the relevance. To address the perceived irrelevance properly, it might be useful to join forces with the behavioral or psychological field. To start, spread and hold the ‘new’ narrative: care decision conversations as a normal, regular, recurring part of the consultation to align treatment with patients goals and values.

Although we directed our research to physician-patient communication about the topic of care decisions, there are some pioneering studies that experiment with involving other healthcare professionals such as dedicated nurses. An interesting development that warrants further investigation as well.

Furthermore, we advise future studies that aim to combine video-analysis with other methods to consider incorporating a cascading consent into their methods (e.g. consider to ask for audio-recordings if no consent for video-recordings, and separate consent for other measurements). Besides, it is important to choose the endpoints of the research in this topic carefully. In our opinion not just the *frequency* ('tick the box'), but the *quality* of care decision conversations matter, so we recommend to use outcomes that measure (patient-assessed) quality of communication, or patient satisfaction regarding the specific care decision conversation.

Finally, the multiple perspectives we combined in this thesis were very valuable as they triangulated results. The qualitative interviews provided possible explanation for observations we did in the quantitative studies. And because both the physician and patient are necessary in the conversations, it was insightful to deepen our knowledge on both perspectives. On top of that, the combination of medical, educational and communication and linguistics glasses offered important information. We would like to advocate for combining these perspectives and research methods more often, especially within topics in which communication plays a key role as in care decision conversations, but actually in the entire medical world.

Future perspectives – clinical practice

As we discussed before, the perceived irrelevance is one of the key points to address in order to improve care decision conversations. If the relevance is not seen, these important conversations are not conducted at all. This calls for a change of the care decision narrative. In the current perceptions, care decisions are associated with the end of life, sensitive, leading to binding decisions, overwhelming, and irrelevant. Although it can be argued that there are some outpatient clinic patients in whom care decision conversations can be trivial (e.g. the often cited example '30-year old otherwise healthy women with hyperthyroidism'), this is not the case if you approach care decisions in the broad spectrum of alignment of treatment with patients goals and values. Although the consideration of thiamazole vs radioactive iodine vs operation probably is classified as shared decision-making and not care decisions, maybe it should not be that distinct. It can all be seen in a scale from shared decision-making (between treatment options) to care decisions (with more emphasis on the potential for opting out of diagnostic or treatment interventions). And from care decisions to advance care planning (with further emphasis on aspects as how one sees the end of life, and how and where to spend the last stages of life). If you approach the topic like that, sensible care decision conversations should be a normal, regular, recurring part of the medical consultation. Care decision conversations are a continuous, dynamic process, relevant at any given time and under any kind of circumstance. Framing it as a ‘current plan’ could possibly be helpful in seeing it as currently relevant and flexible, rather than fixed. This ‘new’ narrative – care decision conversations as normal, regular, recurring part of the consultation to align treatment with patients goals and values – also removes the problem of choosing the best setting: it should not be *either* the outpatient clinic *or* the emergency department. *Either* the emergency department *or* during admission. *Either* the general practitioner *or* the hospital physician. It should be *and - and - and*. Patients assign physicians a key role in the care decision process, so we should *all* pick up this gauntlet.

To accomplish the embracement and wide dissemination of this new narrative, patients, physicians and the community at large should be educated. We need to engage the physician and the patient, play some music and make sure there is a dancing floor!

Physician training – learn how to start dancing, dance, and lead

First of all, training in care decision conversations should be introduced into the medical curriculum. Currently this is lacking, both in the basic medical training to become a physician, and in further specialization. Besides, observing others or being observed and receive specific feedback is often lacking as well. We recommend to introduce training either at the end of the basic medical curriculum or at the beginning of specialization or clinical work

We recommend incorporation of a number of important components in physicians’ training. Physicians should be educated in the role patients assign them: the expectation of patients that the physician initiates this conversation, informs them, and does so with sensitive communication skills. The training should provide the physician with background medical knowledge on certain treatments, its outcomes, and (patient)factors that influence these outcomes. Besides, the vision of care decisions as a continues process to align treatment with patient preferences, not just ‘the resuscitation question’, and therefore relevant at any given time and circumstance should be shared. However, physicians should also be aware of the caveat that patients often (still) associate the topic with the end of life. Until that association is removed, common ground has to be created and accounts must be provided to introduce the topic of care decisions. It is important to point out that using utterances to frame the topic as relevant in the future sustain the relevance paradox. It is helpful to practice the creation of common ground, use of accounts, and sensitive communication skills in small groups.

Patient education – be willing to dance and learn how to dance

Patients should be on board to conduct care decision conversations as well. Removing the barriers that come from the association with the end of life and fear for fixed decisions are the first step. Therefore, the narrative of care decisions being about the alignment of treatment with the patients’ preferences, desires, goals, and values, inclusive of the potential for opting out of further diagnostic or treatment interventions or put limits to this. A continuous, dynamic process, relevant at any given time and circumstance, should be disseminated. The best way to do so is yet to be determined. Only after the patient is aware of the relevance (is willing to dance) information provision about certain treatments and its outcomes sustains (and the patient can learn how to dance).

Community awareness – music

Although the best way to create awareness is not determined yet, the COVID-19 pandemic showed us that engagement of the community at large can be effective. We recommend creating public awareness, by media attention or even a national campaign.

Practical necessities – dancefloor

Lack of time is a vast barrier to care decision conversations. Although we believe that by making care decisions a more normal and regular part of the consultation, it will become less time-consuming, time is still needed to provide information and explore patients’ wishes. Although prioritizing the topic with more awareness might help, the current system does not support care decision conversations very well (there is not much of a dance floor). A possible improvement could be longer time slots (financed) at outpatient clinics visits for care decision conversations. Besides, adjustment of the electronic health record might be helpful. We suggest to put more emphasis on the exploration of goals and values (and space to record this), instead of on fixed decisions (resuscitation yes or no, intensive care admission yes or no). Finally, this information should be easy to find and accessible by other healthcare providers (e.g. the general practitioner) involved with the patient as well.

To conclude, we need to train the physician, educate the patient, create awareness and ensure that the physician and patient are not hindered by practical obstacles.

So… Let's dance and make way for fruitful care decision conversations!

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APPENDICES

Nederlandse Samenvatting

Dankwoord

List of publications

About the author

Nederlandse samenvatting

Het bespreekbaar maken van behandelwensen en -grenzen is belangrijk om de behandeling af te stemmen op de wensen, doelen en waarden van de patiënt. Hierbij kan de behandeling ook betekenen dat wordt afgezien van verdere diagnostiek of therapeutische interventies. *Niet alles wat kan, hoeft.* Zowel artsen als patiënten vinden deze gesprekken vaak lastig. In dit proefschrift onderzoeken we diverse interventies om zowel de arts als de patiënt te helpen dit gesprek beter te voeren.

