Optimizing implementation of patient-centered innovations

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Learning from cancer care practice

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CHAPTER 1

1

General introduction

Patient centeredness: an ideological shift in health care

Traditionally health care was characterized by paternalism, but already more than 20 years ago a change towards a partnership between patients and physicians was recognized.[1] In the same period, patient-centered care became an important feature of consistent, high-quality health care, being one of the six improvement aims to enhance the quality of healthcare by the Institute of Medicine (IOM, currently known as the National Academy of Medicine, NAM).[2] The IOM referred to six dimensions of patient-centered care: (1) respect for patients' values, preferences, and expressed needs; (2) coordination and integration of care; (3) information, communication, and education; (4) physical comfort; (5) emotional support—relieving fear and anxiety; and (6) involvement of family and friends. Many other different definitions and models for patient-centeredness exist.[3] Merging many of them, Castro et al. proposed the following definition: "Patient-centeredness is a biopsychosocial approach and attitude that aims to deliver care that is respectful, individualized and empowering. It implies the individual participation of the patient and is built on a relationship of mutual trust, sensitivity, empathy and shared knowledge."[4] They emphasized that patient-centeredness closely relates to patient participation and patient empowerment.

Participation originally emerged from 'citizen participation' in the 1960's and was divided into eight levels and nowadays it is usually divided into five ascending levels: informing, consultation, advising, partnership and control.[5, 6] The first three levels reflect participation while decision-making is still in hands of the researchers: Participants are being informed, being consulted or asked for advice. The latter two levels reflect participation with actual decision-making power: Participants decide in partnership with researchers or are in control of decision-making. In this thesis participation and involvement are used interchangeably, by means of varying levels of participation in the Dutch context, in line with the aforementioned participation ladder and the Dutch research institution ZonMW recommendations.[7] Castro et al elaborate on the definition of individual patient participation: Patient participation revolves around a patient's rights and opportunities to engage in the decision making about his care through a dialogue attuned to his preferences, potential and a combination of his experiential and the professional's expert knowledge.[4] Patient participation may then facilitate patient-centeredness, which in turn may lead to patient empowerment. Individual patient empowerment is then defined as a process that enables patients to exert more influence over their individual health by increasing their capacities to gain more control over issues they themselves define as important.[4] Importantly, patients, providers and healthcare systems may all contribute to individual patient empowerment. The patients' context, characteristics, illness-related circumstances, social support and personal values may moderate their empowerment capacities and behavior.[8] Individual healthcare providers may facilitate by practicing

empowering interventions, such as shared decision-making (SDM). Healthcare systems may contribute by organizing care programs facilitating patient empowerment, such as education or a self-management program. Collective patient empowerment revolves around the power of groups of patients to express and take action to meet their needs. Collective patient participation is their (representing) contribution in shaping health and social care services by means of active involvement. Together these concepts resemble the ideological shift from paternalistic health care to a participation-based health care, resulting in a new balance of power between professionals and patients.[4]

This shift is also seen in cancer care. The IOM also reported about improving the quality of cancer care and the number one priority was engaging patients in their care, including patient-centered communication and SDM.[9] Furthermore, several examples in practice resemble the attention for patient-centeredness in oncology: First, strategies that support SDM and patient-centered communication are being implemented.[10, 11] Second, patient-reported outcomes are frequently being used in addition to provider-reported outcomes, sometimes aiming to discuss them with patients.[12, 13] Efforts are also being made to include patient-centered outcomes in oncology care financing.[14] This emphasizes the relevance of patient-centered interventions or innovations in cancer care.

An important stakeholder in cancer care innovation with regard to patient centeredness is academia, reflected by more that 150 clinical trials regarding 'patient centered care' and 'cancer' from 2011 onwards (PubMed, accessed 21 dec 2021). In addition to academia, patient-centeredness has also been prioritized from different angles in society, such as policy makers. Several governmental programs aim to catalyze patient-centered care innovation, also in cancer care. Examples in the Netherlands may regard SDM, electronic health (e-health) and multidisciplinary team (MDT) care.[15-20] Besides government, many other stakeholders may participate in cancer care innovation for various reasons. In the Netherlands these include, amongst others, healthcare professional associations, fundraisers and insurers. Furthermore, pharmaceutical or other (technical) companies may subsidize such innovation. And last but not least, patients may collectively participate by means of patient associations.[4]

Usually, the implementation of typical patient-directed medical interventions requires strategies to adopt and integrate such evidence-based medical interventions into clinical and community settings in order to improve patient outcomes and benefit population health.[21] In other words, after efficacy and effectiveness of an intervention have been proven in 'classical' epidemiological studies, successful implementation is required for real world uptake into routine use, requiring identifying and addressing barriers and facilitators.[22] However, patient-centered care innovation is quickly progressing and many

participating stakeholders may benefit from quick implementation of interventions. A classical scientific evaluation by clinical trials may not be part of all innovation projects. This may lead to new standards of care without such robust scientific evidence. In this thesis I address four patient-centered innovation projects regarding cancer care treatment decision-making and patient empowerment by electronic health applications.

Decision-making in cancer care

Decision-making in cancer care may regard various decisional moments, for example prevention, screening, diagnosis, treatment, survivorship and end of life.[23] When people make decisions about cancer, a complicated mental process takes place that involves emotions and cognition. Since the nineteen-fifty's scientists have tried to explain the decision-making process. A recent theory states that decision-making involves verbatim and gist representations.[23] Verbatim representations capture the surface form of information such as exact words, numbers or pictures. Gist representations capture the meaning of information, which is shaped by many factors, amongst whom culture, emotion and knowledge. The underlying values and principles, which are stored in long-term memory, may only be variably retrieved. The actual decision is based on gist and therefore comprises much more than the information that is provided. Decision-making is optimized when people engage both intuition and deliberation.[24]

The aforementioned decision-making attributes mostly regard the individual aspects, but to a lesser extent the interpersonal aspects.[25] Usually, when suspected or diagnosed with cancer, a patient meets a hospital clinician such as a medical oncologist or surgeon. This clinician 'in charge' of the patient informs the patient and deliberates with the patient about options and therefore becomes an important participant in the (informed) decision-making process. Usually, other healthcare disciplines are also involved, such as a nurse practitioner, radiotherapist, physiotherapist and social worker. They do not necessarily share the same attentional focus. And while decision-making during clinical encounters mostly only involves the patient and the clinician, a multidisciplinary team is often involved in decision-making 'behind the scenes'. Additionally, a network of relatives and family usually surrounds a patient.[26] This social and professional network may impact the patients' autonomous decision-making in both positive and negative ways.[27] Altogether, various health care professionals and departments may be involved caring for one patient and sometimes a patient may even need to visit more than one healthcare institution. This may add up to the complexity of cancer care decision-making, besides the complexity of cancer care itself, involving multiple diagnostic and treatment modalities, often with significant benefits and side effects.

In such complex decision-making, actions are undertaken provisionally and conditionally and patients' goals or preferences may vary during time.[9, 24] In practice, cancer care decision-making is a continuous process involving various decisional moments, different healthcare providers and relatives.[26] In this thesis we focus on the treatment and to a lesser extent the diagnostic phase of decision-making. Here, two important decisional moments can be recognized: Decision-making during a multidisciplinary team meeting and in the dyad of the patient and the clinician in charge.

Multidisciplinary teams: enhancing patient centeredness.

The first important decisional moment in cancer care decision-making involves a multidisciplinary team (MDT, also called tumor board). This is a group of healthcare professionals from different disciplines, such as physicians, nurses and allied-health personnel, meeting on a regular base to discuss patient cases. In the setting of cancer care, MDTs have been widely introduced to facilitate team discussion and decision-making regarding cancer diagnosis, treatment and follow-up.[28] The MDT aims to formulate an advice to the clinician(s) in charge of the patient. The patient is being represented by the clinician or a nurse practitioner, as MDT decision-making usually takes place 'behind the scenes' without the patient being present.[29]

The introduction of MDTs dates back from before the millennium.[28] Nowadays, the MDT plays a central role in the cancer care pathway.[30] In Europe and Northern America it is the current standard of care to discuss each patient with cancer at least once in a multidisciplinary team meeting (MDTM).[31, 32] In Dutch cancer care it is a mandatory activity that is performed in most cases.[16, 33] The MDT implementation is associated with changes in cancer assessment, diagnosis and management,[34-36] while not necessarily with improvement of patient survival.[36, 37]

Patient-centered factors, such as psychosocial and psychological information and patient preferences, are relevant for MDT decision-making and implementation of the MDT treatment recommendation.[34, 38-42] However, observational studies showed limited availability of non-medical information in MDT meetings[43, 44] and in one interview study the need for this information was voiced by health care professionals.[45]. 'Non-medical' characteristics or information are defined as characteristics that have no direct clinical or other medical relevance, such as psychosocial information.[44] Additionally, lack of patient-centered information or information about patient preferences is an important reason for non-implementation of a MDT advice.[46-53] These findings underline the importance of patient-centered information exchange in the MDT meeting to make decisions in line with patients' goals and preferences, especially in complex decision-making.[34]

Although the relevance of patient-centeredness on oncological MDTs seems obvious, several barriers have been recognized. First, some healthcare providers believe the MDT is meant to decide upon biomedical information and that patient-centered information is not essential. In other words, the MDT culture may not be aimed at patient-centeredness.[54] Second, possibly in line with this, nurses often are knowledgeable about unique patient-centered information and try to take on the role of patient advocate during MDT discussions, but more senior MDT members may dismiss them.[30, 34, 38-40] Third, physicians are not always familiar with the patient's situation, limiting the availability of detailed information.[43, 55] Fourth, when the patients' preferences are mentioned they are mostly not taken into account and sometimes there also seems to be reluctance to follow a patient's preference.[43] Fifth, time pressure at MDT meetings can rush or compromise decision-making[34, 39, 43, 56, 57] or may prevent adequate preparation,[34] which may lead to the avoidance of extended elaboration on the complexity of a case. Sixth, uncertainty regarding the MDT decision is often not discussed with the patient.[42] In most cases only a single treatment option is communicated to the patient, although a broader spectrum of possible treatment options might have been discussed.[43] And finally the MDT documentation does not reflect the nuances of the issues discussed.[40] These barriers may hinder successful implementation of patient centeredness in MDTs.[58]

To enhance patient centeredness in MDTs, strategies are needed to overcome these barriers. In several studies aiming to enhance MDT decision-making and effectiveness, strategies to improve patient-centeredness have also been suggested.[28, 30, 34, 38, 41, 59] In a pivotal study, specifically aiming to improve patient-centeredness on MDTs, a number of strategies were proposed: Regarding representation of the patient, the availability of patient-centered information and how to handle disagreement.[55] The first two strategies were confirmed in an interview study with patients and MDT members.[45] However, further information about healthcare professionals' needs regarding patient centeredness in MDTs is limited. Concluding, more information about these needs and subsequent strategies to enhance patient centeredness is needed. Strategies would then align with clinical needs, aiming to overcome the aforementioned barriers.

From 2016, a Dutch government-financed project 'MDO 2.0' aimed to improve the efficiency of cancer MDT's.[15] At that time the Quality of Care consortium of the Netherlands Federation of UMCs (NFU, https://nfukwaliteit.nl/en/) started a project on improving MDT's. This project aimed, first, to analyze the performance of MDTs with regard to patient centeredness. Second, it aimed to identify strategies to enhance patient centeredness in MDTs. The project omitted to explore the needs of MDT members with regard to (enhance) patient centeredness in MDT's.

Shared decision-making: A gap in hematologic oncology

The second important moment in cancer care decision-making is the decision by the patient and the clinician in charge. Subsequently to the MDT meeting, the clinician discusses the MDT advice with the patient and a final decision is made for the diagnostic or treatment plan. In the past this used to be a rather one-sided announcement of the decision that had been made (informed decision-making), but while shifting towards participation-based healthcare the concept of shared decision-making (SDM) made appearance in the last decades.

SDM is increasingly used in health care practice as a model to engage patients in the process of health care decisions, especially when a decision is preference sensitive. A decision is preference sensitive when well-informed patients considerably differ in their trade-offs between the pros and cons of one option, or when more than one equal treatment options are available, including no treatment. The first mentioning of the concept dates back almost 50 years, but only in the past one or two decades it gained more clinical acceptance.[60] During these years the SDM model has repeatedly been adapted. The most recent version by Elwyn et al. dates from 2017 and proposes a 'three-talk model' that consists of team talk, option talk and decision talk.[61] At the team talk step, the professional informs the patient that a decision is to be made and that the patient's opinion is important. The emphasis is on working together as a team as professional and patient. At the option talk step, the professional explains the options and the pros and cons of each relevant option. Subsequently these options can be compared to each other. The final step, decision talk includes patient preference elicitation and making the decision. Stiggelbout et al. prefer to split the decision talk in to two steps: first, the professional and patient discuss the patient's preferences and the professional supports the patient in deliberation. Second, the professional and patient discuss the patient's decisional role preference, make or defer the decision, and discuss possible follow-up.[60] In addition to this well-known model of SDM, which is mostly focused on the patient-physician encounters, the decision-making process may be extended outside these encounters and take into account the other factors that impact and shape the patients' decision-making process.[26]

As most patients with cancer prefer to be actively involved in decision-making, SDM also suits cancer care decision-making.[62] Indeed, many interventions have been studied that intend to support the decision-making process in cancer care.[63, 64] The use of a decision aid improved, amongst others, attributes of the choice made (knowledge, risk perception and congruence between choice and values), decisional conflict, patient-physician communication, participation in decision-making, the proportion of undecided patients and in some studies satisfaction.

A group of cancer patients that does not appear much in SDM literature are patients with a hematologic malignancy. Most studies in this field were performed about ten years ago and only reported about patients' preferences for control in the decision-making process, but not about shared decision-making perception or observation. These studies showed that about half of the patients wish to be actively or collaboratively involved in treatment decision-making.[65-69]. In a more recent Dutch study this was three-quarters.[70] Only one study amongst patients with multiple myeloma assessed SDM perception but did not report the actual SDM perception scores.[71]

In various countries policy-makers pay attention to the implementation of SDM, also in the Netherlands.[17] SDM has been subject of governmental, patient association and professional association policies in the last decade, resulting in research stimulation by grants, but also in efforts to implement SDM by campaigns.[17, 72-74] In the field of hematology two Dutch decision aids have been developed: one for chronic lymphatic leukemia (CLL) and one for acute myeloid leukemia (AML) in elderly patients (www.keuzehulp.info). As the development of more decision aids is already being planned, more information about the perception of patients with a hematologic malignancy and their physicians is needed to guide development.

Empowering patients with hematologic malignancies using e-health

One of the attributes of patient empowerment and an antecedent of patient participation is providing tools, techniques and support.[4] In the current era of digitalization electronic health (e-health) seems promising to provide this kind of support. E-health can enable people to choose when and where they want to access healthcare. It can create a lower threshold to access healthcare.[75] Access to the Internet is nowadays available to almost everyone in the Western world (97% in NL in 2019, www.cbs.nl), providing patients with lots of information and communication techniques.

E-health is the application of digital information and communication to support or improve health and healthcare.[76] It has been widely introduced in cancer care.[77-79] By using real-time, dynamic technologies, e-health has the potential to improve patient-provider communication, to enhance symptom and toxicity assessment and to optimize patient engagement. It may provide or improve autonomy and respect, knowledge, skills and perceived support. Therefore, e-health may enhance patient-centered care delivery and empower patients.[80, 81] Vice versa, patient empowerment and self-management contribute to the success of an e-health intervention.[82] More recently mobile health (mHealth) interventions resulted in less decisional conflict, increased decisional self-efficacy and greater knowledge regarding breast cancer screening and prevention. It also empowered patients during and following breast cancer treatment.[83]

Despite being promising, in the past many applications have been developed without sufficient involvement of patients, resulting in low use.[84, 85] Besides patients, healthcare innovation design should also involve healthcare professionals, such as physicians, nurses and pharmacists. E-health interventions not aligning with the healthcare professionals' workflow more often fail to succeed.[82] Furthermore, other stakeholders may be involved with e-health innovation, such as supporting staff, IT specialists, quality improvement employees and IT developers. Stakeholders may also be involved collectively, for example by patient or healthcare professional associations. It is important to take all involved stakeholders into account during e-health innovation design, especially the end-users.[75, 86]

There are various approaches to involve stakeholders in healthcare innovation design, such as design thinking or user-centered design.[86, 87] The 'solution-focused research approach' aims to fit into the fabric of patients' lives and accommodate practitioners' workflows.[88] One extensive example is the holistic approach by the group of van Gemert-Pijnen et al.[75] Central to this approach is the '*CeHRes Roadmap*' framework, based on existing frameworks, insights from practice and empirical research.[89] It proposes a flexible and iterative design involving all stakeholders, including those not being part of the main development team, aiming to define the added value of a technique for each stakeholder. Another approach that extensively involves stakeholders is co-creation.[90] It is mentioned as 'a collaborative knowledge generation by academics working alongside other stakeholders'.[91] This method depicts the scientific counterpart of the earlier mentioned shift in healthcare: the shift from knowledge translation from academia to the lay people to a collaborative knowledge production.

Patient portals: limited involvement of patients with hematologic malignancies

One of the earlier arisen e-health technologies are electronic patient portals. Although they are defined in several ways, a portal is generally a website where patients can access health information, often supplemented with different options such as making an online appointment or getting a repeat recipe.[92] However, more options are potentially available and various platforms exist to access portals, such as applications on mobile devices. Electronic patient portals require Electronic Medical Records and may be associated with personal health records.[93] Electronic Medical Records are digital records of the patient, including test results and health care professionals' notes, controlled by the health care institution. A personal health record is a collection of an individual's medical documentation maintained by the individuals themselves or by a caregiver.

Electronic patient portals have been introduced for patients with cancer a while back already.[94] An evaluation in 2014 in Texas, USA, showed that patients with cancer mostly

view test results, messages and appointments.[95] An electronic patient portal for Dutch breast cancer patients scored well on usability and satisfaction, while having modest clinical impact on quality of life.[96] The same group showed that an electronic patient portal increases autonomy, knowledge and psychosocial and behavioural skills of lung cancer patients.[97] However, in both studies only a minority of the patients attending the clinic participated in the study and the participating patients indicated the electronic patient portal could benefit from tailoring and interface improvements. In another study, patients with cancer and their health care professionals indicated concerns about uncertainty and anxiety when access to information is possible.[98] This emphasizes the importance of involving patients in electronic patient portal design, trying to align with the needs of patients.

In 2014 the Dutch government actively encouraged e-health and subsidized electronic patient portal development and implementation.[19, 20] This program mostly aimed to disclose information from the EHR to patients, setting targets for the percentage of hospitals having electronic patient portals, the type of information that should be disclosed at minimum, and the percentage of patients using the electronic patient portals. There was no guidance however for aligning these technical developments with the care pathway, nor for developing the electronic patient portal technology with the relevant stakeholders. Meanwhile, the available literature about portal (design) needs or requirements for patients with a hematologic malignancy is limited to one out-dated study.[94] Therefore, more information from these patients is needed in order to align the electronic patient portal with their needs.

