Physician-related Factors concerning Treatment Limitations

A qualitative study

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Abstract

Discussing patient preferences regarding treatment limitations is important for patient-centred care. This leads to higher satisfaction among patients, lower rates of anxiety of family members and lower health care costs. However, most physicians found it hard to initiate these conversations with their patients and therefore it is common for physicians to avoid them. The aim of this qualitative study was to examine the perspectives of physicians regarding the discussion of treatment limitations and the factors that might influence them in discussing treatment limitations at the outpatient clinic. Besides that, it examined if a communication training affects the physicians in their discussions about treatment limitations. Therefore, physicians were observed during consultations with patients at the outpatient clinic, both before and after they participated in a communication training about treatment limitations. Barriers that were found included practical barriers, like a lack of time, and personal barriers, like a different cultural background. Facilitators that were found included a more informed patient and agreement on criteria. This study confirmed prior research that treatment limitations were discussed in a minority of the consultations at the outpatient clinic. The communication training was especially helpful because it created awareness about this topic, the physicians received feedback from colleagues and for recognition between the colleagues.

Keywords: treatment limitations, patient preferences, communication, physician perspectives, advance care planning, outpatient clinic

Physician-related Factors Concerning Treatment Limitations

Research shows that patient-centred care improves disease outcomes and quality of life and therefore this topic is receiving more attention in today's health care (Epstein, Fiscella, Lesser, & Stange, 2010). An important attribute of patient-centred care is to involve and actively engage patients in treatment decisions (Barry & Edgman-Levitan, 2012). To achieve this, it is important to discuss both the possibilities and the limitations of a treatment. The goal of these conversations is to get a better understanding of a person's value and goals regarding their treatment (Sinuff et al., 2015). It is, for example important to discuss the preferences of a patient concerning themes like resuscitation, medical ventilation and admission on the intensive care unit (ICU) (UMC Utrecht, 2018). Stimulating patients to make decisions about their future health care is known as advance care planning. This is associated with higher satisfaction among patients, lower rates of anxiety among patients and their family members and lower health care costs (Detering, Hancock, Reade & Silvester, 2010; Sinuff et al., 2015; Zhang et al., 2009).

Despite the benefits of discussing patients' preferences regarding their treatment and possible treatment limitations, most physicians find it hard to initiate these conversations. Therefore, it is common for physicians to avoid these conversations (UMC Utrecht, 2018; Walczak et al., 2013). One reason for this seems to be a lack of communication skills (Anselm et al., 2005; Tulsky, Chesney, & Lo, 1995). To encourage physicians to discuss treatment limitations, training the required communication skills may be helpful (Légaré & Thompson-Leduc, 2010; Romotzky et al., 2015; Walczak et al., 2013).

At this moment there is a big difference in how and when physicians discuss the preferences of a patient concerning treatment limitations (UMC Utrecht, 2018). Kunneman et al. (2015) found that treatment limitations are discussed in a minority of the consultations. This leads to that these discussions are often held at the emergency room or during acute

patient events (Tandon, 2018). This causes stress for patients, their families and their physicians. Also, by delaying these discussions about treatment limitations patients may become incapable of making treatment decisions, for instance due to cognitive impairment (Brinkman-Stoppelenburg, Rietjens & van der Heide, 2014). It is therefore important to discuss these topics early and not only during acute and emotional moments (Bernacki & Block, 2014; UMC, 2018). This can be done by having these discussions about treatment limitations at the outpatient clinic, where patients visit their physicians for their regular consults (Tandon, 2018; UMC Utrecht, 2018). According to Chandar et al., (2017) a majority of the health care providers working with patients with advanced cancer and congestive heart failure, agree that the best location to discuss advance care planning preferences is the outpatient clinic. However, no research is done about the perspectives of physicians regarding discussing treatment limitations at the outpatient clinic, with patients with less acute and more chronic illness.

This study. A better understanding of the perspectives of physicians regarding the discussion of treatment limitations at the outpatient clinic, can contribute to more insight into the difficulties physicians experience and what could facilitate them in these conversations. These perspectives could give an insight into which interventions would adequately educate and facilitate the physicians, in their own context and environment (Anselm et al., 2005; You et al., 2015). This will be helpful for the implementation of interventions that will be necessary to increase the conversations with patients about their preferences concerning treatment limitations. These perspectives could include both personal as work-related factors. This leads to the following research questions:

a) Which physician-related factors are influencing Dutch physicians on their discussion of treatment limitations with their patients at the outpatient clinic?

b) What is the influence of a communication training for Dutch physicians on discussing treatment limitations with their patients at the outpatient clinic?

Theoretical Framework

Patient-centred care. Patient-centred care is defined as "care that is respectful and responsive to individual patient preferences, needs and values, and ensuring that patient values guide all clinical decisions" (Epstein et al., 2010; Morgan & Yoder, 2012). Instead of physician-dominated dialogues, patient-centred care is concerned with engaging patients as active participants (Epstein & Street, 2011). Enabling patients to actively participate in their treatment decisions will result in improved health outcomes and better emotional health and wellbeing of patients (Epstein et al., 2010; Oates, Weston & Jordan, 2000). When the physician is aware of the patient's values and preferences, it will help the physician and the patient in making decisions that are collaborative and in the patient's best interest (Levinson, Lesser & Epstein, 2010). Besides, patient-centred care leads to more efficiency of care, because fewer diagnostic tests are applied and less referrals take place (Epstein et al., 2010; Oates et al, 2000).

Advance care planning. Advance care planning is part of patient-centred care. Discussing patients' preferences about treatment limitations helps patients to make plans about their future health care (Brinkman-Stoppelenburg et al., 2014; Rietjens et al., 2017). This advance care planning enables individuals to define goals and preferences for future medical treatment (Rietjens et al., 2017). It also helps physicians to better understand the patients' values and preferences regarding life-sustaining measures (Chandar et al., 2017). The goal is to enable patients to make decisions about their future treatment, in an attempt to give them care according to their preferences when they are no longer capable of making such decisions (Brinkman-Stoppelenburg et al., 2014). Therefore, it increases patients' satisfaction and their quality of life. Having these discussions early has been associated with less

aggressive care near death and better reported quality of life (Chandar et al., 2017).

Shared decision making. Within patient-centred care the patients' values and preferences are important. In these conversations shared decision making is fundamental. (Légaré & Thompson-Leduc, 2010). Shared decision making (SDM) means that physician and patient exchange information and debate together to come to a decision that matches the patient's values and preferences (Elwyn, Tsulukidze, Edwards, Légaré & Newcombe, 2013). SDM requires (1) announcing that a decision needs to be made based on the patient's preference, (2) providing balanced information about the options, and the pros and cons of each, (3) jointly constructing the patient's preference on the basis of their values and beliefs, and (4) making a decision that matches these preferences (Elwyn et al., 2013). This shared decision making differs from paternalism, in which the physician makes the decision and from informed choice, in which the physician only provides information and the patient makes the final decision after receiving information (White, Braddock, Bereknyei & Curtis, 2007). This shared decision-making process leads to more patient involvement (Brinkman-Stoppelenburg et al., 2014, Kunneman et al., 2015; Rietjens et al., 2017). It is also linked with positive patient outcomes, both in satisfaction as in improvement of their medical status (Charles, Gafni & Whelan, 1997).

Communication. One important factor that physicians appoint as a reason for not discussing treatment limitations or advance care planning is a lack of communication skills (Anselm et al., 2005; Chittenden, Clark & Pantilat, 2006; Slort et al., 2011; Visser, Deliens & Houttekier, 2014). However, especially in topics like treatment limitations, communication is of great importance, both for the outcome of care as the satisfaction of the patient (Ammentorp, Sabroe, Kofoed, & Mainz, 2007; Berkhof, van Rijssen, Schellart, Anema, & van der Beek, 2011). Important to notice is that discussions about care planning and treatment limitations are not a 'one size fits all' conversation (Waldrop & Meeker, 2012).

Communication about a patient's preferences at the end of life can be emotional, difficult and challenging for both patients and physicians (Waldrop & Meeker, 2012). Most physicians practise their communication skills on their own. According to Levinson et al., (2010) physicians almost never get feedback about their interactions with patients, after they leave medical school. Training these communication skills with a training can help a physician to overcome his uncertainty about a specific communication task (Ammentorp et al., 2007).

According to Berkhof et al., (2011) training programmes about communication are effective if they last for at least one day, are learner-centered and focus on practising skills. The communication training is most effective when they include role-play, feedback, and small group discussions. Fallowfield, Jenkins, Farewell and Solis-Trapala (2003), and Bernacki and Block (2014) found that after participating in a communication training, physicians feel more confident, show improved communication skills, use more patient-centered techniques and respond better to patients' emotional cues.

Factors of influence. Except a lack of communication skills, several factors can potentially influence the physicians in discussing treatment limitations. Physicians own barriers may lead to infrequent or inadequate conversations about treatment limitations (Chittenden et al., 2006). A better understanding of these barriers, can help physicians to overcome these barriers and can facilitate better communication (Chittenden et al., 2006). Some research examined the barriers and facilitators of physicians in discussing treatment limitations, however this research mainly focussed on end of life discussions with serious- ill patients at the ICU or about palliative care between patients and their general practitioner, not on discussing treatment limitations in early stages of disease at the outpatient clinic (Slort et al., 2011; Visser et al., 2014).

In previous studies the barriers that were found, were related to physicians' knowledge and skills, their personal attitudes or practices (Visser et al, 2014). Regarding physicians'

knowledge and skills, the most important influencing factor that was found was physicians' lack of training in communication skills (Chittenden et al., 2006; Visser et al, 2014; Waldrop & Meeker, 2012). Regarding physicians' attitudes, the physicians' personal beliefs and values, ethical frameworks and fear of taking hope away were factors of influence (Chittenden et al., 2006; Visser et al, 2014). Regarding physicians' practice, a lack of time or availability seems to be important (Slort et al., 2011; Visser et al, 2014). Visser et al., (2014) found that different disciplines emphasized different factors that were of influence, however some overlap was found. Especially a lack of communication training and a lack of time were mentioned by all disciplines. Because different disciplines emphasized different factors, it is important to discover the factors of physicians in their own context and environment. For no research has been done on the factors that could influence these discussions at the outpatient clinic, the aim of this research is to give more insight in the perspectives of Dutch physicians on discussing treatment limitations at the outpatient clinic with regular patients. Besides, this study will observe if a communication training influences the discussions about treatment limitations at the outpatient clinic of the department of internal medicine at UMC Utrecht.

Method

Research design

To answer the research questions, a qualitative case study was conducted. The main focus of this research was to gather more insight into the perceptions of the physicians concerning the discussion of treatment limitations with patients at the outpatient clinic. By using a qualitative case study, an in-depth study could take place of the participants in their natural setting, so there could be made sense of the phenomena in turns of the meaning people bring to them (Denzin & Lincoln, 2008). Because not much research has been conducted about discussing treatment limitations at the outpatient clinic, this study will help to get a

better understanding of the subject. This study is part of a larger mixed method project, which was initiated by the University Medical Center (UMC) Utrecht. The focus of this larger project is to measure the satisfaction of both patients and physicians about the conversation of treatment limitations, before and after the physicians participated in a communication training.

In this study Dutch physicians were recorded during their regular patient consults both before and after they participated in a communication training. After the training, the physicians were interviewed. Data was collected in two ways, by in-depth interviews and non-participating observations. To answer the first research question, semi-structured individual interviews were conducted with the participating physicians to gather more insight into the perceptions of the physicians about discussing treatment limitations at the outpatient clinic, which barriers and facilitators they experienced and their vision on the communication training. To answer the second research question, non-participating observational research was conducted, by analysing video recordings of conversations between physicians and their patients at the outpatient clinic before and after the physicians participated in a communication training, to see if the communication training had any influence on these conversations.

Participants

This study was conducted at the division of Internal Medicine and Dermatology at UMC Utrecht. UMC Utrecht is one of the largest public health care institutions in the Netherlands. The division of Internal Medicine and Dermatology focuses on internal and dermatological diseases. It consists of several departments. One of the departments is the department of Internal Medicine, which is focused on diagnosing and treating patients with complaints on their internal organs.

Ten physicians working at the outpatient clinic of the department of Internal Medicine

at UMC Utrecht were included to participate in the communication training. The participating physicians were recruited for the interviews through criterion sampling, because the participating physicians needed to meet the criterion of participating in the communication training. This is a form of purposive sampling, which is used for selecting individuals that are experienced with a specific phenomenon (Palinkas, Horwitz, Green, Wisdom, Duan, & Hoagwood, 2015). Seven specialists and three residents were included. Three of the physicians were male. Seven of them were female. The participants had different ages and differed in years of experience. These ten participants participated in the communication training and were recorded during their consultations at the outpatient clinic. All ten physicians were approached for an interview.

Excluded were physicians who already participated in a pilot communication training about treatment limitations before the start of this study. The reason for this is that the participating physicians should not be aware of the topic of this study during the recordings before they participated in the training about treatment limitations, so their conversations were not influenced by it.

