Collaborative goal-setting: stakeholders' experiences, barriers and facilitators

V. Sangster, BSc, 5610796.
Supervisors: prof. dr. J.J.M. van Delden, dr. H. Wessels-Wynia.

Abstract

Background:
Goal-setting is an approach that encourages the use of self-defined goals of care in the process of decision-making. It is already a commonly known concept in rehabilitation and end-of life care. Several positive effects have been listed in previous research. At University Medical Center Utrecht it appears that only few doctors document goals of care in patient records. This study aims to identify stakeholders' experiences with goal-setting and the barriers and facilitators to discussing, documenting and using goals of care in individual health care.

Methods:
A qualitative study design was used. In-depth topic-interviews were held with 19 healthcare professionals (HCPs) and 7 patients.

Results:
Although the majority of HCPs and patients share a positive attitude towards goal-setting, it appears hard to accomplish. This study identified that that most HCPs are not consistent in discussing values, preferences and goals with their patients. Many different barriers to goal-setting are identified, including the ambiguity concerning the interpretation of goals, organisational barriers, patient-related barriers and the uncertainty about the usefulness and feasibility of goal-setting in every setting or situation. Most stakeholders agree that the current methods of goal-setting are not adequate.

Conclusion:
Based on our findings, the formulation of purely medical goals might be useful to improve communication between HCPs and provide clarity to patients. However, purely medical goals attribute less to performing care that is person-centered. Further research is recommended to identify ways to overcome the barriers and to develop a strategy for meaningful goal-setting in different care settings.

Department: Medical Humanities, Julius Centrum, UMC Utrecht.
January 17th 2022 - April 8th 2022.

1. Introduction

In person-centered care, a patient is viewed as a unique human being within their own context.[1] Patients are seen as persons with their own strengths, weaknesses, history, rights, values and future plans. They are no longer seen as passive targets of the healthcare system, reduced to their disease alone. Person-centered care is a development of patient-centered care. On a surface level, these two concept share similar aspects, such as the need for empathy, engagement, two-way communication, shared-decision making and a holistic and individualized focus. However, important differences are seen regarding their goals. While patient-centered care strives for a functional life for the patient, person-centered care desires a meaningful life, which requires an understanding of the patients' values.[2,3] An approach to achieve this, is by implementing goal directed care, which encourages the use of self-defined goals in the process of decision-making.[4]

This goal-directed care, or goal-setting, is already a commonly known concept in rehabilitation and end-of-life care.[5] It requires a conversation between physician and patient, starting with gaining shared understanding of the health condition and the possible outcomes, followed by a discussion of goals and values. These goals can involve decisions for the future or decisions about present treatment, and they are not bound to the medical domain.[6] Goals can be medical, functional, spiritual and psychosocial. Key characteristics of 'good goals' are that they are attainable and that attainment leads to some form of personal satisfaction. Goals should be re-evaluated and reconstructed, as patients' status or preferences may change.[7]

Several positive effects of goal-setting are listed in literature. It is described to enhance patient motivation, confidence, self-image and engagement in treatment.[5,6] It enables them to actively create meaning to their life and it enhances satisfaction with care.[6] Furthermore, it improves team communication and coordination of care, as all healthcare professionals focus on the same goals and outcomes.[5,8] It is shown that goal-setting has the potential to result in better treatment-outcomes.[9-11]

Collaborative goal setting is however often described as something that can be hard to accomplish.[10] Healthcare professionals (HCPs) have listed several barriers, such as lack of time, the need for training, high staff-turnover and pressure of competing priorities.[5,8,11] Furthermore, some HCPs are concerned for the identification of unrealistic or unachievable goals, or they doubt the patients' ability to participate effectively. This might be due to (perceived) lack of knowledge, poor health-literacy, psychosocial factors or disease-related biological factors.[5,7,10,11] Additionally, some patients do not appreciate the need for goal-setting, due to fear of failure, previous negative experiences with goal-setting, depressions or the wish to keep their values and plans private.[5,7] It is also described that there are discrepancies between the views of patients and professionals regarding the level of patient involvement and the preferred goals.[11] Goals set by professionals tend to be specific, relatively narrow, short-term and focused on biological or functional problems, while patients' goals tend to be long-term, fluctuating, broad and personal, sometimes linked to 'life projects'.[5,12]

In 2018, the Patient Participation programme is initiated in University Medical Center Utrecht (UMC Utrecht), The Netherlands. Its primary goal is to ensure patients' involvement in health care, research and education. An important instrument for the involvement of patients is the process of Shared Decision making (SDM), which entails shared understanding, decision making and evaluation. The processes of goal-setting and SDM are strongly connected to each other. Since 2013, it is required in UMC Utrecht that goals of care are documented for each patient after admission in the hospital. This is according the standards of the international accreditation organisation JCI (Join Com-mission International). However, it appears that in reality only few doctors document goals of care in patient records. The reason behind this is yet unclear. One hypothesis is that it is related to the JCI standard which requires goals to be formulated as discharge-criteria. Other hypotheses include barriers that are mentioned above.

The primary aim of this qualitative study is to identify the experiences of doctors, nurses and patients in UMC Utrecht with discussing, using and documenting goals of care. The secondary aim is to identify the barriers to goal-setting and what is needed and desirable to overcome these barriers.

2. Methods

2.1 Data Collection

Setting
Participants were recruited from four different hospital wards within the University Medical Center Utrecht (UMCU). This is a tertiary hospital, which comprises the faculty of medicine, the Whilhelmina Children's hospital and the Academic Hospital. It focusses its efforts in healthcare, education and research.

Study Design
A qualitative study was conducted using in-depth topic-interviews with stakeholders, to identify experiences with and facilitators and barriers to discussing, documenting and using goals of care in individual health care.

Population
The study population consisted of two groups of stakeholders. The first group of stakeholders consisted of doctors and nurses. The following inclusion-criteria were used: 1) the doctor or nurse is involved in direct patient care and 2) works at a hospital ward at which goals of care are scarcely or frequently discussed and documented, according to the results of a previous JCI-tracer study. No exclusion-criteria were used. The aim was to draw an aselect study sample from staff-lists per ward. However, this proved to be unachievable and therefore a convenience sample of doctors and nurses was used. The second group of stakeholders consisted of patients from a patient-panel. A convenience sample of patients were invited to join a focus group. The inclusion-criterion was that the patients had proper technical skills, since the focus group took place via Teams. The sample was checked for diversity in experiences with chronic care setting or acute care setting, to reach a certain diversity.