Integrated e-health applications

Besides electronic patient portals, many other e-health technologies are nowadays being used in cancer care, using a variety of functions or modules.[81] In the context of patient-centered care, frequently used modules may, first, assess patient reported outcomes (PROs).[79, 99, 100] PROs include patient reported outcome and experience measures (PROMs and PREMs). PROM measurement may be included in the cancer care pathway for managing symptoms or side effects and was associated with improved survival and quality of life and a reduction of Emergency Room visits.[79, 101] PREM measurement may provide insight to care delivery and help improving care.[102, 103] Second, applications may use communication systems between patients and/or health care providers, such as those in electronic patient portals.[85] Third, they may use interventions aiming to influence behavior or empower patients, such as applications aiming to improve medication adherence.[104, 105] Finally, they may provide education for patients, for example about symptoms.[99, 100]

A successful PROM-guided symptom management application was developed following an extensive design process, including testing with the relevant stakeholders.[79, 106] However, this may not guarantee success. An e-health application for cancer survivors, that was developed based on patients' needs, did not improve outcomes as expected, possibly due to selecting patients at a wrong time point.[107, 108] In other words, the application did not align with the care pathway for all patients. This emphasizes the importance of e-health application development addressing added value for *all* relevant stakeholders, including those not in the main development team.[75]

In the 2019-2022 Dutch government coalition agreement, one of the main aims was to reorganize care to 'the right care at the right place'.[18] The three sub-aims were to: i) prevent (more expensive) care; ii) shift care (closer) to home when possible and centralized when needed for quality reasons; iii) replace current care delivery by other care delivery, such as e-health, with comparable or better quality. To support the third sub-aim a grant was provided for projects, distributed by the healthcare insurers. One of the projects using this grant was a value based healthcare project, aiming to evaluate and improve the care pathway for Multiple Myeloma, including developing an e-health application.

General aim and research questions

During our work as practicing clinicians, the implementation of several patient-centered innovations was planned by healthcare institutions, academia and/or policy makers. The rationale for the aforementioned innovations was often based on healthcare policy or theoretical models and to a lesser extent tailored to the reality of daily clinical practice and the patients and healthcare professionals' needs. In turn, this might hinder actual implementation and societal impact of these innovations. This leads to the general aim of this thesis: To contribute to sustainable implementation of patient-centered innovations in cancer care, by means of a critical assessment of current patient-centered innovations from a practice driven viewpoint. The projects were chosen based on relevance and actuality and regarded cancer care treatment decision-making and patient empowerment by electronic health applications.

The research questions were:

- What are the needs of multidisciplinary team (MDT) members for improvement of patient-centeredness in oncological MDT meetings and which strategies do they recommend to improve patient-centeredness in complex oncological MDT decision-making?
- What is the perception of shared decision-making by patients with a hematologic malignancy and their physicians and which possible areas for quality improvement regarding shared decision-making in hematologic oncology may be recognized?

- What are the wishes, expectations and thoughts of patients with a hematologic malignancy and their physicians with regard to the electronic patient portal?
- What is the optimal design of a multi-modality e-health application for multiple myeloma patients and their health care providers, aligning with the multiple myeloma care pathway?

Outline of the thesis

In **Chapter 2** we describe the results of a qualitative interview study with healthcare professionals participating in five Dutch academic cancer MDTs. The study evaluated the healthcare professionals' needs and relating strategies to improve patient centeredness in MDTs. The results of this study can inform about possible successful strategies to improve patient centeredness in MDTs.

In **Chapter 3** we report a questionnaire survey, that evaluates the perception of SDM by patients with a hematologic malignancy and their physicians, following a preference-sensitive decision. The study was performed at the outpatient clinic in a Dutch academic and non-academic hospital. The results may help determining the focus for future SDM initiatives in this field.

In **Chapter 4,** we report the results of a questionnaire survey assessing the wishes, expectations and thoughts of patients attending a Dutch academic hematologic oncology outpatient clinic, with regard to an electronic patient portal. The results of this survey may help to optimize portal design for these patients, aligning with their needs.

In **Chapter 5,** we report the iterative development process of a multi-modality e-health application for MM patients and their health care providers aligning with the new MM care pathway and including participation of all relevant stakeholders. The study was performed at a large non-academic Dutch hospital. We critically discuss the development process, focusing on stakeholder participation. The results of this study may inform about further improvements towards future implementation and scientific evaluation of this application.

Finally, we summarize our findings in **chapter 6**. We discuss the strengths and limitations, provide additional considerations, assess the implications and provide future perspectives with regard to patient-centered innovations in cancer care.

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CHAPTER 2

2

The next step toward patient-centeredness in multidisciplinary cancer team meetings: An interview study with professionals

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Abstract

Background: Patient-centeredness is essential in complex oncological multidisciplinary team decision making. Improvement seems to be needed, while there is a lack of knowledge about health care providers' needs for improvement. We aimed to explore multidisciplinary team members' perspectives on the need to improve patient-centeredness in complex decision making, and subsequently, the strategies to enhance it.

Methods: This was a qualitative descriptive interview study. The participants were twenty-four professionals who attended multidisciplinary cancer team meetings weekly. The setting was five multidisciplinary teams (gastrointestinal, gynecological, urological, head and neck, and hematological cancer) in a Dutch academic hospital. Data were collected by semi-structured interviews and were analyzed with a combination of inductive and deductive content analysis.

Results: The participants voiced the need for additional information (patient-centered information, patients's needs and preferences, individualized medical information) during the multidisciplinary team meeting, to be more patient-centered in the decision making conversation with the patient following the meeting, and for more information following the meeting to support patient-centeredness. The strategies, which mostly originated from the needs, were categorized as organization, decision making, and communication. The most prominent strategies were those aimed at collecting and using patient-centered information, and to facilitate the decision making conversation with the patient following the multidisciplinary team meeting.

Conclusion: Our findings highlighted the need to improve patient-centeredness in oncological multidisciplinary teams and provided a comprehensive overview of strategies for improvement, supported by multidisciplinary team members. These strategies emphasize involvement of patients troughout the continuous process of decision making for patients with cancer. These strategies may be implemented in other oncological multidisciplinary teams, taking in mind the local needs. Future research may help to prioritize the strategies and to determine and evaluate the effect on endpoints, like patient or professional satisfaction, shared decision making, and on the decision that was made.

Introduction

In the cancer care setting, multidisciplinary teams (MDTs), also called tumor boards, have been widely introduced to facilitate team discussion and decision making regarding cancer diagnosis, treatment, and follow-up. In Europe and North America, it is the current standard of care to discuss each patient in a MDT meeting.[1,2] Health care professionals involved in cancer care, such as physicians and nurses, attend these meetings to enable interdisciplinary information exchange. MDTs are now widely accepted and their implementation is associated with changes in cancer assessment, diagnosis, and management.[3–5] Intensive interdisciplinary teamwork is also associated with a higher score on patient-centeredness.[6]

Patient-centeredness is a biopsychosocial approach and attitude that aims to deliver care that is respectful, individualized, and empowering. It implies the individual participation of the patient and is built on a relationship of mutual trust, sensitivity, empathy, and shared knowledge. Therefore the core attributes of patient-centredness are the biopsychosocial perspective, treating the patient as a unique person and a sustainable and genuine patient-caregiver relationship.[7] Patient-centered care is regarded an important feature of consistent, high-quality health care.[8] Previous research has shown that patient-centeredness may need to be improved in MDT decision making.[5,9–15] This need mostly originated from MDT quality improvement studies. Discussing patient-centered factors, such as psychosocial and psychological information and patient preferences, was shown to be relevant for MDT decision making and implementation of the MDT treatment recommendation.[5,9–12] Subsequently, observational studies showed the lack of patient-centered information and patient preferences in MDT meetings.[13,14,15] The need for patient-centered information was voiced by MDT members in one interview study.[15] Additionally, an important reason for non-implementation of MDT advice was a lack of information about patient preferences.[17–24] These findings underline the importance of patient-centered information exchange in the MDT meeting to make decisions in line with patients' goals and preferences, especially in complex decision making.[5]

Although there seems to be room for improvement in patient-centeredness on oncological MDTs, several barriers are recognized from the health care provider's perspective. First, nurses often try to take on the role of patient advocate, but more senior MDT members may dismiss them.[5,9–11] Second, physicians are not always familiar with the patient's situation.[13,25] Third, time pressure at MDT meetings can rush decision making.[5,10,13,26] This affects the quality of the decision making, due to reduced task-oriented communication and reduced socio-emotional interactions between MDT members.[27,28] Fourth, although MDT members may have an open attitude towards psychosocial aspects and patient

preferences, they may perceive several regulatory or organizational restraints.[26] Finally, in most cases, only a single treatment option is communicated to the patient, although a broader spectrum of possible treatment options has been discussed.[13] These barriers may hinder the successful implementation of strategies to improve patient-centeredness.[29]

Earlier, several studies provided strategies to improve MDTs, mostly aimed at improving the decision making procedure and effectiveness.[5,9,12,30–32] Two studies provided strategies aimed explicitly at patient-centeredness.[16,25] These studies focused on patient representation at the meeting, knowing patient preferences for treatment, and communicating with patients about MDT recommendations. They did not cover the whole spectrum of patient-centeredness and it's attributes.[7]

To further enrich the strategies that may improve patient-centeredness in oncological MDTs, more empirical information is required about MDT members' needs for patient-centeredness and about what strategies might address these needs. Therefore, the aim of this study was to obtain insights into the perspectives of MDT members for:

- the need for improvement of patient-centeredness in oncological MDT meetings, and,
- a broad spectrum of strategies that may improve patient-centeredness in complex oncological MDT decision making.

Material and Methods

Design

We designed a qualitative descriptive study using semi-structured interviews to examine patient-centeredness on oncological MDTs. To explore the strategies, we used a guiding framework based on key publications on patient-centeredness in MDTs and expertise of the research team.[5,7,12,18,25,33–36]

Setting

The setting was a Dutch academic hospital that has local non-academic as well as regional academic referral functions. Members of five different MDTs participated: gastrointestinal, gynecological, urological, head and neck, and hematological cancer. The MDT meetings are periodic meetings physically attended by hospital professionals involved in cancer care, such as a medical oncologist, hematological oncologist, radiation oncologist, surgical oncologist, nurse practitioner, radiologist, pathologist, gastroenterologist, and many residents. Compared to the others, the gastrointestinal and head and neck MDT meetings were attended by a relatively large variety of these professionals. The

hematology MDT meeting was attended mostly only by hematologists and either a pathologist or radiologist. In all MDT meetings, patients were mostly discussed at mandatory moments according to national guidelines: The first presentation, after surgery, and at disease recurrence or a new decision moment. In all MDT meetings, patients were also discussed that were referred from other hospitals and had not yet attended the academic clinic, although this was far more common in the gastrointestinal and gynecological MDT meeting. Registering a patient for the MDT meeting was usually performed by the treating physician or nurse practitioner. At the gastrointestinal MDT meeting, this was strictly a paper referral, while at the gynecology MDT meeting, physicians from the referring hospital attended the meeting by video conversation to discuss the case. At the gastrointestinal and gynecology MDT meeting, the nurse practitioner or attending physician introduced the patient case, while at the other three MDT meetings, this was usually done by the physician in charge of the patient. In general, a geriatrician, palliative care specialist, social worker, or the general practitioners did not attend the meetings. Patients do not attend the meetings. The MDT members discussed patient cases with the intention of generating diagnostic or treatment advice for the physician in charge of the patient.

Participants

The participants were 24 hospital professionals who participate weekly in oncological MDT meetings ("MDT members"). We used purposive sampling based on which of the five MDTs the MDT member attends, as well as the MDT members' profession (such as specialist, specialist in training, or nurse practitioner), discipline, age and gender. We intended to select at least two influential members of each MDT, such as the chair and participants involved in most case discussions. We excluded medical students. MDT members were contacted face-to-face or by phone for participation in the interviews and were informed briefly about the research goal beforehand.

Data Collection

Data were collected in a period of three months. Seven (bio)medical or health science students, who were selected on the basis of previous study results and motivation for this project, and two Ph.D. candidates performed the interviews. The research team included experts in the field of patient-centeredness, clinicians, and experts in qualitative research. One Ph.D. candidate (WS) was already an experienced interviewer. The other eight interviewers were trained by the senior members of the research team. Twenty-one interviews were attended by two members of the research team, and three interviews were attended by one member. In the case of two attendants, one was the lead-interviewer, and the other was the observer who took field notes and occasionally supported the interviewer by asking in-depth questions. The research team members,

including the interviewers, observed each participating MDT meeting at least once prior to the interviews to get acquainted with the context. Characteristics of the MDT case discussions were collected using a standardized data collection sheet (Supplement 1).

The interviews were performed following an interview guide with open questions (Supplement 2).[33] The interview guide was based on a consultation of experts within the research group and the strategies section also on the guiding framework (Supplement 3). The first two interviews were used for piloting the interview guide, after which some adaptions were made. In the interviews, we used the term 'patient-centeredness' to mean recognizing the individual patient's needs, preferences, values, and concerns regarding cancer treatment while also considering the patient's biological, psychological, and social context. At the start of the interview, the interviewer asked the MDT member about his or her definition of patient-centeredness and explained our definition, if needed. We used the term 'non-medical information' for psychosocial or psychological information. Characteristics like comorbidity, performance status, age, and gender were referred to as 'medical information'. The interviews were conducted in either Dutch or English, based on the language preference of the participant.

In the first part of the interview, the MDT member was asked to elaborate on their experiences with and views on the current level of patient-centeredness on the MDT, and their perceived needs felt to improve it. Subsequently, the interviewer used so-called complex cases to stimulate and illustrate this elaboration. These complex cases were derived from case-level observation data of the participating MDT meetings. Two complex patient cases were selected for each MDT, based on pre-defined selection criteria: the cases fulfilled at least one or two of the following inclusion criteria:[34] duration of discussion longer than average (based on local data on the average duration of discussion per patient), the number of MDT members involved was more than two, more than one treatment option was discussed further, or the content of the discussion included non-oncological issues.

In the second part, the interviewer asked the MDT member to provide and discuss strategies that spontaneously came to mind for improving patient-centeredness in MDT meetings. Then, a printed list of strategies according to the guiding framework could be presented in case no (additional) strategies spontaneously came to mind. The MDT member was asked to reflect on one or a few of these strategies.

The interviews lasted 30 to 45 minutes and were performed at a location of the participants' convenience. MDT members were asked to give their unrestricted views,

without being hindered by feasibility restrictions. The interviews were audiotaped and transcribed verbatim.

Data Analysis

Data were analyzed by combining inductive and deductive content analysis:[39,40] First, two research team members read and coded the interview transcripts independently. To analyze the perceived needs for improvement, text fragments were highlighted and coded inductively. To analyze the strategies, an unconstrained categorization matrix was used with pre-existing codes following the guiding framework for the deductive analysis. Additionally, new codes were created inductively for text fragments describing strategies not yet on the list. Second, the two team members compared these codes, and a final code for each fragment was generated by consensus. These codes were summarized in a codebook. For each subsequent coded transcript, the most recent codebook version was used and updated. This provided one final codebook (available from the authors on request). Field notes were used to gain additional insight, mainly contextual information that was relevant to understanding the interview transcript. They were not transcribed or coded. Third, for further analysis, the codes regarding the needs and strategies were both organized into new categories and subcategories that represented the most relevant themes. These categories were discussed recurrently within the research team until a consensus was reached on the meaningful presentation of the findings.

Twenty-two initial interviews were performed. To assess data saturation, a batched analysis based on codebook development was performed.[41] The first 15 interviews were preliminarily analyzed as "batch one" and it was decided to perform two additional interviews. We regarded the data was saturated when no new codes emerged. The second batch of seven interviews provided additional codes, although few, to the first. The two additional interviews did not provide any new codes, and therefore, data saturation was confirmed.

NVivo version 11.0 for Mac was used for analysis.

Trustworthiness

To secure credibility, prolonged engagement with the interview setting and MDT members was guaranteed by MDT observations. Furthermore, two research team members had been member on one or more MDTs, and one had a supporting role in many MDTs. The selection of MDT members from different disciplines provided different perspectives (data and sources triangulation). Researchers with different backgrounds and levels of research experience were involved (investigator triangulation). Peer debriefing was realized by a recurrent discussion of the analysts' findings within the research team. Furthermore, a member check was done by sending the participating MDT members a

copy of the interview transcript for comments and by discussing the summary of results with each MDT. Patients from four national cancer patient organizations (colon, gynecological, prostate, and head and neck cancer) were invited to two focus group sessions. It turned out that the patients acknowledged the strategies and no new strategies arose. Finally, reflective process notes were made in the analysis process, and all codebook versions were saved.

To secure transferability, rich information about the research setting and the research team was provided, and all (sub) categories in the analysis were provided with quote exemplars. The COREQ checklist was used for thorough reporting.

Ethical Considerations

The Medical Ethical Commission of Maastricht University Medical Centre confirmed that full ethical approval for the study protocol was not indicated. Verbal consent was obtained before the start of the interview from all participants, just before the audiotape started. The participants consented to anonymized responses being published. Data were analyzed and reported confidentially and anonymously and were stored afterward in a protected data area.

Results

Twenty-four of the 25 MDT members who were approached consented to participate. Their characteristics are displayed in Table 2.1 and the MDT case discussion characteristics in Table 2.2. The needs and strategies are discussed consecutively.

Needs

Analysis of the MDT members' needs for improvement of patient-centeredness on MDTs resulted in three categories: Information in the MDT meeting, decision making, and information following the MDT meeting (Table 2.3).

Information in the MDT Meeting

Almost all MDT members expressed a need for additional information being available in the MDT meeting, which would enable individualization of the MDT recommendation, e.g. by reporting two alternative recommendations. First, most of these needs regarded *patient-centered information*, such as psychosocial information or information about the patient's personal circumstances. Second, the need to know the *patient*'s *goals or preferences* was put forward, which some members made concrete in that one should "know" or "see" the patient in person. Third, the need for *individualized medical information*, for example, the

Table 2.1: MDT members' characteristics (n = 24).

	Characteristic	Total
MDT – N		
	Gastroenterology	8
	Gynecology	4
	Urology	2
	Head and neck	3
	Hematology	7
Discipline – N		
	Hematologic oncologist	6
	Medical oncologist	2
	Radiation oncologist	3
	Head and neck surgical oncologist	3
	Gastrointestinal surgical oncologist	2
	Gynecological surgical oncologist	3
	Urological surgical oncologist	1
	Gastroenterologist	1
	Nurse practitioner	3
Age range – yr.		29–63
Gender – N		
	Male	10
	Female	14

Abbreviations: MDT, multidisciplinary cancer team.

Table 2.2: MDT case discussion characteristics.

MDT	**Total cases (number)**	**Average duration and range of case discussion (min:sec)**	**Average participating clinicians (n)**	**More than one treatment option discussed (%)**	**Use of non-medical information (%)**
Gastroenterology	24	4:43 (1:20–11:30)	6	35	29
Gynecology	28	2:58 (1:00–6:40)	4	18	18
Urology	22	4:08 (0:50–14:10)	5	39	18
Head and neck	31	5:30 (2:05–11:10)	7	15	6
Hematology	24	4:41 (1:10–10:25)	4	43	25
Total	129	4:25 (0:50–14:10)	5	27	19

Abbreviations: MDT – multidisciplinary cancer team.

Table 2.3: Overview of needs for patient-centeredness.