Een van de aanleidingen voor dit onderzoek was het ‘Verstandig Kiezen’-programma van de Federatie Medisch Specialisten en ZonMw[1]. In de geest van de wereldwijde ‘Choosing Wisely’-campagne, die bedoeld is voor artsen en patiënten om in gesprek te gaan over het nut en de noodzaak van zorgmogelijkheden, hebben diverse beroepsverenigingen voor specialisten Verstandige Keuzes geformuleerd. Verstandige Keuzes zijn wetenschappelijk onderbouwde aanbevelingen waarover artsen en patiënten het gesprek zouden moeten voeren om te bepalen wat de best passende behandeling is voor deze patiënt. Eén van de Verstandige Keuzes van de Nederlandse Internisten Vereniging (NIV) is: *“Bij het bespreken van de behandeling met de patiënt ook de behandelbeperkingen bespreken.”*

De term ‘*behandelbeperkingen*’ vermijden wij bewust. Het doel en de focus zou naar onze mening niet moeten liggen op *beperkingen* – met alle negatieve associaties die dat kan oproepen – maar op de afstemming van de behandeling op de wensen van de patiënt. Behandelwensen en -grenzen kunnen betrekking hebben op – maar zijn niet beperkt tot – voorkeuren met betrekking tot reanimatie, beademing en opname op de Intensive Care (IC). Daarnaast kunnen behandelwensen en -grenzen ook betrekking hebben op allerlei andere mogelijke behandelingen zoals dialyse, sondevoeding, ziekenhuisopname en (invasieve) diagnostiek. Het bespreken van behandelwensen en -grenzen leidt vaker tot het afzien van een bepaalde behandeling, dan wanneer dit niet wordt besproken. Hiermee kunnen de zorgconsumptie en kosten worden gereduceerd zonder dat dit ten koste gaat van patiënttevredenheid. Kostenreductie is echter niet het doel, maar een bijkomend voordeel. Het doel is het afstemmen van de behandeling op de behoeften en voorkeuren van de patiënt. *Meer zorg is niet altijd betere zorg.*

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[1] Een financieringsorganisatie van innovatie en onderzoek in de gezondheidszorg

In de Kwaliteitsstandaarden van de NIV staat dat er bij iedere opgenomen patiënt een behandelcode gedocumenteerd moet zijn. In een behandelcode zijn voorkeuren ten aanzien van specifieke behandelingen vastgelegd, meestal: reanimatie, beademing en IC opname. Hoewel de Verstandige Keuze van de NIV suggereert dat behandelwensen en -grenzen altijd en bij iedere patiënt besproken zouden moeten worden, gebeurt dit niet. Aangezien deze gesprekken vaak worden vermeden en uitgesteld, en de eerder genoemde behandelcode bij opname moet worden vastgelegd, vinden deze gesprekken vaak plaats op de spoedeisende hulp (SEH). Gezien de acute situatie en de vaak beperkte tijd lijkt deze locatie en timing verre van ideaal. Daarbij ligt de focus vaak op het registreren van een keus, niet op het verkennen van de wensen, doelen en waarden van de patiënt om gezamenlijk een afweging te maken. *Het maken van de beste keus voor die patiënt.*

In dit proefschrift onderzoeken we het effect op de kwaliteit van het gesprek over behandelwensen en -grenzen van het trainen van artsen en het geven van voorlichting aan patiënten. Deze interventies worden op twee behandelplaatsen binnen de interne geneeskunde onderzocht: de polikliniek en de SEH. Daarnaast analyseren we hoe deze gesprekken op dit moment worden gevoerd, en wat we hiervan kunnen leren. Verder onderzoeken we hoe artsen en patiënten naar het onderwerp behandelwensen en -grenzen kijken en hoe het bespreken hiervan wordt ervaren. Waarmee wordt dit onderwerp geassocieerd en wat kan behulpzaam of belemmerend zijn in het bespreken van dit onderwerp. Tot slot beschrijven we de impact van de COVID-19 pandemie op geregistreerde behandelcodes. Middels deze studies proberen we de vraag te beantwoorden: "*Hoe kunnen gesprekken over behandelwensen en -grenzen verbeterd worden?*"

In **hoofdstuk 2** beschrijven we het effect op patiënttevredenheid van het trainen van artsen en het geven van voorlichting aan patiënten op de polikliniek van de interne geneeskunde. In deze studie hebben we artsen halverwege de studieperiode getraind met een e-module en oefengesprekken in kleine groepjes met simulatiepatiënten. De e-module bevatte informatie over het doel van het bespreken van behandelwensen en -grenzen, filmpjes van zorgverleners, een patiënt, een ethicus en een jurist die het belang benadrukken, achtergrondinformatie over behandelingen en uitkomsten, een kennisclip over cultuur-sensitieve communicatie, en een aantal voorbeeldfilmpjes uit de spreekkamer. Patiënten in de interventiegroep ontvingen per email een link naar een webpagina met informatie over behandelwensen en -grenzen. In de voorlichting wordt uitgelegd wat de betekenis van het gesprek is, waarom het zinvol is hierover te praten en wie beslissingen kan nemen. Tevens wordt er achtergrondinformatie over bepaalde behandelingen en mogelijk uitkomsten hiervan gegeven, die te bereiken zijn via hyperlinks. Er werden vier groepen gevormd: artsen voor de training met wel of niet voorgelichte patiënten, en artsen ná de training met wel of niet voorgelichte patiënten. Naast onze primaire uitkomstmaat (patiënttevredenheid), onderzochten we een aantal secundaire uitkomstmaten met betrekking tot zowel de arts als de patiënt.

We zagen geen toename van de patiënttevredenheid met het poliklinische bezoek na de invoering van onze interventies. Dit kan betekenen dat de interventies geen effect hadden, maar er zijn ook andere verklaringen mogelijk. Zo was de patiënttevredenheid vóór de interventies al zeer hoog (gemiddeld een 8.6) en wordt algemene patiënttevredenheid door veel aspecten beïnvloed. In de secundaire uitkomsten zagen we wel een aantal positieve resultaten. Artsen voelden zich na de training beter voorbereid op het gesprek over behandelwensen en -grenzen. Daarnaast gaven patiënten aan dat zij zich door de patiëntenvoorlichting niet méér angstig, verdrietig of onzeker voelden, iets waar artsen vaak bang voor zijn. Opmerkelijk genoeg vonden patiënten de voorlichting informatief en beoordeelden zij het met goede cijfers (mediaan 8). Zij waren echter neutraal over of het behulpzaam was geweest bij het vormen van een mening omtrent behandelwensen en -grenzen en het bespreken hiervan. Tot slot gaf slechts 28% van de patiënten aan dat het onderwerp behandelwensen en -grenzen ter sprake was gekomen tijdens het poliklinische bezoek. Een beperking van dit onderzoek was de lage deelname. Een belangrijke verklaring hiervoor was dat de poliklinische consulten werden opgenomen met een videorecorder. Wij combineerden ons kwantitatieve onderzoek (**hoofdstuk 2**) met kwalitatief onderzoek van opgenomen authentieke gesprekken (**hoofdstuk 3**). Veel patiënten die niet wilden deelnemen, gaven als reden hiervoor de video-opnames. Toch hebben we belangrijke lessen kunnen leren uit deze studie. Zowel met betrekking tot onderzoek naar dit onderwerp (o.a. de keuze van de uitkomstmaat en het gebruik van video-opnames) als met betrekking tot onze onderzoeksvraag. Onze training zorgde ervoor dat artsen zich beter voorbereid voelden voor het gesprek over behandelwensen en we hebben geleerd dat patiënten niet angstig werden van onze voorlichting. Beide bevindingen zijn eerste stappen ter verbetering van gesprekken over behandelwensen en -grenzen. Tot slot riepen de resultaten de vraag op waarom patiënten de voorlichting wel informatief vonden, maar neutraal waren ten opzichte van de behulpzaamheid. Deze discrepantie vormde de aanleiding voor het onderzoek dat we beschrijven in **hoofdstuk 4**.