Recruitment
This study aimed to include 12 doctors and 8 nurses from four different hospital wards. The final number of participants was determined by the point of data saturation. The hospital wards were identified using data of a previous JCI tracer-study on goals of care. This JCI-study was conducted by means of a self-evaluation tool, between March 1st and April 30th 2021. Forty wards at UMC Utrecht answered whether they 1) report a goal of care and treatment-plan for each patient in the patient record within 24 hours after admission, 2) discuss this goal and treatment-plan with the patient within 24 hours after admissions and 3) use the goal and outcomes to evaluate the provided care with the patient prior to discharge from the hospital. Two wards who ranked low and two wards who ranked high on this self-evaluation were considered relevant for this study. The HCPs received an email with information on this research and an invitation to sign up. The aim was to include at least 5 patients. Patients were recruited from a patient-panel and they received an email with an invitation to join the focus group.

Procedures
Whenever stakeholders responded to the recruitment request, agreements were made on a time and place to conduct the semi-structured in-depth topic-interviews. The interviews were held face-to face or via Teams. Different options for locations were offered: meeting/consultation rooms at the hospital ward, cafeteria at the hospital or other locations preferred by the stakeholder. The focus group was held via Teams. When patients were not able to join the focus group, they were interviewed separately. The interviews started with a detailed introduction and description of the research and the use and anonymity of the data. Informed consent was obtained.

Interviews
Interviews were conducted between February 11th and April 1st 2022 by VS, who had a training-sessions with a skilled interviewer (HWW) beforehand. For this study, a topic-list was developed using relevant literature and input from a patient who had experience with goal-setting. Beforehand,

adjustments were made based on feedback from experienced qualitative researchers (HWW & JVD) (see Appendix 1). During the course of the study, alterations to the topic-list were made when new topics or insights arose, following an iterative approach. In approximately 30 minutes, the following topics were discussed: association with 'goals of care', experiences with goals of care in practice, the present use and documentation of goals, possible barriers to discussing goals and potential solutions and desirability to overcome these barriers. All interviews were recorded with an audio recorder.

Focus group

The focus group with patient-representatives was conducted on March 30th by VS and HWW. A topic-list was created by using the topic-list for HCPs and by adding a section of initial results from this study (see Appendix 2). In approximately 90 minutes the following topics were discussed: association with 'goals of care', experiences with goal-setting, the desirable way of working with goals, and views on the initial results of this study. The focus group was recorded with an audio recorder.

2.2 Data analysis

Analysis

All interviews and the focus group were transcribed verbatim, partly by the interviewer, and partly by a transcription company (uitgetypt.nl). All transcribed interviews were checked by the interviewer for missing information. In the initial stage of the analysis, all interviews were read thoroughly to become aware of the general opinions and ideas of the participants. In this stage, the interviews were divided into segments and coded using open coding. Subsequently, an initial code-tree was developed, using more and more deductive codes that were based on the research questions: 1) what are the experiences with discussing, using, and documenting goals of care and 2) what are the barriers to goal-setting and what is desirable and needed to overcome these barriers? When new inductive codes were identified, they were added to the code tree. The final code tree was discussed between VS, HWW and JVD. During the axial and selective coding, the constant comparative method was used to identify possible connections between the codes. These possible connections were verified in the segments and discussed with a second researcher. Data from several segments was combined to form an answer to the research questions.

All interviews were coded in NVivo. In order to ensure the quality and validity of the coding-process, a second researcher (HWW) replicated the coding of two interviews. Disagreement and differences in coding or interpretation of codes were resolved through discussions.

3. Results

3.1 Participants

In total, 26 HCPs an invitation to join the study, of which 19 responded and participated in the study (see **Table 1**). None of the HCPs denied participation after responding to the invitation. Amongst the participants, there is a spread in gender and years of experience. Slightly more doctors than nurses participated (respectively 10 and 9).

For the focus group, 12 patients received an invitation, of which 7 responded. Four patients joined the focus group and three patients were interviewed separately. A spread is seen in gender and experience with acute of chronic care.

Nurses		Doctors		Patients	
Variables	**n (N=9)**	**Variables**	**n (N=10)**	**Variables**	**n (N=7)**
Gender		Gender		Gender	
Male	1	Male	5	Male	2
Female	8	Female	5	Female	5
Years of experience		Years of experience*		Experience with	
1-5	2	1-5	1	Chronic care	2
5-10	2	5-10	4	Acute care	1
10-15	4	10-15	2	Both	4
15-20	-	15-20	1		
20-25	1	20-25	1		
25-30	-	25-30	1		

Abbreviations: **n** = number of stakeholders, **N =** total number of stakeholders per group.
* Number of years as resident plus the number of years as specialist.

Table 1: Characteristics of the study population

3.2 Experiences with goals of care

First of all, the experiences of stakeholders with the present use and documentation of goals are discussed. It is necessary to clarify the associations stakeholders have with the term 'goals of care' beforehand.

Associations with goals of care
Different associations with 'goals of care' are found among HCPs. First of all, nearly all doctors and nurses associate them with the purpose of the treatment or of the hospital admission for this specific patient. Two-third of the HCPs feel that goals are twofold: on one hand there are medical goals, the medical actions that are needed, and on the other hand there are personal goals of the patient. A minority of these HCPs believe that goals are in essence personal and patient-bound and that the conversation on goals should take place before even forming an idea about the medical actions that are needed.

> *'There are medical goals for the doctors and there are patient-bound goals. For example, the doctor might say: 'The CRP-level should be lowered', while the patient says: 'I want less pain'. These are different goals.' (HCP 10)*

Secondly, almost one-third of the HCPs associate goals of care with discharge criteria. When the goals are achieved, the patient is ready to be discharged from the hospital. A few other HCPs immediately associate goals with JCI and the required action to formulate goals as discharge criteria in order to prevent claims. Thirdly, a small minority of HCPs think of the discussion of treatment limitations. And lastly, a small minority of HCPs associate goals of care with the existence of bigger, overarching goals.