Dropout. One physician refused to participate in the interview. The motivation for this was a lack of time. Another physician was invited two times for the interview but did not show up, so it was assumed that participation was declined. Because two of ten physicians refused to be interviewed, one extra physician was selected who did participate at the communication training but who was not recorded during the consultations.

Procedure

Recordings. Data collection took place from February to May at the department of Internal Medicine at UMC Utrecht. Physicians were recorded on video during regular consults at the outpatient clinic at the department of Internal Medicine. The consults lasted their regular time, which is about 15 minutes. There was a variety of patients, with different

diseases and different stages of their diseases. Only consultations of patients who did not yet discussed their preferences regarding treatment limitations, based on their digital file, were recorded. They were recorded through a small camera, which was placed in a relatively discrete position in the room. Both physicians and patients were not instructed on the topics they were supposed to discuss during the consultations. For every physician that was interviewed, one observation was recorded before participating in the training and one observation in the first weeks after the communication training. The recorded videos were transcribed and analysed. Both the physicians as the patients gave informed consent to have their conversations at the outpatient clinic recorded. The signed forms are stored on YODA, which is a safe databank.

Communication training. Physicians participated in a communication training about treatment limitations, which consisted of an e-learning module and a scenario training (Appendix 1). The communication training was designed specific for this study. A pilot training was carried out before the start of this study. The e-learning consisted of clips of different experts explaining why it is important to discuss treatment limitations, different simulation conversations about treatment limitations, theoretical background information, pitfalls for these conversations and explanation on how to document the patient choices in the digital file. The e-learning could be done at the physicians' own time and place.

During the scenario training the physicians practiced their conversations with simulation patients. The physicians were divided in small groups of two or three physicians. All physicians practiced three different scenarios. These conversations were observed and discussed afterwards with each other, where the physicians provided each other with feedback. The goal of this training was to improve the skills of the participating physicians in their communication about treatment limitations.

Interviews. Interviews were held after the physicians had the communication training. The interviews took place within the hospital. All interviews were held in Dutch. During the interviews only the interviewer and the participant were present. Before the interview started, the researcher gave a clear introduction to explain the purpose of the study, told that participation is voluntary and explained the structure of the interview. The interviews were recorded with a voice recorder, so the interviews could be transcribed later. All participants received and information letter and gave active informed consent to be interviewed (Appendix 2&3). Informed consent forms are stored on YODA, which is a safe data bank.

Instruments

Face to face semi-structured individual interviews were held with nine participating physicians. The purpose of the interviews was to explore the perspectives of the physicians regarding the topic of treatment limitations. According to King (1998) using interviews is especially suited for examining topics in which different opinions need to be explored. The interviews contained questions based on the topic list and are described in the interview guide (Appendix 4 & 5). The main themes that were discussed during the interviews included the physicians' perception of discussing treatment limitations at the outpatient clinic, how and when treatment limitations are currently discussed, which barriers are experienced, what could facilitate the physician in these discussions, and their experience with the communication training. Because the interviews were semi-structured, some questions were discussed in more detail and follow up questions were asked. The instrument changed during data collection, due to evolving insights (Guba, 1981; King 1998). All changes that occurred during the interviews are described in an auditlog (Appendix 6).

Data analyses

Interviews. After conducting the interviews, all interviews were transcribed. All transcripts were scanned and prepared for analysis. The data was coded using Nvivo 12.0.

The interviews were analysed through template analysis (King, 2010). The choice for template analysis was made because it is a flexible technique and works especially well when the aim of the study is to compare perspectives of different participants in a specific context (King, 1998). This style of analysis is used regularly to analyse data from individual interviews (King, 2012). An initial coding template was developed with some a priori codes, which consisted of themes identified as important from the literature (Appendix 7). The initial coding template consisted of the topic treatment limitations and when and where they were discussed currently, barriers related to the physicians' personal attitudes, practices and knowledge and skills, the physicians' facilitators, and their experience with the communication training.

All transcripts were read systematically and relevant sections of text were marked with the a priori codes from the initial template. Thus, sections of the text which were identified as important for this study were labelled with a code. Themes that seemed to be important were organized in meaningful clusters (King, 2012). In this way new codes were developed during the analysis to include the new relevant material (Appendix 6). So, the initial template was used to analyse the text but was also revised during the ongoing analysis. The final coding scheme is included as Appendix 8. After the coding, analysis took place (Appendix 9)

Coding of the interviews. Different themes were coded during the analysis of the data. The first theme that was coded, was the process of discussing treatment limitations, with sub concepts like timing and place, on whose initiative the conversation started and criteria. The second theme consisted of the different barriers such as practical barriers, personal barriers, and barriers concerning the physicians' knowledge and skills. The third theme consisted of the different facilitators which were experienced by the physicians.

Observations. For the observational research, the 16 video recordings were first viewed globally, to get a general idea of the content of the consultations at the outpatient

clinic. The video recordings were transcribed and analysed for the verbal behaviour of the physician and the patient. The video recordings were analysed using template analysis. Although template analysis is commonly used for interview transcripts, the flexibility of the technique makes it also suitable for different data, such as the transcripts of observations (Brooks, McCluskey, Turley & King, 2015). The observational data was used to complete the data gathered from the interviews and to see if the observations matched with the perceptions of the participants.

Coding of the observations. The most important theme in the video recording was if treatment limitations were discussed. If treatment limitations were discussed, the conversation was analysed further by looking at several themes. Themes that were analysed were if a decision was made, who initiated the conversation about treatment limitations and if the patient of physician reacted emotional. The observations were also used to see what time a regular consult with or without discussing treatment limitations took. These themes were analysed because they seemed to be important according to the physicians. A coding scheme for the observations is included as Appendix 10. After coding analysis took place (appendix 11).

Quality criteria

To ensure the validity of this research different procedures have been used, to take into account the credibility, transferability, dependability and conformability.

In this research triangulation was used (Anfara Jr, Brown & Mangione, 2002; Guba, 1981). Triangulation is a validity procedure where researchers use multiple and different sources of information to form themes in a study (Creswell & Miller, 2000). In this study both observations of the conversations and interviews with the participants have been used for analyses. In this way confirming evidence was provided, which is essential for the credibility. After transcribing the interviews, member checking has been used, which means the

participants checked the transcripts for interpretation (Cresswell & Miller, 2000). According to Lincoln and Guba (1985) member checking is the most crucial technique for establishing credibility. This did not result in any changes.

This study was done in a specific context, which has been described in detail. Therefore, all assumptions are only made regarding this context. In this way transferability is guaranteed (Lincoln and Guba, 1985).

To ensure the dependability of this study an audit trail was logged, which consists of a journal with all notes and decisions, in this way it should be clear how this study might be influenced. By giving full insight in the coding scheme and the process of analysing the data, all findings, conclusions and interpretations are traceable (Guba, 1981). The audittrail is included as Appendix 6.

Feedback from peers was used for confirmability (Cresswell & Miller, 2000). The analytical process was audited by a peer to check the codes for interpretation. Changes which have been made are included in Appendix 6.

Results

Both the results of the interviews as the observations are described below. The most important themes of the interviews and the observations are discussed. One coded transcript and one transcript of an observation are included as an example (Appendix 12&13). Al other transcripts are stored on YODA. The quotes that are used in this result section are translated, the original Dutch quotes are included as Appendix 14.

Interviews

Treatment limitations. All physicians agreed that discussing treatment limitations is an important aspect of their jobs. They all thought it was important to be informed about the preferences of their patients regarding topics as resuscitation, medical ventilation and admission at the ICU. All physicians did have experience with discussing treatment

limitations, especially during their shifts at the emergency room or intensive care unit.

Timing and place. All physicians agreed that currently treatment limitations were not discussed regularly at the outpatient clinic. The opinions differed among the physicians about what the best timing and place was for discussing treatment limitations. Most of the physicians said it would be best to discuss the preferences concerning treatment limitations at the outpatient clinic only if certain criteria were applicable or if there was a direct cause to discuss treatment limitations. They thought it was unnecessary to discuss treatment limitations with every patient, because for some patients it was not relevant at all at this moment. These physicians did think, that for patients for whom these topics were relevant, the outpatient clinic was the best place to discuss the preferences of a patient concerning treatment limitations instead of the emergency room or the ICU. Reasons that were given were that a physician at the outpatient clinic normally knows the patient very well, has a long treatment relationship, and the quiet setting at the outpatient clinic: “I think it is good to discuss treatment limitations at the outpatient clinic because of the quiet setting, the generally good relationship between the physician and the patient and the fact that they have a long-term treatment relationship.” (Physician 8).

Some physicians would prefer to talk about this subject with all their patients at the outpatient clinic. By discussing this topic regularly with all patients, patients would know it is part of the routine and will feel less overwhelmed by it. For physicians, it would be easier to discuss this topic, because they do not have to decide if the topic is applicable for a specific patient. “It would help if you could say to the patient, I’m not only discussing this with you, but we discuss this with all our patients.” (Physician 1). The reason that these physicians are currently not discussing treatment limitations with all their patients is that at the moment there is no general agreement within the hospital about this topic.

One physician thought the best time and place to discuss treatment limitations was

during admission at the hospital or at the emergency room because at that moment it was really applicable. However, this physician agreed that if there was a direct cause for discussing treatment limitations, the best place was the outpatient clinic.

Criteria. Most of the physicians agreed that currently there is no general agreement on criteria or a guideline about when to discuss treatment limitations. According to some physicians it would be helpful to agree nationally or within the hospital on criteria about when to discuss treatment limitations. By arranging several criteria, it would feel less random to discuss treatment limitations and patients would be less overwhelmed. Criteria that were mentioned were age, the prospect of a disease and comorbidity. Other physicians stated that agreement on criteria was not necessary. Reasons these physicians mentioned were that it is difficult to set up criteria because it depends on various factors and that physicians are able to decide for themselves if discussing treatment limitations is applicable for a specific patient: "It's not exact science. It is not that simple that you could say, we discuss this with everybody above 70 years old or something. That's just not how it works." (Physician 9).

Initiative. Conversations about treatment limitations are mostly initiated by the physician and not by the patient. "No, patients never start about treatment limitations in the outpatient setting." (Physician 5). All physicians agreed that the physicians, and not the patient, are responsible for discussing treatment limitations. Patients could experience boundaries in discussing this topic, because of their emotions or the heaviness of this topic: "You need to support and facilitate the patient in it. And that means, you need to ask the question. Because it's not the patients' job to start about it out of the blue during the consult. So, it is your responsibility, as a doctor." (Physician 2). However, some patients feel relieved when the physician initiated the conversation about treatment limitations. These patients already thought about treatment limitations or even discussed it with the general practitioner, but never discussed it with a physician at the hospital.

Barriers. Physicians mentioned several barriers for discussing treatment limitations at the outpatient clinic. The most important barriers are discussed below.

Practice. Practical issues that can prevent a physician in discussing treatment limitations at the outpatient clinic with their patient are a lack of time and no direct cause for it.

Time. All physicians mentioned a lack of time as a barrier to discuss treatment limitations during their consults at the outpatient clinic. They all stated that it would take too much time to discuss treatment limitations with all the patients. Regular consults at the outpatient clinic are supposed to have a duration of 15 minutes. Most physicians mentioned there was already a lack of time, even without discussing treatment limitations with their patients. They already had to discuss several topics and perform medical examination in these 15 minutes. Especially the fact that discussing treatment limitations could be an emotional topic and that there is no control over the patients' reaction, made it difficult for the physicians to estimate how much time the discussion would take. So, some physicians mentioned it was more the feeling of not having enough time for a profound conversation as a reason for not initiating the discussion about treatment limitations: "It's a difficult subject. So, if you bring it up, you have to take the time for it. You cannot start about it and think it will be discussed in 30 seconds. So, if you already run out of time, then you just don't do it." (Physician 2). One physician stated that a lack of time was definitely a problem but was perhaps used as an excuse, so a physician would not have to talk about treatment limitations: "I think that sometimes, we misuse the factor time as a doctor, because we find it a difficult topic. We rather talk about a lab result or an operation, than having conversations about treatment limitations. Also, because we have no control over the conversation, because we have no idea how the patient will respond." (Physician 11).

Direct cause. More than half of the physicians mentioned that if there was no direct

cause to discuss treatment limitations, it was more difficult to bring the topic up. They thought it would overwhelm the patient to mention treatment limitation without a direct cause. Especially discussing this topic with relatively young patients, who were chronically ill but not at risk for acute events like a cardiac arrest or admission on the hospital, was experienced as difficult. When there was a direct cause or a patient meets certain criteria, physicians thought it was less difficult and more logical to bring the topic up. “Recently, I tried to talk about treatment limitations with someone who was still rather stable, but it was so out of the blue, it really scared the patient. That’s when I thought, this is not the right way to do it.” (Physician 3).