Category	Subcategory
Information in the MDT meeting	Need for patient-centered information
	Need for knowing goals and preferences
	Need for individualized information.
Decision making	Need for patient-centeredness in consultation with the patient
	Need for patient-centeredness during MDT decision making process
	Resistance to more patient-centeredness
Information following the MDT meeting	Need for more information following MDT meeting
	Need to register/document information
	Need to discuss information with the patient

Abbreviations: MDT, multidisciplinary cancer team.

most recent performance status, how well a patient had recovered from earlier treatment, or the results of a geriatric assessment. This need was mostly felt by members from MDTs that included patients that were referred from another clinic without a consultation with one of the MDT members. This example summarizes various information needs:

> *"Yeah, when you are deciding whether you want to do an operation – yes or no – of course, then you have to know about her fitness. And if you want to give chemotherapy, you should know about the social situation: Whether the patient lives alone, whether she still has some level of autonomy, can do things by herself. I think that's the most important to have a good idea about a social situation and what she can do."*
>
> [Participant 12, MDT 4]

Decision Making

These needs regarded the decision making process during the MDT meeting or the process with the patient. Mostly, the MDT members felt a need for patient-centeredness *in the consultation with the patient* following the MDT meeting, as the physician in charge and the patient could then individualize the MDT recommendation:

> *"Because all the MDT can say: 'well option A is most valid, but if the patient does not want that, it is option B'. Then the final decision is when you are with your patient and not when you are with the MDT."*
>
> [participant 11, MDT 3]

The MDT members stated that the case discussions at the MDT meeting should primarily be medically based. Some expressed the need for patient-centeredness *during the MDT* decision making process. They stated that some cases, mostly surgical ones, needed a technical, medical discussion closely adhering to guidelines, while other cases needed a more patient-centered discussion, tailoring the recommendation to the individual. They voiced the need for a shared understanding to what extent patient-centeredness applies to each case discussion.

In contrast, others expressed *resistance* to the need for more patient-centered decision making: For example, when only one realistic treatment alternative was available, when withholding treatment was medically not desirable or when the trade-offs were complicated to a level that the professional expected the patient not being equipped to take the decision. Another MDT member indicated that the MDT advice should not be primarily guided by the patient's preferences, as they might change over time during the course of the disease or treatment. One MDT member expressed the need to keep the patient's autonomy limited, as he believed patients might make decisions they would later regret.

Information Following the MDT Meeting

The MDT members expressed a need for the transfer of information from the MDT to the patient or physician in charge. They wished for *more information* being *registered* in the MDT report to support their understanding of the case discussion. For example, the pros and cons that were discussed and a conclusion of the recommendation(s) should be clearly reported. One MDT member indicated a need to register the psychosocial information that was discussed, as it would help to determine the applicability of the recommendation:

> *"Then what is written in the MDT report is not always what has been discussed in those five minutes, because it is a resume. And then I miss the psychosocial part in the letter. Especially with patients who have little social support and where a very complicated extensive treatment is recommended."*
>
> [participant 25, MDT 4]

Additionally, one MDT member indicated the need that MDT recommendations would be *discussed with the patient* as neutral as possible, as the preference for a certain recommendation by a professional might influence the patient's choice, and then all options would not be equally considered.

Strategies

Analysis of the strategies identified three main categories for improvement of patient-centeredness in MDTs: organization, decision making, and communication. Each category consisted of subcategories, which are presented in Table 2.4 and described in detail below, which also depicts the corresponding need for each subcategory.

Table 2.4: Overview of strategies to improve patient-centeredness.

Category	Subcategory	Strategy	Corresponding need
Organization	People management	Involve staff with an attention to patient-centered information (nurse, psychologist, social worker, geriatrician, general practitioner, clinician familiar with patient). Delegate goal clarification to general practitioner.[a] Attendance of clinician who is familiar with the patient.	Patient-centered information. Knowing goals and preferences. Individualized information.
	Information management	Show picture of patient on screen.[a] Enable teleconferencing for e.g. general practitioner, physician from referring hospital.[a]	Patient-centered information. Individualized information.
	Meeting management	Organize more or longer MDT meetings to relieve time pressure.[a] Guarantee adequate MDT preparation time for physician in charge of patient. Introduce structured patient presentation. Guarantee access to patient information timely before MDT meeting, also with referrals. Oblige completing patient file before MDT meeting. Chair is responsible for patient-centeredness. Co-chair with secretary role. Chair works following strict principles.	-
	Education	Train MDT on Shared Decision Making (SDM).[a] Train chair for patient-centeredness.[a] Exchange best practices between MDTs. Teach patient-centeredness to interns/residents. Teach chairing task to interns/residents.	-

Table 2.4: Overview of strategies to improve patient-centeredness. (continued)

Category	Subcategory	Strategy	Corresponding need
Decision making	MDT process	Select patients for detailed discussion or short discussion. Discuss alternative treatments with pros and cons.[a] Case close off with recommendation, arguments/rationale, and level of agreement.[a] Do not aim for consensus in complex cases, but eg, provide a list with options.[a] Postpone decision to next meeting in referral patients instead of giving a conditional advice.	Patient-centeredness during MDT decision making process.
	Patient process	Elicit patient values, preferences, and goals with tools.[a] Make asking values, preferences, and goals a routine. Use decision aid.[a] Support of GP to clarify values.[a] Invite the patient to MDT meeting,[a] or have two consecutive meetings with and without patient.	Patient-centeredness in consultation with the patient. Patient-centered information. Knowing goals and preferences. Individualized information. To discuss information with the patient.
	Patient advocacy	Assign a patient advocate (nurse, GP, physician in charge).[a] Define the role of the patient advocate, eg to present the patient, to clarify the values, to ask patient-centered information, to advocate the patient's opinion.	Patient-centered information. Knowing goals and preferences.
Communication	Information to MDT	Presence of professional with info, eg, nurse, assistant, general practitioner, physician in charge, geriatrician. Standardize collection of patient-centered information or individualized medical information by: - Questionnaire, tool, or list.[a] - Text block in MDT forms. - Work-up-day to gather all information in one day Determine a standard presentation format including the mentioning of patient-centered information. All involved specialties prepare relevant cases.	Patient-centered information. Knowing goals and preferences. Individualized information.

Table 2.4: Overview of strategies to improve patient-centeredness. (continued)

Category	Subcategory	Strategy	Corresponding need
	Information following MDT	Standardize the written report, including options, pros and cons, arguments, or uncertainties.[a] Chair supervises thorough reporting. Designate a co-chair for thorough reporting. Clinic appointment with most relevant specialties following MDT meeting ("carrousel meeting"). Physician in charge discusses MDT report with patient, eg, options, pros and cons, uncertainty. Disclose MDT written report to the patient.	More information following MDT meeting. To discuss information with the patient.

Abbreviations: MDT, multidisciplinary cancer team. GP, general practitioner. [a] items (partially) derived from the list of strategies

Organization

The MDT members suggested organizational improvements to ensure a more effective and, in turn, more patient-centered MDT meeting. Many considered *people management*: They recommended that various types of professionals may attend the meeting, provide information during the meeting or have a consultation with the patient beforehand. To provide medical and patient-centered information, preferences, or clinical assessment information, the general practitioner (GP) or geriatrician were most often mentioned. Also, although less frequently, the anesthetist, nurse (practitioner), social worker, and psychologist were mentioned.

> *"For example, you could arrange a consultation with a social worker, or someone who can speak about the patient's thoughts, or a geriatrician. That would add something. (…) To know how they are in life. If they want to prioritize survival or quality of life."*
>
> [participant 2, MDT 2]

Some MDT members recommended involving the GP for goal clarification, although most regarded this as their own responsibility. In two MDTs where the attendance of the physician in charge was less frequent and more referral patients were seen, all participants recommended the attendance of a clinician who was familiar with the patient.

Additional strategies involved *information management*, such as using a video call with the GP. Some surgeons recommended displaying the patients' photograph on the screen, mostly for patient recognition. A hematologist warned not to estimate performance status based on the photograph, as it may not resemble the patient's current status.

Also, MDT members recommended strategies about *meeting management*, for example regarding the chair: first the chair should specifically pay attention for patient-centeredness and stimulate the other participants in this respect when needed. Second, the chair may in general more optimally perform this task when the MDT culture allows strict, well-organized chairing. One MDT member suggested delegating some chair tasks to a co-chair:

> *"The secretaries do that wrong because often medical terms are mentioned. Sometimes they know them, but sometimes they hear new words. That is not good; it takes time, also for the other attending professionals. So it would be better to do it [chairing] with two people."*
>
> [participant 16, MDT 1]

Some MDT members recommended scheduling more meeting or preparation time. Others suggested strategies that may save time: more structured patient presentation, (obligation of) completeness of the information document that is used to present the patient, and only brief discussions on patient cases that seem to clearly fit to the guidelines.

Finally, organizational strategies involving *education*. First, the fellows and some specialists focused on the role of the specialist in training. They emphasized involving and supervising them towards patient-centeredness, thereby also providing them autonomy to discuss their own recommendations with the MDT. They recommended giving feedback, preferably after the meeting. One of the MDT members emphasized their pre-MDT meeting, where cases were already discussed in a postgraduate training setting. Second, some MDT members recommended training the MDT participants individually or as a team, amongst others, in shared decision making. However, some MDT members were doubtful about training, for example because they believed it would not be suitable for experienced clinicians:

> *"A specific training? I do not know, I think it is also a bit part of the personality, like how much time you take. You cannot really train it. Although maybe a bit of strategy can be helpful, but then I think you have to do it early in the medical education before people become a doctor."*
>
> [participant 11, MDT 3]

Decision Making

The MDT members recommended strategies to improve the decision making process during the MDT meeting, or with the patient and strategies about patient advocacy.

The first strategy for decision making in *the MDT meeting* was to adequately select the patients who need more elaborate decision making as opposed to more straightforward decisions. The second, when possible, to discuss treatment alternatives or recognize that alternatives are available and provide these in the MDT report instead of formulating one single recommendation. This would leave room for the physician in charge to discuss the alternatives and the related pros, cons, and uncertainties with the patient:

> *"Yes or when there is a conflict, yes that's possible, that you leave this space open. Because then you give room to the physician in charge to consider the options that have been discussed. That could be pleasant for some people.*

> *'Actually, I prefer option a, but in certain circumstances option b is also fine.' And that you get approval of the MDT to do so."*
>
> [Participant 4, MDT 3]

Some MDT members emphasized not to turn discussing treatment alternatives into a routine obligation, but only when realistic alternatives are available.

The third strategy was to check and agree on the recommendation(s) in the report at the end of each case discussion by all attendees or by the chair. Finally, one MDT member of a MDT with many referral patients suggested postponing a decision to the next meeting when not all required information was available, instead of making hypothetical recommendations based on limited information.

Decision making with the patient: Almost all MDT members responded to the listed strategy to invite the patient to the MDT meeting. All MDT members, but one nurse practitioner, rejected this strategy. Most thought the patient would be distressed and/or the professionals would not be able to discuss the case as frankly as they would otherwise. The recommended strategies focused on clarifying patients' treatment values and goals, although there was no consensus among the MDT members within and between the various MDTs. The methods that were discussed to clarify values and goals were using a decision aid, using the Outcome Prioritization Tool,[30] consulting or delegating it to the GP, and by just asking the patient directly in the consultation. Here, a radiotherapist describes how to time the use of a decision aid:

> *"Regarding patient decision aids: of course, it is supportive for a patient. And most if it is already given before the consultation, because after a consultation with the physician the patient is already biased. (…) It provides opportunities to participate more [in decision making]."*
>
> [participant 20, MDT 5]

Finally, the MDT members recommended strategies on *patient advocacy*, mostly by a nurse practitioner. The patient advocate could be a provider of values, preferences, and patient-centered information:

> *"Well, because he [the GP] is medically oriented and is not as the patient is in the meetings, but he is presenting from the patient view, and he can add more patient-centered information. Maybe we didn't know that the patient is abus-*

ing alcohol or drugs and they say "do you know that the patient…" You know sometimes it is medical information, but it's lacking. So he is kind of the spider on the web, and he knows everything from the medical information and the specialist kind of view and from the patient, so he is the perfect solution to give us more appropriate and needed information."

[Participant 19, MDT 1]

As an alternative to being a passive information provider, the nurse practitioner could present the patient, to become more involved in the case discussion, or even actively represent the patient, thereby defending the patients' views.

Communication

Two communication subcategories were recognized: information from the patient to the MDT and information processing following the MDT.

Various strategies about *information to the MDT* were recommended. The most frequently mentioned strategies were using a questionnaire, tool, or list to collect this information, whether or not in combination with a text block in the MDT patient file. Complementing the strategy to involve various professionals in the MDT meeting, some MDT members suggested delegating the task of collecting this information to a professional. Other strategies were a standard presentation format including all relevant information types, obliging MDT preparation for the participants so they would already be familiar with the most important information and a "work-up-day" where all information is gathered in one day:

"So maybe we need to move back to do everything in one day and then followed by the MDT meeting. I also read in a book that is what the patient wants. Then you have anesthetics, fitness test, geriatric screening available at the MDT meeting. As they sometimes help in the MDT decision making."

[participant 24, MDT 1]

Additionally, some MDT members expressed resistance to the standardization of information collection. They emphasized that it should not become a burden for the professional or the patient and that the information should add value to the MDT discussion. In line with this, another MDT member recommended using a summary of the information, just as with medical information like CT scans.

To process the *information following the MDT meeting*, two groups of strategies were recommended. The first group involved strategies to improve the written report of the MDT by documenting different options, arguments, or patient-centered information. The second group contained strategies on how to communicate this information to the patient. Most MDT members thought the physician in charge should discuss the options, pros and cons, or uncertainties with the patient. Some MDT members recommended that the patient would have a joint consultation with specialists involved in the specific case:

> *"So how would I ideally see this? That we would have a joint consultation. So two specialists sit together with a patient. And then you can give the information in the most objective way to the patient."*
>
> [participant 20, MDT 5]

Finally, one MDT member suggested giving the patient the written report of the MDT meeting.

Discussion

In this study, we first explored MDT members' perspectives on the need for improvement of patient-centeredness in oncological MDT meetings, and secondly, their perspectives on strategies that may improve patient-centeredness in complex oncological MDT decision making. We identified three needs: Information in the MDT meeting, decision making, and information following the MDT meeting. The improvement strategies regarded the organization, decision making, and communication. Mostly, the strategies corresponded with a need. The following novel strategies were recommended: first, designating a co-chair with secretary role; second, pre-selecting patients for a detailed or short discussion; third, designating a patient advocate who has a clear defined role; and finally, a joint consultation after the MDT meeting. Our findings may be used as a practical guide to apply or formulate strategies in other hospitals. As the starting point for this study was the local situation, we recommend assessing the local needs and taking them in mind while using our findings. Our group currently participates in a Dutch collaboration, aiming to further implement patient-centeredness in MDTs in the Netherlands by developing and evaluating an integrated oncological decision making model, supported by the Dutch Cancer Society (KWF project number 12921).

A prominent finding in this study is the need to involve patient-centered information in the MDT meeting and the MDT members' recommendation of corresponding strategies, such as methods for collecting it beforehand or by involving people in the MDT meeting who are aware of this information. This is in line with other studies.[13,14,16] Our findings also confirm that decision making in the MDT meeting is primarily based on medical information.[15,16,42] Therefore, we propose improving the collection and use of patient-centered information in MDT meetings, which seems to be an essential first step towards patient-centered MDT decision making.

A new finding in our study was that the MDT members voiced a need for more information following the MDT meeting to facilitate more patient-centeredness in the decision making conversation with the patient. Subsequently, many of the recommended strategies aimed for thoroughly documenting and communicating the decision making process. For example, by discussing and reporting treatment alternatives instead of providing one treatment recommendation. Or, when applicable, by arranging a joint consultation: such a 'mini-MDT' may provide the patient with the opportunity to discuss the treatment alternatives with the relevant specialties, without attending the MDT meeting. Based on this finding, we propose strategies that facilitate the decision making conversation with the patient following the MDT meeting, which could be regarded as the second essential step towards patient-centered MDT decision making.

The recognition of these two steps seems crucial in transforming cancer-related decision making to a patient-centered process. In practice, cancer-related decision making is a process with interdependent decisional moments in which a MDT decision is embedded, instead of the MDT being a one-shot moment.[15] Figure 2.1 depicts this decision making process and the corresponding Shared Decision Making phases.[43,44] The MDT is a crucial step in the decision making process and currently patients usually do not participate in MDT meetings. Although currently patient participation in an MDT is being examined,[45] our findings show that there was little support base for this strategy. Therefore, implementing strategies involving both aforementioned essentialsteps may be a valuable alternative to involve the patient perspective in the decision making process. Furthermore, although we did not regard patients as the primary source for this study, patients may think of additional strategies.[16] These may be explored in the future.

Another notable finding is that some of the recommended strategies did not clearly relate to a voiced need. A first explanation may be that some strategies do not specifically address patient-centeredness, such as those regarding time pressure, chairing, or the education of young professionals. They frequently overlap with well-known strategies that address the effectiveness of the meeting and the decision making process.[5,9,12,30]

Taking in mind the definition of patient-centeredness, the MDT members may not have initially expressed corresponding needs. However, as they were elaborating during the interview, they may have thought of these strategies on second hand. Therefore, it is important to take in mind that other aspects of the MDT meeting, like organization and education, may be enablers of patient-centeredness. Second, some strategies not corresponding to a need originated from the list that was presented to the MDT members and did not arise spontaneously. This does not immediately implicate that these strategies should be discarded for implementation in practice. For example, displaying a patient photograph during the meeting is a quick and easily applicable strategy that was strongly supported. However, some of these strategies require more reflection. Our findings show that MDT members were ambiguous about the training of chairs and other members on patient-centeredness or shared decision making. However, leadership skills of the chair and team skills of the MDT are known to be important for effective decision making.[30,32] Therefore improving patient-centeredness in MTDs by training, based on the local preferences, may still be a promising strategy.

One of the motives for this study was the recognition of several barriers to patient-centeredness. Connecting the strategies to underlying needs may increase the chance for succesfull implementation and subsequently, overcoming some of the aforementioned barriers. However, it should be noted that not all health care professionals will embrace these initiatives. Implementing supportive instead of activist type strategies may help keeping all MDT members on board. For example, designating a co-chair with secretary

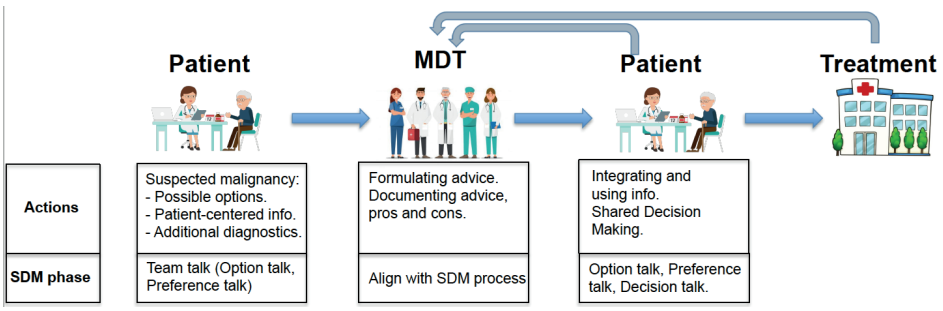

Figure 2.1: *Cancer-related decision making process. At suspicion of malignancy the physician discusses the possible diagnosis and treatment options with the patient (team talk and, if possible, option talk). Patient-centered information is acquired (preference talk) and additional diagnostics are ordered. The treating physician discusses the patient case in the MDT meeting, where an advice is formulated and well-documented. The team aims to align MDT decision making with Shared Decision Making with the patient. Then, the physician translates the MDT advice to the patient and integrates this with the patient towards a personalized treatment plan. Options are explained with pros and cons (option talk) and preferences are discussed (preference talk). The treatment is applied. During decision making or treatment, the MDT may be consulted again, when necessary. SDM: Shared Decision Making.*

role, to thoroughly report the MDT discussion with pros and cons for treatment options, may provoke discussing more than one option with the patient without being too much compelling.

Strengths and Limitations

Using explorative interviews with open-ended questions provided richer information on strategies than, for example, survey[24] and a literature review[5,30,32] methodologies. This lead to several novel strategies.