In **hoofdstuk 3** analyseren we authentieke poliklinische gesprekken om meer inzicht te krijgen in hoe het gesprek over behandelwensen en -grenzen op dit moment wordt gevoerd. Hiervoor maken we gebruik van conversatie analyse[2]. De focus lag hierbij op de introductie van het onderwerp behandelwensen en -grenzen in het gesprek: *hoe vaak*, *wanneer* (in het gesprek) en *hoe* wordt het onderwerp behandelwensen en -grenzen geïntroduceerd. We zagen dat in 21 gesprekken (14%) het onderwerp behandelwensen en -grenzen werd geïntroduceerd, 17 keer door de arts en 4 keer door de patiënt. Dit is minder dan het aantal patiënt-gerapporteerde gesprekken (**hoofdstuk 2**). Dit verschil kunnen we niet verklaren door het aantal mislukte video-opnames. Een mogelijk verklaring is dat patiënten, ondanks de instructie dat de vragenlijst over het laatste poliklinische consult ging, toch hebben aangegeven dat het ter sprake was gekomen terwijl dit in een ander gesprek aan de orde was gekomen. Aangezien er te weinig gesprekken waren om de verschillende interventiegroepen te vergelijken, en de training van artsen en voorlichting van patiënten geen specifieke gespreks-(initiatie)technieken bevatten, hebben we de gesprekken gezamenlijk geanalyseerd. Onze conversatie analyse liet zien dat het erg lastig is om het onderwerp behandelwensen en -grenzen in het gesprek te introduceren. Er is geen vast moment of fase in het gesprek waar het thuis hoort. Vaak is het een laatste agendapunt aan het eind van het gesprek. Verschillende fenomenen (aarzelingen, herformuleringen en hypothetische formuleringen) laten zien dat het een gevoelig onderwerp is. Artsen gebruiken vaak een aantal verantwoordingen om het onderwerp te introduceren, soms extern ("het ziekenhuis wil dat we dit bespreken"), soms patiënt-gerelateerd ("gezien je huidige conditie", "gezien de recente

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[2] Conversatie analyse is een onderzoeksmethode waarbij wordt onderzocht hoe mensen dingen voor elkaar krijgen in gesprekken. Hierbij wordt gekeken naar wat mensen zeggen en hoe ze dat doen, inclusief 'rommeligheden' in het gesprek zoals haperingen, pauzes en herformuleringen. Hiermee wordt inzicht verworven in hoe het gesprek georganiseerd is en hoe betekenis wordt gegeven aan op wat wordt gezegd en gedaan: de sociale interactie om tot begrip van elkaar te komen.

operatie"). Deze verantwoordingen worden in conversatie-analytische termen 'accounts' genoemd. Deze worden gebruikt om 'common ground' te creëren: de gesprekspartners moeten een gemeenschappelijke basis delen om begrepen te worden en een zinvol gesprek te voeren. Tot slot was er een relevantie-paradox. Artsen framen het onderwerp als 'relevant in de toekomst' maar 'moet nu besproken worden'. Deze relevantie-paradox onderhoudt het idee dat behandelwensen en -grenzen op dit moment niet relevant zijn. Deze bevindingen gaven handvatten voor aanpassingen aan de artsentraining en patiëntvoorlichting.

Hoofdstuk 4 geeft inzicht in het perspectief van patiënten op behandelwensen en -grenzen. De aanleiding hiervoor was de discrepantie tussen het wel informatief maar niet behulpzaam beoordelen van de patiëntvoorlichting. Door middel van semigestructureerde interviews hebben we uitgediept hoe patiënten naar het onderwerp behandelwensen en -grenzen kijken. Hieruit kwamen twee diepe overtuigingen naar voren: 1) patiënten associëren het onderwerp met het einde van het leven, en vinden het daardoor een gevoelig onderwerp dat zij op dit moment voor zichzelf niet relevant vinden. 2) patiënten hebben het (foutieve) idee dat het bespreken van behandelwensen en -grenzen leidt tot vaststaande beslissingen die niet meer kunnen wijzigen, terwijl hun gedachten en wensen wél kunnen wijzigen. Een meer praktisch georiënteerd thema dat naar voren kwam was dat patiënten vinden dat het onderwerp behandelwensen en -grenzen gaat over 'of de behandeling het waard is'. Hierin speelden een aantal subthema's een rol, waaronder kwaliteit van leven en familie. De studie bracht ook de sleutelrol die patiënten aan artsen toewijzen aan het licht: volgens de patiënten bepaalt de arts wanneer het relevant is, start de arts het gesprek, geeft informatie, verkent de gedachten van de patiënt, en moet dit doen op een sensitieve en empathische manier. Bovenal hebben we van deze studie geleerd dat de associatie van behandelwensen en -grenzen met het einde van het leven (en daardoor nog niet relevant) diep geworteld is, en niet zomaar verdwijnt door uitleg in een patiëntvoorlichting. Wat de tweede overtuiging betreft: in de voorlichting stond dat keuzes altijd kunnen wijzigen, iets wat blijkbaar niet beklijft. Het is zaak deze belemmerende overtuigingen om te buigen naar nieuwe positieve overtuigingen en gedachten over het gesprek over behandelwensen en -grenzen. Dit zal het (starten van) het gesprek ten goede komen.

In drie **intermezzo's** laten we de resultaten zien van semigestructureerde interviews waarin het perspectief van artsen op het onderwerp behandelwensen en -grenzen werd verkend. Dit was een kleine studie, maar leverde resultaten op die zeer herkenbaar waren en de resultaten van onze andere studies trianguleerden[3]. Artsen gaven aan niet regelmatig over behandelwensen en -grenzen te spreken op de polikliniek. Zij vinden het, net als de patiënten (**hoofdstuk 4**), hun taak om het onderwerp te introduceren, maar vinden dit lastig als er geen 'haakje' is. Met een 'haakje' bedoelen zij een reden, directe aanleiding of verantwoording om het onderwerp behandelwensen en -grenzen te introduceren. Dit zijn de 'accounts' die wij in **hoofdstuk 3** observeerden. Hoewel patiënten denken dat de arts weet wanneer het relevant is om over behandelwensen en -grenzen te praten, vinden artsen dit lastig te bepalen. Daarnaast verschillen de meningen tussen artsen. Zij gaven aan dat algemene criteria – door het ziekenhuis opgesteld of landelijk – dit zou kunnen vergemakkelijken maar op dit moment ontbreken. Daarnaast gaven artsen aan behandelwensen en -grenzen een gevoelig onderwerp te vinden waar zij weinig controle over hebben. Bovendien is het lastig te voorspellen hoe de patiënt zal reageren. Verschillen in culturele achtergrond kunnen het gesprek verder bemoeilijken. Als laatste – maar meest genoemde – barrière werd het gebrek aan tijd genoemd. Binnen de beperkte tijd, waarin ook allerlei andere dingen besproken moeten worden, wordt dit onderwerp niet geprioriteerd. Tegelijkertijd gaven de artsen aan tijd soms als excuus te 'misbruiken', omdat ze liever over andere dingen praten. Artsen noemden ook zaken die het gesprek over behandelwensen en -grenzen makkelijker kunnen maken, zoals het gevoel competent en ervaren te zijn. Maar ook een goed geïnformeerde patiënt, bewust van het belang van het gesprek, helpt. Net als bewustwording bij henzelf en de maatschappij als geheel. Dit inzicht in barrières en randvoorwaarden door de ogen van artsen gezien, geeft handvatten voor het verder verbeteren van het gesprek over behandelwensen en -grenzen.

In 2020 bereikte de COVID-19 pandemie Nederland. Naast alle negatieven gevolgen, bood deze pandemie ook mogelijkheden voor ons onderzoek.