Personal. Physicians could experience personal factors that could prevent them from discussing treatment limitations. For instant personal difficulties or a different cultural background between the patient and the physician would make it harder to discuss this topic.

Personal difficulties. Some physicians described that discussing treatment limitations could have an influence on the patient-physician relationship, which could be positive or negative. The positive influence included more profound conversations or talking freely about emotions. These physicians thought these conversations were very valuable. The negative influence included patients feeling overwhelmed and blaming the physician for it. Residents experienced that they did not regularly see the patients at the outpatient clinic and therefore did not have a personal connection with them as a barrier in discussing treatment limitations. Some of the physicians explicitly stated that they were in doubt if the patients really had the need to discuss treatment limitations. They thought more research was necessary to explore the needs of the patients regarding this topic. None of the physicians had personal objections in discussing treatment limitations.

Culture. Almost half of the physicians mentioned that discussing treatment limitations with patients with a different cultural background was more difficult. Most patients with a

different cultural background were less used to discuss topics like treatment limitations. Physicians experienced that these patients are more willingly to have treatments at every cost. So, the fact that patients could have a choice in limiting a treatment or even end a treatment, felt difficult to discuss. Physicians especially felt boundaries to discuss these topics with non-western or Islamic patients. These patients were less used to discuss treatment limitations. One physician stated that the Netherlands is ahead compared to other Western or European countries in discussing treatment limitations, so it could scare patients from other countries that these topics would come up.

Knowledge and skills.

Feeling competent. All physicians, both specialist and residents, felt competent about discussing treatment limitations: "Although it's always possible to learn new things, but I already felt really confident about it." (Physician 5). A lack of communication skills was not mentioned as a barrier. Although treatment limitations were discussed in a minority of the consultations at the outpatient clinic, all physicians were experienced in discussing treatment limitations with patients at the emergency room or during admission.

Skills. Most physicians learned to talk about treatment limitations through their own experience. Except for one physician, none of them could recall having a formal training about treatment limitations, apart from the training in this study. The one physician who did have experience with a formal training about treatment limitations organized this herself at a different hospital. All physicians did have experience with regular communication training at medical school.

Facilitators. Besides the barriers, the physicians also spoke about factors that help them to discuss treatment limitations. These facilitators are discussed below.

Informed patient. All physicians mentioned it would help them to discuss treatment limitations if patients were informed about the subject at forehand. In this way patients would

not feel overwhelmed by it and they would easier understand the content. Giving all patients a flyer with information, could prepare patients for his conversation and seemed helpful for most physicians. However, some were sceptical if the patients would read all this information, especially when it was not applicable yet for the patient.

General awareness. Two physicians argued that it would be good to create more general awareness in the whole population about treatment limitations. They stated that people should, for example talk more regularly about preferences concerning resuscitation and not only at acute moments. In this way, family members are informed about the wishes and preferences someone has at the end of life: "I think that in general people should talk more about these topics. Not only about the wish to be resuscitated but also about how you want your life to end. That it would be more socially accepted. But perhaps that is just a nice dream." (Physician 6).

Agreement criteria. Almost half of the physicians stated it would be helpful to have some agreement on criteria about when to discuss treatment limitations. Currently there is no general agreement on criteria when to discuss treatment limitations with patients at the outpatient clinic, according to the physicians. Physicians suggests that agreement on certain criteria would make it easier to discuss this topic: "If we agree on certain criteria, it would feel less random". (Physician 1). Others explicitly stated that they would not benefit from agreement on criteria.

Communication training. In a minority of the interviews, the communication training was explicitly mentioned as a facilitator. However, while all physicians already felt confident about their communication skills regarding treatment limitations, almost all of the physicians thought the communications training was useful. Physicians mentioned creating awareness, feedback from colleagues and recognition in the same struggles, as the benefits of the

communication training: “I think it is more the awareness you will create. So you think, I should be more focused on it, instead of really changing your skills.” (Physicians 7).
A couple of physicians mentioned that it would be useful to repeat the communication training every year or to integrate it in regular education. Others thought this would not be useful because they already felt confident about their skills. Physicians thought the communication training would be especially helpful for residents, because they have a lack of experience with this topic.

More contact general practitioner. A couple physicians mentioned that it would be easier to discuss treatment limitations if there was more contact with the general practitioner and the physician. According to these physicians the responsibility to talk about treatment limitations lies as the general practitioner, since he knows the patient best. At the moment the exchange of information between the general practitioner and the physician at the hospital about the patient’s preferences concerning treatment limitations is insufficient and could be improved.

Recordings

Eight physicians were recorded during their regular consultations with patients at the outpatient clinic**.** The patients in the recordings have different ages and different diseases. The recordings were analysed to see how the conversation about treatment limitations occurred, both before and after the training.

Before training. Before the communication training, treatment limitations were not discussed during the recordings. Therefore, no further analysis could be made.

After training. In four recordings treatment limitations were discussed. These conversations were analysed further.

Decision. In one of the four consults a decision about treatment limitations was made. In the other conversations about treatment limitations the decision was not made. In one of the

conversations the physician wanted to prepare the patient for potential choices in the future, but explicitly stated that it was not applicable yet.

Initiative. In all four conversations the topic treatment limitations was initiated by the physician.

Emotions. In one of the consults a patient admits to the physician the subject treatment limitations affected him. He stated it made him insecure about his body and illness. However, he also stated that this insecurity was especially because he had no control over his illness: "Besides, I don't feel really pleasant. My legs, but also the feeling I've lost control over my body. My kidneys. But this also depends on what we've just talked about. That made an impression." (patient 1). The physician and the patient talked a little while about taking back control and the patient ends this conversation that it helped him to get more confidence. In the other consults where treatment limitations are discussed, the patients did not show or expressed emotions. None of the physicians seemed to be emotionally affected by the discussion about the treatment limitations.

Time. When looking at all recorded conversations, both before and after the training, the consultations had an average time of 18 min 52 s. The consultations where treatment limitations were not discussed, had an average time of 19 min 38 s. When treatment limitations were discussed, the consultations lasted on average 17 min 26 s.

Discussion

Due to the increasing interest in patient-centred care, involving patients in their treatment is getting more important (Epstein et al., 2010; Barry & Edgman-Levitan, 2012). Therefore, it is important for physicians to be informed about the preferences of a patient regarding treatment limitations. This study has answered the two research questions, a) which physician-related factors are influencing Dutch physicians on their discussion of treatment

limitations with their patients at the outpatient clinic?

b) What is the influence of a communication training for Dutch physicians on discussing treatment limitations with their patients at the outpatient clinic? Regarding the first question, this study identified the most important physician-related factors. Important barriers that are identified included a lack of time, no general agreement on criteria, patients with a different cultural background and no direct cause for initiating the conversation about treatment limitations. Important facilitators that are identified included a more informed patient, general agreement on criteria and training communication skills.

Regarding the second research question, the observations of the consultations at the outpatient clinic gave insight in the influence of a communication training on these consultations. None of the physicians discussed treatment limitations during the recorded conversations before they participated in the communication training. After the communication training, treatment limitations were discussed in half of the conversations. According to the physicians, the communication training was especially helpful because it created awareness, they received feedback from colleagues and they could recognize different pitfalls.

The physician-related factors that were found in this study can be divided into three main themes, practical, personal and factors regarding knowledge and skills. Practical factors include a lack of time, no agreement on criteria, no direct cause for discussing treatment limitations, a more informed patient and contact with the general practioner. Personal factors that are found are the influence a discussion of treatment limitations can have on the physician-patient relationship, not having a personal or close connection with a patient and a different cultural background. Regarding the factors knowledge and skills, it seemed that most Dutch physicians in this study learned their skills by experience and felt competent in discussing treatment limitations.

Meaning and important of the findings

This study distinguishes itself from prior research by focussing on the perspectives of physicians about discussing treatment limitations with a general outpatient population instead of a specific patient group. Findings of this study indicate that most physicians agree that the outpatient clinic is a right place to discuss treatment limitations, provided that the patient meets certain criteria. However, all physicians feel restraints due to a lack of time.

This lack of time is in line with prior research and confirms the findings of Slort et al. (2011) and Visser et al. (2014). Therefore, this lack of time seems to be a structural problem among different health care professionals. When looking at the time of the recorded conversations, most of them lasted more than the prescribed 15 minutes. The conversations were treatment limitations were discussed did not seem to take more time, however it is possible that the physicians only discussed treatment limitations when they thought they would have enough time. According to one of the physicians, this lack of time was not only a structural problem, but perhaps also used as an excuse for the physicians' personal barriers. This is an interesting statement and gives some insight in the possible coherence between the different barriers. However, it was not confirmed by other physicians.

In contrast to findings reported by Visser et al. (2014), Chittenden et al. (2006), and Waldrop and Meeker (2012) a lack of communication skills was not confirmed as a barrier by the participating physicians. All participating physicians felt capable of discussing treatment limitations and were confident about their skills, even before they participated at the communication training. So different than prior research, where a communication training led to more confidence in the physicians' communication skills, the communication training in this study especially created awareness about the subject. This awareness probably led to the increase of discussing treatment limitations at the outpatient clinic. The reason that the physicians already felt capable and confident in discussing treatment limitations before the

communication training, is probably due to the fact that these physicians are already experienced in discussing treatment limitations, for example during their shifts at the emergency room.

Limitations and implications for further research

Although this research was carried out very carefully, some limitations of this study should be kept in mind. This study was conducted with a limited number of participations. Therefore, this study is not suited to be generalised. It confirms however prior research that different disciplines emphasize different factors (Visser et al., 2014).

As stated earlier, after the communication training, treatment limitations were discussed more than before the communications training. Besides the awareness the communication training created, it is also possible that the physicians were biased, for they were aware the subject of the study and they knew they were recorded. Because all observations were recorded within a couple weeks after the physicians participated in the communication training it would be interesting to investigate what the long-term effect of the communication training will be. To observe the physicians after a certain time, without explicitly stating what the reason for observation will be, could gather more insight in the real effect of the communication training.

Physicians experienced boundaries in discussing treatment limitations because they thought patients would be overwhelmed by discussing treatment limitations at the outpatient clinic. However, some physicians mentioned that patients did feel relieved when the physicians initiated treatment limitations. Different than prior research, this study focused on a general outpatient clinic population instead of a specific patient group. Next to the physicians' perspectives, it would be interesting to study what the opinion is of the patient population at the outpatient clinic regarding the discussion of their preferences of treatment limitations at the outpatient setting. Further research is necessary to answer the question if it

should be necessary to discuss treatment limitations with all patients at the outpatient clinic or with just a specific group of patients.

Implications for practice

All physicians mentioned a more informed patient as an important facilitator. A more informed patient could influence personal barriers, because the physicians would feel less to overwhelm the patient with the subject. Besides it could decrease the time that is necessary during the consultation, because the patient is already informed. According to the physicians, creating a flyer would be most suitable. This study therefor gives direction for health care policymakers, that creating an information flyer could facilitate the physicians in discussing treatment limitations at the outpatient clinic.

Although all physicians felt confident over their communication skills, the majority of physicians experienced difficulties in discussing treatment limitations with patients with a different cultural background. To make the communication training more suited for this specific group of physicians, a communication training specifically focused on patients with a different cultural background could give these physicians more support.

Conclusion

In conclusion, discussing patients' preferences concerning treatment limitations is an important attribute of patient-centred care. This kind of care planning helps to increases patients' satisfaction and their quality of life. By identifying the different factors that are important for physicians in their discussion of treatment limitations more insight was gathered in what could impede or help the physicians in discussing treatment limitations at the outpatient clinic. Getting more insight in the perspectives of the different physicians, could help in the process of effectively implement interventions and in the design process of an effective communication training.

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Appendix 1- Information letter

Informatie deelnemer

‘CONTACT’: Onderzoek op de polikliniek interne geneeskunde

U doet mee aan het CONTACT onderzoek op de polikliniek interne geneeskunde. Het doel van dit onderzoek ligt bij het verbeteren van de kwaliteit van het gesprek en daarmee de tevredenheid van arts en patiënt. Voor de kwalitatieve analyse van dit onderzoek is Lisa Berghuis betrokken, zij volgt een master Onderwijswetenschappen. Voor haar master thesis is zij geïnteresseerd in de beweegredenen van artsen die deelnemen aan de CONTACT studie, om behandelwensen wel of niet te bespreken op de poli. Hierover gaat zij graag met u in gesprek tijdens een interview. De informatie verkregen uit dit interview zal gebruikt worden voor de beantwoording van de onderzoeksvraag.

U beslist zelf of u meedoet aan het onderzoek. Deelname is vrijwillig. Als u wel meedoet, kunt u zich altijd bedenken en toch stoppen, ook tijdens het onderzoek. U hoeft niet te zeggen waarom u stopt. De gegevens die tot dat moment zijn verzameld, worden gebruikt voor het onderzoek. Op uw verzoek kunnen uw gegevens dan gewist worden. Dit kan alleen als de gegevens nog niet gebruikt zijn voor de analyse.