> *'On the one hand, there are goals of care and on the other hand, there are treatment limitations. Although I'm a supporter of discussing goals of care, I notice that in practice my thoughts are often: 'what are the limitations, what can't we do?' instead of 'what can we do?'' (HCP 5)*

All of the patients associate goals of care with the desired result or outcome of the treatment. Each of them mentions that doctors and patients might have different views or goals. Therefore, goals should be jointly set by patient and doctor.

> *'I notice that goals are often medical. I think this illustrates the difference between patients and doctors. The doctor uses a medical approach, while the patient might want something different. My goals are way more personal and they may change over time.' (Patient 6)*

Conversation on goals of care
A minority of HCPs feel that they are consistent in discussing goals of care with their patients. Most of these HCPs, however, do not label this as 'goals' in the conversation or in the patient file. Some HCPs start a conversation at the polyclinic about the outcomes that the patient desires and the things that the patient values. Other HCPs mention that they discuss goals by explicitly asking patients about their expectations of the treatment, or by discussing discharge criteria during patient rounds. A few other HCPs feel that they are discussing goals by asking patients 'what do you want?' after explaining the diagnosis and the medical treatment options.

> *'During the round with doctors and nurses, we ask patients about their expectations and preferences. I always make sure to start with asking them: 'What would you like to discuss with us? What are your concerns?'. At the polyclinic I always ask patient: 'I expect you came here with certain ideas and expectations of this appointment. What can I do for you?' That implicitly concerns their goals of care.' (HCP 15)*

On the other hand, the majority of HCPs feel that they are not consistent in explicitly asking patients about values, preferences and goals. These HCPs mention that most of this information is implicitly accumulated during the hospital stay from conversations between patients and HCPs, mostly from nurses. A few HCPs mention that sometimes patients start the conversations themselves, by sharing their opinions and ideas. Furthermore, almost half of the nurses mention that there are questions on patients' goals in the intake form. However, often patients do not fill in the answer to these questions when given the paper form.

> *'Discussions about the patients' preferences are not conducted explicitly. This information has to be obtained from daily rounds and signals from the nurses. But it is not explicitly asked.' (HCP 2)*

The majority of the patients feel that they are usually aware of the goals of their treatment, but that most doctors do not explicitly discuss preferences or goals as such. Some patients mention that, therefore, they have learned to start these conversations themselves. On the other hand, a minority of patients feel that these conversations do take place and are initiated by the doctors. A minority of patients feel that they are not always aware of their treatment goals, or that it is differs per treatment and doctor.

'My experience is that questions on goals are not asked. When you arrive at the hospital, the doctor just starts the diagnostic process or the treatment. And that is it. Goals are not discussed, let alone means or evaluation.' (Patient 7)

Documentation

None of the HCPs recently used the 'goals of care' checkbox in the electronic patient file. Some HCPs mention that they document goals as the reason for admission, problem-list and treatment plans. When patients' personal preferences of goals come to light during the admission, some doctors document them in the 'summary' and a few nurses write them down in the intake-form or nurse-summary. However, some HCPs feel that not all information on patients' preferences is written down, and some HCPs question whether the documented information is being used. Lastly, a few HCPs mention the existence of prespecified lists of goals for each different condition, but they mention that these lists are seldomly used to document goals.

I recently identified a patients' goal. I wrote in the nurse-summary that the patient wished to achieve this goal after five days. However, no one else has read it since. We are not used to it. (HCP 10).

The majority of patients also mention that goals are not explicitly documented in the patient file. Some of the patients do not know whether goals are documented, because they do not read their electronic patient file or they do not know where to find goals. A small minority of patients mention that their goals are documented.

'The doctor did not explicitly ask me about my treatment goal. I think it was clear that my goal was to be cured. We did, however, specifically discuss the road towards that goal. However, I do not think that the goal is documented as such.' (Patient 3).

Roles of doctors and nurses

Almost all doctors feel that they are not fully aware of the nurses' role in goal-setting, or whether nurses draw up their own goals or treatment plans. More than half of the doctors feel that the communication between doctors and nurses and role of nurses should be enhanced. On the other hand, the majority of nurses mention that they are aware of the treatment plans and decision of the doctors. These are discussed during the daily nurse-physician rounds. More than half of nurses are satisfied with the collaboration with the doctors. They feel they are working towards the same goals, and in respect use their own specific nurse-plan.

'Doctors and nurses often communicate poorly on the treatment goal. Let alone that the patient knows. They are often not informed at all.' (HCP 8)

A minority of nurses, however, express that they experience some barriers to the collaboration with doctors. They feel that doctors and nurses work too separately and that it is regrettable that nurses are not present during the weekly patient rounds. These nurses feel that they have important information on patients' preferences, because they see patients more often. However, they feel that this information does not always reach doctors, or that doctors do not always listen to it. Furthermore, a minority of nurses express that they have difficulty seeing that the doctors sometimes ignore their patients' needs.

'This morning I had to administer intravenous antibiotics to one of my patients. Unfortunately, her IV needle slipped out. My patient told me: 'I would really like to receive my antibiotics intravenous, because I have had bad experiences with oral treatment. Last time, the oral treatment was not effective so I ended up in the hospital again a few weeks later'. I went to the doctor, to ask for permission to insert a new IV needle. Their reaction was: 'No, she will be treated with oral antibiotics and tomorrow she will be discharged and go home'. The patient and the doctor had different opinions, but there was no conversation between them.' (HCP 10)

Patient and family involvement

A minority of HCPs involve patients by asking them about their personal situation, expectations, values and goals. Another minority of HCPs mention that they are involving patients by discussing the

diagnosis, treatment options and discharge criteria. Furthermore, a few HCPs mention that family is involved when patients are not able to express their own wishes, for instance when they are too ill or too young. The majority of HCPs feel that patients should be more involved in the treatment, or be better informed about the treatment. Furthermore, as mentioned earlier, a few nurses feel that there should be more SDM at the hospital. They feel that patients' needs are not always listened to.