Some limitations may apply to our study. First, the use of multiple interviewers may have slightly impeded in-depth questioning. Furthermore, by interviewing various MDT members from five different MDTs, we obtained rich information. This may explain why the sample was quite big to reach data saturation.

Second, the study was performed in our specific setting. As the composition and functioning of MDTs in different hospitals and countries may vary, this may affect the transferability of our findings. We recognized that there were differences between the five MDTs in our hospital, for example, to what extent the MDT discussed referral patients. MDTs without tertiary referral functions may less likely encounter patients only being referred 'on paper' instead of physically attending the hospital. On the other hand, the majority of needs and strategies originated from professionals from various MDTs, suggesting transferability. We thoroughly described our MDT members and setting to aid others in making a judgment about the transferability to their situation.

An important footnote with regard to our findings is that we did not apply prioritizing exercises and therefore formally we cannot prioritize in the list of strategies. More research following these principles may gain insight into how to successfully implement these strategies.

Conclusion

Our findings highlight the MDT members' perceived need to improve patient-centeredness in MDTs. Various well-supported strategies for improvement were recommend, that may be implemented in practice. Many strategies regard collecting and using patient-centered information before the MDT, such as patient-centered information, needs and preferences. Others regard facilitating the decision making conversation with the patient following the MDT meeting. These strategies underscore the involvement of patients troughout the continuous process of decision making for patients with cancer.

Future research may aim to prioritize these and other strategies and to determine and evaluate the effect on endpoints, like patient or professional satisfaction, shared decision making, and on the decision that was made.

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Supplementary Material

Supplement 1: Standardized Data Collection Sheet

Names of non-participant observers: _____

Date of observation: _____

Characteristics of the Multi-Disciplinary Team			
Tumor board: _____	Total number of Part.: ___	Number of cases discussed: ___	Total duration of meeting: ___ Min.

Participants: chair and disciplines represented – information to be taken from tumor board letter afterwards.

Notes on participants and condition for teamwork: (e.g., chair, medical oncologist, oncological surgeon, radiotherapist, pathologist, nurse, GP)

Supplement 1: Standardized Data Collection Sheet (continued)

Characteristics of Case Discussion							
Code	**Chair involvement/ number of participants involved in discussion/ total duration of case**	**Case-manager**	**Non-medical info**	**Treatment options discussed**	**Treatment decision/ trial participation discussed**	**Potentially useful for interview**	**Comments: (e.g., on non-medical info discussed: mental health, socio-economic status, personal circumstances, treatment preferences, openness about uncertainty)**
	Chair involved: □ yes □ no No. of participants in discussion: _____ Case duration: _____ min.	□ pre □ abs	□ yes □ no	□ 1 □ >1 □ pat. pref. considered □ not relevant	□ actual debate □ monologue Trial: □ yes □ no	□ yes □ no	

Supplement 2: Interview Guide

Introduction to the Participant (2 minutes)

Thank you for your time and willingness to participate in this interview. I am an honors/ Ph.D. student from [name hospital].

Our research question is: *What are the experiences of [name hospital] tumor board clinicians with patient-centredness in complex decision-making in tumor boards? Do they feel a need for improvement? How can the level of patient-centredness be enhanced?*

The interview will take 30–45 minutes and consists of general and specific questions about your experiences and views. We would like to ask you to share everything that comes to your mind: there is no right or wrong answer. We want to learn from you as an expert.

Everything that you say during this interview is treated with confidentiality, and we will anonymize any statement made. Therefore, none of us should mention your name or any patient's name during the audiotaping.

Do you have any questions before we start? Are you okay with me starting the audiotape?

Start audiotape I have now started the audiotape, as you agreed to be interviewed.

Opening Question (warm-up 3 minutes)

First, please tell me what **your** role is on the tumor board.

Key Questions (15–30 minutes)

How do **you** experience the current level of patient-centeredness on your tumor board?
- Can you give an illustration of patient-centeredness within your tumor board?
- What is your opinion on patient-centredness?

STIMULUS show pre-selected case from observations

What was your experience of patient-centeredness in this case?

Do **you** feel a need to improve the level of patient-centeredness in your tumor board?

- If not, how do you think patient-centredness is implemented otherwise for your patients?

Do you have an idea for a strategy that would work for **you** to make the tumor board meetings more patient-centered?

STIMULUS Show best practices list

Ending Question (5 minutes)

We wanted to discuss patient-centredness during tumor board discussions. Is there anything we missed?

- Do you want to add something we did not pay attention to today?

Probing strategies and questions

- … nodding … (use silence)
- Paraphrasing: repeat the last phrase in a questioning way
- Can you tell me more about … your experience/wish/expectation?
- What do you mean, can you give an example?
- What conditions or situations, in your experience, influence this?
- What does patient-centeredness mean to you?
- How do you experience the general attitude towards patient-centeredness?
- What have you already done to improve patient-centeredness?
- How do you translate MDT advice to the consult with the patient?
- What kind of information or method or … would have helped to improve the quality of decision making?

Supplement 3: List of Strategies

Strategies were categorized according to their relation with the MDT meeting in time: before, during, and after the meeting.

Theme A: Generic[5]

Improve sensitivity to patient's preferences

- Train the entire tumor board on Shared Decision-Making.
- Train chair to ensure patient-centeredness and engage staff closest to the patient.
- Improve organizational management to ensure staff members can attend meetings.

Theme B: Before MDT meeting[33,34, 36, Citrienfonds]

- Collect non-medical patient data.
- Find out about patient values with standardized tools.
- Delegate the task of finding out about patient preferences to GP.

Theme C: During MDT meeting[5,12,18,25,35,research-team,quality employee]

- Show additional information on screen.
- Section for anesthetics, including info on the patient's fitness for treatment.
- Non-medical information and a portrait of the patient.
- Enhance decision-making behavior of clinicians
- Use systematic speaking order to reduce intimidation of non-physicians.
- Close each case by repeating the recommendation and underlying reasoning; otherwise record disagreement.
- Do not aim for consensus in complex cases: list >1 treatment option to be discussed with the patient.
- Prescribe patient decision aid in complex cases.

Invite patient representative to the tumor board meeting

- A patient "advocate", e.g., GP or nurse.
- Patient attends meeting him- or herself.

Theme D: After MDT meeting[25]

- Discuss recorded disagreement during the tumor board meeting with the patient.

CHAPTER 3

3

The perception of shared decision-making in hematology by patients and physicians seems satisfactory, but important steps are still ahead of us.

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Abstract

Background: While knowledge about shared decision making (SDM) experiences from patients in solid oncology is abundant, it is limited in hematologic oncology. Our objective was to assess to what extent elderly patients with a hematologic malignancy and their treating professionals perceive SDM, when they were recently involved in a preference sensitive decision. We also assessed which decision-making process steps and patient or professional characteristics influence the perceived level of SDM.

Methods: patient data were collected with a questionnaire including the 9-item Shared Decision Making Questionnaire (SDM-Q-9), Decisional Conflict Scale (DCS) and Control Preferences Scale (CPS). The treating physician received a questionnaire including the SDM-Q-Doc and the Provider Decision Process Assessment Instrument (PDPAI). Scores were calculated and differences were analyzed with non-parametric tests.

Results: Patients and physicians evaluated SDM with median SDM-Q-9 and SDM-Q-Doc scores of 84 (IQR 63-98) and 82 (IQR 73-89). The median DCS score was 27 (IQR 16-38) and PDPAI score 19 (IQR 6-31). Patients and physicians scored the questions regarding preference elicitation and deliberation significantly lower than the other questions. Additionally, patients above 75 years, those discussing non-curative treatment and those who encountered a hematologist in training experienced less SDM and more decisional conflict. Patient and physician scores correlated moderately.

Conclusion: The perception of SDM by hemato-oncologic patients and physicians was satisfactory in general and comparable to other studies. Preference elicitation and deliberation, the most elderly patients, decisions about non-curative treatment and hematologists in training require additional research. The relation between patient and physician SDM perception requires further exploration.

Introduction

Patients with a hematologic malignancy face important decisions that may be life changing or life saving and frequently multiple treatment alternatives are to be considered. They increasingly prefer to be actively involved in treatment decision-making.[1, 2] Shared decision-making (SDM), a process that supports decision-making in preference-sensitive decisions, fits well with this need. A decision is preference sensitive when well-informed patients considerably differ in their trade-offs between the pros and cons of one option, or if more equal treatment options are available, including no treatment. SDM involves several steps: The first is choice talk, where the professional informs the patient that a decision needs to be made between the various relevant options and that the patient's opinion is important. The second is option talk, where the professional explains the options and their pros and cons. In the third step, preference talk, the professional and the patient discuss the patient's preferences. The professional supports the patient in deliberation. The final step is decision talk, where the professional and patient discuss the patient's decisional role preference, make or defer the decision and discuss possible follow-up.[3, 4]

As the preference for decision involvement differs between patients with solid and hematological cancer,[1] the perception of SDM may also differ. We have some understanding of the perception of SDM in patients receiving medical therapy in solid oncology,[5-11] but such data are scarce in hematologic oncology. Only one study measured SDM with myeloma patients, but did not report the actual scores.[12] A handful studies regarding control preferences showed that about half of patients with a hematologic malignancy wish to be actively or collaboratively involved in treatment decision-making.[1, 2, 13-16] These limited data are insufficient for hematologists wishing to integrate SDM in clinical decision-making with patients, and more empirical information is needed to support them.

Therefore we explored the extent to which patients with a hematologic malignancy and their physicians perceived SDM, when facing a preference-sensitive treatment decision. Additionally, we aimed to recognize patient or physician characteristics as possible successful SDM determinants and we assessed the separate steps in the decision-making process, to detect areas for quality improvement regarding SDM in hematologic oncology.

Methods

Design

Cross sectional survey with multiple questionnaire instruments.

Participants

The study included patients of 65 years and older with a hematologic malignancy, attending the hemato-oncology outpatient clinic at an academic (Maastricht University Medical Centre, MUMC+) and a non-academic (Zuyderland Medical Centre) hospital in the southern region of the Netherlands. The study also included the treating physicians of these patients.

Inclusion criteria

Patients 65 years and older were included, when a preference sensitive treatment decision was made regarding their hematologic malignancy. This both included decisions regarding newly diagnosed and relapsed or refractory patients. We hypothesized seeing more preference-sensitive decisions in this elderly population versus a younger population, as in our experience their treatment decisions have more trade-offs compared to younger patients, for example as they more often discuss palliative treatment. Patients had to be able to understand Dutch language.

The hematologists and physicians in training to become hematologist at both hospitals were approached to participate, when their patient was included.

Exclusion criteria

Patients referred from another hospital (second opinion or tertiary center referrals) were excluded, unless the treatment decision was clearly only discussed in the hospital they were referred to. Patients could not enter this study more than once.

Patients being treated by the principle investigator (PG) were not included. Physicians could be included more than once if more than one of their patients were included.

Recruitment and data collection

By using a list of applicable scenarios (*Appendix 1*), based on consensus in the research team, preference-sensitive treatment decisions were identified by screening electronic patient health records within one-week time after a clinic visit over a period of 1.5 years. After pre-consent by phone call, eligible patients and their physician were sent a battery of questionnaires accompanied by an informed consent form and a letter of introduction that also notified on which decision the questionnaire applied. Patients were asked

to take this decision in mind while filling out the questionnaires. The questionnaires are described below. Demographic and disease-specific data were collected from the patients and demographic and profession-related data were collected from the physicians at time of inclusion (*Appendix 2*).

Patient questionnaire

The questionnaire included the Dutch version of the following instruments: Shared Decision Making Questionnaire 9-item (SDM-Q-9), Control Preferences Scale (CPS) single item, Decisional Conflict Scale (DCS) and the 5-level EQ-5D (EQ-5d-5L) quality of life VAS scale. The details of these instruments are shown in table 1. The full questionnaire battery in Dutch and English is shown in Appendix 3. The DCS subscales were not used, as the factorial validity was not proven in the Dutch language validation study.[17]

Table 3.1: instrument details.

Instrument	SDM-Q-9[18]	CPS[19, 20]	DCS[21, 22]	EQ5D-5L VAS[23]
No. of items	9	2	16	1
Outcome	Perception of SDM process	Involvement in a decision, preferred and perceived	Perception of decisional conflict	Quality of life
Item scale	0 (completely disagree) – 5 (completely agree)	1 (patient made decision alone) – 5 (doctor made decision)	1 (strongly disagree) – 5 (strongly agree)	0 (worst health) – 100 (best health)
Score scale*	Sum score of items, rescaled to 0 - 100	Individual item score, 1 – 5	Sum score of items, rescaled to 0 -100	VAS scale, 0 – 100
Interpretation	Higher score depicts more shared decision making	Higher score depicts more physician involvement	Higher score depicts more decisional conflict	Higher score depicts more quality of life
Validation	Yes, in Dutch[24]	Yes, in English[19, 20] and also frequently used in Dutch[25, 26]	Yes, in Dutch[17]	Yes, in Dutch[27]

* Scores were calculated as described in the original reference studies. If applicable, they were changed to the original scoring scale beforehand.

Physician questionnaire

The questionnaire used the Dutch version of the instruments SDM-Q doctor version (SDM-Q-Doc) and the Provider Decision Process Assessment Instrument (PDPAI). These instruments more or less resemble the patient version of SDM-Q-9 and DCS, but the questions are specifically modified for the physicians' viewpoint. Both instruments have been validated in Dutch language [24, 28]. The full questionnaire battery in Dutch and English is shown in Appendix 4.

Data analysis

Data were analyzed using SPSS (SPSS statistics, version 23.0, IBM). Demographic data are reported with medians or frequencies. Depending on the description by the authors in the original reference article of the instrument, missing questionnaire items were either analyzed as missing data or were imputed.[18, 21] We calculated questionnaire scores as depicted in table 3.1 and report medians or frequencies. As there is no defined cut-off for SDM-Q and the scores were not normally distributed (Shapiro-Wilk test), we also analyzed SDM-Q scores in three groups that we considered clinically relevant: first, the group of individuals with a maximum score of 100, as this group may contain patients who do not perceive any shortcomings regarding SDM. Second, the group of individuals with a score <60, as this would require disagreement on at least one question. Third, the group of individuals with intermediate scores. The CPS five-point scale was also calculated into a three-point scale: active, collaborative and passive. The DCS was also analyzed for scores exceeding 37.5 and scores below 25. A score <25 is associated with implementing decisions, a score >37.5 is associated with decisional delay of feeling unsure about implementation.

The following subgroups were analyzed using the Mann-Whitney-U test: patient age (≥75 years and <75 years), gender and education (primary to secondary vocational and higher professional to university), treatment intention (curative or not), disease type (lymphoid, myeloid and plasma cell disease), physician and hospital type. Relative risks were calculated for a low (<60) or high (100) SDM-Q score and for decisional regret (>37.5) or decision implementation (<25) for each subgroup. The p-value was corrected with the Bonferroni method. To assess the steps in the decision-making process, each SDM-Q item was compared to the mean score of the questionnaire and tested for significance using the Wilcoxon ranks test. Correlations were calculated between questionnaire scores with Spearman's Rank Correlation and bootstrap was used for additional significance assessment.

Sample size.

Sample size was calculated for a confidence level of 95% and a confidence interval of 5 points on the 0–100 SDM-Q-9 scale, based on a pilot evaluation following the first 34 included patients. To avoid loss of power due to possible incomplete questionnaires we added an extra 10% and determined the sample size at 90 patients. We also calculated a sample size of minimum 61 patients to prove a significant correlation of 0.4 or higher between the questionnaire scores (PASS, version 15.0.2).

Ethical considerations

The Medical Ethical Commission of Maastricht University Medical Centre confirmed that full ethical approval for the study was not indicated. Nevertheless the patients and researcher signed an informed consent form that was included in the introduction letter.

Results

Participants

After electronic health record screening 195 patients were eligible for participation, of which 166 consented by phone to participate and were sent the questionnaire. Of those, 95 (57%) returned the questionnaire. Of the physician questionnaires matching to these 95 patients, 64 (67%) were returned. Seventeen physicians participated in the study with a median of 6 patients per physician (range 1–13). Patient and physician characteristics are shown in table 3.2.

Questionnaires

The completion rate for each patient and physician questionnaire item was ≥90%. Table 3.3 shows all questionnaire scores and additionally findings are described below.

SDM-Q

The median SDM-Q score was 84 for patients and 82 for physicians. A maximum score of 100 was given by 20 patients (23%) and 19 patients (22%) scored <60 (Figure 3.1).

The physicians mostly (90%) scored in between these values, as they never scored 100 and only 6 times (10%) scored <60. Patients scored the two questions regarding treatment preferences and weighing (item 6 and 7) significantly lower than the others. Physicians scored items 2 (knowing about patient's decision involvement preferences) and 6 (asking patient's preference) significantly lower than the others. Also see table 3.4. Patients <75 years more often filled out the maximum score than patients ≥75 years (relative risk 4.9, 95% CI 1.2–19.7). Patients who discussed curative treatment more often scored the maximum score than patients who discussed non-curative treatment, although the difference was not significant (relative risk 1.7, 95% CI 0.8–3.7). Hematologists in training more often scored <60 than fully trained hematologists (relative risk 6.1; 95% CI 1.3–30.2) and patients scored <60 more often when the physician was a hematologist in training, although not significantly (relative risk 1.9, 95% CI 0.8–4.1). For all other subgroup analyses of the mean and grouped SDM scores, no significant differences were found. The SDM-Q-Doc correlated with the SDM-Q-9 (*rho*= 0.36; 95% CI 0.10 to 0.60).

Table 3.2: patient and physician characteristics.

Characteristic		Result
Patients, n		95
Patient age, median in years (range)		72 (65–92)
Patient sex, n (%)		
	Male	59 (62)
	Female	36 (38)
Disease type, n (%)		
	Lymphoid	43 (45)
	Myeloid	27 (28)
	Myeloma	21 (22)
	Other or unknown	4 (4)
Treatment intention, n (%)		
	Non-curative	66 (73)
	Curative	24 (27)
Hospital type, n (%)		
	Academic	70 (74)
	Peripheral	25 (26)
Patient education, n (%)		
	Primary to secondary vocational	60 (66)
	Higher professional to university	31 (34)
Physicians, n		17
Physician age, range in years		28–63
Physician type, n (%)		
	Hematologist in training	7 (41)
	Full-trained hematologist	10 (59)

Remaining questionnaires

The CPS indicated that 12 patients (13%) preferred to leave the decision to the physician and 24 (25%) preferred the physician making the decision after considering the patient's opinion. The remaining 56 patients (61%) preferred shared or autonomous decision-making. In two thirds of the patients the perceived decisional role matched the preferred role and if not so, it mostly only differed 1 point on the 1-5 scale.

The median DCS score was 27 (IQR 16-38). In 26% of patients the score exceeded 37.5, the cut-off that is associated with decisional delay or feeling unsure about decision implementation. In fourty-four percent of patients the score was below 25. Patients that discussed curative treatment more often scored low decisional conflict (score <25) than those who discussed non-curative treatment (relative risk 1.7, 95% CI 1.1-2.7). There was a trend that patients 75 years and older more often scored high decisional conflict (rela-

tive risk 1.8, 95% CI 0.9-3.6). The median PDPAI score was 19 (IQR 6-31) and there were no significant subgroup differences. There was no significant correlation between DCS and PDPAI.