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[3] Trianguleren betekent dat je verschillende methodes, bronnen of onderzoeken gebruikt om hetzelfde probleem te onderzoeken. Het idee is dat als verschillende benaderingen tot vergelijkbare resultaten leiden, je meer vertrouwen kunt hebben in de nauwkeurigheid en betrouwbaarheid van je bevindingen.

Berichten vanuit de praktijk suggereerden een toename van gesprekken over behandelwensen en -grenzen. Om dit te objectiveren hebben wij in **hoofdstuk 5** gedocumenteerde behandelcodes bij opname vergeleken tussen een cohort van COVID-19 patiënten, en een cohort van patiënten die vóór de COVID-19 pandemie met een infectie werden opgenomen. We vonden vergelijkbare aantallen van een gedocumenteerde code in beide groepen. Ook was in gelijke aantallen gedocumenteerd dat deze code was besproken met de patiënt. Echter, in het cohort van COVID-19 patiënten was er in deze behandelcodes veel vaker een beperking afgesproken. Met name 'niet beademen' en 'geen IC opname' kwamen vaker voor. Wij denken dat bewustwording – awareness – hier een belangrijke rol in heeft gespeeld. In de media waren bijvoorbeeld beelden te zien van IC-afdelingen waar patiënten aan de beademing lagen. In de krant en op tv werden discussies gevoerd over de voor- en nadelen van behandelingen. Door deze realistische maar indrukwekkende beelden wisten mensen beter wat deze behandelingen inhielden. Het is goed voorstelbaar dat mensen hierdoor onderling én met de arts sneller het gesprek aangingen over de wenselijkheid of onwenselijkheid van deze interventies, en vaker afzagen van deze behandelingen. Daarnaast waren artsen zich bewust van de taak om zorgvuldig om te gaan met (beperkte) beschikbare middelen, waardoor zij wellicht meer tijd investeerden in uitleg over de nadelen van een behandeling. Ook kon de media-aandacht als 'haakje' worden gebruikt. Eerder onderzoek laat zien dat het informeren van patiënten vaak leidt tot een restrictiever beleid. Het vaker afspreken van behandelgrenzen in COVID-19 patiënten suggereert dat er bewuster over behandelwensen en -grenzen is nagedacht en gesproken. Wij weten echter niet wat de kwaliteit van de gevoerde gesprekken is geweest en of er, naast de behandelcode, ook aandacht is geweest voor andere onderdelen van behandelwensen en -grenzen, zoals de doelen en waarden van de patiënt. Wel suggereren de resultaten dat bewustwording (bij artsen, patiënten en de maatschappij) van behandelingen, de implicaties hiervan, en het belang van het voeren van gesprekken over behandelwensen en -grenzen, kan bijdragen aan het verbeteren hiervan.

Op basis van alle voorgaande resultaten hebben wij de training voor artsen en de voorlichting aan patiënten aangepast. Daarnaast hebben we de patiëntenvoorlichting in foldervorm omgezet, zodat deze makkelijker verspreid kan worden op de SEH.

In **hoofdstuk 6** onderzoeken we het effect van deze interventies op SEH. Hierbij hebben we rekening gehouden met onze geleerde lessen. Als primaire uitkomst gebruikten wij een door de patiënt ingevulde 'kwaliteit van communicatie' vragenlijst. Deze bestond uit vragen over de algemene kwaliteit van communicatie en vragen over de kwaliteit van communicatie over behandelwensen en -grenzen specifiek. Beide interventies (de training voor artsen en folder voor patiënten) werden op hetzelfde moment ingevoerd. We vonden een significante verbetering van de kwaliteit van communicatie over behandelwensen en -grenzen ná onze interventies. Daarnaast steeg het aantal door de patiënt gerapporteerde gesprekken over behandelwensen en -grenzen. Dit kan ofwel een daadwerkelijke toename in gesprekken betekenen, of een toename van de herinnering aan deze gesprekken. Beide zien wij als een positief effect. Slechts 12% van de patiënten gaf aan de folder te hebben ontvangen, hetgeen suggereert dat vooral de training van artsen deze positieve effecten heeft veroorzaakt. In de secundaire uitkomsten van deze studie vroegen wij patiënten wat zij geschikte locaties voor gesprekken over behandelwensen en -grenzen vinden. De SEH werd door 32% genoemd als geschikte plaats. Andere locaties, die in de medische wereld vaak 'geschikter' worden gevonden, werden echter nog minder vaak genoemd: slechts 29% vond de huisarts een geschikte plek, 15% een eerste poliklinische afspraak en 14% een vervolg poliklinische afspraak. De meest genoemde geschikte plek was tijdens opname op een verpleegafdeling (44%).

In onze discussie (**hoofdstuk 7**) reflecteren we op de studies in dit proefschrift en delen we drie overkoepelende leerpunten, namelijk:

1) *relevantie* is een probleem dat door al onze studies heen speelt. Doordat het onderwerp behandelwensen en -grenzen wordt geassocieerd met het einde van het leven, wordt het (nog) niet relevant gevonden. Dit zien we terug in de lage frequentie van gesprekken op de polikliniek, relevantie-paradox in de wél gevoerde gesprekken, het perspectief van patiënten (die dit bevestigd zien worden doordat ook artsen het onderwerp niet initiëren) en artsen die aangeven behoefte te hebben aan criteria wanneer zij het zouden moeten bespreken.

2) *locatie* hoewel er voordelen te noemen zijn van de polikliniek ten opzichte van de SEH als geschikte plek voor het gesprek over behandelwensen en

-grenzen, brengen beide locaties hun eigen voor- en nadelen met zich mee. Patiënten noemen de verpleegafdeling, tijdens een opname, het meest als geschikte locatie. Aangezien de Kwaliteitsstandaarden van de NIV stellen dat er een behandelcode geregistreerd moet zijn bij opname, hebben wij deze locatie niet onderzocht. De recent gepubliceerde handreiking "Behandelafspraken voor patiënten in de acute setting" biedt hier wel ruimte voor. Toekomstig onderzoek zou deze setting verder kunnen exploreren.

3) *meerdere perspectieven* verbinden, zowel in onderzoeksmethoden, in het onderzoeksteam als bij 'proefpersonen' (specialisten, artsen in opleiding, patiënten), is waardevol. Overeenkomsten en terugkerende thema's trianguleerden onze resultaten. Daarbij kon een andere invalshoek soms een verklaring geven voor bevindingen. Het patiëntperspectief (de associatie met het einde van het leven) (**hoofdstuk 4**), liet ons beter begrijpen waarom patiënten de voorlichting informatief maar niet zo behulpzaam vonden (**hoofdstuk 2**). Zij vonden het namelijk nog niet relevant voor henzelf. Dit gaf verdieping aan de bevindingen en leverde nuttige inzichten op.