Voor dit onderzoek worden uw persoonsgegevens verzameld, gebruikt en bewaard. Dit geldt ook voor de antwoorden die u geeft tijdens dit interview. Het verzamelen, gebruiken en bewaren van uw gegevens is nodig om de vragen die in dit onderzoek worden gesteld te kunnen beantwoorden en de resultaten te kunnen publiceren. Wij vragen voor het gebruik van uw gegevens uw toestemming.

Om uw privacy te beschermen krijgen uw gegevens een code. Uw naam en andere gegevens die u direct kunnen identificeren worden daarbij weggelaten. Ook in rapporten en publicaties over het onderzoek zijn de gegevens niet tot u te herleiden.

Uw gegevens moeten 15 jaar worden bewaard op de onderzoek locatie. Het wordt bewaard om daarmee in de loop van dit onderzoek nog nieuwe analyses te kunnen doen die te maken hebben met dit onderzoek.

U kunt uw toestemming voor gebruik van uw persoonsgegevens altijd weer intrekken. Dit geldt voor dit onderzoek en ook voor het bewaren en het gebruik voor het toekomstige onderzoek. De onderzoeksgegevens die zijn verzameld tot het moment dat u uw toestemming intrekt worden nog wel gebruikt in het onderzoek.

Bij vragen over dit interview of de kwalitatieve analyse van deze gegevens kunt u contant opnemen met Lisa Berghuis (l.a.berghuis2@students.uu.nl).
U wordt niet betaald voor het meedoen aan dit onderzoek.

Appendix 2 - Informed consent

UMC Utrecht

Universiteit Utrecht

Toestemmingsformulier deelnemer

'CONTACT': Onderzoek op de polikliniek interne geneeskunde

Ik heb de informatiebrief gelezen en kon aanvullende vragen stellen aan de onderzoeker wanneer ik iets niet begreep. Mijn vragen zijn genoeg beantwoord en ik had genoeg tijd om te beslissen of ik meedoe aan dit onderzoek.

Ik weet dat meedoen geheel vrijwillig is. Ik weet dat ik op ieder moment kan beslissen om toch niet mee te doen, daarvoor hoef ik geen reden te geven.

Ik geef toestemming om de gegevens verkregen uit dit interview te gebruiken voor de beantwoording van de onderzoeksvraag in dit onderzoek.

Naam deelnemer:

Handtekening: Datum : __ / __ / __

Ik verklaar hierbij dat ik deze proefpersoon volledig heb geïnformeerd over het onderzoek.

Naam onderzoeker (of diens vertegenwoordiger):

Handtekening: Datum: __ / __ / __

Appendix 3- Information about communication training

Achtergrond

Behandelwensen en –grenzen bespreekbaar maken is vaak nog geen onderdeel van de dagelijkse klinische praktijk en in de spreekkamer. In het gesprek met de patiënt lijkt het vaak niet relevant en/of lijkt de tijd te ontbreken om het hierover te hebben. Ook ervaring en 'how-to-do' speelt mee. Behandelwensen en –grenzen gaan over meer dan alleen een niet-reanimeer afspraak; het gaat bijvoorbeeld ook over de verschillende behandelmogelijkheden, over doen of laten. Uiteraard hoort hierbij het geven van een goede uitleg aan patiënten.

Training

Een getrainde specialist begeleidt de bijeenkomst. Eenieder wordt welkom geheten en krijgt uitleg over de training.

Twee specialisten (io) verenigen zich, samen met één simulatiepatiënt. De casuïstiek wordt door de zorgprofessional ter plekke voorbereid. De simulatiepatiënt is al eerder voorbereid en gebriefd. Eén arts gaat in gesprek met de patiënt zoals het gesprek op de polikliniek gevoerd zou worden. De andere arts observeert na instructie van een aantal observatiepunten (contact maken, non-verbaal gedrag, basishouding, vragen stellen, adviseren, ordenen, inhoudelijk, gesprek afsluiten). Na afloop van het gesprek geven zowel de observerende arts als de simulatiepatiënt feedback op het poligesprek. Hierna wordt gewisseld. Per persoon worden er twee casus besproken (ca. 20-30 minuten per casus).

De bijeenkomst wordt gezamenlijk afgesloten met een plenaire evaluatie, wrap up en leermomenten.

Appendix 4 - Topiclist

A topiclist is described below. The topiclist was used to create the interviewguide. In the topiclist you can find on which concepts and subconcepts were derived from the literature and on which literature the different concepts were based. You can also find an example question per concept.

Table 1.

Topiclist

Concept	Subconcept	Example	References
Treatment limitations		How are treatment limitations currently discussed What isthe best time and place to discuss treatment limitations	Kunneman et al. (2015), Sinuf et al. (2015), Detering et al. (2010), Zhang et al. (2009), Walczak et al. (2013), Tandon (2018)
Barriers			
	Practice	What practical barriers do you experience?	Visser et al. (2014), Slort et al. (2011)
	Personal	What perosnal barriers do you experience? Do you feel personal boundaries?	Visser et al. (2014), Waldrop & Meeker (2012), Chittenden et al.(2006)
	Knowledge and skills	Do you feel competent enough discussing treatment limitations?	Visser et al. (2014), Waldrop & Meeker (2012), Chittenden et al. (2006),
Facilitators		What could help discussing treatment limitations at the outpatient clinic?	
	Communication training	What was your experience with the training? Was the communicationtraing helpful?	Walczak et al. (2013), Levinson et al. (2010) , Ammentorp et al. (2007)

Appendix 5 - Interviewguide

Below you can find the interviewguide, which was used as a guideline during the interviews. The interviedguide is based on the topiclist (Apendix 4).

Introduction: The interviewer and the participant introduce themselves to each other. The purpose of the interview was discussed. The interview was done in Dutch and therefor the interview questions are in Dutch.

Behandelbeperkingen op de poli

- Hoe kijkt u aan tegen het bespreken van behandelbeperkingen op de poli?
- Bespreekt u momenteel behandelbeperkingen op uw poli?
- Zijn er algemene criteria afgesproken wanneer dit besproken moet worden?
- Op wiens initiatief wordt dit gesprek gevoerd?
- Welke factoren zijn voor u van invloed op het bespreken van behandelwensen en grenzen?

Barriers

- Welke belemmeringen ervaart u in het bespreken van behandelbeperkingen op de poli?
- Wat vindt u moeilijk in het bespreken van behandelbeperkingen?
- Ervaart u mogelijke praktische bezwaren, bezwaren in kennis en kunde of persoonlijke bezwaren?

Facilitators	- Wat zou u kunnen helpen in het bespreken van behandelbeperkingen?
Communicatietraining:	**-** Hoe heeft u de training ervaren?
Overig	- Heeft u nog toevoegingen over dit onderwerp?

Appendix 6 - Audit trail

Below an audit trail is described, with the justification of the most important choices that were made during this study.

Participants

The first intention was to include all ten physicians who participated in the communication training for the interviews. This was already a limited number of participants, so I discussed my concerns with my supervisor, but because of the specific context it was not a problem. Unfortunately, two participants dropped out for the interviews. I have tried to retrieve the reason for this drop out. The drop out was due to limited time of the participants and it was not possible to motivate them to participate. While there was already a limited number of participants and two of the participants dropped out, the decision was made to interview one extra participant, who was not recorded during her consultations but who did participate in the communication training. The reason for this was that her input about the communication training and treatment limitations could be of value, despite the fact that she did not participate at the observations.

Due to time limits it was decided to only use one observation before and one after the training. I have watched several observations before the training, but no difference was seen in discussing treatment limitations.

Interviewguide

The questions in the interviewguide were based on the topic list. During the first interview it seems that certain criteria could be of influence, so I included a question if there were a certain agreement on criteria or if the physician had its own criteria when to discuss treatment limitations.

After the second interview the physician indicated that physicians mostly took the initiative to talk about treatment limitations, so I included a question about on who’s initiative the

conversation about treatment limitations normally started.

The third interview was with a resident instead of specialist and she appointed a specific barrier of a personal connection with the patients. This was due to the fact that the activities of the residents change after a couple of months and they leave the outpatient clinic. Because the interview guide already had a question about personal factors, it was decided not to change the interview guide specially for residents.

Because after three interviews it was clear that most Dutch physicians felt competent about their skills, I added a question about were they learned their skills and if they already participated in a communication training about treatment limitations.

Coding

In appendix 7 & 8 you can find the initial coding scheme and the final coding scheme. The initial coding template was derived from the literature. The initial coding scheme included the most important barriers derived from the literature; personal attitude, knowledge and skills and practical barriers, facilitators, the communication training and the concept treatment limitations. After analysing three interviews, there seemed to be a concept of 'proces of treatment limitations'. This included when to discuss this topic, on who's initiative and which criteria. These codes were first gathered as 'remaining' but the overall concept was 'proces'. During all the interviews I asked how treatment limitations were discussed now and how the physicians thought about discussing treatment limitations at the outpatient clinic with a general patient population. I first coded this as treatment limitations. After analysis with the peer I discovered this code was too vague and decided to code it as timing and place. It seemed to be part of 'process'.

The initial coding scheme did not specify different facilitators. During the interviews several facilitators came up. Most mentioned was a flyer with information for the patient. After analysis 'informed patient' was more suitable than 'a flyer'. An information flyer is

used as an example for an informed patient but the code was renamed as ‘informed patient’.

During several interviews physicians talked about criteria when to discuss treatment limitations. Some mentioned direct cause, others talked about criteria. First I coded these two together, but after analysis it seemed that there was a slight difference. I coded direct cause as a barrier and agreement criteria as a part of the ‘proces’. However, after analysis it seemed to be that agreement of the criteria was also experienced as a facilitator. So ‘agreement of the criteria’ was included as a facilitator.

Observations

I started with a simple initial coding scheme, how treatment limitations were currently discussed. Most important for me to see was if treatment limitations are discussed. And if so; how do they differ after the communication training. Observations before the training took place: treatment limitations were not discussed at al. I did not know how to code this. I discussed it with my supervisor and because this was as expected, I coded as ‘not happened’. After the communication training there were four observations where treatment limitations were discussed. Based on the interviews I was curious on who’s initiative the conversation about treatment limitations started, if a decision was made and if the patient or physicians expressed emotions. Because a lack of time was mentioned a lot during the interviews, I was curious how much time the consults took and if there was a difference in time if treatment limitations were discussed.

Communicationtraining

The communication training was facilitated by UMC Utrecht. It was supposed to be later in the study but that would lead to the fact that there were not enough recordings after the training. Therefor the training was moved to an earlier time. Information about the training is included as Appendix 1.

Data analysis

During the data analysis I measured how much certain codes came up. This can be found in Appendix 9. I studied if certain codes had matching themes. Already during the coding process I found that some codes had some overlapping theme. During this process I found out that there was a theme of 'process of treatment limitations'. Besides I found that criteria was both part of the process as a facilitator. After analysing the heading 'remaining', contact with the general practioner came up several times. This seemed to be a facilitator. Also different codes were divided in to barriers and facilitators. This process was discussed with a critical peer.

Feedback

I have received several types of feedback, both from my peers as my supervisor. With one of the peers I have checked my codes, to see if it felt logic for her and I checked my decisions. Besides this peer and my supervisor gave feedback over the whole thesis.

Appendix 7- Initial coding scheme

Below you can find the initial coding scheme. This coding scheme consist of a priori codes, which are derived from the literature which is described in the theoretical framework.