Table 3.3: questionnaire scores

Scale	Measure	Outcome
SDM-Q-9 (scale 0-100)	Median (IQR)	84 (63-98)
SDM-Q-Doc (scale 0-100)	Median (IQR)	82 (73-89)
DCS (scale 0-100)	Median (IQR)	27 (16-38)
PDPAI (scale 0-100)	Median (IQR)	19 (6-31)
CPS perceived - %		
	Active	22
	Collaborative	39
	Passive	39
CPS preferred - %		
	Active	15
	Collaborative	46
	Passive	39
QoL VAS score (scale 0-100)	Median (IQR)	66 (59-80)

Abbreviations: SDM-Q-9: Shared Decision Making Questionnaire 9-item, DCS: Decisional Conflict Scale, CPS: Control Preferences Scale, QoL: Quality of Life, VAS: visual analog scale, SDM-Q-Doc: Shared Decision Making Questionnaire Doctor version, PDPAI: Provider Decision Process Assessment Instrument.

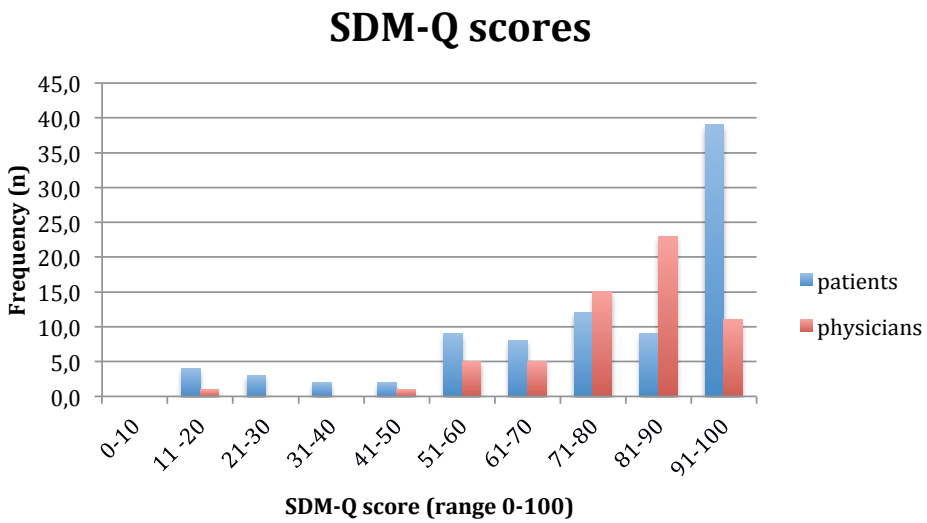

***Figure 3.1**: SDM-Q scores. Frequencies of SDM-Q scores are shown in tens for patients (blue) and physicians (red). Zero depicts low SDM and 100 depicts high SDM.*

There was a negative correlation between SDM-Q-9 and DCS (*rho*= -0.55; 95% CI -0.69 to -0.35) and SDM-Q-Doc and PDPAI (*rho*= -0.46; 95% CI -0.63 to -0.23). Thus when experiencing higher SDM, patients and physicians experienced lower decisional conflict. There were no significant correlations between SDM-Q-9 and DCS with CPS and QoL.

Table 3.4: SDM-Q responses per item.

Item*	N	Median score patients (IQR)	Median score physicians (IQR)
1. My doctor made clear that a decision needs to be made	94	5.0 (4.0-5.0)	5.0 (4.0-5.0)
2. My doctor wanted to know exactly how I want to be involved in making the decision	92	4.5 (3.0-5.0)	3.0 (3.0-4.0)
3. My doctor told me that there are different options for treating my medical condition	93	5.0 (3.0-5.0)	4.0 (4.0-5.0)
4. My doctor precisely explained the advantages and disadvantages of the treatment options	91	4.0 (3.0-5.0)	4.0 (4.0-5.0)
5. My doctor helped me understand all the information	93	5.0 (4.0-5.0)	4.0 (4.0-5.0)
6. My doctor asked me which treatment option I prefer	90	4.0 (2.8-5.0)	4.0 (3.0-4.0)
7. My doctor and I thoroughly weighed the different treatment options	89	4.0 (2.0-5.0)	4.0 (3.0-5.0)
8. My doctor and I selected a treatment option together	90	5.0 (3.0-5.0)	4.0 (3.0-5.0)
9. My doctor and I reached an agreement on how to proceed	93	5.0 (4.0-5.0)	5.0 (4.0-5.0)

*as stated in patient questionnaire; the physician questionnaire contains the same items, that are paraphrased slightly different to comply with the physician's viewpoint.

Discussion

Summary and main results

The objective of this study was to explore to what extent SDM is perceived by patients with a hematologic malignancy and their physicians, when facing a preference-sensitive treatment decision. According to our interpretation, it seems that patients and physicians perceived SDM to be satisfactory in general, but preference talk needs attention. Subgroup analysis showed that patients aged 75 years and older and patients that discussed palliative treatment experienced less SDM and more decisional conflict. Patients and physicians experienced less SDM when the physician was a hematologist in training.

Study results in perspective

To our knowledge we are the first to report thoroughly about patient and physician SDM perception in hematologic oncology. The best comparison for SDM perception by patients in hematologic oncology is a handful of studies regarding patients with medical therapy for solid cancer.[5-11] The mean score of 84 is relatively high, comparing to

these studies where mean SDM-Q-9 scores vary from 63 to 87. The mean SDM-Q score of 82 by the physicians is comparable to the scores ranging from 76 to 91 in other studies, although the study populations are more heterogeneous.[7, 29-32] We also assessed the impact of the decision with DCS. The mean score of 27 in our study is comparable with the 35 studies in cancer patients that were recently reviewed.[33] There are no studies available in cancer populations to compare the PDPAI findings. Interestingly, although SDM and decisional conflict correlate with each other in our study, the patient and physician questionnaires did not or only very limitedly correlate with each other. In six studies in various cancer and non-cancer patient populations the correlation between SDM-Q-9 and SDM-Q-Doc was also weak or absent.[11, 29, 30, 34-36] Although these questionnaires have not been originally designed to compare with each other,[37] these findings suggests an added value of a dyadic approach where both perspectives are taken into account. In addition, SDM may also be measured from an observer perspective, which may not necessarily correlate with the subjective measures.[9] In future SDM initiatives, subjective measurement from both perspectives and objective measurement would ideally complement each other.

Some notable findings in our study are worth mentioning. First, the relatively low scores of the items regarding treatment preferences and weighing was also shown in two of the three comparable studies in solid cancer[5, 8, 10] and in a qualitative study in breast cancer.[38] These items fit into the third step of SDM, 'preference talk', where the professional takes an explorative stance and tries to learn about the patient's preferences.[3] Furthermore, unlike the patients, the physicians reported relatively low scores for assessing patients' wishes for involvement in decision-making. It seems the hematologists perform well at informing patients, but are less able to extract information or preferences from the patient. As the latter is an essential part of the decision-making process, we recommend that interventions to optimize SDM in hematologic oncology focus on preference talk. For example, outside of the consultation patients may be supported by decision aids that include preference-elicitation exercises. During the consultation physicians may support patients by presenting options side-by-side in table format, aligned to the core outcomes and patients' frequently asked questions (FAQs).[3]

Second, the patients aged ≥75 years and patients that discussed non-curative treatment experienced less SDM and more decisional conflict than patients 65-74 years old and those who discussed curative treatment. Treatment intention may partially be related to patient age, and therefore SDM, as we had already hypothesized in our selection process. SDM poses several challenges in the elderly: there is often less evidence available, the medical situation is more complex and it may be difficult to share information with the elderly. Furthermore, decision-making with elderly may be more difficult due to

cognitive, hearing, visual and stereotype problems.[39] Although an age difference has not been shown in most comparable studies, one study described that patients below 60 years experienced less SDM than those above 60 years[8] and one study reported higher SDM-Q-Doc scores with younger patients[7]. Future SDM initiatives in hematologic oncology should take age and treatment intention into consideration and SDM perception by younger patients may be evaluated.

Finally, patients and physicians perceived less SDM when the physician was a hematologist in training compared to a fully trained hematologist. One study reported that older physicians had more attention for patient preferences.[29] These findings may reflect limited attention paid to SDM in the educational program on the one hand, but on the other hand the physicians in training may just not be experienced enough to integrate SDM successfully in their daily clinical care. As they treat 'real' patients, this requires attention.

Strengths and limitations

First, the high response rate of 57% in an elderly cancer patient population and the strong focus on a preference-sensitive decision are strengths of this study, as they increase the representativeness of the findings for clinical practice.

Second, we pooled various decisional moments for a variety of diseases in one analysis. Although every decision may differ with regard to SDM and may benefit from separate analysis, we intended to reflect the everyday practice of a clinical hematologist. There were no significant differences between the three main disease categories, which supports the validity of the pooled analysis and data presentation.

Third, we applied SDM-Q-9 and SDM-Q-Doc, which are relatively robust subjective measures,[40] as we believe SDM perception was the most important outcome. However, we did not use observer-based measures, which may have complemented our findings.

Finally, limitations to our sampling may be applied regarding age. As we purposefully selected an elderly population, comparison with young patients was not possible.

Conclusions

In conclusion, it seems that patients and physicians perceived SDM to be satisfactory in general, but preference talk needs more attention. This should be reflected in future initiatives to use and improve SDM in hematologic oncology and may provide educational opportunities. Here, dyadic subjective and objective measurement would ideally complement each other. Additionally, further research may be needed for the most elderly patients, patients who discuss non-curative treatment and physicians that are in training.

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Appendices

Appendix 1: list of preference sensitive scenarios

Consideration for study inclusion is based on the treatment indication beforehand, not on the actual decision. Patients must be aged 65 or higher.

Aggressive lymphoma	
Any 1st line or subsequent treatment	yes
Indolent lymphoma and chronic lymphatic leukemia (CLL); including Waldenstroms disease	
Without treatment indication, watch and wait policy	no
Any 1st line or subsequent treatment	yes
Chronic myeloid leukemia (CML)	
Any 1st line or subsequent treatment	yes
Acute leukemia's (AML and ALL)	
Any 1st line or subsequent (consolidation) treatment	yes
Myelodysplastic syndromes (MDS)	
Without treatment indication, follow-up policy	no
Any 1st line or subsequent treatment, including supportive care	yes
Multiple myeloma (MM)	
Any 1st line or subsequent (consolidation) treatment	yes

Myeloproliferative disorders	
Without treatment indication, follow-up policy	no
Any 1st line or subsequent treatment, including supportive care	yes
Systemic AL-amyloidosis	
Any 1st line or subsequent (consolidation) treatment	yes
Other disease entities: discussion per individual case	

Appendix 2: list of demographic, disease specific and profession related data

Patient data

Gender (male, female)

Age (years)

Disease type (diagnosis)

Treatment intention (curative, non-curative* or not known/applicable)

Area of residence (rural, city)

Highest education (as in Dutch education system)

Hospital type (academic, peripheral)

*non-curative: both including chronic treatment to alleviate or prevent symptoms as palliative end-of-life treatment.

Physician data

Gender (male, female)

Age (years)

Physician type (in training, full-trained)

Hospital type (academic, peripheral)

Appendix 3: patient questionnaire

Dutch questionnaire

Inleiding:

De volgende vragenlijsten gaan over de beslissing over uw behandeling. Deze beslissing kan zijn genomen in één gesprek, maar ook na meerdere gesprekken in de laatste 2 weken met uw behandelend arts. Neem bij het invullen van de vragenlijsten dit gesprek of deze gesprekken in gedachten en baseer daarop uw antwoord op de vragen.

In uw geval gaat het om de volgende beslissing: ……

Wat genomen is in het gesprek met dokter: ……..……

Algemene gegevens:

Wat is uw geslacht?*

o Man

o Vrouw

Wat is uw leeftijd: ……. jaar

Wat is uw woonplaats? ……

Wat is de hoogste opleiding die u heeft afgerond?*

o Wetenschappelijk onderwijs (Universitair)

o Hoger beroeps onderwijs (HBO)

o Middelbaar beroeps onderwijs (MBO)

o Middelbare school (VMBO, HAVO, VWO, etc)

o Basis school (lager onderwijs)

*Kruis aan wat van toepassing is

Onderdeel A1: stellingen over het gesprek met uw arts.

Hieronder worden een aantal stellingen gegeven die betrekking hebben op het gesprek met uw arts over de boven genoemde beslissing. Kunt u per stelling aangeven in hoeverre u het hier mee eens bent, door een cirkeltje te zetten om het nummer van uw antwoord?

Antwoord categorieën:

o Geheel mee oneens (score 0)

o Sterk mee oneens (score 1)

o Enigszins mee oneens (score 2)

o Enigszins mee eens (score 3)

o Sterk mee eens (score 4)

o Geheel mee eens (score 5)

1. Mijn arts heeft me duidelijk gemaakt dat er een beslissing genomen moet worden.

0 1 2 3 4 5

2. Mijn arts wilde precies van me weten hoe ik betrokken zou willen worden bij het nemen van de beslissing.

0 1 2 3 4 5

3. Mijn arts heeft me verteld dat er voor mijn klachten verschillende behandelingsmogelijkheden zijn (inclusief de mogelijkheid om niet te behandelen).

0 1 2 3 4 5

4. Mijn arts heeft me de voor- en nadelen van de behandelingsmogelijkheden precies uitgelegd.

0 1 2 3 4 5

5. Mijn arts heeft me geholpen alle informatie te begrijpen.

0 1 2 3 4 5

6. Mijn arts heeft me gevraagd welke behandelingsmogelijkheid mijn voorkeur heeft.

0 1 2 3 4 5

7. Mijn arts en ik hebben de verschillende behandelingsmogelijkheden grondig afgewogen.

0 1 2 3 4 5

8. Mijn arts en ik hebben samen een behandelingsmogelijkheid uitgekozen.

0 1 2 3 4 5

9. Mijn arts en ik hebben een afspraak gemaakt over het verdere vervolg.

0 1 2 3 4 5

Onderdeel A2: stellingen over het gesprek met uw arts.

Mensen verschillen in de mate waarin zij betrokken willen worden bij het nemen van beslissingen over hun medische behandeling. Sommige mensen willen wél graag betrokken worden bij deze beslissingen, anderen laten dit liever aan hun behandelend arts over. Kunt u per stelling aangeven welke omschrijving het beste bij u past?

(één hokje aankruisen)

Stelling 1: als het gaat om hoe u het liefste betrokken zou willen worden bij de bovengenoemde beslissing over uw behandeling.

o Het liefst neem ik zelf de beslissing over mijn behandeling.

o Het liefst neem ik zelf de beslissing over mijn behandeling, maar houd daarbij sterk rekening met de mening van mijn behandelend arts.

o Het liefst neem ik samen met mijn behandelend arts de beslissing over mijn behandeling.

o Het liefst laat ik de beslissing over mijn behandeling over aan mijn behandelend arts, waarbij deze wel sterk rekening houdt met mijn mening.

o Het liefst laat ik de beslissing over mijn behandeling over aan mijn behandelend arts.

Stelling 2: als het gaat om hoe u daadwerkelijk betrokken bent geweest bij de bovengenoemde beslissing over uw behandeling.

o Ik nam zelf de beslissing over mijn behandeling.

o Ik nam zelf de beslissing over mijn behandeling, maar hield daarbij sterk rekening met de mening van mijn behandelend arts.

o Ik nam samen met mijn behandelend arts de beslissing over mijn behandeling.

o Mijn behandelend arts nam de beslissing over mijn behandeling, waarbij deze wel sterk rekening hield met mijn mening.

o Mijn behandelend arts nam de beslissing over mijn behandeling.

<u>English questionnaire (not clinically used, but for reader understanding only)</u>

Introduction:

The following questionnaires regard the decision about your treatment. This decision may be taken in one consultation or in a series of consultations with your treating physician. Please refer to these consultation(s) when filling out this questionnaire.

In your case it regards the following decision: ……
That has been taken in consultation with doctor: ……

General information:

What is your gender?*

o Male

o Female

What is your age: ……. years

What is your residence? ……

What is the highest eductation that you completed?*

o University

o Higher professional education

o Secondary vocational

o Primary vocational

o Primary school

*Tick what applies to you

Part A1: theses about the consultation(s) with your physician.

Below you can see a series of theses that apply to the consultation(s) with your treating physician about the above-mentioned decision. Please indicate how much you agree to each thesis by circling the number of the answer that applies to you.

Response categories:

o Completely disagree (score 0)

o Strongly disagree (score 1)

o Somewhat disagree (score 2)

o Somewhat agree (score 3)

o Strongly agree (score 4)

o Completely agree (score 5)

1. My doctor made clear that a decision needs to be made.

0 1 2 3 4 5

2. My doctor wanted to know exactly how I want to be involved in making the decision.

0 1 2 3 4 5

3. My doctor told me that there are different options for treating my medical condition (including the option of no treatment).

0 1 2 3 4 5

4. My doctor precisely explained the advantages and disadvantages of the treatment options.

0 1 2 3 4 5

5. My doctor helped me understand all the information.

0 1 2 3 4 5

6. My doctor asked me which treatment option I prefer.

0 1 2 3 4 5

7. My doctor and I thoroughly weighed the different treatment options.

0 1 2 3 4 5

8. My doctor and I selected a treatment option together.

0 1 2 3 4 5

9. My doctor and I reached an agreement on how to proceed.

0 1 2 3 4 5

Part A2: theses about the consultation(s) with your physician.

People may differ in their wish to be involved in taking decisions about medical treatment. Some prefer to be involved in decision-making, others prefer to leave this to their treating physician. Please tick which description fits you best. *(Only tick one box)*

Thesis 1: regarding how you prefer to be involved with the abovementioned decision:

o I prefer to make the final decision about which treatment I receive.

o I prefer to make the final decision about the treatment after seriously considering my doctor's opinion.

o I prefer that my doctor and I share responsibility for deciding which treatment is best for me.

o I prefer that my doctor makes the finale decision about which treatment will be used, but seriously considers my opinion.

o I prefer to leave all decisions regarding my treatment to my doctor.

Thesis 2: regarding how you have actually been involved with the abovementioned decision:

o I made the decision about which treatment I would receive.

o I made the final decision about my treatment after seriously considering my doctor's opinion.

o Both my doctor and I shared the responsibility for deciding which treatment is best for me.

o My doctor made the finale decision about which treatment would be used, but seriously considered my opinion.

o I left all decisions regarding my treatment to my doctor.

Appendix 4: physician questionnaire

Dutch questionnaire

Inleiding:

De volgende vragenlijsten gaan over de beslissing die u genomen heeft met uw patiënt over de behandeling van zijn/haar ziekte. De onderzoeker heeft u laten weten op welk beslismoment bij welke patiënt de vragen betrekking hebben. Deze beslissing kan genomen zijn in één gesprek, maar ook na meerdere gesprekken de laatste 2 weken. Neem bij het invullen van de vragenlijst dit gesprek of deze gesprekken in gedachten en baseer daarop uw antwoord op de vragen.

In dit geval gaat het om de volgende beslissing: ……..…

Algemene gegevens:

Wat is uw geslacht?*

o Man

o Vrouw

Wat is uw leeftijd: ……. jaar

Wat is uw huidige status als arts?

o Arts in opleiding tot specialist

o Medisch specialist

*Kruis aan wat van toepassing is

Onderdeel 1: stellingen over het gesprek (de gesprekken) met de patiënt.

Hier onder worden 9 stellingen gegeven die betrekking hebben op het beslismoment met uw patiënt. Kunt u per stelling aangeven in hoeverre u het hiermee eens bent. Omcirkel één score.