Verder beschrijven we in **hoofdstuk 7** – middels een metafoor van een (stijl) dans – alle passen voor een goed en zinvol gesprek over behandelwensen en -grenzen. *Als een dans van de arts en patiënt.* Artsen moeten getraind worden met betrekking tot de relevantie, hun rol in de ogen van de patiënt, en gesprekstechnieken zoals het gebruik van verantwoordingen en het vinden van 'common ground' bij het initiëren van het gesprek. *De dans uitnodigen, starten, dansen, en leiden.* Daarnaast moet de patiënt voorgelicht worden, vooral over wat het bespreken van behandelwensen en -grenzen inhoudt en de relevantie. Pas als patiënten het onderwerp niet meer associëren met het einde van het leven, en het onderwerp relevant voor zichzelf vinden, zullen zij openstaan voor verdere informatie en een gesprek. *Zodat ze open staan voor de dans en kunnen leren hoe te dansen*. Hiervoor kan het zinvol zijn om maatschappelijke bewustwording te creëren, *muziek*. Tot slot zijn er een aantal praktische randvoorwaarden, *de dansvloer*: de mogelijkheid om tijd vrij te maken (financiering), een ondersteunend elektronisch patiëntendossier met aandacht en ruimte voor patiëntgebonden doelen en waarden met uitwisseling tussen zorgverleners.

Samenvattend moet bewustwording gecreëerd worden. Het bespreken van behandelwensen en -grenzen betekent de afstemming van de behandeling op de wensen, doelen en waarden van de patiënt. Dit is veel meer dan ‘de reanimatievraag’. Dit is een continu en terugkerend proces. Dit is áltijd relevant. Er is geen ‘beste’ locatie, niet *of/ of*, maar *en/ en*: bij de huisarts *en* in het ziekenhuis. Op de polikliniek *en* de SEH. Op de SEH *en* op de verpleegafdeling.

Zoals Hippocrates (460 v.Chr.-370 v. Chr.) al zei:

“Het is belangrijker om te weten wat voor soort persoon een ziekte heeft dan om te weten wat voor soort ziekte een persoon heeft.”

Dankwoord

Promoveren doe je niet alleen. Er zijn veel mensen die ik graag wil bedanken voor hun betrokkenheid en bijdrage aan dit proefschrift.

Allereerst wil ik alle **patiënten** en **artsen** die hebben meegewerkt aan de onderzoeken in dit proefschrift ontzettend bedanken voor hun tijd, moeite en openhartigheid. Zonder jullie was dit niet mogelijk geweest!

Geachte promotor, prof. dr. Kaasjager, beste **Karin**. Mijn hele promotietraject, en eigenlijk al ver daarvoor, geloof jij in mij. Tijdens mijn onderwijsstage in het laatste jaar van geneeskunde, toen ik solliciteerde voor de opleiding interne geneeskunde, en bij de start van mijn onderzoek. De eerste berg was er al nog voor ik met mijn promotieonderzoek begon. Onderzoek? Promoveren? Dat vond ik niks voor mij. Jij geloofde vanaf het begin in mij als onderzoeker, maar gaf me ook de ruimte om dat zelf te gaan zien. Ik mocht een ‘project’ doen (want het onderwerk sprak me wel aan) en voor ik het wist was ik boven op die eerste berg, promotieonderzoek aan het doen. Je hebt me in de afgelopen jaren regelmatig uit mijn comfortzone gehaald, naar voren geschoven, in de spotlight gezet en betrokken bij diverse projecten. Soms vroeg ik me af of ik niet om een nieuwe berg heen kon, maar jij stimuleerde me altijd om erop te klimmen, terwijl je tegelijkertijd rekening hield met wie ik ben. Ik hoefde het niet alleen te doen, en dankzij jouw onuitputtelijke aanmoedigingen, steun en het vertrouwen dat je altijd in mij had, had ik ook het vertrouwen dat ik het kon. Jij appt voor een praatje dat ik het kan, en erna dat ik het super goed heb gedaan. Dankzij jou kan ik nu niet alleen trots zijn op dit proefschrift, maar ook op de overwinningen (want zo voelde het soms) op de route hier naartoe. In onze wekelijkse overlegmomenten was er altijd tijd en ruimte om te bespreken waar ik tegenaan liep, maar ook daarbuiten mocht en mag ik je altijd appen, hoe druk je ook bent. Je bent geïnteresseerd in mij als persoon, hoe het thuis en met de kinderen gaat, en hoe het met mijn opleiding gaat. Bedankt voor al je vertrouwen in mij, als onderzoeker, als dokter, en als persoon!

Geachte copromotor, dr. van Charldorp, beste **Tessa**. Wat een aanwinst voor mijn onderzoek en promotietraject was het dat jij mijn copromotor wilde worden! Ik heb ontzettend veel van je geleerd en jouw ‘andere blik’ was ontzettend waardevol. Jij ondersteunde me bij mijn eerste stapjes in ‘jouw wereld', en wist me met de juiste vragen en bronnen te leiden van soms warrige en wollige observaties naar objectieve termen om dit te beschrijven. Jij weet altijd de juiste woorden te vinden. Ik bewonder je manier van begeleiding, waarbij je praktische hulp bood wanneer dat nodig was (bijvoorbeeld met transcriberen), maar je me nog veel vaker precies de goede vragen stelde, waardoor ik weer verder kon. Je ondersteunde me, gaf me het gevoel dat ik het niet alleen hoefde te doen, maar gaf me ook de ruimte en daagde me uit om mijn eigen gedachtes te ontwikkelen en te groeien als onderzoeker. Daarnaast ben je ook altijd geïnteresseerd in hoe het met mij persoonlijk gaat en ben ik meermaals welkom geweest in je prachtige huis en tuin. Net als de plantjes in je moestuin, heb je mij altijd precies gegeven wat nodig was om te groeien en bloeien. Bedankt!

Hooggeleerde beoordelingscommissie en promotiecommissie, prof. dr. **J. Frenkel**, prof. dr. **S.E. Geerlings**, prof. dr. **M. Huiskes**, prof. dr. **M.F. van der Schaaf**, prof. dr. **F.E. Scheepers**, dr. **E. de Groot**, dr. **M.J. van Dam**, bedankt voor uw interesse, tijd en uw kritische blik op dit werk.

Jan Willem, **Paula**, **Maria**, **Wendy**, **Marieke**, **Harriët**, **Titus** en **Elsemieke**, met jullie als collega's en kamergenoten heb ik mijn onderzoeks-avontuur mogen delen. Bedankt voor alle gezelligheid, de vaste half 11 koffiepauzes, middagwandelingen (want je kan niet de hele dag achter de computer zitten!), opbeurende gesprekken als iets tegenzat, (statistische) adviezen, vakantietips, olympische poules, informatie over voetbal, lacrosse en veel te lange hardloopwedstrijden, en gesprekken over alles en niks. **Maria**, speciale dank aan jou voor het opzetten van de CONTACT-studie, waardoor ik op een rijdende trein kon starten, en dat ik altijd jouw epidemiologische kennis kon raadplegen.

Ook wil ik **Jan Jelrik**, **Henri**, **Bianca**, **Sonja**, **Jesper**, **Patrick**, **Eva**, **Berend**, **Quinten**, en de rest van de researchbespreking, bedanken voor het meedenken, de kritische vragen, de feedback, het enthousiasme om naar de eindpresentaties van al 'mijn' wetenschapsstudenten te luisteren, de mogelijkheid om altijd vragen te stellen, de vele inkijkjes in andere onderzoeken, én natuurlijk voor de leuke uitjes!