> *'I think that there is friction between what the patients wants the doctor to do and what the doctor is actually doing. The doctor is just finishing his list of medical goals. My colleagues and I find that difficult to see. For example, a doctor said to me: 'replace the probe', while the patient had consciously removed it and has said to me: 'I do not want this anymore'. Sometimes patients have said it many times, but the doctor simply had not listened. Occasionally, when I know patients are sure about their decision, I decide to listen to the patient and refuse to perform the medical action. (HCP 17)*

A minority of patients feel that they are satisfied with the extent of involvement in their care. However, the majority of patients feel that that they should be more involved. Some of the latter mention that some doctors do not listen to patients or do not ask them about preferences or goals. A minority of patients feel that some doctors involve patients only too late in the treatment.

> *'Many specialists do not involve us in the development of the treatment plan. Only when the treatment plan is created, they will describe it to us and ask: 'Do you understand what I just told you?'. However, that is not the same as involving patients.' (Patient 7).*

> *My specialist knows how I am doing and what I consider important in life. He knows about my family and my job. I feel that this is important, because you can only provide good care when you know what someone's life looks like and what is important to that person. It determines the treatment.' (Patient 1).*

Evaluation of goals
More than half of the HCPs mention that treatment plans and action lists of doctors and nurses are kept up-to-date. When specific goals are set, they are used to determine the moment of discharge. When necessary, goals and plans are revised. A minority of HCPs mention that there is not always an appropriate follow-up on goals, and therefore they find it difficult to say whether goals are evaluated. A small minority of patients feel that their treatment goals are adequately evaluated.

3.3 Appreciation of value of goal-setting

A majority of HCPs think that working with treatment goals might be valuable. A number of potential effects has been listed. First of all, almost half of the HCPs think it might help to manage expectations. By explicitly asking patients about wishes and by being transparent about the prospects, patients are able to manage their expectations of the treatment and of the length of the hospital stay. Secondly, a minority of HCPs feel that goal-setting creates a collaborative conversation between HCPs and patients. This subsequently results in care that meets the patients' needs and prevents unwanted treatment and unwanted diagnostic tests. Thirdly, one-third of the HCPs think that the formulation of clear goals enhances team communication and teamwork, since all HCPs will be working towards the same goals. Fourth, a small minority of HCPs feel that goals-setting might shorten the length of the hospital stay, because it enables timely preparation of discharge. And lastly, a few doctors mention that it enhances patients' motivation and therapy compliance.

> *'In a system with high staff-turnover, it might help to explicitly ask ourselves: 'Why is the patient here?'. And that implies: 'What is the goal of this hospital admission?'. More than once, when I get involved with a new patient, I have to thoroughly search the patient file for information on why they are here. It might help to explicitly formulate this.' (HCP 3)*

On the other hand, a minority of HCPs question the added value of working more explicitly with treatment goals. They generally feel that there is nothing wrong with the current working-methods, or they would like to see solid evidence that discussing treatment goals ensures better care.

'I think that the current method is fine. I'm afraid that it will just provide just another box that we have to fill in. I don't think whether that is going to be helpful.' (HCP 16)

The majority of patients also think goal-setting is valuable. They mention that explicit goals provide guidance and clarity to patients and ensures that doctor and patients are working towards the same goals. Furthermore, a minority of patients mention that goals might help to enhance communication between HCPs. On the other hand, a small minority of patients do not see the need for explicit formulation and documentation of goals in their specific situation.

'It is a method to monitor whether we are aligned. Do we both want the same thing? I might not cure me faster, but it will definitely make me more satisfied.' (Patient 4)

3.4 Barriers

Several barriers to discussing and documenting goals have been listed.

Ambiguity concerning interpretation of goals
One-third of the HCPs are not sure about the exact meaning and interpretation of 'goals of care'. This is illustrated by the different associations HCPs have with goals. A few HCPs mention that this lack of clear interpretation might complicate the implementation of goal-setting. Furthermore, the majority of HCPs are unsure about the correct methods of implementing the goal-setting approach and the documentation of goals. For example, some find it hard to summarise an entire conversation into one specific 'goal of care'.

'I think that goal-setting is a fairly new concept. It feels like an umbrella term that allows many different interpretations, which might complicate its use in practice.' (HCP 13)

Uncertainty about the usefulness of goals in different situations
As described above, a few HCPs question the value of goals as such. Furthermore, more than half of the HCPs think that some situations are more suitable for working with goals than others. For example, a minority of HCPs mention that goals are not considered useful or valuable when they are used to solely describe the medical treatment. Another minority of HCPs feel that goals have little use in the surgical field, since all patients share the same goals: 'independent mobility, clean wound, preparation for discharge'. Lastly, less than half of the HCPs think that the goals-setting might be hard to accomplish in acute care situations, during the night or when patients suffer from dementia or delirium.

'It is not useful to document goals such as: 'the patient is suffering from pneumonia, so the goal is to treat the pneumonia'. This is not helpful in the care-process at all, because I would have started the antibiotics either way.' (HCP 1).

A small minority of patients also feel that goals are less useful in acute setting, especially when the problem and solution are fairly straightforward, for example in case of appendicitis. Other patients mention that the patients' ability to conduct such conversations might be limited in acute setting, due to pain or distress.

Differences in goals or expectations between patients and doctors
More than half of the HPCs express that there are discrepancies between patients' and doctors' goals and expectations. For example, a few HCPs mention that patients sometimes expect doctors to solve all their problems, even when the problems are not related to the reason of hospitalisation. And some mention that the doctors' goals are in general more medical than patients' goals. Half of the HCPs feel that this difference creates the opportunity to start a conversation and manage expectations. However, a minority of HCPs find it difficult when patients identify goals that HCPs believe to be unrealistic and unattainable. These HCPs do not like to confront or to disappoint patients.

'I often see that doctors set technical medical goals, while patients want to achieve different things. For example, patients want to go home and they wish to be able to mobilise independently. Some

medical-technical things are not that important to them. It is important to align these expectations, to make sure that goals are not solely medical.' (HCP 14)

'I think that we are afraid that more, perhaps unrealistic, goals will come to light when we ask patients about their goals. We are afraid that we have to tell patients that we cannot help them with certain goals during this specific treatment. And we do not like to disappoint patients.' (HCP 11)

Most of the patients also mention these differences in expectations and goals between patients and HCPs. They mention that doctors' approach is generally medical while patients' goals are more personal. A few patients also mention that doctors sometimes have different views on the preferred treatment.