Antwoord categorieën:

o Geheel mee oneens (score 0)

o Sterk mee oneens (score 1)

o Enigszins mee oneens (score 2)

o Enigszins mee eens (score 3)

o Sterk mee eens (score 4)

o Geheel mee eens (score 5)

1. Ik heb mijn patiënt duidelijk gemaakt dat er een beslissing genomen moet worden.

0 1 2 3 4 5

2. Ik wilde precies van de patiënt weten hoe hij/zij betrokken zou willen worden bij het nemen van de beslissing.

0 1 2 3 4 5

3. Ik heb de patiënt verteld dat er voor zijn/haar klachten verschillende behandelingsmogelijkheden zijn.

0 1 2 3 4 5

4. Ik heb de patiënt de voor- en nadelen van de behandelingsmogelijkheden precies uitgelegd.

0 1 2 3 4 5

5. Ik heb de patiënt geholpen alle informatie te begrijpen.

0 1 2 3 4 5

6. Ik heb de patiënt gevraagd welke behandelingsmogelijkheid zijn/haar voorkeur heeft.

0 1 2 3 4 5

7. patiënt en ik hebben de verschillende behandelingsmogelijkheden grondig afgewogen.

0 1 2 3 4 5

8. De patiënt en ik hebben samen een behandelingsmogelijkheid uitgekozen.

0 1 2 3 4 5

9. De patiënt en ik hebben een afspraak gemaakt over het verdere vervolg.

0 1 2 3 4 5

English questionnaire

Introduction:

The following questionnaires regard the decision you have taken with your patient about the treatment of his/hear disease. The researcher has indicated to you on which decision the questionnaires apply. This decision may be taken in one consultation, but also after several consultations in the past 2 weeks. Please refer to these consultation(s) when filling out this questionnaire.

In this case it regards the following decision: ……..

General information

What is your gender?*

o Male

o Female

What is your age: ……. years

What is your current status as a physician?*

o Hematologist in training

o Full-trained hematologist

*Tick what applies to you

Part 1: theses about the conversation(s) with the patient.

Below you may find 9 theses regarding the decision with your patient. Please indicate how much you agree to each thesis by circling the number of the answer that applies to you. Only circle one score.

Answer categories:

o Completely disagree (score 0)

o Strongly disagree (score 1)

o Somewhat disagree (score 2)

o Somewhat agree (score 3)

o Strongly agree (score 4)

o Completely agree (score 5)

1. I made clear to my patient that a decision needs to be made.

0 1 2 3 4 5

2. I wanted to know exactly from my patient how he/she wants to be involved in making the decision.

0 1 2 3 4 5

3. I told my patient that there are different options for treating his/her medical condition, including no treatment.

0 1 2 3 4 5

4. I precisely explained the advantages and disadvantages of the treatment options to my patient.

0 1 2 3 4 5

5. I helped my patient understand all the information.

0 1 2 3 4 5

6. I asked my patient which treatment option he/she prefers.

0 1 2 3 4 5

7. My patient and I thoroughly weighed the different treatment options.

0 1 2 3 4 5

8. My patient and I selected a treatment option together.

0 1 2 3 4 5

9. My patient and I reached an agreement on how to proceed.

0 1 2 3 4 5

CHAPTER 4

4

Developing a patient portal for haematology patients requires involvement of all stakeholders and a customised design, tailored to the individual needs.

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Abstract

Background: Electronic patient portals are increasingly being implemented, also in (haemato) oncology. However, portal usage is low and depends on user and provider engagement. We explored wishes, expectations and thoughts of patients with a haematologic malignancy and their physicians with regard to the electronic patient portal.

Methods: Based on insights from literature and a focus group discussion we built a 44-item questionnaire. This questionnaire was spread amongst patients with a haematologic malignancy at the outpatient clinic that was not yet exposed to patient portal facilities. Haematologists completed a questionnaire based on literature.

Results: Patients were interested in many different types of access to information and portal functionalities. However, their opinions varied about the provision of access to the portal to other people, the role of the physician, possibilities for communication via the portal and timing of access. The physicians acknowledged the relevance of the electronic patient portal, but had some worries about the patients' autonomous information handling, organizational and technical issues. Patients frequently expressed to be open about the potential of the patient portal to orchestrate their care. Nevertheless, most physicians appreciated their supporting role towards the patient.

Conclusion: Patients and physicians appreciated the electronic patient portal. Both groups need to be involved in further portal development to improve engagement by meeting patients' wishes, taking into account organizational and professional issues and managing expectations for both parties. To fit various patient profiles, portal design should be flexible and individualized. Further research should focus on the perceived added value and the impact on patient related outcome measures of portals.

Introduction

The patients' role in health care decisions is increasingly active and participatory, as illustrated by the implementation of shared decision making (SDM).[1] By empowering patients they can make well-informed decisions. In the era of digitalization, an electronic patient portal can contribute to this empowerment. An electronic patient portal is "a website where patients can request their medical records, often supplemented with different options such as making an online appointment or getting a repeat recipe". Patient portals are increasingly implemented; the Dutch minister of health even set a goal of 80% implementation in Dutch hospitals by 2019.[2] Among selected groups of patients electronic patient portal implementation has already shown improvements in medication adherence, management of chronic disease, disease awareness, patient safety, improved patient experience, patient satisfaction and patient empowerment. An increase in preventative medicine and decrease in the number of office visits have also been reported.[3,4]

However, the use of patient portals is generally low.[5] Patients tend to use electronic Health (eHealth) services more when the development of the service has focused on the patients' needs.[5,6] Provider endorsement and engagement is also an important factor for patient engagement, as in most pre-portal studies physicians expressed various concerns about portal implementation.[5,6] Therefore it is advised to involve both patients and health care providers in portal development.

Cancer patients, amongst whom patients with a haematologic malignancy, require frequent visits to their doctor, receive many lab results and are in need of various types of care. In cancer patients, the electronic patient portal adds to the autonomy, knowledge and psychosocial and behavioural skills of patients.[7] A recent example of patient involvement in portal development in cancer patients has been published in lung and breast cancer[8,9] and publication of development methodology is awaited from a patient driven portal in chronic myeloid leukaemia.[10] A Canadian study showed that haemato-oncology patients were interested in using patient portals.[11] However, little is known regarding the preferences of haemato-oncology patients about the use and functions of the patient portal. Information about the health care providers' view is limited in oncology[12-14] and absent in haemato-oncology.

The aim of this study is to explore the wishes, expectations and thoughts of patients with a haematologic malignancy and their physicians with regard to the electronic patient portal, in order to gain more support of patients and physicians for subsequent

portal development. This may stimulate patient centred portal research and clinical development and, subsequently, empowerment in the haemato-oncology practice.

Methods

Study design

Exploratory sequential mixed methods design with two-step data acquisition.[15] First, by a focus group interview. Second, by a questionnaire survey. This method was chosen because the explorative character of the study required a qualitative aspect, while at the same time we aimed to explore a greater part of our patient population to increase the applicability of the results. This way the questionnaire results are better contextualised. Therefore, a patient questionnaire was based on literature research and a focus group discussion to explore relevant thoughts and opinions of the subject. A physician questionnaire was based on literature research.

Participants

For the patient questionnaire survey, adult patients with a haematologic malignancy attending the haemato-oncology outpatient clinic at Maastricht University Medical Centre (MUMC+), an academic hospital in the Netherlands, were invited. The only exclusion criterion was not being able to read or write Dutch language. We aimed to collect data of 200 consecutive patients. Given the explorative character of the study and lack of comparable study results we were not able to calculate a sample size. We intended to include ample participants to analyse subgroups based on age (younger or older than 65) and gender.

For the physician questionnaire survey, all 14 haematologists and residents haematology of the MUMC+ were invited.

The patient questionnaire

Literature research and a focus group discussion provided face validity of a questionnaire about patients' preferences for electronic patient portal functionalities and considerations about using the electronic patient portal. The questionnaire consisted of two parts. First, demographic information was collected: age, gender, area of residence, education, access to Internet and if participants worked in health care. Also the control preference scale (CPS) single item was used.[16,17] We hypothesized that these variables might impact the outcomes.[11] The second part consisted of 44 statements, divided in 9 themes. The statements were to be answered by a 5-point Likert scale ranging from no agreement to high agreement, and there was one open space for suggestions. The

9 themes were: access to different types of information, timing of access, availability of functionalities, communication, safety, providing (partial) access to other people, considerations about using the portal, worries about using the portal. See results table.

Literature research

We searched in PUBMED to explore existing electronic patient portals for haemato-oncology patients, the extent of patient involvement in developing these portals, what functionalities patients preferred for portals and barriers and facilitators for implementation of these portals. We searched by combining the following terms: "Hematologic Neoplasms"[Mesh], "Leukemia"[Mesh], "Lymphoma"[Mesh], "Multiple myeloma"[Mesh], electronic patient portal(s), patient portal(s), portal(s), and electronic health records. The search was restricted to articles starting from the year 1990, since Internet was not available for most people in the years before 1990 and electronic patient portals were not yet used. Also, the reference lists of these articles were scrolled and articles in the authors' databases were used. Inclusion criteria were: (1) containing any information about electronic patient portal development, implementation or evaluation in any haemato-oncologic patient population; (2) English or Dutch language and (3) full text available. As this search yielded a limited amount of results, additionally, a comparable PUBMED search for existing electronic patient portals for oncology patients was performed to supplement the haemato-oncology literature.

Focus group

Seventy patients from the haemato-oncology outpatient clinic at the MUMC+ were asked by phone to volunteer in a focus group discussion, of which eight consented to participate and six eventually attended the focus group meeting. All volunteers had to be 18 years or older, suffered from a type of haematologic malignancy and were able to speak Dutch. Volunteers of different age and gender were recruited. After the volunteers had given verbal consent by phone, they received further information via an e-mail. The focus group took place in MUMC+ and was facilitated by two of the researchers (CA and LJ) as discussion leader and observer. After signed consent the discussion was started. The interview was structured by using an interview guide (Additional file A), with discussion topics based on the literature research. The volunteers who attended the focus group received a small financial compensation including coverage for travel costs. The interview was audio recorded and transcribed verbatim by two researchers (TW and PL). Three researchers independently coded the transcript by thematic coding. Discrepancies were discussed between the three coding researchers and solved by consensus.

The physician questionnaire

Literature research provided face validity of a questionnaire on physicians' considerations about patients using the electronic patient portal. The questionnaire consisted of two parts. First, demographic information was collected: age, gender, staff function and experience working as haematologist. The second part consisted of 21 statements, to be answered by a 5-point Likert scale ranging from no agreement to high agreement, and one open space for suggestions. Also see the results table.

Data collection and analysis

In October and November 2017 outpatient clinic employees approached approximately 250 consecutive patients to fill out the paper based questionnaire, directly before or after attending an outpatient clinic visit. In the same period, 320 patients, who were not approached for the paper based questionnaire, were sent an online version of the questionnaire by email. The age and gender of all patients attending the outpatient clinic in this period were registered. Also in the same period, the 14 physicians were invited by one of the researchers (PG) to fill out the physician questionnaire.

Outcomes of the demographic data were analysed descriptively by calculating means or frequencies. Age was also divided in groups (18-40, 41-50, 51-60, 61-70, 71-80 and above 80 years old). Gender and age groups of the participants were compared with the age of all patients by using the Chi Squared test. The Control Preference Scale was recalculated in three categories (autonomous, collaborative, passive) and analysed descriptively by calculating frequencies.

Analysis with the Kolmogorov-Smirnov test determined that the questionnaire item responses were not normally distributed. The 5-point scale was recalculated in three categories (no agreement – neutral – agreement). The questionnaire items (5 and 3 category) were analysed descriptively by calculating frequencies. Subgroup differences between these frequencies were assessed by the Chi Squared test. For subgroups with more than two categories the Chi Squared test was performed, comparing each category with the others separately, to see which of the categories differed statistically significant. Consistency between items within each theme was tested with Cronbach's alpha and factor analysis was performed, since after an interim analysis we hypothesized that a common construct might influence some of the answers. All calculations were performed with SPSS (SPSS statistics, version 23.0, IBM).

Results

Participants

Of the 570 patients that were invited, 204 (36%) agreed to participate. The quality of the response was satisfactory. There was a high response rate >90% for all questionnaire items, but one item, that was completed by 87% of the responders. Of the 14 physicians that were approached, 13 responded and response to all questionnaire items was 100%.

The demographic and decisional role characteristics of the patients and physicians are shown in table 4.1 and 4.2.

Table 4.1: patient characteristics (n=204)

	Characteristic	Total
Median age (IQR) – yr.		63 (58-70)
Gender - %		
	Male	64
	Female	36
Residence - %		
	Rural	45
	City	55
Access to internet - %		
	Yes	95
	No	5
Employment in health care - %		
	Yes	17
	No	83
Type of questionnaire - %		
	Paper	48
	Digital	52
Control preferences scale, preferred role - %		
	Autonomous	16
	Collaborative	59
	Passive	26
Education - %		
	Low	36
	Middle	28
	High	37

Table 4.2: physician characteristics (n=13)

	Characteristic	Total
Median age (IQR) - yr.		35 (32-54)
Median work experience (IQR) - yr.		4 (2-16)
Gender - %		
	Male	31
	Female	69
Title - %		
	Haematologist	62
	Resident haematology	38

The study population age groups did not significantly differ from the total patient population, with exception of the 18-40 years old group that represented 16% of the total population and 5% of the study population ($P<0.001$). Age was also not different (participants 64% and all patients 54% male, $P=0.2$). Therefore we considered the study patients comparable for age and gender to the total patient population. Furthermore, the study population educational level was compared with the regional and national education level data as provided by the government. The study population well represented these characteristics. Additional patient characteristics can be found in Additional file B.

Patient questionnaire

The results for the 3-category items are shown in table 4.3 and summarised below. The 5-category items did not add additional value to the results and are therefore not shown, they are available on request. Subgroup analyses revealed few relevant differences between groups, including the outcomes per type of questionnaire (paper or digital). We consider the implications of the differences in subgroups not relevant for the interpretation of our data because of the limited size of the differences, unless otherwise specified below. All statistically significant subgroup differences are shown in Additional file C.

Items 1 to 18: the large majority of patients (>75%) would like to see or use 15 of the 18 proposed types of access to information and portal functionalities. A bit less robust, but still more than 50% was interested in the ability to take notes in the portal, to fill out questionnaires in the portal and to have access to patient organization information.

Items 19 and 20: more than two thirds of the patients would like to see the information as in items 1 to 8 both directly when it is available as well as after a physician consultation. We expected that patients would give a preference for either one of these two items, but more than half of the patients (55%) answered both items the same. Of the

Table 4.3: patient questionnaire (responses in percentages)

	Item	Disagree	Neutral	Agree
I would like to see the following about myself in the electronic patient portal				
	1. Laboratory results	5	13	81
	2. Imaging results	6	16	78
	3. Medical patient file	4	10	86
	4. Reporting to other physicians	5	13	82
	5. Appointments in the hospital	3	5	91
	6. Personal data	5	9	87
	7. Current medication list	4	5	91
	8. Medication history	5	14	81
I would like to have the following other functionalities in the patient portal				
	9. Make appointments	4	19	77
	10. Reminder for appointments	4	11	85
	11. Request medication recipe	3	10	87
	12. Change personal data	3	6	91
	13. Make personal notes	15	32	53
	14. Fill out questionnaires	6	25	69
	15. Medication information	3	11	86
	16. Disease information	4	16	80
	17. Glossary of medical jargon	5	14	82
	18. Patient organization information	6	28	66
I would like to see the information above (item 1-8) about myself in the portal at the following moment				
	19. Directly when available	10	19	71
	20. After my physician discussed them with me	7	12	82
I would like to have the following communication options				
	21. With fellow patients	23	51	26
	22. With allied health professionals	20	41	39
	23. With my own physician	4	9	88
The following is important to me about patient portal safety				

Table 4.3: patient questionnaire (responses in percentages) (continued)

	Item	Disagree	Neutral	Agree
	24. Decide by myself about who gets access	7	8	85
	25. Secure access	4	5	91
I would like to give the following persons full access to my patient portal, besides myself				
	26. Partner	4	8	88
	27. Volunteer caregiver	35	35	30
	28. General practitioner	2	3	95
	29. Other physicians in hospital	4	10	86
I would like to give the following persons partial access to my patient portal, besides myself				
	30. Other physicians in hospital	3	8	89
	31. Other health care professionals	19	26	56
	32. Nurses	12	21	67
	33. Apothecary	12	20	69
The following is important to me about the patient portal access				
	34. Use it for clinic appointment preparation	4	16	81
	35. See what my physician writes about me	4	13	83
	36. Control my health care situation	3	14	83
	37. Use it as a reference after a clinic appointment	4	9	88
	38. I think it's my right to see my results and file	3	14	84
	39. Usage of plain language instead of physicians' jargon	5	14	81
	40. Information only opens after deliberately opening, not spontaneously	12	13	75
I have the following concerns about the patient portal				
	41. Worry when I see results before the clinic appointment with my physician	33	16	51
	42. Receive information I don't understand without my physician's help	25	15	60
	43. The clinic appointment is focused more on portal details, instead of a personal conversation with my physician	26	25	50
	44. My physician expects me to study my portal information before attending an appointment	26	18	56

remaining 45%, the majority preferred immediate access to information to access after an appointment with their physician (*P*=0.02).

Items 21 to 23: most patients were interested to contact their physician (88%) by the portal. Less than half of the patients would like to contact other patients or health care providers other than their own physician.

Items 24 to 33: almost all patients would like to decide by themselves who gets access to their portal. The patients varied in their preferences whom to provide access to their file. The great majority would like to give access to their partner, general practitioner and other physicians in the hospital. Patients were less interested to provide access to nurses, the pharmacist and allied health professionals and only 31% would like to give access to their volunteer caregiver.

Items 34 to 44: more than 75% of the patients agreed to the different motivations to use the patient portal. Also they would like physicians to use plain language instead of medical jargon. On the contrary, opinions were divided regarding possible concerns about the portal. Most noticeably, one third of the patients indicated that they would not be concerned about seeing their test results before the appointment with their physician, but more than half indicated that they would be concerned. Higher educated patients had less concerns than other patients, most pronounced in item 41 where almost half (48%) of the high educated patients disagreed as opposed to moderate (24%) and low (19%) educated patients.

Physician questionnaire

The results of the 3-category items are shown in table 4.4 and are described in summary below.

Table 4.4: physician questionnaire (response in percentages)

	Item	Disagree	Neutral	Agree
The following is important to me about patients accessing the portal				
	1. Patients study the portal information before attending an appointment	31	62	8
	2. Patients can see what we write about them	15	54	31
	3. Patients can have all results available to them	15	15	69
	4. Patients can use the portal as reference after an appointment	15	0	85

Table 4.4: physician questionnaire (response in percentages) (continued)

	Item	Disagree	Neutral	Agree
	5. It more actively involves patients with their treatment	0	23	77
	6. I think patients have the right to see their data	0	15	85
	7. Portal information is written in plain language without medical jargon	39	39	23
	8. Patients can only open information deliberately	0	15	85
	9. The information to patients only is available when results are definite	0	0	100
	10. The patient can not see information before an appointment with a physician	0	0	100
	11. The patient is able to contact the hospital more easy	15	31	54
	12. The patient is able to contact other patients	31	39	31
I worry about the following, when patients will use the patient portal				
	13. Patients get worried about accessing information before a physician appointment	0	8	92
	14. Patients obtain information they don't understand without the physicians' support	0	0	100
	15. The clinic appointment is focused more on portal details, instead of a personal conversation with the patient	8	15	77
	16. The patient might feel obligated to study the patient portal before an appointment	46	39	15
	17. The doctor-patient relationship might change	8	46	46
	18. My workload might increase	15	31	54
	19. I would get technical questions about the portal by patients	8	46	46
	20. I might not respond soon enough to digital conversations and therefore the patient relationship changes	8	39	54
	21. My schedule might have to change to account for patient portal activities	0	39	62

More than two thirds of the physicians acknowledged the importance of the ability for patients to access the portal to see test results, as a reference after an outpatient clinic appointment, to be more actively involved in their treatment and because they have the right to be able to access their patient file. They rarely agreed that patients would access

the portal to prepare for an outpatient clinic appointment (8% agree) or to see what the physicians write about them in the patient file (31% agree).