Treatment limitations

Where discussed

When discussed

Barriers

Practice

Time

Place

Knowledge

Learned skills

Communication skills

Personal

Personal difficulties/objections/ own values+ beliefs

Culture

Facilitators

Communicationtraining

Experience

Appendix 8- Final coding scheme

Below you can find a display of the final coding scheme. The codes that are highlighted have been changed in comparison with the initiel coding scheme

Treatment limitations
- **Proces**
  - Time and place
    - *Outpatient clinic as best place, every patient*
    - *Outpatient clinic if criteria applicable*
    - *Not at outpatient clinic but*
  - Criteria
  - Initiative
- **Barriers**
  - Practice
    - *Lack of time*
    - *No direct cause*
  - Knowledge and skills
    - *Feeling competent*
    - *Learned skills*
  - Personal
    - *Personal difficulties*
      - *personal objections*
      - *effect on physician-patient relationship*
    - *Different cultural background*
- **Facilitators**
  - Informed patient
    - *Flyer*
  - Agreement Criteria
  - Communication training
  - More contact GP

Communication training
- **Experience**
  - Useful
    - *Creating awareness*
    - *Recognition*
    - *Feedback*

Appendix 9 - Analysis interviews

Table 2. Analysis interviews

Subject	Participants
Process Treatment limitations	
Timing and place	
Outpatient clinic as best place, for every patient	1, 11
Outpatient clinic if criteria applicable	2,5,6,7,8,9
Not at outpatient clinic but different setting	3
Criteria	
Which criteria are considered	
Age	1, 2,3,5,6,7,8
Disease	1, 2,3,5,6,7,8
Co-morbidity	1, 2,3,5,6 ,8
No general guideline currently	1, 2,3,5,6,7,8
Initiative	
Conversation about treatment limitations is started by the physician	1, 2,3,5,6,7,8, 9,11
Barriers	
Practice	
Lack of time	1, 2,3,5,6,7,8, 9,11
No direct cause for initiating the conversations about treatment limitations	2,3,5,6,9
Personal	
Personal difficulties	
Physician feels no personal objections	1, 2,3,5,6,7,8, 9,11
Physician experiences an effect on physician-patient relationship	1,11, 2,5
Needs of the patient	3,7
Residents personal connection	6,7
Different cultural background	2,3,6,7
Knowledge	
Feeling competent	1, 2,3,5,6,7,8, 9,11
Learned by experience	2, 7, 8,9, 11
Facilitators	
Informed patient	1,2,3,5,6,7,8,11
General awareness	6,11
Agreement criteria	1,2,6,9
Communication training	5,11
More contact GP	6,7

Communication training	
	1,2,3,5,6,8,11
Useful	
Creating awareness	1, 7, 11
Recognition in difficulties between colleagues	11,2, 5, 8
Feedback from colleagues	3, 5,6, 8

Appendix 10 - Coding scheme observations

Treatment limitations

- Outcome
  - *Decision made?*
    - *which form?*
  - *Decision delayed?*
- Initiative
  - *Patient*
  - *Physician*
- Emotions
  - *Patient*
  - *Physician*

Appendix 11- Analysis observations

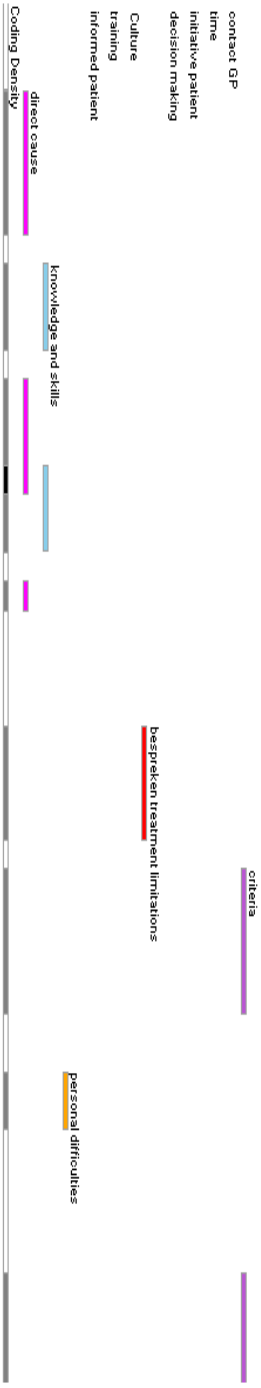
Table Analysis observations

Outcome	Frequency
Treatment limitations discussed	4
Decision made	1
Decision delayed	3
Initiative	
Patient	0
Physician	4
Emotions	
Patient	1
Physician	0

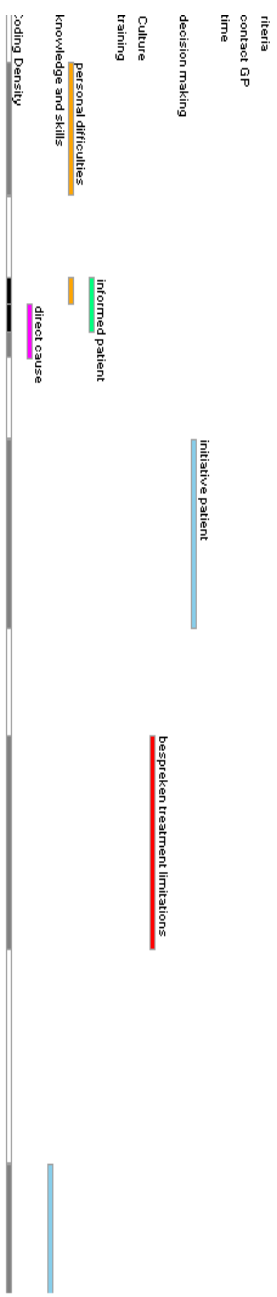
Appendix 12- Transcript Interview

Interview arts 3 17-04-2019

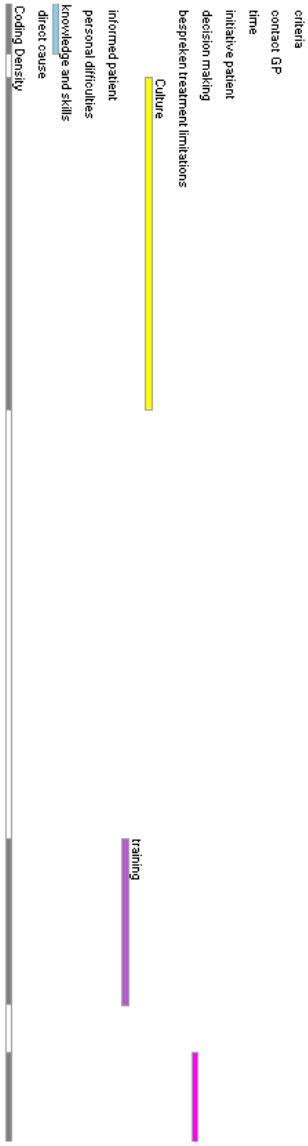
O: Hoe jij kijk aan tegen het bespreken van behandelbeperkingen op de poli?
A;Ik vind het op de poli een lastig onderwerp, op het moment dat iemand gewoon voor zn normale controle komt. En als er niet echt een aanleiding voor is. Ik denk dat als je een oncologie poli doet, dus met allemaal mensen die kanker hebben dan is dat heel anders. Mijn patienten zijn over het algemeen heel stabiel, en ik probeer ze van de dialyse af te houden.
O:Ja
A; dus de behandelbeperkingen rondom dialyse bespreken, dat vind ik niet zo moeilijk, dus gaan we wel of niet dialyseren. Maar dat doe ik eigenlijk wel pas als dat een beetje in de buurt komt.
O;jaja
A; en ik merk nu met die gesprekken die worden opgenomen, dan denk ik ja, deze patient gaat nog jarenlang niet dialyseren, ik ga het daar gewoon niet over hebben, om te bespreken gaan we wel of niet dialyseren. Dat is een hele rare vraag, want ik weet dat het voorlopig niet aan de orde zal zijn. Dus als de aanleiding er is en het is logisch om zo'n gesprek te voeren, dan vind ik het helemaal niet moeilijk. Maar ik vind het wel lastig om dat zomaar out of the blue aan te stippen.
O; ja
A; er moet echt een goede aanleiding zijn om dat te doen.
O; kan je benoemen wat dan een goede aanleiding zou zijn? Je noemde al even, als we richting het dialyseren gaan, Heb je andere punten, dat je denkt dat voelt wel als een aanleiding om behandelbeperkingen te bespreken op de poli?
A; uhmmm, ja bij mij is het natuurlijk toch vaak dat de dialyse eerder komt dan, ja dat dat een logischer gesprek is dan reanimeren bijvoorbeeld. Of intensive care opname. Ik moet zeggen dat ik dat soort gesprekken logischer vind op de afdeling of de spoed eisende hulp. Er wordt heel vaak gezegd van, de spoedeisende hulp is daar niet de juiste plek voor. Maar aan de andere kant is de spoedeisende hulp daar juist een hele logische plek.
O;ja
A: als iemand heel ziek binnenkomt dan is het wel logisch om te bespreken, wat gaan we nog wel en wat gaan we niet doen. En patienten die gewoon heel stabiel op je poli komen, dan is dat eigenlijk een hele rare vraag soms.En ik snap wel als ze zieker worden of ouder, dat dat een keer aan de orde moet komen. Uhm, maar dan moeten ze dus wel eerst zieker of ouder zijn.
O;Ja
A; ik merk nu in de studie dat ik, dan worden mensen gefilmd en dan denk ik; ja, zal ik het nou hier gaan bespreken? Maar dan voelt het zo raar om te doen. En dan denk ik, ik doe hier mijn patienten niet goed mee.
O; Dat is ook niet de bedoeling van de studie hoor, dat je dan denkt van dan ga ik het maar bespreken, want ik heb die camera op mn gezicht.
A; nee dat weet ik.
O; we willen juist ontdekken van, is het een logische plek om dit op de poli te doen.
A: Ja
O; Wat voor mij interessant is, zijn er richtlijnen voor, wanneer je het gaat bespreken?
A; nee in principe niet.



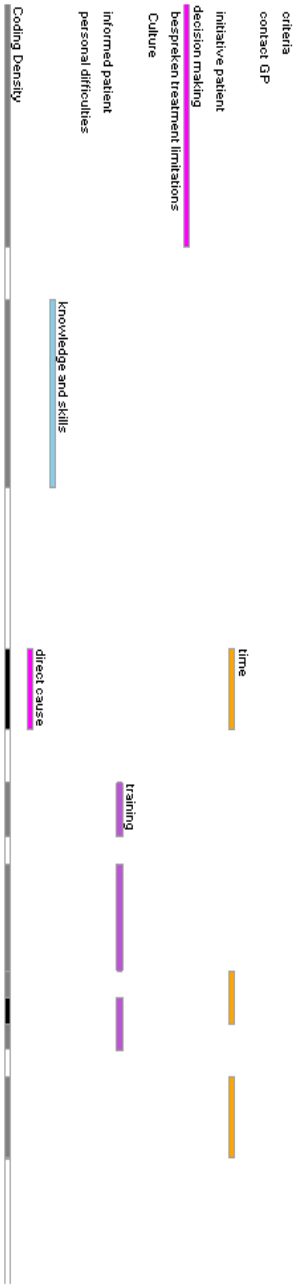
O; Tot je dus op een punt komt, wel of niet dialyseren of als iemand veel zieker wordt of ouder?
A; precies. Toen ik het laatst probeerde met iemand te bespreken, iemand die nog redelijk stabiel was, en dat kwam dan zo out of the blue, diegene die schrok er echt van. En toen dacht ik, dit is dus niet de goede manier. Je moet pas over dialyseren beginnen als je toch denkt dat dat er n keer aankomt. En dat heb ik natuurlijk lang niet bij iedereen. En dan voelt het heel raar om het daarover te hebben.
O; stel, het wordt beleid van het ziekenhuis om wel met iedereen behandelbeperkingen te bespreken op de poli, net als allergieen, zeg je van dat zie ik zitten of voelt dat heel onnatuurlijk?
A; Ja. Dat voelt heel onnatuurlijk. En ik denk dat mensen daar heel erg van schrikken. Je zou dan eerst bijvoorbeeld een folder uit moeten delen of een filmpje laten zien. En dan nog, denk ik dat het een beslissing is die je pas kan nemen als je ook echt ziek bent. Het is een hele, driekwart van mijn patienten of misschien wel 80-90%, daarvan zeg ik ook gewoon medisch van die moeten we ook gewoon reanimeren of op IC leggen als er wat gebeurt. En de mensen waarbij ik vind dat dat niet meer moet, die zijn er maar heel weinig op mn poli.
O; ja ja. En komt er wel eens vanuit de patient zelf? Dat die begint met een gesprek over behandelbeperkingen?
A; ja, maar meestal alleen als ze opgenomen liggen. Of op de spoedeisende hulp ofzo, daar kan ik mij nog wel van herinneren dat het soms vanuit de patient wordt gezegd. En heel soms heb je wel eens, als je het dan toch gaat bespreken, dat iemand zegt: oh maar dat wil ik echt niet, gereanimeerd worden ofzo. Maar dat heb ik eigenlijk niet zo heel vaak. Ik heb vaker dat mensen er toch een beetje van schrikken.
O; ja ja ja. En, even voor mijn beeld, naast poli doe jij ook afdeling en eerstehulp diensten?
A; ja zeker.
O; Voer je daar deze gesprekken wel eens?
A; ja op de afdeling veel meer. En dan ben ik er als supervisor, dus dan laat ik meestal mn arts assistent de gesprekken voeren. Waar ik het het meeste doe, zijn mijn peritoneaal dialyse patieten, dat zijn mensen die buikspoelingen doen. Want die zijn echt van mij, dan ben ik hun dokter. En die zitten eigenlijk in de laatste fase van hun leven. En daarbij doe ik eigenlijk bij iedere stap die ik zet, ieder onderzoek dat ik aanvraag; wilt u dit? Gaan we dit echt doen? Want dat zijn veel ziekere mensen en veel kwetsbaarder. Dus daar is het veel logischer om die afwegingen continu te maken.
O; Ja
A; Dat is echt mijn patienten groep waarbij ik het heel erg doe en heel vaak. En bij de dialyse patienten, de gewone dialyse patienten, ook. Maar dan heb ik daar een arts assistent lopen en dan zeg ik van, we moeten even goed bespreken of we dit nog wel doen.
O;Ja
A; Dus daar doe ik het niet zo heel veel zelf, maar ben ik er op de achtergrond bij betrokken. En bij de dialyse patienten, die zie ik allemaal 1 keer per jaar en dan bespreek ik het ook met ze. Dat is een veel, die mensen zijn toch behoorlijk ziek. Die dialyseren, daar is het een hele logische vraag. Daar heeft iedereen, die hebben er al overnagedacht en iedereen heeft daar een antwoord op.
O; En vind je dit soort gesprekken dan moeilijk?
A; Nee helemaal niet. De lastigste gesprekken is nog uit mn opleiding, dat je zieke buitenlandse mensen hebt, waarbij je zegt van, hier moeten we eigenlijk niets meer doen en