Patient-related barriers
HCPs identified different barriers that are related to patients' ability or willingness to discuss goals. More than half of the HCPs describe that some patients find it difficult to identify their own goals. They say that some patients have never thought about goals or expectations before, and are now too ill, tired of occupied to think clearly and to understand what is expected of them. Furthermore, a small minority of HCPs mention that some patients, especially the older ones, do not appreciate the need to be involved. They want doctors to decide what is best for them. Furthermore, it is mentioned that that differences in culture and language might complicate the conversation, due to different views on healthcare and communication methods.

'Goals of care describe what someone wants to achieve and what someone considers important in life. When you are very ill, it is most helpful if you have thought about these things earlier on.' (HCP 5)

Patients also feel that their ability to discuss goals is less optimal when they are ill. A few patients mention that they are more likely to follow the doctors plan when they are ill. Furthermore, some patients say that not all patients are assertive or willing enough to discuss goals. Additionally, a small minority of patients mention that they are hesitant to go against the doctor, or that they are afraid to make the wrong choices.

'I like the ability to make my own choices, but it is also difficult because I do not know what the future holds. Can I make the right choice? I want to be involved, but sometimes it would be easier to think: 'I will just follow my doctors' plan'. (Patient 1)

HCP-related barriers
Almost half of the HCPs mention that HCPs are trained to act fast, to think in medical problems and to make medical decisions. Some say that this might cause HCPs to make assumptions about the patients' understanding of the situation and about their values. According to a small minority of HCPs, the identification of patients' goals has no priority yet in care. Secondly, a minority of HCPs mention that poor communication between healthcare professionals might complicate the matter. Most doctors are not aware of the nurses' role in goalsetting, and they do not read the information in the nurses' file. Additionally, one nurse experiences a threshold among her and her colleagues to express concerns about treatment or patient preferences to the doctor.

'It is a pitfall to assume that patients will understand what is happening. It is important to be aware of that.' (HCP 15)

A few patients feel that doctors need to be stimulated to do use SDM and goal-setting. A minority of patients mention that doctors do not always listen to the patients' wishes.

'When I talk to doctors and nurses about SDM, they often say that they are already doing it. However, they are not doing it at the level they are supposed to do. [...] And I asked medical students: 'What do you think of patient involvement and SDM?'. They answered: 'We'll do it when we have enough time'.' (Patient 5).

Organisational factors

A majority of HCPs mention that lack of time and administrative burden are important barriers to goal-setting. The conversation on goals is something that takes time, which is not always available in the hustle of the day. The need for documentation adds an additional administrative burden. Secondly, the majority of HCPs feel that the current methods of goal-setting are not sufficiently working. For example, presenting the questions on a paper sheet is not effective since most patients do not fill in the answers. And solely describing medical treatment or adding goals from a prespecified list, are not considered helpful. Thirdly, a minority of HCPs mention other barriers, such as a multitude of different projects at the same time and the lack of hospital-wide policy on the matter. HCPs mention that they are tired of new implementations. Furthermore, a small minority of HCPs view the existent hospital culture as a barrier, because of its focus on medical treatment and its reluctance to SDM. Additionally, a minority mention that, due to high staff-turnover and the increasing amount of superspecialisms, doctors are losing sight of the bigger picture and therefore feel no responsibility for the discussion of treatment goals. Lastly, a minority of HCPs consider the mandatory documentation of goals according to the JCI-standards a burden. The mandatory component gives a feeling of lack of confidence in their knowledge and expertise.

> *I think it is right to test whether hospitals meet the quality requirements. However, we feel this is not the best way to do so. Will we provide better care, by making us do more 'tick-box exercises'? (HCP 9)*

> *'Because of high staff-turnover, no one feels responsible for the bigger picture. When there is a different doctor every day, no one will discuss the long-term goals of care. When a doctor meets a patient for the first time at the second day of their admission, the doctor will not start the discussion on goals anymore.' (HCP 15)*

3.5 Facilitators

Stakeholders mention many facilitators to discussing goals of care. Most of the barriers consist of dealing with the facilitators.

Education and training

More than half of the HCPs think it is important to raise awareness of goalsetting among doctors and nurses. Preferably this is incorporated into the education of medical students and student nurses. Additionally, a few HCPs mention that education at the hospital wards might help to encourage HCPs to recognise the importance of truly listening to patients. Half of the patients also feel that education of HCPs on goal-setting and SDM would be most helpful.

> *'I think it is important to educate medical students and doctors. Patients sometimes tell me: 'The doctor does not understand me, they do not listen to me'. It is important for doctors to learn what it is like to be admitted to a hospital, to feel what it is like when you are not being listened to. There is too little awareness.' (HCP 17)*

> *'I think training of doctors and nurses is very important. It requires training and a professional approach to conduct conversations on goals in such a way that it ensures care that meets the patients' needs.' (Patient 5)*

Enhance patient and family involvement

A majority of HCPs mention the need for the enhancement of patient and family involvement. Almost half of the HCPs point out the importance of explicitly asking patients about their goals, expectations and needs at the start of the hospital admission. Furthermore, almost half of the doctors feel that patients should be better prepared, by helping them think beforehand about what they value in life and, if possible, about what they hope to achieve. General practitioners and polyclinic doctors might play a role in this preparation. Lastly, a minority of HCPs feel that patients should be better informed about the treatment and expectations of the HCPs.

'In my opinion, it is imperative to discuss the patients' goal during the intake with patients and their family. It is important that we tell them: 'During this admission we will work towards your goals. And when your views or preferences change, we will revise the goals.' Patients are reluctant to start these conversations themselves.' (HCP 17)

As mentioned earlier, all patients feel that goals should be formulated jointly. Therefore, the majority of patients wish for doctors to explicitly ask them about goals and preferences. Furthermore, a small minority of patients feel that it would help if they are given guidance to think about goals, values and preferences prior to the treatment.

'When setting goals of care, it is important to discuss what the patient considers important. While the doctor might have a clear plan in mind, it is possible that the patient wants something different. This implies that one should attempt to comprehend the other persons' values.' (Patient 1).