Nearly all physicians felt that information should only be available after deliberately opening it, that only definite results should be available and that results should only be available to patients after a visit with the physician. Less than half of the physicians thought it is important for patients to contact other patients with the portal and about half to contact the hospital more easily. Only one physician agreed to report in the patient file in plain language, without jargon.

Physicians were concerned that patients might be anxious by seeing results before meeting the physician (92%) or without further explanation by the physician (100%). They we also concerned that by using the patient portal, outpatient clinic visits would be more focused on discussing details and questions regarding available biomedical results than on personal conversation on values and preferences. About half of the physicians were concerned that the portal could change the doctor-patient relationship. Few were concerned that a patient would feel obliged to prepare the outpatient clinic appointment by studying the portal information. Finally, physicians were moderately concerned about several logistic and technical issues.

Discussion

Overview

In this questionnaire study we assessed the wishes, expectations and thoughts of patients with a haematologic malignancy and of their haematologists regarding electronic patient portals. Due to the widespread rise of eHealth, many health care providers are under pressure to offer access to these portals. Unfortunately, portal utilization by patients has been generally low and one of the proposed solutions is to use participatory design approaches.[5] Participation starts with exploring preferences. Advances are being made in the field of (haemato) oncology and our questionnaire study complements previous work that has mainly been small-scale research. The questionnaire was applied before the electronic patient portal was available in the hospital under study, which provided us with an unbiased opinion of these patients.

Main findings

Our study showed that more than 75% of patients were interested in being provided with various types of access and functionalities in an electronic patient portal. Nevertheless, at the same time patients' opinions differed on various topics: the provision of access to

the portal to other people, the role of the physician, possibilities for communication via the portal and timing of access. The physicians acknowledged a supporting role of the electronic patient portal, although they have some doubts and they still appreciate their own supporting role towards the patient.

Study results in perspective

Previous studies in lung cancer, breast cancer, haematology and colorectal cancer showed similar interest of patients to portals as in our study.[11,13,18,19] These studies were either small-scale or assessing only a limited amount of variables regarding electronic patient portals. Our study improves the scale and generalizability of these results.

Patients are clearly interested in using an electronic patient portal, but they vary in their individual preferences for practical use of the portal. Interestingly, these differences existed mostly throughout various subgroups of patients (age, gender, education), and less between these subgroups. A series of articles by Baudendistel and colleagues,[12-14] where 14 patients with a colorectal malignancy were interviewed in 3 focus groups, confirms this variety of wishes, expectations and thoughts regarding electronic patient portal usage. This suggests there is not just one way of designing a portal for all patients and demands for customisation and flexibility of both developers and users.

Both physicians and patients think an electronic patient portal can empower patients in their health care situation, but from different viewpoints. The physicians in our study believe that patients need their help and guidance in understanding the information that is accessible in the portal, and worry about anxiousness when patients see this information without their help. In the study by Baudendistel, health care professionals were also concerned about patients autonomously handling information.[14] This is in line with findings in non-oncologic populations.[5,6,21] Interestingly, a quarter to a third of our patients does not expect to be anxious. A French study showed no mean difference in anxiety when patients gained access to a paper based medical file.[20] An evaluation of a patient portal implementation in a Dutch academic patient population showed that a minority of patients indicated that they did not like to see results on beforehand and would even be anxious about it.[22] The impact for these patients seeing their results could be large. This supports the need for customisation and flexibility of portals.

Furthermore, most patients indicated they preferred a glossary of medical jargon and the use of plain language instead of jargon by physicians. On the contrary, the physicians did not think information should be written in plain language. In another study by Baudendistel patients also expressed their wishes for a glossary.[13] Yet two other studies showed that such a reference library was only seldom used in practice.[23,24] Having to

write all medical notes in plain language would be a radical change of practice, moreover it would probably increase workload, which could be undesirable. Therefore, this topic requires further elaboration.

Indeed, patient portal implementation can also change the daily workflow, and possible workload, for health care employees. In our study, most physicians worried that their workload would increase. Baudendistel showed that health care professionals worry about receiving more messages by patients, when they get unrestricted information access.[14] Post-implementation, a MyChart study showed that only 5% of the activities originating from patient-to-healthcare messages were handled by physicians while the largest part was handled by nurses.[25] Thus, implementing a portal with communication functionalities will challenge not only physicians, but may even have more impact on the workload of other health care providers.

The mainly collaborative desired role in decision-making of our patients is noticeable. Previous studies in haematology populations in Germany and Australia showed that patients were more passive towards this role.[26,27] Since shared decision-making has taken a rise in the past years, the results in our study might reflect a more active participation of patients in their healthcare management these days. Otherwise, the attitude of patients in different countries could differ. This might also influence eHealth preferences.

Finally, a small number of patients indicated that they did not have access to the Internet. So even in the current digital era, also these patients and their needs have to be taken into account.

Altogether, the above findings show that there is no 'one-size-fits-all' electronic patient portal. Since portal implementation is an intervention in daily clinical practice it requires an added value for patients and physicians to facilitate its actual adoption. A theoretical approach to further elaborate the added value is the capability approach, that states that people adopt an intervention when they perceive its empowerment.[28,29] The variability of answers to the questions that assessed the motivations to use the portal suggest that some patients perceive a different added value of a portal than others. In order, this may require different portal functionalities for different patients. For example, a patient that values a thorough preparation of a clinic visit may need to see certain results timely and complete. While another patient who is anxious to see results in advance and who values a possibility to easily contact the clinic with questions afterwards, may need an easy method to communicate with the clinic. Therefore, developing a portal sets the developer and health care provider up for challenges: offering a broad range of possibilities, changing the current practice workflow and workload, and exploring where

wishes and preferences meet the limit of current practice flexibility. This also means that expectations of users and professionals need to be managed, since not all expectations may be met.

Strengths and limitations

The underpinning of the patient questionnaire items by literature and qualitative data emphasizes the robustness of our data. Our study was conducted in a haematology patient population in the Netherlands. Our results are complementary to earlier studies in the oncology field that have reported similar findings, and therefore we expect them to be applicable in a broader population than only haematology patients. Due to our fairly large sample size, we have been able to show that even within a relatively homogenous patient population there is variance of preferences.

Although the use of a 5-point Likert scale might reduce choice stress, it can also lead to a ceiling effect. We experienced a ceiling effect (many 'complete agree' responses) mainly on the variety of items assessing preferences for access and functionalities. This could imply that patients very clearly want to have all these different options. However, a large American study evaluating MyChart has shown that most patients only use a selection.[24] Factor analysis revealed that the responses in these categories were determined by a common construct. Therefore, our data cannot discriminate between these preferences and we prefer to conclude that patients are interested to use portal accessibilities and functionalities in general. Possibly, a discrete choice experiment could help to discriminate if this is desired.

The items assessing the timing of access to information in the portal also support that comparing items with each other is complicated. Although we expected patients to prefer one of both options, more than half of the patients answered these items the same. This might implicate that there is no fixed preference of access timing for the different types of information as in items 1 to 8. Another possibility is that patients did not relate the items to each other, which makes comparison less possible.

Recommendations for practice

When health care providers are offering or planning to offer an electronic patient portal service, patients should be involved in the development, implementation and evaluation. Preferably different types of patients (acute and chronic care, cancer and non-cancer patients) should be involved.

Health care providers should also be involved in the development and implementation of the patient portal. Specifically, they can advice how the implementation of a patient

portal could supplement the existing health care practice. This could ensure the continuing, though changing way of health care providers' support to patients in the digital era.

The design of a portal should be customisable for each individual patient. Since patients will have different values and preferences, even within an apparently homogenous patient group as in our study, one should not limit the design of a patient portal to a single rigid format. This would make the portal more personal. For example, an introduction feature, exploring the individual patients' preferences when first accessing the portal, and enabling tailoring to the individual patient's needs, could be implemented. This would also require timely collaboration with information technology specialists to align the clinical wishes with technical availabilities.

Recommendations for academia

Future research should confirm whether the above mentioned recommendations increase patient related outcome measures like patient satisfaction, quality of life, portal usage and empowerment, or health care associated outcomes like therapy adherence.

Furthermore, the perceived added value of patient portals to patients with a hematologic malignancy can be further explored, for example by using qualitative research methods. This may provide better understanding of the response variability to our questionnaire and subsequently improve further patient-centred portal development.

Conclusions

Health care is continuously evolving and the digital revolution is an important development. Electronic patient portals are a major part of this. Our study shows that haematology patients are definitely open-minded to use an electronic patient portal. However, individual needs and preferences and the on-going involvement of health care providers urge portal developers to design these portals in a flexible, individualized way that fits various patient profiles. Our study results may help to develop more patient-centred portals with support from patients and physicians. Further research may focus on the perceived added value of patient portals and on the impact on patient related outcome measures of portal implementation.

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Appendices

Appendix A: interview guide.

Main questions (with suggestion topics if no discussion rises):

Where do you think of, when you hear about a 'patient portal'? (15 mins)

Do you have experience with using a patient portal in any other hospital? (5 mins)

What could a patient portal mean for you in practice? (20 mins)

Preparation for physician appointment

Better insight in health care situation

Practical issues

What information or functionality would you prefer in a portal? (20 mins)

Imaging

Lab results

Correspondence

Medical file

Medication

Questionnaires

Making appointments

Contact/communication

Email consults

Backup questions in case of extra time:

Do you have worries considering a portal

Anxiousness

Confrontation with disease

Privacy

Ambiguity when reading medical jargon

Who would you give access to your portal file?

Health care providers

Family

When would you like to see your results (e.g. lab)

Before or after clinic appointment

Influence on appointment preparation

What problems do you then expect?

Would you be disturbed by the use of medical jargon?

Appendix B: additional demographics

Table S1: Patient characteristics

Characteristic		Digital (%)	Paper (%)	All patients (%)
Gender				
	Male	70	58	64
	Female	30	42	36
Age				
	<40 years	6	4	5
	40-50 years	7	4	5
	50-60 years	29	18	24
	60-70 years	36	44	40
	70-80 years	21	22	21
	>80 years	2	7	5
Residence				
	Rural	43	46	45
	City	57	54	55
Highest education **				
	None	6	13	9
	LBO, VBO, VBMO	13	18	16
	MAVO	9	15	11
	MBO	24	21	22
	HAVO, VWO, WO propedeuse	8	3	6
	HBO, WO bachelor	26	26	26
	WO doctoral, master	16*	5*	11
Access to internet				
	Yes	95	91	93
	Only through others	3	4	3
	No	2	6	4
Working in healthcare				
	Yes	21	14	17
	No	79	86	83
Control Preferences Scale				
	Self	5	0	2
	Self, considering physician opinion	12	15	13

Table S1: Patient characteristics (continued)

Characteristic		Digital (%)	Paper (%)	All patients (%)
	Shared	62	56	59
	Physician, considering my opinion	15	22	19
	Physician	7	7	7

* statistic significant difference between both types of questionnaire
** education levels are in the Dutch language and are displayed from the lowest (no education) to the highest level (doctoral or master degree) downwards.

Appendix C: subgroups

For all items with statistical significance between the item responses between subgroups, frequencies are shown. All other items are not shown. Table S2 to S5 show these results for the categories with only 2 subgroup categories (binary subgroups). Table S6 and S7 show cross tables for the categories with 3 subgroup categories. For city/rural residence no significant differences were observed

Table S2: gender subgroups (response in percentages)

Item	Male			Female		
	Disagree	Neutral	Agree	Disagree	Neutral	Agree
30	4	5	91	1	15	84
43	32	27	41	14	23	63

Table S3: health care employment subgroups (response in percentages)

Item	Work(ed) in healthcare			Not work(ed) in healthcare		
	Disagree	Neutral	Agree	Disagree	Neutral	Agree
1	0	0	100	5	13	81
2	0	3	97	6	16	77
3	0	0	100	5	10	86
4	0	0	100	6	15	79
11	0	6	94	5	22	73
22	6	43	51	23	40	37
26	6	18	77	3	6	91
35	0	3	97	5	16	79
39	15	15	71	3	14	83

Table S4: questionnaire type subgroups (response in percentages)

Item	Paper questionnaire			Digital questionnaire		
	Disagree	Neutral	Agree	Disagree	Neutral	Agree
3	8	7	85	1	12	87
4	9	14	77	2	12	86
6	8	8	84	1	10	90
8	8	10	81	2	18	80
11	9	17	75	0	20	80
13	7	9	85	0	11	89

Table S4: questionnaire type subgroups (response in percentages) (continued)

Item	Paper questionnaire			Digital questionnaire		
	Disagree	Neutral	Agree	Disagree	Neutral	Agree
14	6	6	89	0	7	93
17	7	9	85	0	13	87
20	10	21	70	3	35	62
21	32	48	20	15	54	31
22	30	37	33	11	44	45
23	7	11	82	1	7	92
25	8	4	88	1	5	94
26	7	12	82	2	5	93
35	9	13	78	0	14	87
36	7	18	76	0	12	89
38	4	7	89	1	20	79

Table S5: age subgroups (response in percentages)

Item	<65 years old			65 years and older		
	Disagree	Neutral	Agree	Disagree	Neutral	Agree
13	1	7	93	6	15	80
17	1	15	84	6	7	88
25	1	5	94	8	5	87
27	42	33	24	25	38	38
35	1	13	86	8	14	78
39	3	20	77	8	7	85

Table S6: control preferences scale subgroup differences (response in percentages)

	Characteristic	Disagree	Neutral	Agree
Item 9				
	Autonomous*	22	7	70
	Collaborative*	5	17	78
	Passive	11	27	62
Item 11				
	Autonomous*^	7	0	93
	Collaborative*#	2	17	81
	Passive^#	6	31	63
Item 18				
	Autonomous*^	7	0	93

Table S6: control preferences scale subgroup differences (response in percentages) (continued)

	Characteristic	Disagree	Neutral	Agree
	Collaborative*#	1	16	83
	Passive^#	6	25	69
Item 24				
	Autonomous	3	10	86
	Collaborative*	6	3	92
	Passive*	13	15	73
Item 26				
	Autonomous*^	14	10	76
	Collaborative*	3	6	92
	Passive^	0	13	87
Item 44				
	Autonomous	25	11	64
	Collaborative*	25	26	50
	Passive*	30	7	63

*^# subgroups that statistically differ are marked in pairs.

Table S7: education subgroup differences (response in percentages)

	Characteristic	Disagree	Neutral	Agree
Item 1				
	Low*	7	20	73
	Moderate^	4	17	80
	High*^	3	3	94
Item 3				
	Low*	9	15	77
	Moderate^	2	13	85
	High*^	0	3	97
Item 4				
	Low*	6	18	77
	Moderate^	6	13	82
	High*^	0	6	94
Item 5				
	Low*	6	12	82
	Moderate	2	6	93
	High*	0	0	100
Item 6				
	Low*	6	18	77
	Moderate	4	6	91
	High*	1	4	94

Table S7: education subgroup differences (response in percentages) (continued)

	Characteristic	Disagree	Neutral	Agree
Item 8				
	Low*	8	25	67
	Moderate	4	13	83
	High*	1	7	92
Item 14				
	Low*	6	9	84
	Moderate	0	8	92
	High*	0	3	97
Item 30				
	Low*	3	15	82
	Moderate	4	6	90
	High*	1	1	97
Item 35				
	Low*	11	15	74
	Moderate	0	16	84
	High*	0	10	90
Item 36				
	Low*	8	17	76
	Moderate	0	16	84
	High*	0	12	88
Item 37				
	Low*	8	15	77
	Moderate	0	8	92
	High*	1	3	96
Item 39				
	Low	6	9	85
	Moderate*	0	8	92
	High*	7	23	70
Item 41				
	Low*	19	24	57
	Moderate^	24	12	65
	High*^	48	12	41
Item 43				
	Low*	12	31	57
	Moderate	25	23	52
	High*	35	23	42

*^ subgroups that statistically differ are marked in pairs.

CHAPTER 5

5

Rationale and development of an e-health application to deliver patient centered care during treatment for multiple myeloma: the MM E-coach.

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Abstract

Background: Patients with multiple myeloma (MM) increasingly face complicated treatment regimens. E-health may support patients and healthcare providers in enhancing a patient-centered healthcare approach. Therefore, we aimed to develop a multi-modality e-health application, assess the application for usability and end-user experiences and subsequently formulate additional requirements for improvement.

Methods: The application was developed following an iterative 'action-based' methodology using the design thinking approach. Key end users participated, and relevant stakeholders were consulted in the development process. First, the care pathway was evaluated, the focus of development was determined and a solution ideated during recurring multidisciplinary meetings. Second, a prototype was tested and improved. Third, a subsequent prototype was evaluated during a pilot study with patients and healthcare professionals on usability, usage and experiences.

Results: The multi-modality application, named the 'MM E-coach,' consisted of a newly developed medication module, patient reported outcome (PRO) questionnaire assessments, a messaging service, alerts, information provision and a personal care plan. The median system usability score was 60 on a scale of 0-100. Patients appreciated the medication overview, healthcare professionals appreciated the outpatient clinic preparation module and both appreciated the messaging service. Recommendations for improvement mostly revolved around the flexibility of functionalities and look and feel of the application.

Conclusion: The MM E-coach has the potential to provide patient-centered care by supporting patients and caregivers during MM treatment and is a promising application to be implemented in the MM care pathway. A randomized clinical trial was initiated to study its clinical effectiveness.

Introduction

Multiple myeloma (MM) is a blood cancer of monoclonal plasma cells that accumulate in the bone marrow and may be complicated by organ dysfunction, such as hypercalcemia, renal insufficiency, anemia and bone destruction. It accounts for 1% of neoplastic diseases and is the second most common hematological malignancy.[1] Over past decades, the survival of patients with MM has improved due to new treatments.[2] Current effective regimens combine three or four anti-myeloma drugs.[3-5] These drugs are applied in complicated treatment schedules, with concomitant drugs to prevent or treat infection, thrombosis, nausea and pain. Such treatment schedules may be difficult to understand for patients.[6] Furthermore, these new treatments have been investigated in randomized clinical trials, and most patients in the real-world setting are not considered eligible for such trials.[7] Therefore, experts agree that the applications of these new treatments in the real-world setting may be limited due to various patient-, treatment-, and disease-related factors.[8] They recommend patient-centered healthcare delivery,[9] where patient reported outcomes (PROs), such as symptom burden and side effects, and patient preferences may be considered, in addition to treatment effectiveness.[8] Besides the systematic collection of PROs and preferences, this implies offering personalized, accessible and flexible care to patients. In addition, due to COVID-19, remote consultation and treatment is recommended for the management of patients with MM.[10] Therefore, the care pathway for patients with MM receiving active treatment may benefit from electronic health (e-health) innovations to support patients and healthcare professionals.