die dat eigenlijk niet willen. Die alle behandeling nog willen, alles wat kan. Dat vind ik de moeilijke gesprekken, echte moeilijke gesprekken.
O; Kan je aangeven wat je dan moeilijk vindt?
A; Dat er een heel groot cultuur verschil zit in dat, als je zo ziek bent en je hebt kanker en je weet dat je niet meer beter gaat worden, dan zullen bijna alle Nederlandse, van oorsprong Nederlandse mensen zeggen van, dan ga ik niet meer naar de IC. En reanimeren, nee natuurlijk niet dokter. En sommige mensen die willen dat nog wel, maar als je dat uitlegt dan snappen ze dat je dat niet meer moeten doen. Maar bij mensen uit het buitenland, is dat gewoon niet aan de orde. Zelfs bij een kans van 0,001% dan willen ze dat alsnog gedaan hebben.
O; Want ze zijn dan wel op de hoogte van die kansen, maar ze?
A; Ja dat zijn de dingen die ik vertel. Ook als je reanimeert dat ze er slecht uit kunnen komen. Maar dat maakt ze helemaal niet uit.
O:nee
A: en dat vind ik de moeilijke gesprekken. Dan zie je zo'n hoopje mens in bed liggen en dan denk je ja, ik ga niet, deze persoon nog naar de IC brengen. Daar doe ik niemand een plezier mee. Dat is mens onwaardig. Dat vind ik moeilijk.
O; ja. Omdat het ook tegen je eigen gevoel in gaat?
A; Ja
O; komt andersom ook wel eens voor? Dat jij denkt we moeten nog van alles en de patient dat niet wilt?
A; ja, veel minder wel natuurlijk. Ik heb nu toevallig een patient, begin 60 en nierfalen en dan zegt; nee transplantatie daar ben ik echt veel te oud voor, die moet naar jonge mensen. Terwijl zij een perfecte kandidaat is. Dus daar ben ik nog wel mee bezig om te zeggen dat ze dat eigenlijk wel moet doen. Maar dat heb je niet zo heel vaak. En als zij uiteindelijk besluit om dat niet meer te willen, dan kan ik daar ook prima mee leven. Dus dat is wel makkelijker. En ik moet eerlijk zeggen dat ik bijvoorbeeld bij reanimeren, ik vind dat niet zo erg, als mensen dat perse willen. Als ik al inschat dat de kans dat het gaat lukken miniem is, en iemand wil dat perse, dan denk ik prima, dan reanimeren we. De kans dat het lukt is toch 0. Dan wil ik best diegene beloven dat we dat doen dan. Maar de intensive care, dat het een lijdensweg wordt met een eindeloze opname, ja daar heb ik veel meer moeite mee. Maar dat is een beetje per persoon verschillend.
Maar vooral cultuur vind ik dus een heel moeilijk ding.
O;Ja. En worden jullie, tijdens de opleiding tot arts of internist iets van een training hierin getraind?
A; Ja, ik ben hier in Utrecht opgeleid en heb al die jaren van mijn studie communicatietraining gehad dus dat is wel tot in den treure, heb ik dat geoefend. En ook wel in de rest van mn opleiding, toen ik al internist in opleiding was, kwam dat ook veel aan de orde. Maar het zijn ook dingen die je in de praktijk gewoon moet oefenen. En uhm, ik denk wel dat je er nog beter in kan worden hoor. Dat je bepaalde vaardigheden kan leren om het makkelijker te maken, het gesprek. Maar juist over die interculturele verschillen vind ik moeilijk. En van die dingen van, dan vragen we de imam, dat voelt dan eigenlijk als een zwaktebod.
O; Omdat je er eigenlijk zelf uit wil komen?
A; Ja. Dus ik moet eerlijk zeggen, dat ik wel eens heb gedacht van, prima als jullie dit willen, dan doen we dat maar. En dat is eigenlijk niet helemaal, ja, dan doe je iets tegen je

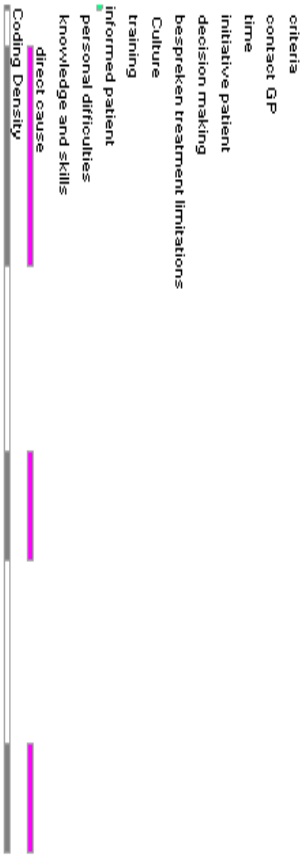


overtuiging in. Dat vind ik wel moeilijk. Soms is dat de enige manier. Ook om mensen niet al te boos te laten worden.
O;Ja je komt dan aan de wens van de patient tegemoet?
A; ja maar je mag niet medisch zinloos handelen he. Dus dat is, daar wringt het. Als je denkt van, ik ga maar reanimeren want dat is voor de familie beter, ja. Aan de andere kant heb ik ook wel eens iemand horen zeggen van, die familie moet er mee verder leven. En als die er meer vrede mee hebben als wij 3 keer gereanimeerd hebben, ja prima, dan doen we dat.
O;Ja, dan leg je je daar bij neer?
A; Ja, dan leg je je daar bij neer.
O; en ik hoor je dus wel zeggen, zolang er een goede aanleiding is om te doen, vind je het geen moeilijke gesprekken om te houden, los van de interculturele onderdeel?
A: Het zijn natuurlijk niet de makkelijkste gesprekken om te voeren, maar het zijn vaak wel hele waardevolle gesprekken. Helemaal de patienten die ik goed ken, dus mijn eigen PD patienten, als ik er ook de tijd voor neem en rustig met ze praat, dan zijn het ook wel gesprekken waar je heel veel voldoening uit haalt. Mensen zijn vaak emotioneel, ze moeten er goed overnadenken. Het is heel fijn om op zo'n manier met je patienten te kunnen praten en daar heel eerlijk over te zijn. Mensen waarderen dat heel erg. Dus dan vind ik het, niet de makkelijkste gesprekken maar ook wel interessante gesprekken om te voeren.
O; ja precies. En dat zijn dus gesprekken die meestal op de afdeling plaatsvinden? Of is dat op de poli?
A; ja op de poli,althans dat is de dialyse, maar dat oogt als een poli.
O; en voel je daar dat er genoeg tijd en ruimte voor die gesprekken is?
A; ja, want die tijd die neem ik wel. Op de PD hebben we in principte een uur per patient. Dus die tijd die heb ik, die is altijd genoeg.
O; hmhm. Dat is heel wat anders dan een kwartier.
A; ja zeker. Dus daarom vind ik de gewone poli ook niet geschikt. Je kan niet out of the blue, in 5 minuten even zo iets erdoor rammen. Zonder aanleiding.
O; Er is een training opgezet, zowel de elearning als het oefenen met de simulatiepatienten. Hoe heb je dat ervaren?
A; De elearning, dat was prima, een beetje een open deur maar dat ik dacht, ja dit heb ik toch allemaal al een keer geleerd of gehoord.
O; er kwam daar niets nieuws in naar voren?
A; Nee. En het oefenen, dat vind ik opzich wel leuk, daar leer je heel veel van en het is ook leuk om elkaar feedback te geven. En het is toch wel dat je dan weer dingen doet waarvan je denkt, goh dat doe ik eigenlijk helemaal niet zo goed. En het is fijn dat iemand dat dan een keer zegt.
In een ideale situatie heb ik alle tijd en praat ik over gevoelens en alles, maar de realiteit is, die heb ik niet. In korte tijd moet je proberen zoiets goed onder woorden te brengen. Ik vond de feedback die ik kreeg van (..) erg leuk, daar heb je dan ook echt wat aan.
Het is wel vaker dat je bij patienten aanvoelt dat er nog iets emotioneels zit, maar het is ook een bewuste keuze om dan daar niet over te praten. En dat is misschien niet goed hoor, maar ik ben geen psycholoog. Ik kan mijn poli niet een uur laten uitlopen omdat iemand zn hart wil uitluchten. Maar op de PD poli heb ik daar wel tijd voor, dus dan kan ik rustiger het gesprek voeren.
O; En daar bespreek je dus regelmatig de behandelbeperkingen. Worden ze daar op voorbereid?



A; Nee. Maar juist omdat er een direct aanleiding is, ze komen bij me en de cardioloog heeft bedacht dat ze gecatheteriseerd moeten worden en dan vragen ze dokter, hmhm moet ik dat nou wel doen? En dat is natuurlijk een goede aanleiding om te zeggen van, wat zouden we dan doen met die resultaten en wat zou dat betekenen. Ja deze dingen moeten we misschien nog wel doen en deze dingen niet. En wat als u in een reanimatiesetting komt, wat wilt u dan eigenlijk? Dus dan heb je vaak een hele goede aanleiding en zijn ze ziek genoeg om er een goed gesprek over te hebben.
O; en maken ze dan vaak direct een keuze? Of is het iets wat ze overwegen en later op terugkomen.
A; over het algemeen maken mensen direct de keuze. Ik zeg altijd, denk er rustig over na en je mag er altijd op terugkomen. Maar mijn ervaring is dat mensen dat eigenlijk heel goed weten.
O; ja. Denk jij dat het kan helpen, als ze daarna nog bijvoorbeeld een folder meekrijgen of een verwijzing om iets te lezen?
A; zeker. Ik mis daar echt wel informatie over. Gewoon een folder die je mee zou kunnen geven. Bijvoorbeeld op de poli zou het kunnen doen met, nou we willen van alle patienten weten hoe we over bepaalde dingen denken, hier heb je een folder, lees het rustig door en dan bespreken we het volgende keer. Dan heb je in ieder geval al, hebben ze zich een beetje te kunnen inlezen. Want ik vind het doodnormaal om dit soort gesprekken te voeren, maar ik merkte in mijn omgeving dat mensen dit lastig vinden. Dus ik moet bij mijn patienten ook niet inschatten dat het allemaal maar doodnormaal is.
O;jaja
A; dus soms denk ik ook van, wij vinden het zo doodnormaal om het daarover te hebben, maar dat is misschien niet zo.
O; Heb je het idee dat mensen daar dan van schrikken?
A: ja heel erg.
O; en waarvan vooral? Het onderwerp de dood of heb wel of niet behandelen?
A; allebei. Want zelfs wel of niet dialyseren schrikken mensen soms van. Ja dat het leven eindig is, daar denken veel mensen niet overna of drukken dat heel ver weg. En dat ze daar keuzes in hebben. Maar ik vind het wel vantevoren lastig om in te schatten, er zijn er ook die daar gewoon al over na hebben gedacht. En dan breng ik het heel voorzichting en dan zeggen ze, ja maar dokter dat gaan we toch niet meer doen.
Maar ik kan het niet altijd vantevoren goed inschatten, het is niet dat ik daar al een gevoeldingetje voor heb.
O; Hebben jullie daar een lijntje mee met de huisarts? Of daar bijvoorbeeld dingen al besproken zijn?
A; Ja dat hoort natuurlijk heel erg gelijk te zijn. Heel soms op een verwijsbrief staat al een, bijvoorbeel een reanimatiecode. En dat is een hele mooie aanleiding, om te zeggen ik heb hier in de verwijsbrief staan dat u niet meer gereanimeerd wil worden. Klopt dat, mag ik dat ook hier noteren. Dat is een hele fijne aanleiding. Maar dan heeft dus al iemand dat gesprek gevoerd.
O;ja precies. Heb jij nog aanvullingen over dit onderwerp?
A; Ik denk dat wat meer informatie die ik uit kan delen zou echt helpen. En ik denk dat we, als je echt oprecht vind dat we iedereen een behandelbeperking geregistreerd moet zijn, dan is het denk ik als ziekenhuis ook heel goed om duidelijk en open over te zijn. En dat je dan ook zegt, we doen het bij iedereen. Want dan is het makkelijker. Maar nogmaals, ik denk dat dat niet reëel is en niet goed.