Meerdere wetenschapsstudenten hebben een bijdrage geleverd aan mijn promotietraject. **Danÿ** en **Lisa**, vanuit een 'ander' veld was jullie blik op de

CONTACT-studie en de interviews met artsen waardevol. **Alissa**, bedankt voor je interviews met patiënten, je hebt een hoop werk verricht in een korte stage. **Noa**, je hebt een grote bijdrage geleverd aan de interview studie met patiënten. Ook na je wetenschapsstage heb je veel tijd gestoken in analyses, data-sessies en overlegmomenten, bedankt! **Noushin** en **Umo**, jullie durfden het aan om in het diepe te springen en met mij mee te worstelen met transcriberen en conversatie analyse. **Judith**, dankzij jouw harde werk konden we snel inspringen op de COVID-19 pandemie en beschrijven wat dit deed met behandelcodes. **Denise** en **Susanna**, bedankt voor al jullie harde werk, inclusies, analyses en inzichten in de data bij de ICARE-studie. Zonder jullie was het me nooit gelukt om (hoogzwanger over de afdeling waggelend…) alle patiënten te includeren. Het was een voorrecht om jullie allemaal te mogen begeleiden en te zien groeien in jullie wetenschapsstage. Tot slot **Emma**, ik heb jou niet zelf begeleid, maar ik heb ervan genoten om op de achtergrond jouw scriptie mee te lezen en jouw conversatie analytische blik op data te zien.

Mijn dank gaat verder uit naar mijn **coauteurs**. Ook dank aan de **NIV** en met name **Samara Jaber** voor de kans om, destijds in het kader van Choosing Wisely, Verstandige Keuzes uit te werken waaronder het bespreekbaar maken van behandelwensen en -grenzen. Daarnaast wil ik de researchverpleegkundigen **Bianca Silvius**, **Inge Klaassen** en **Corina Joosten** bedankten voor hun hulp bij het includeren van patiënten in de CONTACT-studie en **Inge Wisselink** voor de hulp bij het includeren van patiënten in de ICARE-studie. **Marieke Vianen**, bedankt voor je hulp bij datamanagment. **Paco Welsing**, bedankt voor je uitgebreide en geduldige uitleg bij statistische vragen. Ook wil ik alle **simulatiepatiënten** die betrokken zijn geweest bij de vele trainingen die we in studieverband én daarna hebben gegeven bedanken voor hun bijdrage en feedback aan de trainees en mij als trainer.

Alle deelnemers aan het **BasisNetwerk Behandelwensen** wil ik graag bedanken voor de tijd, betrokkenheid en het enthousiasme. Onze plannen waren groots om geleerde lessen en onderwijsmaterialen snel en makkelijk met elkaar te delen, en ik waardeer het dat zovelen uit verschillende ziekenhuizen hierbij betrokken waren. Helaas zijn de plannen in COVID-tijd gestrand, wellicht is dit een mooi moment om het nieuw leven in te blazen?

Beste **Marjel van Dam** en **Bernard Fikkers**, jullie stonden met Karin aan de wieg van het BasisNetwerk Behandelwensen. Toen ik als promovendus betrokken raakte, schoven jullie mij zonder twijfel naar voren terwijl jullie mij op de achtergrond ondersteunden. Bedankt voor die leerzame ervaring! **Marjel**, bedankt voor je betrokkenheid en inzichten bij de start van mijn project. We zijn elkaar rond COVID helaas uit het oog verloren, maar gelukkig neem je nu plaats in mijn promotiecommissie. **Bernard**, bedankt voor al je belangstelling in mijn onderzoek, je enthousiasme en je aanmoedigingen, ook als ik weer eens vergat terug te mailen.

Beste **Jan Willem Fijen**, **Lenneke van Lelyveld-Haas** en **Martine Otten**, bedanken voor jullie interesse in de studies in dit proefschrift en de uitnodiging om hierover in het Diakonessenziekenhuis onderwijs te geven.

Beste **Joppe**, bedankt voor je hulp bij de laatste loodjes van de ICARE-studie. Dankzij jou is het gelukt om dit stuk af te krijgen!

Naast de personen die betrokken zijn geweest bij mijn proefschrift, wil ik deze mogelijkheid ook graag gebruiken om iedereen die een bijdrage aan mijn opleiding tot internist en ontwikkeling als dokter heeft geleverd te bedanken.

Allereerst alle **internisten**, **MDL-artsen** en **klinisch geriaters** uit het **Diakonessenziekenhuis**. Vers uit de schoolbanken kwam ik bij jullie als ANIOS, en ik mocht vervolgens ook de eerste jaren van de opleiding tot internist onder jullie hoede doorlopen. In het Diakonessenziekenhuis heb ik vele 'eerste keren' als dokter meegemaakt. Bedankt voor de fijne begeleiding, goede sfeer, alles wat ik van jullie heb mogen leren, en de leuke tijd met gezellige borrels, uitjes en weekenden. Ook dank aan mijn **collega-A(N)IOS** hiervoor! Mijn speciale dank gaat uit naar dr. A.F. Muller, beste **Alex**, wat een ontzettend fijne opleider was jij! Jij zag mij ook als ik niet direct op de voorgrond stond en toonde jouw vertrouwen in mij. Ik denk nog regelmatig aan jouw opmerking dat bescheidenheid (ook) een goede eigenschap is. Doordat jij uitdroeg dat je ook mensen nodig hebt die 'gewoon goede dokters zijn', heb ik nooit de druk gevoeld te moeten promoveren. Bedankt voor de fijne tijd en begeleiding! Mijn dank gaat ook uit naar de **intensivisten**, **cardiologen** en **longartsen** van het **Diakonessenziekenhuis** voor de leerzame stages die ik bij jullie heb gehad.

Mijn opleiding tot internist heb ik vervolgd in het **UMC Utrecht**. Ik wil alle **stafleden** en **collega-A(N)IOS** uit het UMC Utrecht bedanken voor de leuke en leerzame tijd, en denk met veel plezier terug aan de onderwijsmiddagen.

Ook wil ik graag **Sanne**, **Els**, **Iris** en **Esther** bedanken. Jullie stonden altijd klaar om mij te ondersteunen, (weer) een wijziging in RGS door te voeren en te helpen met de praktische organisatie van de training 'bespreekbaar maken van behandelwensen en -grenzen' voor A(N)IOS. Daarnaast waardeer ik het begrip en de ondersteuning van **Jan Jelrik** en **Roos** om mijn opleiding te vervolgen in het Amsterdam UMC.

Beste **Frederiek van Doormaal**, **Frits Holleman**, **Prabath Nanayakkara**, opleidingsteam van de acute geneeskunde, en **Suzanne Geerlings**, hoofdopleider, bedankt voor de mogelijkheid om mijn differentiatie acute geneeskunde in het Amsterdam UMC te doen. Beste **Frederiek**, bedankt dat je als opleider altijd interesse toont, duidelijk maakt dat niet iedereen hetzelfde hoeft te zijn, en meedenkt in mogelijkheden in plaats van onmogelijkheden, ook met betrekking tot werk-privé balans. Je enthousiasme en inzet voor de opleiding acute geneeskunde, én organisatie van borrels, waardeer ik. Beste **Frits**, ook al heb je het stokje overgedragen, opleiden en opleider zijn zit in jou. Je straalt altijd tijd en rust uit voor uitleg of supervisie, zelf als je op dat moment niet eens supervisie hebt. Beste **Prabath**, ook al hebben we op de werkvloer nog weinig samengewerkt, je bent altijd enthousiast en geïnteresseerd, ook in mijn onderzoek, bedankt daarvoor! En uiteraard wil ik ook de rest van de internisten acute geneeskunde **Jarom**, **Jonne**, **Yvo**, **Remco**, **Marjolein** en **Paul** bedanken voor de leerzame momenten die er al geweest zijn, en ongetwijfeld komend jaar nog zullen komen!