Bigger role of nurses

The majority of HCPs feel that nurses should play a bigger role in the process of goal-setting. A majority of doctors think that it might help if nurses asked patients about their preferences and goals, preferably during intake. They say that nurses see patients more often and are generally closer to them. Furthermore, more than half of the HCPs mention that there is a need for better collaboration and communication between doctors and nurses. Around half of the nurses feel that goals of care should be a standard issue of discussion in daily rounds. This should ensure that doctors, nurses and patients are all working towards the same goals. Additionally, two HCPs feel that nurses should be present during patient rounds and conversations with family.

'The nurses see the patient and family more often and they have different approaches and perspectives. They have valuable information and I think we underestimate that. […] Furthermore, I think that it is important to present ourselves - doctors, nurses and other disciplines - as a team.' (HCP 13)

Most patients also feel that nurses are important to patients, since nurses see patients more often than doctors do. A minority of patients feel that the communication between nurses and doctors about personal information of the patient could be improved. However, a minority of patients feel that the nurse should complement the doctor's role, and not replace it.

'The nurses generally have an important role and they provide us with information. However, their role is not to compensate a lack of empathy and patient-centered approach of the doctor. In de past I have experienced that my nurse had to explain the treatment plans to me, because my doctor did not. I do not think that is right way. Their roles should be complementary.' (Patient 7)

Organisational changes

A few HCPs mention the need for a hospital-wide policy on the matter and the need for a change in culture in this hospital. Furthermore, a few HCPs feel that doctors and nurses should have more time to conduct a meaningful conversation with patients, which might require different funding strategies. Lastly, two HCPs mention the need for doctors who keep sight of the bigger picture and long-term, by creating continuity of care or hiring more generalists.

Some patients also feel that there should be more time to conduct these conversations. Furthermore, a small minority of patients mention that is it desirable that patients are present at multidisciplinary meetings, since it would help to ensure that everyone envisions the same goals. Lastly, patients mention that it is not desired to create a guideline on the discussion of treatment goals, since the process is tailored to the specific condition, prognosis and person.

'It does not feel that there is enough time to properly talk during the daily rounds. I feel that they are in a hurry and I do not want to waste their time. […] Personally, I did not have much questions, but if I did, I would have felt hesitant to ask them.' (Patient 2)

Desired way of documentation

Most of the HCPs are uncertain about the correct way to document goals. More than half of the HCPs think that goals should be explicitly documented in the electronic patient file. Most of them feel that goals of the doctors, nurses and patients should be documented separately and at a location that is accessible for all disciplines. A minority of HCPs feel that doctors, nurses and patients should form one common goal, since it is preferred that everyone is working towards the same goals. HCPs mention that when a patient is being treated by different doctors, there might be different goals for each treatment. When a patient has overarching goals, this should have its own place in the patient file.

Half of the patients mention that they want their goals to be documented in the electronic patient file. More than half of the patients mention that it is desired to break goals down into smaller steps. Furthermore, a minority of patients mention that the doctor and patient should critically examine together whether goals are attainable and realistic, before writing them down in the patient file.

Different situations

As mentioned earlier, many HCPs feel that it depends on the situation whether goalsetting is useful and possible. They mention that in urgent situations, in which for example acute operations are necessary, it might be difficult to discuss different preferences and goals in detail. And they mention that goals are less useful when used to solely describe medial treatment of for surgical patients. HCPs feel that it is more helpful to use goals for chronic sick patients, for patients in polyclinic setting, for patients who are at risk for functional decline or readmissions, or for patients in the diagnostic process of many (undiagnosed) medical complaints. On the other hand, one-third of HCPs feel that goal-setting should be used in every situation and for every patient.

> 'My initial reaction is that it is relevant for every patient to think about goals and the things that we would like to achieve.' (HCP 13)

> 'It is difficult to discuss goals of care in acute care setting. Patients often answer: 'I want to get better.' But the meaning of 'better' is different for every individual. That is challenging and this conversation takes time. And time is limited at the emergency room.' (HCP 5)

The majority of patients feel that goals should be discussed with every patient, regardless of the situation.

> 'But even then, you can never make presumptions about the other persons' preferences. You will need to ask them, even in acute setting.' (Patient 5)

Desired moment and evaluation

The majority of HCPs feel that goals should be discussed as early as possible in the treatment, preferably during the intake or at least within 24 hours after admission. Furthermore, a minority of HCPs mention that the goals subsequently can be discussed and if necessary revised during the daily rounds with doctor, nurse and patients. Most of the patients also feel that goals should be discussed as early as possible in the treatment, preferable privately and at a moment which feels comfortable for the patient.

> 'I think it is very important that doctors regularly reflect on the goals during the appointments, and check with us: 'Do you still want this, or have you changed your mind?'.' (Patient 6)

Desired way of implementation

The majority of HCPs are unsure about the correct way of implementing the goal-setting approach. A minority of HCPs mention that there should be a clear and unambiguous under-standing of the meaning and interpretation of 'goals of care'. Some patients share the same opinion. A minority of HCPs feel that it might help to start with pilots at wards who share a positive attitude towards goal-setting, so they can try out what works best and can set an example for the rest of the hospital.

> 'It must be clear what you mean by 'goals'. How can you implement something that every doctor interprets differently? (HCP 16)

4. Discussion

This study showed that HCPs have different associations with goals of care, varying from patient-bound goals to the discussion of treatment limitations. Although the majority of HCPs and patients share a positive attitude towards goal-setting, it appears hard to accomplish. Patients confirm that the majority of HCPs are not consistent in asking patients about values, preferences and goals. Main barriers described by HCPs are the ambiguity concerning the interpretation and correct way of implementation of goal-setting, uncertainty about the usefulness and feasibility of goals-setting in every situation, differences in goals or expectations between patients and HCPs, barriers related to patients' ability or willingness to discuss goals, HCPs' focus on medical aspects of care, poor communication between HCPs and organisational factors. Most HCPs agree that the current methods of goal-setting are not adequate. Therefore, HCPs and patients propose different strategies to overcome these barriers.