O; nee. Want jij vind niet dat dit beleid zo zou moeten toch?
A; Nou, nee. Ik denk dat je daar heel veel mensen mee laat schrikken, dat je niet bereikt wat je wil bereiken en dat je heel veel weerstand krijgt. Want mensen kunnen pas goed over dat soort dingen nadenken als er ook een aanleiding is. Het enige wat je ermee vangt zijn de mensen die pertinent niet gereanimeerd willen worden. Maar dat zijn vaak de mensen die dat zelf wel noemen. Die bedenken ook wel dat als ze in het ziekenhuis komen dat ze dat vast laten leggen.
O; want je hebt niet het idee dat er momenteel vaker zorg geleverd wordt, zoals reanimatie of opname op een IC, bij mensen die dat eigenlijk niet willen, maar waarvan dat nog niet gedocumenteerd is?
A: uhhm, nou ik denk dat dat opzich wel gebeurt. En dat zou niet moeten. Dus je moet die gesprekken wel voeren, maar de vraag wanneer je ze precies voert dat is een tweede. En met wie. Ik denk bijvoorbeeld bij de oncologie, waar ze mensen hebben die echt snel ziek kunnen worden, omdat ze chemo krijgen, dat het dan meer aanleiding is om zo'n gesprek te voeren. En dat vind ik bij mijn chronische patienten toch wel lastig. En (..) met wie ik de training volgde, die dan allemaal jonge patienten heeft met alleen maar hormoonafwijkingen, ja dat is dan niet de groep waarbij je dit gaat bespreken.
O; nee
A; dus dat ehh, Er heeft een keer een hele mooie column gestaan, van een amsterdamse internist, in ons internistenblaadje gestaan. Ik kan hem niet meer precies navertellen, maar dat had ook dezelfde strekking. Je moet echt alleen maar behandelbeperkingen bespreken als daar een aanleiding voor is. Want anders kwetst je mensen en bereik je niet wat je wilt bereiken. Dus ik denk dat ik daar wel achter sta.



Appendix 13- Transcript observation

Below you can find a transcript of an observation of a conversation between the physician (A) and the patient (P).

A; Hoe is t met u?
P; goed hoor
A; ja?
P; Tenminste, ik voel me goed ja.
A; Kunt u genieten van het mooie weer?
P; Dat moet nog. Het wordt goed weer. We gaan 4 mei met vakantie. Drienehalve week, met de caravan. Naar Zeeland. We gaan niet meer naar het buitenland hoor. Ik wil wel, maar zij niet.
A; Maar Nederland is ook zo mooi.
P; Jawel hoor.
A; Ik heb hier uw uitslagen.
P; Ja
A; Dan ziet u dat het kreatinine gehalte 195 is. De vorige keer was het 200. Dus het blijft heel mooi stabiel. En ook de stofjes in uw bloed zijn prachtig. Uw bloedgehalte is iets lager. Maar nog steeds prima.
P;ja?
A; ja.
P; Ik moet zo doorgaan.
A; u moet zo doorgaan. Ik was wel benieuwd naar uw bloeddruk.
P; Dat moeten we nog even meten.
A; Laten we dat even doen.
A: Ik ben eigenlijk heel bij met deze uitslagen, het ziet er keurig uit. Het is eigenlijk zo goed dat ik u nog niet de voorlichting ga geven over wat als de nieren er mee ophouden.
P: Ja.
A: Die kans is er natuurlijk wel een keer.
p: Ja.
A; En dan zou je moeten dialyseren. Ik weet niet of u weet wat dat is?
P: Nee.
A: Als je nieren niet meer werken dan word je bloed niet meer schoongemaakt. En als je bloed te vies wordt, te giftig zeg maar dan moet ik spoelen.
p: Ooh ja, dan moet ik spoelen, ja
A: Ja, dialyseren heet dat. Bij deze waarden is dat nog niet aan de orde, maar mocht dat slechter worden als dat getal richting de 15 gaat. Dan kan het zijn dat de dialyse wel in zicht komt en dan moet je natuurlijk ruim van tevoren moet je daar dan voorlichting over krijgen over wat is het nou precies en wat houd thet in.
P: Ja, ik heb dat wel eens gezien namelijk.
A: Ik denk dat die voorlichtingsdag echt nog niet aan de orde is. Als dat in zicht gaat komen op uw leeftijd moeten we ook goed bespreken of u dat wel zou willen. Want je kan ook zeggen met die slechte nierfunctie probeer ik het toch met pillen zo lang mogelijk goed te houden.
P: Ja.
A: En dat je dan van de dialyse zegt, dat is eigenlijk een brug te ver. Daar valt wel iets voor te zeggen.

P: Ja dat is natuurlijk niet prettig nee.
A: Nee.
P: Kijk ik heb vroeger wel eens gezien, toen ik nog werkte, bij mensen geweest die zo'n dialyse hadden onder zo'n grote machine. Het zal natuurlijk niet meer zo'n grote machine zijn natuurlijk. Maar het is niet leuk.
A: Kijk het is in ieder geval drie keer per week naar het ziekenhuis.
p: Dan moet je wel drie keer per week naar het ziekenhuis.
A: Ja, ja. Of spoelen via de buik dat kan ook.
p2: Ik denk ook dat als je een bepaalde leeftijd hebt dat je dan goed door moet denken of je nog wel bepaalde behandelingen wil.
A: Precies. We weten van mensen boven de 80 dat als je gaat dialyseren of niks doet dat je dan eigenlijk even lang leeft.
P: Ja, ja.
A: Dus dat het niet heel veel bijdraagt
P: Ja, ik ben 81 en ik word 82
A: Ja, ja.
P: Dus ja goed, ik voel me niet oud hoor, ik wil ook niet dat mensen zeggen hee ouwe of iets dergelijks daar hou ik niet van.
A: Nee, maar dat is
p: Dat zeggen mijn kinderen ook niet hoor.
A: Nee. Maar u zou nu in prima conditie zijn om allerlei behandelingen wel te kunnen ondergaan he, het is niet dat u te zwak bent voor behandeling.
P: Nee, nee
A: Maar nogmaals het is ook nu niet aan de orde, maar het is iets voor de toekomst.
P: Nee, nee, maar moet je wel in de gaten houden en blijven doen wat ik nu doet.
A: En hopen dat
P: En hopen dat het niet meer naar beneden gaat
p2: Ik ben ervan overtuigd dat het beter gaat.
P: Ik ben benieuwd naar de bloeddruk waarde
A; 176/75.
P; dat is wel hoog he?
A; Uw onderdruk is aardig, maar uw bovendruk is aardig hoog. Maar de vraag is, wat gaan we eraan doen. Want.
P2; dat is wel raar
P; ik heb andere keren gehad dat ie wel goed was.
A; Ja. Mag ik eens even naar uw benen kijken? Wel een beetje vocht he?
P; nou valt wel mee hoor. Dit komt door die steunkousen.
A; Ik zie nog wel wat winst te behalen. Wat we zouden kunnen doen, is die X (naam medicijn) nog wat kunnen ophogen. Want dan plast u het vocht uit.
P: Ja?
A: Ja, want dan plast u dat vocht uit wat daar in die benen zit. Worden ten eerste de benen mooier van.
P; Zoveel hoef ik niet te plassen overdag eigenlijk.
A: Nee, maar u moet dus wat meer uit, want dan moet de bloeddruk lager.
P: Ja, ja.
A: Want u heeft nu 2 keer per dag 20 milligram he?
P: Ja.
A: Een half tabletje denk ik?
P: Even kijken wat ik heb hoor, (pakt zijn notities erbij). Ja ik heb 20.
A: Ja van die 20 milligram ga ik dan naar 40 milligram.

P: Oke
A: Ja, net een beetje wat vocht eruit, dan worden die enkels slanker en dan gaat de bloeddruk omlaag.
P: Ja, dat hoop ik
A: dat denk ik
P; daar gaan we vanuit.
A; dan is dit denk ik nog wel een goede zet. Voor uw nierfunctie is 2x 40 mg nog steeds een beetje weinig. Dus u moet de volgende keer kijken of dat vocht wel echt weg is. Want 2x80 zal ook een logische dosering zijn. Ik kan tot 2x500. Dus we hebben ruimte.
P; dat is prima, dan hou ik dat in de gaten.
A; Verder geen klachten? Niet benauwd?
P; nee dat heb ik niet nee. Ik ga 3x per week naar de fysio, dan ga ik even op de loopband.
A; wat goed.
P; dan loop ik n uur. Ik liep altijd 5 km per uur. Maar ik heb nou vaatvernauwing een beetje. Maar dan kan je beter blijven lopen zei ze.
A; ja goed zo.
P; Maar ik had t wat verwaarloosd, maar nu loop ik weer 3 keer in de week.
A; het is wel goed voor u hoor.
P; ze zeiden van, u hebt een keuze of opereren of lopen. Dus toen heb ik dat gekozen.
A; ja lopen is eigenlijk beter he.
Ik wens u een fijne vakantie. En een labformuliertje voor de volgende keer. Over 3 maanden zien we elkaar weer. Mocht u klachten krijgen, dan moet u bellen.
Nemen afscheid.

Appendix 14 – Translation of the quotes

Below you can find the different quotes, which are used in the results section. These quotes were derived from the interviews. The quotes are followed by their original Dutch quotes.

physician 8; "I think it is good to discuss treatment limitations at the outpatient clinic because of the quiet setting, the generally good relationship between the physician and the patient and the fact that they have a long-term treatment relationship."
"ik vind het goed vanwege: de rustige setting als poliklinische dokter, je gaat samenwerken aan een langetermijns beleid en daar hoort ook gewoon behandelbeperkingen bij en je hebt over het algemeen een goede relatie met de patient."

physician 1; "It would help if you could say to the patient, I'm not only discussing this with you, but we discuss this with all our patients."
"Het helpt als je vol overtuiging kan zeggen van, ik pik u er niet zomaar uit, we doen dit bij iedereen."

Physician 5; "No, patients never start about treatment limitations in the outpatient setting."
"Nee, patienten beginnen er verder never nooit over op de poli."

Physician 2; "You need to support and facilitate the patient in it. And that means, you need to ask the question. Because it's not the patients' job to start about it out of the blue during the consult. So, it is your responsibility, as a doctor."].
"Dus daar moet je de patient voor ondersteunen, faciliteren. En dat betekent wel dat je de vraag moet stellen. Want het is niet de taak van de patient om midden in zo'm consult op tafel te gooien. Dus die verantwoordelijkheid heb je."

physician 2; “It’s a difficult subject. So, if you bring it up, you have to take the time for it. You cannot start about it and think it will be discussed in 30 seconds. So, if you already run out of time, then you just don’t do it.”
Maar het is ja het is wel een beladen onderwerp. Dus als je dat doet, dan moet je wel ook. Je kan niet eraan beginnen en denken, ik ben in 30 seconde klaar. Dus als je al een halfuurtje uitloopt, dan ga je dat dus niet doen.”

physician 11; “I think that sometimes, we misuse the factor time as a doctor, because we find it a difficult topic. We rather talk about a lab result or an operation, than having conversations about treatment limitations. Also, because we have no control over the conversation, because we have no idea how the patient will respond.”
“Ik denk ook wel dat we als dokter tijd een beetje misbruiken ook he, omdat we het toch wel lastig vinden. Je praat liever over een labuitslag of over een operatie, dan dat je dit soort gesprekken aangaat. Ook omdat je niet helemaal de controle hebt, je weet niet helemaal wat de patiënt gaat zeggen.”

Physician 3; “Recently, I tried to talk about treatment limitations with someone who was still rather stable, but it was so out of the blue, it really scared the patient. That’s when I thought, this is not the right way to do it.”
“Toen ik het laatst probeerde met iemand te bespreken, iemand die nog redelijk stabiel was, en dat kwam dan zo out of the blue, diegene die schrok er echt van. En toen dacht ik, dit is dus niet de goede manier.”

Physician 5; “Although it’s always possible to learn new things, but I already felt really confident about it.”

“Je leert altijd wat nieuws. Maar ik voelde me er echt al wel bekwaam in.”

physician 6; “I think that in general people should talk more about these topics. Not only about the wish to be resuscitated but also about how you want your life to end. That it would be more socially accepted. But perhaps that is just a nice dream.”

“ik vind dat over het algemeen, dat je dit veel meer bespreekbaar moet maken. Dat mensen het er thuis al over hebben, dus dat ze zelf het dan al met de huisarts kunnen bespreken. Niet alleen maar van wil ik gereanimeerd worden maar ook hoe wil ik het einde van mn leven doormaken? Wat wil ik wel en wat wil ik niet? Dat we met zn allen daar wat actiever in zijn. Maar goed, dat is een mooie droom. “

physician1; “If we agree on certain criteria, it would feel less random”.

O; “en met handvaten bedoel je dan, die eventuele criteria? “

A; “Ja. Tenminste, dat lijkt mij goed. Dat we niet op willekeurige basis doen.”

Physicians 7; “I think it is more the awarness you will create. So you think, I should be more focused on it, instead of really changing your skills.”

“Ik denk dat het meer awareness is, wat je dan creert. Dat je denkt, hier moet ik nog op letten, dan dat je skills echt anders worden.”