Daarnaast wil ik alle **stafleden** en **collega A(N)IOS** in **het Amsterdam UMC** bedanken voor het warme welkom, de vele leerzame momenten, en het begrip voor de (soms lastige) overstap naar een groot nieuw ziekenhuis in een nieuwe regio. De afdelingen **tropengeneeskunde** en **ouderengeneeskunde** wil ik extra bedanken voor de leerzame stages.

Tot slot heb ik een deel van de differentiatie in het **OLVG** mogen doen, waar ik opnieuw ontzettend veel heb mogelijk leren van alle **stafleden**, **collega A(N)IOS**, en met name van de internisten acute geneeskunde **Ineke**, **Marieke** en **Jan Willem**. Bedankt voor de leerzame tijd!

In de drukke jaren van de opleiding onderbreken voor promotieonderzoek, de COVID-tijd, de geboorte van onze eerste zoon, weer starten met de opleiding, de overstap naar een andere regio, de geboorte van onze tweede zoon, en tussendoor nog de afronding van dit proefschrift, kon ik altijd rekenen op de steun en een luisterend oor van familie en vrienden. Ik kan dit dankwoord dan ook niet anders afsluiten zonder stil te staan bij al hun hulp.

Lieve **Marion** en **Chantal**, wat fijn dat jullie mijn paranimfen willen zijn! **Marion**, we kennen elkaar sinds de peuterspeelzaal (dat is al 32 jaar!) en zijn sinds de basisschool bevriend. Ik herinner me nog menig kinderfeestje. **Chantal**, jou ken ik sinds de middelbare school, maar dat maakt onze vriendschap niet minder hecht. De 3 pubers die kletsend en giechelend op de fiets naar school gingen, zijn nu 3 volwassen vrouwen. Wat hebben wij veel met elkaar meegemaakt en gedaan. Vakanties, feestjes, concerten, weekendjes weg, ontelbaar veel uitjes, activiteiten, eten en drinken. Hoeveel liters thee zouden wij samen hebben gedronken? Inmiddels zijn er huizen gekocht (Marion helaas wat verder weg dan vroeger), is er getrouwd en zijn er kinderen geboren (lieve kleine **Dani**, hopelijk volgen er vele speelafspraakjes met Luuk en Koen!). Ook als we elkaar even wat minder spreken, is het altijd gelijk weer als vanouds. Met jullie kan ik altijd lachen, maar is er ook ruimte voor een traan. Ik hoop dat we later als bejaarde omaatjes nog steeds regelmatig thee leuten en terug kunnen denken aan de 3 pubers op de fiets. Bedankt dat jullie tijdens de verdediging aan mijn zijde willen staan! **Dirk** en **Jowin**, bedankt dat jullie in het leven van mijn vriendinnen zijn en hen zo gelukkig maken.

Lieve **Bianca**, **Ilse**, **Imke**, **Marleen**, **Marloes**, **Vivianne**, IL-7, bedankt voor jullie vriendschap. Wat mooi om te zien waar we, van jaar 1 geneeskunde, nu naar zijn uitgevlogen en hoe iedereen zijn eigen richting heeft gekozen. Bedankt voor alle gezelligheid, samen studeren, etentjes, karaoke, (gala)feestjes, afstudeerliedjes, koppen thee, het delen van een huis (Imke) en zolder (Ilse, ik kon me geen beter zoldergenootje wensen). Maar ook de spiegels die jullie kunnen voorhouden, de eerlijke meningen, de koffiedates, de babyshowers en speeldates met de kinderen waardeer ik. Ook al zien we elkaar niet wekelijks, ik kan altijd op jullie rekenen.

Lieve **Thijs**, **Bibianne**, **Lara**, en kleine **deugniet-op-komst**, wat een fijne vrienden zijn jullie! Bedankt voor alle gezelligheid, stranddagen, themafeestjes (waar je blijkbaar verkleed moet komen…), spelletjes, paaseitjeszoeken, creativiteit, etentjes en betrokkenheid.

Lieve **Kees** en **Liesbeth**, wat bof ik met zulke fijne schoonouders. Jullie staan altijd voor ons klaar. Met verhuizen, klussen in de tuin, de zolder, of oppassen op de jongens, we kunnen altijd op jullie rekenen. Jullie zijn een super opa en oma voor Luuk en Koen. Het is ontzettend fijn dat ze elke week een dag bij oma Pater mogen spelen, waar ze enorm verwend worden en ook nog regelmatig hun overgroot oma's kunnen zien! Zonder de vele (extra) oppasuurtjes was dit proefschrift nooit afgekomen, bedankt!

Lieve **opa** en **oma Schipperen**, ik prijs me gelukkig met jullie als opa en oma. Ik heb vele fijne herinneringen aan oppassen en vakanties op de camping. Ik ben altijd welkom voor een kop koffie terwijl Luuk en Koen kijken uit jullie raam naar de treinen en boten kijken, en jullie tonen altijd belangstelling voor waar ik mee bezig ben. Daarnaast zijn jullie een groot voorbeeld, al 68 jaar getrouwd en nog steeds gelukkig samen en jullie ondernemen nog van alles. Op onze bruiloft waren jullie regelmatig op de dansvloer te vinden! Ik hoop dat ik, als ik jullie leeftijd mag bereiken, net zo kan genieten van het leven als jullie.

Lieve **opa Briedé**, u bent altijd geïnteresseerd in mij, mijn gezin, werk en promotietraject. Ik besef me dat ik ontzettend bof met 3 grootouders met wie ik deze belangrijke momenten kan delen, maar dat maakt het gemis van oma niet minder. Helaas heeft zij deze promotie niet meer mee mogen maken. Naast dat oma altijd betrokken was, en mij bijvoorbeeld direct belde om me te feliciteren toen ik naar Amsterdam mocht voor mijn differentiatie, was zij ook een voorbeeld van iemand die heel bewust nadacht over het onderwerp van dit proefschrift, behandelwensen en -grenzen. Ik vind het knap hoe u met dit verlies om gaat en ik ben blij dat ik altijd langs mag komen voor een kopje koffie, thee, of wat sterkers.

Lieve **Sandra**, mijn lieve grote zus en mijn grote voorbeeld. Ik zeg het niet vaak genoeg, dus bij deze schrijf ik het op. Je bent er altijd voor me. Je nam vroeger zelfs je kleine zusje mee op sleeptouw als je ging stappen. Bij jou kan ik terecht voor (opvoed)advies, hulp, en ongezouten kleding-advies. Ik weet soms niet hoe je het voor elkaar krijgt om alles te doen wat je doet. Ik bewonder dat het je lukt om naast werk en een gezin met 3 kinderen en een kat toch ook altijd tijd vrij te maken voor familie en vrienden. Als ceremoniemeester op onze bruiloft had je alles super geregeld en onder controle. Je bent een fantastische moeder voor Mila, Yuna en Ezra en een geweldige tante voor Luuk en Koen. Je paste zelfs een vaste dag in de week op de bofkonten! Bedankt voor al je hulp, steun en vriendschap. Ik had het niet beter kunnen treffen dan met jouw als zus.

Lieve **Dico**, ik bewonder je doorzettingsvermogen en hoe je steeds weer doorgroeit en je verder ontwikkeld, in je werk en als persoon. Je hebt het niet altijd makkelijk gehad, maar kan trots zijn op wat je hebt bereikt. Je bent een fijne oom voor Luuk en Koen en ik waardeer het dat je altijd je best doet voor hen (zelfs toen ze eenkennig waren en het zelf niet waarderen). Bedankt dat je al zo lang onderdeel bent van onze familie, ik geniet van jullie mooie gezin!