Many of the barriers that are mentioned by HCPs in this study align with barriers that are shown in previous research.[5,7,8,10,11,12] A striking barrier is that HCPs in this study questioned the usefulness of goals when used to solely describe the medical treatment, for example: 'treat the pneumonia'. Although this might help to improve communication between HCPs, it does not seem helpful in the care-process. Furthermore, the uncertainty as to whether goal-setting is feasible in acute care setting is also mentioned in previous research. These studies showed that conversations on goals are more difficult in acute setting because it takes time to understand a patient well enough, because patients might be too ill to participate and because doctors need to focus on medical aspects in order to stabilise the patient.[13-16] We did not find a striking difference in experiences and barriers between the included wards that ranked low and the included wards that ranked high on the previous JCI-tracer on goal-setting.

An interesting finding in this study is that doctors seem not fully aware of the nurses' role in goal-setting, while nurses seem to be better informed about the treatment plans and decisions of the doctors. Systematic reviews by House and Havens and Tang and colleagues show similar findings.[17,18] They identified that nurses and doctors have different perceptions of effective collaboration and they found that nurses generally have a more positive attitude towards the collaboration than doctors in some of the included studies. Other studies have shown that it is important for nurses to participate in the decision-making, because they provide valuable perspectives and information.[19-20] The latter is also mentioned by HCPs and patients in this study.

Another interesting discovery in this study is that HCPs experience ambiguity concerning the interpretation and correct way of implementation of goal-setting. A minority of HCPs mentioned that the discussion on goals could take place before forming the treatment-plan. Various studies are conducted on the desired use of goal-setting in practice. Elwyn and Vermunt argue that there are three levels of goals: fundamental goals, symptom- or disease-specific goals and functional goals.[21] They suggest that goal-based SDM is started by the discussion of fundamental goals, which beholds the persons' values and priorities. These fundamental goals guide the discussion on the other goals and consequently on the selection of interventions.[21] Some other studies describe similar approaches, in which patients' personal goals or fundamental goals are at the top of the hierarchy and determine which specific goals or professional actions are aspired.[12,22,23]

Furthermore, in line with previous research, our results show the trend that professional goals tend to be more medical and more narrow than patient-goals.[4,5,12] A possible explanation for this trend might be that goals are rarely a straightforward translation of preferences and wishes of patients and are focused on what HCPs consider achievable within the medical scope.[24] Another explanation might be that patients are not fully involved in goal-setting or only too late in the process, for example at the point of choosing between different treatment options that are already chosen by the HCPs.[25] HCPs and patient in this study think that it might be helpful to educate HCPs about the importance and desired methods of goal-setting and SDM. This is also supported by previous studies.[15,26]

Some HCPs in this study mention that doctors are losing sight of the bigger picture, due to high staff-turnover and the rising amount of superspecialisms. This fragmentation in care is also described by other studies.[12,27,28] In a fragmented system with high staff-turnover, HCPs tend to follow strict clinical guidelines in which patients' values and preferences have limited place. Explicitly formulating (personal) goals might be the first step to provide the counterbalance that is needed.

The strengths of this study lie in the inclusion of both doctors, nurses and patients. Furthermore, by using the results from a previous JCI-tracer, we were able to include hospital wards with a certain diversity in the extent to which they discussed and reported goals. Although it was a self-evaluation tracer, which poses a risk of self-reporting bias, this was the best available strategy. Furthermore, we strengthened the validity of our study by coding several interviews with a second researcher and by checking whether results were recognised by other HCPs and patients. There are several limitations to this study. First of all, we used a convenience sample for both groups of stakeholders instead of an aselect or purposive sample, which causes a risk of selection bias. Furthermore, the study sample of 19 HCPs and 7 patients is relatively small, and therefore it is hard to generalise our results. However, remarks by respondents lead us to believe that our results have meaning for the rest of the hospital as well.

In conclusion, this study has generated insight into the experiences of HCPs and patients with goal-setting. Based on our findings, the formulation of purely medical goals might be useful to improve communication between HCPs and provide clarity to patients. However, purely medical goals attribute less to performing care that is person-centered. For a more person-centered approach it is desirable that HCPs and patients start a process of collaborative conversations on and continue evaluation of preferences, values and goals. The implementation of meaningful goal-setting might require organisational changes, changes in communication between HCPs and training of HCPs. Goal-setting should not become another check-box activity and therefore further research is recommended on the feasibility and desired approach of goal-setting in different situations. Ultimately, the understanding of patients' values and goals is desired in every situation, because it will help to provide care that meets patients' needs.

6. References

1. Ekman I, Swedberg K, Taft C, Lindseth A, Norberg A, Brink E et al. Person-centered care – Ready for prime time. *European Journal of Cardiovascular Nursing*. 2011; 10: 248-251.

2. Håkansson Eklund J, Holmström IK, Kumlin T, Kaminsky E, Skoglund K, Höglander J et al. ''Same same or different?'' A review of reviews of person-centered and patient-centered care. *Patient education and Counseling*. 2019; 201: 3-11.

3. McCormack B. Person-centredness in gerontological nursing: an overview of the literature. *Journal of Clinical Nursing.* 2004; 13: 31-38.

4. Schellinger SE, Anderson EW, Schmitz Frazer M, Cain CL. Patient self-defined goals: Essentials of person-centered care for serious illness. *American Journal of Hospice and Palliative Medicine.* 2018; 35(1): 159-165.

5. What are the barriers and facilitators to goal-setting during rehabilitation for stroke and other acquired brain injuries? A systematic review and meta-analysis. *Clinical rehabilitation*. 2016; 30(9): 921-930.

6. Comer a, Fettig L, Torke A. Identifying Goals of Care. *Medical Clinics of North America*. 2020; 104: 767-775.

7. Filoramo MA. Improving Goal Setting and Goal Attainment in Patients with Chronic Noncancer Pain. *Pain Management Nursing*. 2007 June; 8(2): 96-101.

8. Tinetti ME, Naik AD, Dodson JA. Moving from disease-centered to patient goals-directed care for patients with multiple chronic conditions: patient-value-based care. *JAMA Cardiology*. 2016 April 01; 1(1): 9-10.

9. Levack WMM, Weatherall M, Hay-Smith EJC, Dean SG, McPherson K, Siegert RJ. Goal setting and strategies to enhance goal pursuit for adults with acquired disability participating in rehabilitation. *Cochrane Database of Systematic Reviews*. 2015, Issue 7: 1-166.