Appendix 15- FETC Form

APPLICATION FORM FOR THE ASSESSMENT OF A RESEARCH PROTOCOL BY THE FACULTY ETHICS REVIEW BOARD (FERB) OF THE FACULTY OF SOCIAL AND BEHAVIOURAL SCIENCES

General guidelines for the use of this form

1. This form can be used for a single research project or a series of related studies (hereinafter referred to as: "research programme"). Researchers are encouraged to apply for the assessment of a research programme if their proposal covers multiple studies with related content, identical procedures (methods and instruments) and contains informed consent forms and participant information, with a similar population. For studies by students, the FERB recommends submitting, in advance, a research programme under which protocol multiple student projects can be conducted so that their execution will not be delayed by the review procedure. The application of such a research programme must include a proper description by the researcher(s) of the programme as a whole in terms of the maximum burden on the participants (e.g. maximum duration, strain/efforts, types of stimuli, strength and frequency, etc.). If it is impossible to describe all the studies within the research programme, it should, in any case, include a description of the most invasive study known so far.
2. Solely the first responsible senior researcher(s) (from post-doctoral level onwards) may submit a protocol.
3. Any approval by the FERB is valid for 5 years or until the information to be provided in the application form below is modified to such an extent that the study becomes more invasive. For a research programme, the term of validity is 2 years and any extension is subject to approval. The researcher(s) and staff below commit themselves to treating the participants in accordance with the principles of the Declaration of Helsinki and the Dutch Code of Conduct for Scientific Practices as determined by the VSNU Association of Universities in the Netherlands (which can both be downloaded from the FERB site on the Intranet[1]) and guarantee that the participants (whether decisionally competent or incompetent and/or in a dependent relationship vis-a-vis the researcher or not) may at all times terminate their participation without any further consequences.
4. The researcher(s) commit themselves to maximising the quality of the study, the statistical analysis and the reports, and to respect the specific regulations and legislation pertaining to the specific methods.
5. The procedure will run more smoothly if the FERB receives all the relevant documents, such as questionnaires and other measurement instruments as well as literature and other sources on studies using similar methods which were found to be ethically acceptable and that testify to the fact that this procedure has no harmful consequences. Examples of studies where the latter will always be an issue are studies into bullying behaviour, sexuality, and parent-child relationships. The FERB asks the researcher(s) to be as specific as possible when they answer the relevant questions while limiting their answers to 500 words maximum per question. It is helpful to the FERB if the answers are brief and to the point.

[1] See: https://intranet.uu.nl/facultaire-ethische-toetsingscommissie-fetc

6. **Our FAQ document that can be accessed through the Intranet provides background information with regards to any questions.**
7. The researcher(s) declare to have described the study truthfully and with a particular focus on its ethical aspects.

Signed for approval[2]:
Date:

[2] The senior researcher (holding at least a doctoral degree) should sign here.

A. GENERAL INFORMATION/PERSONAL DETAILS

1.
a. Name(s), position(s) and department(s) of the responsible researcher(s):
L.A. Berghuis, master student, University Utrecht, Educational Science

2. Title of the study or research programme - Does it concern a single study or a research programme? Does it concern a study for the final thesis in a bachelor's or master's degree course?:
Physician-related factors concerning treatment limitations at the outpatient clinic: A qualitative study. It's a final thesis in a master's degree programme. It is part of a larger mixed method project, from UMC Utrecht.

3. Type of study (with a brief rationale):
Qualitative study. Interviews will be held with participating physicians and observational research of recorded conversations between physicians and their patients.

4. Grant provider:
Not applicable

5. Intended start and end date for the study:
February 2019– June 2019

6. Research area/discipline:
Social and Behavioural sciences, Educational sciencs, learning in organisations

8. For some (larger) projects it is advisable to appoint an independent contact or expert whom participants can contact in case of questions and/or complaints. Has an independent expert been appointed for this study?[3]
No*, not for this part of the research. For the larger mixed method project of UMC Utrecht, there is an independent expert appointed. Karin Kaasjager.*

8. Does the study concern a multi-centre project, e.g. in collaboration with other universities, a GGZ mental health care institution, a university medical centre? Where exactly will the study be conducted? By which institute(s) are the executive researcher(s) employed?:
UMC Utrecht

9. Is the study related to a prior research project that has been assessed by a recognised Medical Ethics Review Board (MERB) or FERB?
No

B. SUMMARY OF THE BACKGROUND AND METHODS

[3] This contact may, in principle, also be a researcher (within the same department, or not) who is able to respond to the question or complaint in detail. Independent is to say: not involved in the study themselves. The FERB upholds that an independent contact is not obligatory, but will be necessary when the study is more invasive.

Background

1. What is the study's theoretical and practical relevance? (500 words max.):

Discussions about patients' preferences concering treatment limitations are important for patient-centred care. This advance care planning leads to higher satisfaction among patients, lower rates of anxiety of family members and lower health care costs. However, most physicians found it hard to initiate these conversations with their patients and therefor it is common for doctors to avoid them. This leads to having these discussions too late or at acute or emotional moments. Having these discussions at the outpatient clinic seems to be the right time and place. One factor that might influence these discussions is the lack of communication training of physicians. However, more factors might influence the physicians in their decision in initiating these conversations. The aim of this qualitative study is to examine the perspectives of physicians regarding the conversations about treatment limitations and the factors that might influence them. Besides that, their conversations before and after their communication training will be observed to examine if a communication training affects their discussions about treatment limitations.

2. What is the study's objective/central question?

- *Which physician-related factors are influencing Dutch physicians on their discussion of treatment preferences and limitations with their patients at the outpatient clinic?*

- *What influence has a communication training for Dutch physician on discussing treatment preferences and limitations with their patients at the at the outpatient clinic?*

3. What are the hypothesis/hypotheses and expectation (s)? -
Not applicable

Design/procedure/invasiveness

4. What is the study's design and procedure? (500 words max.):

Qualitative analysis; Interviews and observational research. Case study.
Data collection will take place from February to May at the department of Internal Medicine at UMC Utrecht. Physicians will be recorded on video during regular consults at the outpatient clinic at the internal medicine department. Only consultations of patients who have not yet discussed their treatment preferences, based on their digital file, will be recorded. They are recorded through a small camera, which is relatively discrete placed in the room. Both physicians and patients are not told explicitly to discuss treatment limitations. These conversations are both recorded before and after the physicians had their training. For every physician that will be interviewed, one observation will be analysed before the participating in the training and one observation right after they participated in the training. The recorded videos will be transcribed and analysed.
Physicians will participate at a communication training, which consist of an e-learning and a scenario training. The e-learning consist of clips of different experts claiming why it is important to discuss treatment limitations, different simulation conversations about treatment limitations, theoretical background information, pitfalls for these conversations and explanation on how to document the patient choices. The e-learning can be done at own time and place. During the scenario training the doctors will practice their conversations with simulation patients and have a discussion about treatment limitations. These conversations will be observed and discussed afterwards with each other. The goal of this training is to improve the skills of the participating physicians in communication about treatment

limitations. Topics that will be addressed are the importance of discussing treatment limitations, general and personal pitfalls and tips to improve these skills. The exact timing of this training is not yet known.
Interviews will be held after physicians had the communication training. Before the interview starts the researcher will give a clear introduction, to explain the purpose of the study, that participation is voluntarily, and the structure of the interview. The interviews will be recorded with a voice recorder, so the interviews can be transcribed later.

5.

a. Which measurement instruments, stimuli and/or manipulations will be used?[4]
Observations video recordings of consults
Interviews with physicians

b. What does the study's burden on the participants comprise in terms of time, frequency and strain/efforts?:
Observations: none
Interviews: time

c. Will the participants be subjected to interventions or a certain manner of conduct that cannot be considered as part of a normal lifestyle?:
The participants will be joining a communication training

d. Will unobtrusive methods be used (e.g. data collection of uninformed subjects by means of observations or video recordings)?:
No

e. Will the study involve any deception? If so, will there be an adequate debriefing and will the deception hold any potential risks?:
No

6. Will the participants be tested beforehand as to their health condition or according to certain disorders? Are there any inclusion and/or exclusion criteria or specific conditions to be met in order for a participant to take part in this study?:
The participants need to be a physicians working at the outpatient clinic of the department of Internal Medicine at UMC Utrecht. They also need to participate at a communication training about treatment limitations

7. Risks for the participants -

a. Which risks does the study hold for its participants? *No risks*

[4] Examples: invasive questionnaires; interviews; physical/psychological examination, inducing stress, pressure to overstep important standards and values; inducing false memories; exposure to aversive materials like a unpleasant film, video clip, photos or electrical stimulus; long-term of very frequent questioning; ambulatory measurements, participation in an intervention, evoking unpleasant psychological or physical symptoms in an experiment, denial, diet, blood sampling, fMRI, TMS, ECG, administering stimuli, showing pictures, etc. In case of the use of a device (apparatus) or administration of a substance, please enclose the CE marking brochure for the relevant apparatus or substance, if possible.

b. To what extent are the risks and objections limited? Are the risks run by the participants similar to those in daily life? *Not applicable*

8. How does the burden on the participants compare to the study's potential scientific contribution (theory formation, practical usability)?: *Not applicable*

9. Will a method be used that may, by coincidence, lead to a finding of which the participant should be informed?[5] If so, what actions will be taken in the case of a coincidental finding?: *No*

Analysis/power
10. How will the researchers analyse the data? Which statistical analyses will be used?: *Template analysis*

11. What is the number of participants? Provide a power analysis and/or motivation for the number of participants. The current convention is a power of 0.80. If the study deviates from this power, the FERB would like you to justify why this is necessary:
10 participants. This is the number of physicians who will attend the communication training.

[5] For instance: dementia, dyslexia, giftedness, depression, extremely low heartbeat in an ECG, etc. If coincidental findings may be found, this should be included in the informed consent, including a description of the actions that will be taken in such an event.

C. PARTICIPANTS, RECRUITMENT AND INFORMED CONSENT PROCEDURE

1. The nature of the research population (please tick):
    1. **General population without complaints/symptoms**
    2. General population with complaints/symptoms
    3. Patients or population with a diagnosis (please state the diagnosis)

2. Age category of the participants (please tick):
    - **18 years or older**
    - 16-17 years
    - 13-15 years
    - 12 years or younger

3. Does the study require a specific target group? If so, justify why the study cannot be conducted without the participation of this group (e.g. minors):
Yes, physicians working at the outpatient clinic of the department of internal medicine at UMC Utrecht , who have joined the communication training about treatment limitations

4. Recruitment of participants -
    a. How will the participants be recruited?
    Through purposive sampling. All physicians who participated in the communication training will be invited to participate in the interviews.

    b. How much time will the prospective participants have to decide as to whether they will indeed participate in the study?
    1 week

5. Does the study involve informed consent or mutual consent? Clarify the design of the consent procedure (who gives permission, when and how). Does the study involve active consent or passive consent? If no informed consent will be sought, please clarify the reason:
Informed active consent

6. Are the participants fully free to participate and terminate their participation whenever they want and without stating their grounds for doing so?:
Yes

7. Will the participants be in a dependent relationship with the researcher?:
No

8. Compensation
    a. Will the participants be compensated for their efforts? If so, what is included in this recompense (financial reimbursement, travelling expenses, otherwise). What is the amount?
    No

b. Will this compensation depend on certain conditions, such as the completion of the study?
No

D. PRIVACY AND INFORMATION

1.

a. Will the study adhere to the requirements for anonymity and privacy, as referred to in the Faculty Protocol for Data Storage[6]?:
   - anonymous processing and confidential storage of data (i.e. storage of raw data separate from identifiable data): *Yes*
   - the participants' rights to inspect their own data: *Yes*
   - access to the data for all the researchers involved in the project: *Yes*

If not, please clarify.

b. Has a Data Management Plan been designed?
No

2.

a. Will the participant be offered the opportunity to receive the results (whether or not at the group level)?:
Yes

b. Will the results of the study be fed back to persons other than the participants (e.g. teachers, parents)?:
Yes, other researchers and teachers of the university.

If so, will this feedback be provided at the group or at the individual level?
Individual

3.

a. Will the data be stored on the faculty's data server?
Yes

b. Will the data that can be traced back to the individual be stored separately on the other faculty server available for this specific purpose?
Yes

If not, please clarify where will the data be stored instead?:

[6] This can be found on the Intranet: https://intranet.uu.nl/wetenschappelijke-integriteit-facultair-protocol-dataopslag

E. ADDITIONAL INFORMATION

Optional.

F. FORMS TO BE ENCLOSED (CHECKLIST)

- Text (advert) for the recruitment of participants
- Information letter for participant
- Informed consent form for participants
- Written or oral feedback information (debriefing text)
- (Descriptions of) questionnaires
- (Descriptions of) measurement instruments/stimuli/manipulations
- Literature/references

Signature(s):[7] Date and place:

Name, position:

[7] The senior researcher (holding at least a doctoral degree) should sign here.