Lieve **Mila, Yuna** en **Ezra**, wat fijn dat ik jullie tante mag zijn. Met jullie is het nooit saai (en nooit stil…). Ik wordt blij van alle knuffels en tekeningen die ik afgelopen jaren van jullie heb gehad en Luuk en Koen zijn ook gek op jullie. Het is prachtig om te zien hoe jullie opgroeien en allemaal je eigen karakter ontwikkelen.

Lieve **papa** en **mama**, ik weet niet waar ik moet beginnen. Jullie zijn er altijd voor me. Toen ik op kamers ging, hebben jullie geholpen met verven (roze, zoals ik wilde). Jullie hebben zelfs stiekem voor me behangen toen ik er niet was. Toen ik werd aangenomen voor de opleiding tot internist, stonden jullie voor de deur om het te vieren. Toen we ons huis kochten, namen jullie 2 weken vrij om te helpen klussen, en ook daarna hebben jullie nog vele avonden en weekenden geholpen als we weer eens iets wilden veranderen. Toen ik een halve marathon liep, stonden jullie bij de finish. En toen Luuk en Koen werden geboren, wilde mama zonder twijfel een vaste dag in de week oppassen. Ook als we een keer extra oppas nodig hebben, kan het eigenlijk altijd. Jullie zijn een geweldige opa en oma, voor alle kleinkinderen. Ik vind het fijn dat ik in de auto onderweg naar huis altijd even kan bellen om over de dag te kletsen (of te klagen). Daarnaast geniet ik van onze spelletjes avonden (vooral als ik win, maar zelfs als ik verlies). Ook met onze bruiloft stonden jullie ook voor ons klaar: strijken van de overhemden van Luuk en Koen, ophalen van de bloemen, niks is te veel gevraagd. En jullie passen zelfs je vakantie aan onze vakantie aan, zodat we naar jullie caravan in Ouddorp kunnen. Het is te veel om alle dingen op te noemen die jullie voor me doen, dan wordt dit dankwoord veel te lang, maar ik kan altijd op jullie rekenen. Jullie vinden het allemaal vanzelfsprekend, maar dat is het niet! Bedankt voor alles!

Lieve **Marcel**, ik ben zo gelukkig dat ik je sinds kort mijn man mag noemen. Ik kan niet in een paar zinnen beschrijven waar ik je allemaal dankbaar voor ben en hoeveel ik van je hou. Zonder jouw steun, in mentale én praktische zin, was dit proefschrift er nooit gekomen. Je was de allerbeste coronatijd-thuiswerk-collega die ik me kon wensen en hebt vele cappuccino's met hartjes voor me gemaakt. Mijn omschrijvingen en lelijke penkrabbels toverde jij om tot figuren die nog mooier waren dan ik in mijn hoofd had en ik ben super trots op de mooie cover die jij hebt gemaakt, ook al was mijn planning wat krap. Jij steunt me in alles, maar zorgt tegelijkertijd dat ik niet uit het oog verlies wat écht belangrijk is. Jij bent de liefde van mijn leven, een geweldige vader, mijn rots in de branding en mijn thuis. Samen kunnen we alles!

Lieve **Luuk** en **Koen**, jullie zijn de leuksten en de liefsten! Wat ben ik blij met jullie en wat maken jullie mij gelukkig. Vergeleken daarbij is al het andere onbelangrijk. Het was soms moeilijk om tijd vrij te maken voor de laatste loodjes van dit proefschrift, tijd die ik liever met jullie doorbracht, maar het is gelukt. Ik geniet iedere dag van jullie en vind het heerlijk om te zien hoe jullie steeds weer nieuwe dingen leren, ontzettend lief met elkaar kunnen spelen, en samen boevenstreken kunnen uithalen. Naar jullie kan ik uren kijken. Een lach, kus of knuffel van jullie maakt iedere dag goed. Jullie zijn alles!

List of publications

This thesis

Briedé S, van Goor HMR, de Hond TAP, van Roeden SE, Staats JM, Oosterheert JJ, van den Bos F, Kaasjager HAH. Code status documentation at admission in COVID-19 patients: a descriptive cohort study. *BMJ Open*. 2021 Nov 10;11(11):e050268. doi: 10.1136/bmjopen-2021-050268. PMID: 34758991

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Oral presentations

Briedé S, van Charldorp TC, Peerden JP, Kaasjager HAH. Physicians' training and patient education initiative to improve quality of care decision communication at the emergency department. *Nederlandse Vereniging van Internisten Acute Geneeskunde congres*, jun 2024

Meinardi M, Kaasjager HAH, Fikkers B, **Briedé S.** Workshop Proactieve zorgplanning: de juiste vragen op het juiste moment door de juiste persoon. *Landelijke Opleidingsdag Interne Geneeskunde*, feb 2024

Briedé S, Kaasjager HAH. Bespreekbaar maken van behandelwensen en -grenzen. *8th Netherlands International Sepsis Symposium*, feb 2022

Briedé S, van Charldorp TC, Kaasjager HAH. Introducing a precarious topic: care decisions at the outpatient clinic of internal medicine. *Anéla Working Group Interaction Analysis Conference*, okt 2020

Briedé S, Kaasjager HAH. De patiënt centraal, begint bij de dokter. *Nederlands Vasculair Forum*, nov 2019

About the author

Saskia Briedé was born on June 29th 1990 in Utrecht, the Netherlands. She grew up in Maarssen with her sister, Sandra. After graduating from the Gerrit Rietveld College (Gymnasium) in 2008, she started medical school at Utrecht University. At the end of 2014, she obtained her medical degree. In 2015, Saskia started working as a physician in the Department of Internal Medicine at the Diakonessenhuis in Utrecht, followed by her training as a resident in Internal Medicine in the same hospital, supervised by dr. A.F. Muller. In 2018, she continued her residency at the University Medical Center Utrecht, supervised by prof. dr. H.A.H. Kaasjager. A strong preference for teaching was already evident during secondary school, when she was tutoring as a part-time job. This love for education continued, which can be seen in tutoring throughout medical school and elective educational internships during the master's phase and internal medicine residency.

It was the training and educational aspect of this research project that won Saskia over to start with the study at the outpatient clinic in 2019. Besides, the topic of care decisions ('*behandelwensen en -grenzen*') was close to her heart as she saw the need for improvement of these conversations in everyday practice. Still, she was quite reluctant to look at it as a PhD trajectory. Saskia saw herself more as a clinician and educator than a researcher. She started under supervision of prof. dr. H.A.H. Kaasjager and dr. T.C. van Charldorp, but it was only after the first study raised several new questions, and plans were developed to further investigate those areas, she started to see herself as a researcher as well. During her PhD, she presented her work at several international and national conferences, including the Anéla Working Group Interaction Analysis Conference and the Netherlands International Sepsis Symposium. Saskia further developed the patient educational materials and physicians' training and supervised the physicians' training. After two years, one baby and pregnant from the second, she continued with her training as a resident in Internal Medicine at the Amsterdam UMC, supervised by prof. dr. S.E. Geerlings. She started with the differentiation Acute Internal Medicine, supervised by dr. F.F. van Doormaal and dr. F. Holleman. She will complete the differentiation Acute Internal Medicine at the end of 2025. Saskia lives in Maarssen with her husband Marcel and their children Luuk and Koen.


physician training
patient education
physician initiates
interactional effort
physician key role
hesitations
repairs
no interactional slot
accountability
RELEVANCE
common ground
awareness
physician patient relationship
timing
relevance paradox
~~end of life~~
time