10. Schmidt SG. Recognizing potential barriers to setting and achieving effective rehabilitation goals for patients with persistent pain. *Physiotherapy Theory and Practice*. 2016; 32(5): 415-426.

11. Rosewilliam S, Roskell CA, Pandyan AD. A systematic review and synthesis of the quantitative and qualitative evidence behind patient-centered goal setting in stroke rehabilitation. *Clinical Rehabilitation*. 2011; 25(6): 501–514.

12. Berntsen GKR, Gammon D, Steinsbekk A, Salamonsen A, Foss N, Ruland C. How do we deal with multiple goals for care within an individual patient trajectory? A document content analysis of health service research papers on goals for care. *BMJ Open*. 2015; 5(12).

13. Grudzen CR, Richardson LD, Hopper SS, Ortiz JM, Whang C, Morrison RS. Does Palliative Care Have a Future in the Emergency Department? Discussions With Attending Emergency Physicians . *Journal of Pain and Symptom Management.* 2012 January: 43(1): 1-9.

14. Lamba S, Nagurka R, Zielinski A, Scott SR. Palliative Care Provision in the Emergency Department: Barriers Reported by Emergency Physicians. *Journal of Palliative Medicine.* 2013; 16(2): 143-147.

15. Rosewilliam S, Sintler C, Pandyan AD, Skelton J, Roskell CA. Is the practice of goal-setting for patients in acute stroke care patient-centred and what factors influence this? A qualitative study. *Clinical Rehabilitation*. 2016; 30(5): 508-519.

16. Cott C. Client-centred rehabilitation: client perspectives. *Disability and Rehabilitation*. 2004; 26(24): 1411-1422.

17. House S, Havens D. Nurses' and Physicians' Perceptions of Nurse-Physician Collaboration. *The journal of nursing administration.* 2017; 47(3): 165-171.

18. Tang CJ, Chan SW, Zhou WT, Liaw SY. Collaboration between hospital physicians and nurses: An integrated literature review. *International Nursing Review.* 2013; 60: 291-302.

19. Bacon CT, Lee SD, Mark B. The Relationship Between Work Complexity and Nurses' Participation in Decision Making in Hospitals. *The journal of nursing administration*. 2015; 45(4): 200-205.

20. Fewster-Thuente L. Working Together Toward a Common Goal: A Grounded Theory of NursePhysician Collaboration. *Medsurg Nursing.* 2015; 24(5): 356-362.

21. Elwyn G, Vermunt NPCA. Goal-Based Shared Decision-Making: Developing an Integrated Model. *Journal of Patient Experience.* 2020'7(5): 688-696.

22. Dekker J, Groot V de, Steeg AM ter, Vloothuis J, Holla J, Collette E, Satink T, Post L, Doodeman S, Littooij E. Setting meaningful goals in rehabilitation: rationale and practical tool. C*linical rehabilitation.* 2020; 34(1): 3-12.

23. Vermunt NP, Harmsen M, Elwyn G, Westert GP, Burgers JS, Rikkert MGO, Faber MJ. A three-goal model for patients with multimorbidity: A qualitative approach. *Health expectations.* 2018; 21: 528-538.

24. Levack WMM, Dean SG, Siegert GJ, McPherson KM. Navigating patient-centered goal setting in inpatient stroke rehabilitation: How clinicians control the process to meet perceived professional responsibilities. *Patient Education and Counseling.* 2011; 85: 206-213.

25. Tonelli MR, Sullivan MD. Person-centred shared decision making. *Journal of Evaluation in Clinical Practice.* 2019; 25: 1057-1062.

26. Toro J, Martiny K. New perspectives on person-centered care: an afordance-based account. *Medicine, Health Care and Philosophy.* 2020; 23: 631-644.

27. Rijken M, Struckmann V, van der Heide I, Hujala A, Barbabella F, van Ginneken E et al. How to improve care for people with multimorbidity in Europe? [Internet]. Richardson E, Van Ginneken E, editors. Copenhagen (Denmark): European Observatory on Health Systems and Policies; 2017. PMID: 29144712.

28. Tinetti M, Fried T, Boyd CM. Designing Health Care for the Most Common Chronic Condition – Multimorbidity. *American Medical Association.* June 2012; 307(23): 2493-2494.

7. Appendix

7.1 Interview guide HCP

The following questions and topics were used for the interviews with HCPs. The two main questions were asked in that order. However, the in-depth information was obtained using the topics, which were asked in no particular order.

Introduction
The researcher introduces themselves, the research and the structure of the interview. The researcher obtains informed consent and makes sure that all participants' questions are answered.

Interview questions and topics
1. What associations do you have with 'goals of care'?

2. Do you use goals of care in practice?

    Topics when the answer to the previous question is 'yes':

    - Moment of goal-setting
    - Use in different situations or settings
    - Description of the goals (medical, personal)
    - Roles of different stakeholders (doctor, nurse, patient)
    - Documentation
    - Evaluation
    - Possible effects
    - Barriers
    - Facilitators
    - Desirability of goal-setting

    Topics when the answer to the previous question is 'no':

    - Do they miss goals?
    - Barriers
    - Facilitators
    - Desired interpretation, use and documentation.

7.2 Interview guide patients and focus-group

The following questions and topics were used for the interviews with HCPs. The three main questions were asked in that order. However, the in-depth information was obtained using the topics, which were asked in no particular order.

Introduction
The researcher introduces themselves, the research and the structure of the interview or focus group. The researcher obtains informed consent and makes sure that all participants' questions are answered.

Interview questions and topics
1. What associations do you have with 'goals of care'?

2. What are your experiences with goal-setting?

Topics:
- Description of the situation (acute setting, polyclinic)
- Description of the goals (medical, personal)
- Roles of different stakeholders (doctor, nurse, patient)
- Documentation
- Evaluation
- Did doctors/nurses know personal information about them?
- Barriers
- Facilitators
- Ideal/desired situation

3. What are your thoughts about the following results from the interviews with HCPs?

Topics:
- Different associations with goals of care
- Extent of patient involvement
- Bigger role of nurses
- Usefulness of goals in different situations
- Documentation of goals