E-health is the application of digital information and communication to support or improve health and healthcare.[11] By using real-time, dynamic technologies, e-health has the potential to improve patient-provider communication, to enhance symptom and toxicity assessments and to optimize patient engagement.[12] E-health is already frequently used in cancer care. We earlier concluded that patients with a hematologic malignancy are interested in using e-health applications.[13] Currently, e-health applications for cancer patients are numerous, using a variety of functions or modules.[12] In the context of patient-centered care, application modules may include the following: first, PRO assessments, including patient reported outcome and experience measures (PROMs and PREMs).[14-16] Digital PROMs may be included in the cancer care pathway for managing symptoms or side effects, and their use is associated with improved survival and quality of life and a reduction of emergency room visits,[14,17] as well as measurement of PREMs may provide insight into care delivery and help to improve care[18,19]; second, communication systems between patients and/or healthcare providers[20]; third, intervention modules aiming to influence behavior or empower patients, such as applica-

tions aiming to improve medication adherence[21,22]; and finally, modules may include education, aiming to improve the knowledge of patients.[15,16]

Unfortunately, there seems to be a gap between research and clinical reality for e-health applications.[23] For example, an e-health application for cancer survivors, which was developed based on patients' needs,[24] did not improve the primary outcome (patient activation) as expected, possibly due to selecting patients at a wrong time point.[25] Furthermore, most secondary outcomes, including tumor-specific symptoms, were not significantly different. This emphasizes the need for an added value of an innovation by end users.[13] This requires, besides a needs assessment, an iterative development process with end users to continuously check the intended effect.[26-29]

To address the care needs for patients with MM, we designed a project with the overall aim to improve care for patients with MM, collaborating with all relevant stakeholders. This project was based on a value based healthcare (VBHC) methodology, aiming to improve outcomes for patients with MM.[30] The VBHC project consisted of developing a new care pathway, an outcome set for patients with MM and an e-health application based on the needs and preferences of patients with MM and healthcare providers. In this study, we focus on the development of the e-health application by an iterative process with the participation of all relevant stakeholders.

The aim of the current study is threefold as follows: first, developing a multi-modality e-health application for patients with MM and their healthcare providers, aligning with the new MM care pathway; second, assessing the resulting application for usability and end-user experiences; and third, recommending additional requirements for improvement of the application.

Materials and methods

The study used an iterative 'action-based' methodology and followed the five-step process of the design thinking approach (i.e., empathize, define, ideate, prototype and test) (Figure 5.1).[26,31] The study was performed in recurrent development team meetings, with the final two steps during a pilot study. Additional meetings to design a new MM care pathway and outcome set occurred parallel to the development meetings. Throughout the study, the intended end users (patients, hematologists, and nurse practitioners) and clinical pharmacists actively participated in the application design (co-creation) and additional stakeholders were consulted in a dynamic development process.[32] Figure 5.2 provides an overview of participation for the most relevant stakeholders at each devel-

opment step.[33] Sananet Care B.V, a Dutch e-health development company, performed technical development support.

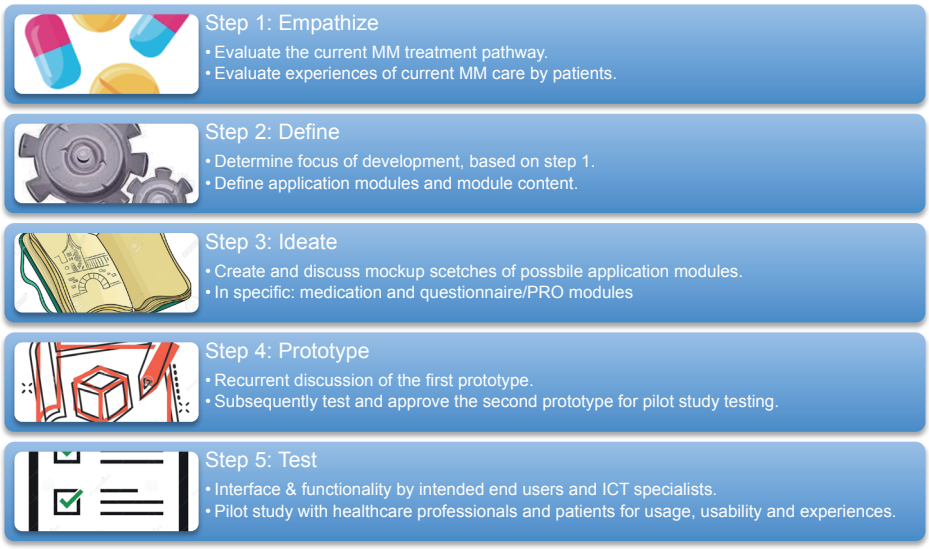

Figure 5.1: *The five-step development process of design thinking.*

	Step 1: Empathize	Step 2: Define	Step 3: Ideate	Step 4 and 5: Prototype & Testing
Control / Direction	Ph NP Pc	Ph NP Pc	Ph NP Pc	Ph NP Pc
Partnership	Dv	Dv	Dv	Pt Dv
Advising	Pt			ICT
Consultating	O	Pt	ICT	
Informing	ICT	O ICT	Pt O	O

Stakeholders:

Patient	Pt	Pharmacist	Pc	Nurse Practitioner	NP
ICT	ICT	Physician	Ph	Developer	Dv
Others	O				

Figure 5.2: *Participation matrix. The columns represent the five steps of the design thinking approach (steps 4 and 5 are depicted in one column), and the rows represent the five ascending levels of stakeholder participation.*

Setting

The study was performed in a large non-academic hospital in the Netherlands, treating about 50 patients with newly diagnosed MM each year. In the MM care pathway, seven hematologists and four nurse practitioners provided care, in collaboration with hospital pharmacists, clinical ward professionals and outpatient daycare clinic professionals. All treatment schedules were applied, including autologous stem cell transplantation,

following MM treatment guidelines (https://hovon.nl/en/treatment-guidelines/myeloma). The hematologist and nurse practitioner performed diagnostics, pre-treatment evaluation and provided information to patients. Oral medication was provided by the pharmacy directly to the patients with instructions. Subcutaneous or intravenous medication was prepared by the pharmacy, distributed to the daycare clinic or clinical ward and administered by oncology nurses. Oncology nurses also administered some medications at home, mostly the medications that were administered subcutaneously. Before each subsequent treatment course, the hematologist performed an outpatient clinic evaluation, including laboratory evaluation and assessment of symptoms or side effects. The nurse practitioner performed periodic well-being assessments and provided supportive care. Between visits, patients could e-mail or call the nurse practitioner or hematologist. For acute health issues, patients were referred to the emergency department or for an outpatient clinic visit.

Steps 1 to 3: empathize, define and ideate

Participants

At the start of the project, all relevant stakeholders involved in the MM care pathway were identified. Representatives of each stakeholder category were invited to participate in the development team by purposive sampling, based on motivation to participate in this project. The development team consisted of two physicians, two nurse practitioners, three pharmacists, a manager, a secretary, a data manager, a quality and innovation department delegate, an information and communication technology (ICT) delegate, two developer employees and a representative of the sponsor. Additionally, three patients with MM and their spouses were invited by convenience sampling.

Procedures

The first three steps were performed during several development meetings. The development team attended all meetings, and the patients and their spouses attended the third meeting. Between and following the meetings, smaller subgroup meetings were organized to elaborate on specific subjects, if needed. The development team also attended the parallel care pathway and outcome set development meetings.

At step 1, empathize, the following information was discussed with the development team: first, a detailed description of the current MM care pathway and second, results of a survey amongst 18 patients with MM, exploring the current experience with care delivery and the needs for improvement. The team agreed on the ideal care pathway by consensus, aiming to provide more patient-centered care. It included integrating an e-health application.

At step 2, define, joint aims and targets were set to determine the focus of development for the e-health application. At this point, the patients and their spouses participated. The team agreed on the desired application modules and content, aligning with the care pathway. The content was also based on the MM outcome set, which was defined by discussing known clinical and patient reported outcomes and a second survey, evaluating current symptoms amongst the 18 patients with MM.

At step 3, ideate, mockup display sketches of the intended application modules were recurrently performed, discussed and optimized among the development team.

Data and analysis

The project manager gathered the data of the development meetings using detailed written summaries. For each subsequent meeting, the summary of the previous meeting was member-checked by the attendees. The summaries were analyzed with content analysis.[34]

Steps 4 and 5: prototype and test

Participants

Four healthcare professionals from the development team (one physician, two nurse practitioners and one pharmacist) and ICT specialists tested the first prototype. The second prototype was tested in a pilot study, including patients and healthcare professionals. Hematologists, nurse practitioners and pharmacists, including those participating in the development team, were approached to participate using purposive sampling. They were involved in MM care and open minded towards innovations. Patients were recruited from the outpatient clinic of the participating hematologists by convenience sampling. Patients 18 years and older receiving treatment for MM according to the International Myeloma Working Group (IMWG) criteria[35] were eligible for inclusion. Exclusion criteria were mental or physical illness requiring clinical admission and lack of wi-fi Internet access. We aimed to include two hematologists, one pharmacist, four nurse practitioners and 20 patients.

Procedures

Prototyping and testing were performed in an iterative manner. The first prototype was assessed for content, interface, comprehensibility, functionality/navigation and usefulness for practice on various devices with test patient cases. Requirements for further development were then provided and performed by the developer. Subsequently, additional verification was performed on these improvements and the development team approved the second prototype for the pilot study.

The second prototype was pilot tested from June 2020 until August 2020, evaluating usage, usability and experiences. The healthcare providers received training from the developer of the application. Patients were asked for informed consent by the hematologist and screened on minimal digital skills and understanding of Dutch language. Then, a nurse practitioner attended participating patients at home for a short introduction of the study and the application. The nurse practitioner also handed the patient a tablet for the study period with access to the e-health application and a video consultation application. Patients received a unique username and password and filled out the first periodic PRO questionnaire during the visit. Subsequently, patients used the application for 8 weeks, during which care was provided following the new care pathway, including the application. This also included more intensive collaboration between the hematology and pharmacy departments.

The results of the pilot study were evaluated during a 2-hour session with the development team, with the exception of patient representatives. Due to the COVID-19 pandemic, patients could not attend the evaluation meeting. During this meeting, the participants agreed on the priority of possible improvements for the application, rating them as 'need to have,' 'nice to have' or 'not necessary.' Patients were sent the results by post, including a form to provide additional feedback and the possibility to elaborate by phone. All patients provided written feedback, and two patients were additionally interviewed by phone. The development team combined the patient feedback with the other feedback and made a list of required improvements for further development.

Data and analysis

The participants provided remarks point by point for each module of the first prototype to the project manager, who made a structured report of all gathered remarks. The report was member-checked by all participants and subsequently analyzed with content analysis.

During the pilot study, usability was evaluated with patients at t=0 (baseline at entry) and t=1 (end of study at 8 weeks) with the system usability scale (SUS).[36] This is a validated 10-item questionnaire covering learnability and satisfaction.[37] The score was calculated on a scale of 0-100, where 100 reflects highest usability. A mean score of 70 is associated with good user-friendliness.[38] The baseline measurement (t=0) was used as a measure for patients' expectations and the t=1 measurement evaluated actual use. Healthcare professionals received a self-developed questionnaire with the following items: ease of use, user satisfaction, functionality, time efficiency, patient feedback, diversity and technical complaints. Additionally, the developer collected the data for usage activities on the application. At the end of the pilot study, an overview was provided including the

usage frequencies of all modules. Data were analyzed by descriptive statistics (medians and frequencies) using SPSS (IBM Corp SPSS Statistics, version 26. Armonk, NY).

Besides usability and usage, qualitative experiences with the application were evaluated. During the pilot study, the participating healthcare professionals filled out 'case forms' when they provided care as a result of using the application. The professional indicated if and how care provision was different from normal care. The case forms were discussed during weekly meetings with the participating healthcare professionals, summarized and provided with comments. Furthermore, patients and healthcare professionals were asked to submit any relevant experiences with the application or recommendations to improve it during the 8-week study period. During the final study evaluation, minutes were written, summarizing the discussion and the final recommendation of each suggested improvement. The phone interviews with patients were summarized with notes. All collected qualitative data were collected by the project manager and analyzed using content analysis. This information was summarized into one list with recommendations.

Trustworthiness

To secure credibility, the empathize step was performed for prolonged engagement and the iterative process for persistent observation. We included researchers with different backgrounds and various stakeholders in the development team (peer debriefing) and used the mixed methods methodology for different perspectives (investigator, data and source triangulation). The evaluation with feedback at the end of the study provided a member check of the final recommendations. The meeting and evaluation summaries were stored and available for review afterwards. To secure transferability, the development team and study setting were extensively described and example figures of the development steps were included in the results.

Ethics

The Medical Research Ethics Committee (METC) of Isala Klinieken approved the study, waiving the requirement for obtaining informed consent (local METC number 200324).

Results

First, we provide a summary of the results of development steps 1 to 3. Then, we describe the development and testing of the first and second prototypes in detail.

Steps 1 to 3: empathize, define and ideate

At the first step, empathize, the care pathway was evaluated. It consisted of a diagnostic, treatment and follow-up phase. With regard to the e-health application, the development team focused on the treatment phase. Here, a patient encountered many medical investigations, visits and medication prescriptions. This required elaborate logistics and information exchange that was mostly organized following hospital logistics. Most actions took place in the hospital at the outpatient clinic, the daycare clinic and the pharmacy. Usually, patients only attended the clinical ward when experiencing severe side effects or complications. A new care pathway integrated several services and was designed more at the convenience of patients. Additionally, the development team created an outcome set, including medical and patient reported outcomes (PROMS and PREMS).

At development step 2, define, the team agreed on six aims and targets that were used as starting principles for the design and development of the e-health application. The first aim was providing treatment and support at home when possible and in accordance with the wishes of patients. The second aim was providing personalized medication overview and support. The third aim was optimizing therapy adherence, including side effect management. The fourth aim was optimizing quality of life. The fifth aim was optimizing patient safety. The final (sixth) aim was improving progression free survival. Based on these principles, the application modules were defined (Table 5.1).

Table 5.1: MM E-coach module overview.

Module	Description	Use
Medication	1. Information and overview of MM medication dose, frequency, and time. 2. Therapy adherence tool with reminders and medication dose registration.	Continuously during treatment.
Outpatient visit preparation	Practical information. Questionnaire with pain, fatigue, shortness of breath, frailty, and neuropathy. An open question: "What do you want to discuss with your hematologist/nurse?"	One week before outpatient clinic visit.
Periodic assessment	Patient reported outcomes.	Every 3 months.
Ad hoc complaint	Ad hoc complaint form with automated advice algorithm.	Continuously available.
Messaging service	Bilateral messaging service with healthcare provider.	Continuously available, reply during weekdays.
Alerts	Algorithm detecting severe complaints or side effects based on 'red flag' thresholds, warning patient and healthcare provider to engage (immediate) contact.	Continuously available for patients, check and reply by provider during weekdays.
Information	Information about MM, linked to healthcare provider website.	Continuously available.
Personal care plan	Overview of disease activity in time.	Continuously available.

At step 3, the application modules were ideated. For example a medication module interface was recurrently reviewed (Figure 5.3). Furthermore, PRO questionnaire algorithms were built, asking tailored follow-up questions depending on earlier answers. For example, when patients indicated not having pain, no follow-up about pain would be asked.

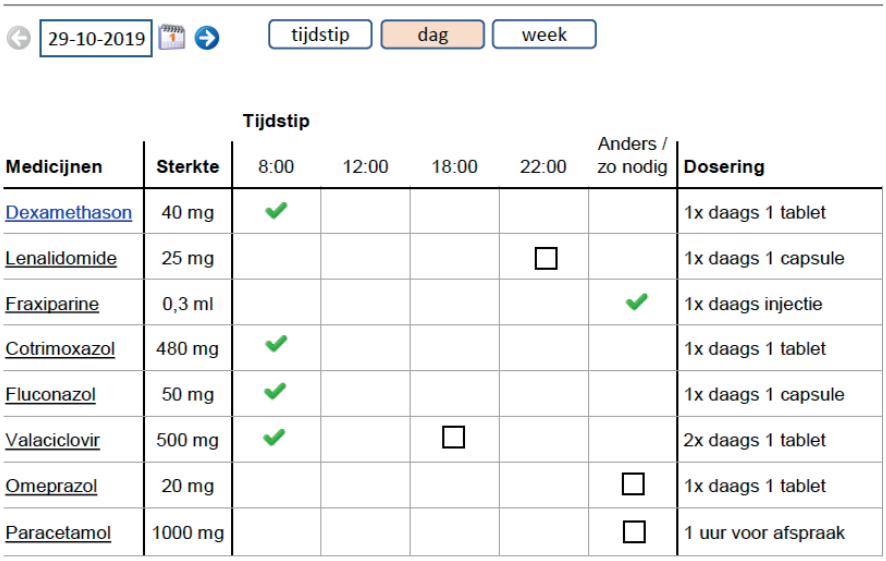

***Figure 5.3**: Medication module mockup.*

Steps 4 and 5: prototype and test iteration 1

The first prototype consisted of all modules as described above, albeit in a simple test layout. Testing generated 81 feedback items with requirements for improvement. These are summarized by category in Table 5.2. Most concerned small interface or functional items, such as "Two icons were depicted on top of each other instead of next to each other." However, some items concerned the algorithm behind the application (e.g., "When I answer that I have taken medication for pain, it does not ask me what medication.").

Steps 4 and 5: prototype and test iteration 2

The second prototype was a web-based application called the 'MM E-coach' that was available on multiple devices, including mobile devices. It required a personal login protected by a secure link with two-way verification. The patient version was used as a stand-alone program (Figure 5.4, index overview). The healthcare provider version was also partially integrated in the electronic health record program (HiX 6.1, Chipsoft).

Patients and healthcare providers received a manual and on-demand technical support from the development company. The MM E-coach included eight modules (Table 1).

Table 5.2: Feedback for improvement of prototype 1, categorized.

Category
Bugs (functionality and interface)
Differences between web-based and mobile device application version
Missing functionalities
Navigation issues
Language/textual problems
Missing content
Error in content (algorithm and information)

***Figure 5.4**: MM E-coach index for patients.*

Module 1: Medication module. It provides a daily overview of prescribed medication (Figure 5.5). For each available treatment course, a template was made, including the anti-myeloma medication and concomitant medication. The patient can register medication intake (Figure 5.6). The healthcare provider can view a daily, weekly or therapy course medication overview, including the registration of the patient to assess therapy adherence.

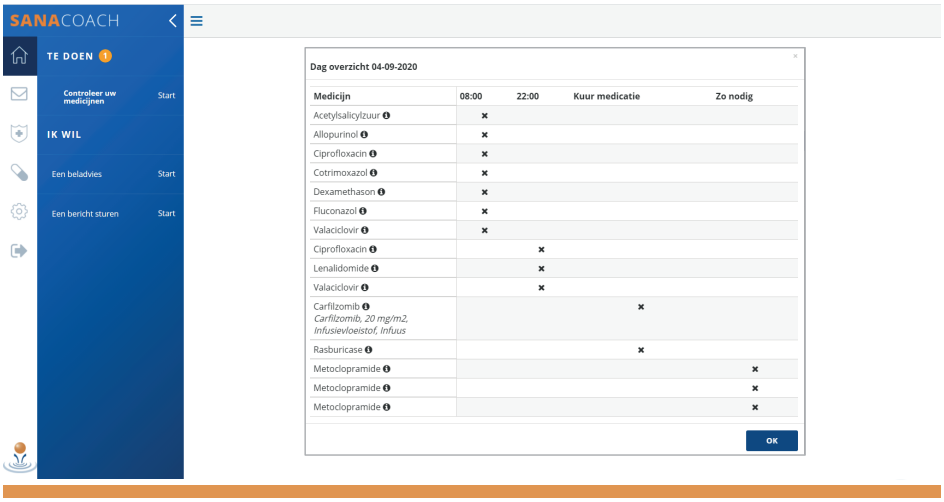

Figure 5.5: Medication overview of one of the treatment schedules (KRd; carfilzomib/lenalidomide/dexamethasone and co-medication)

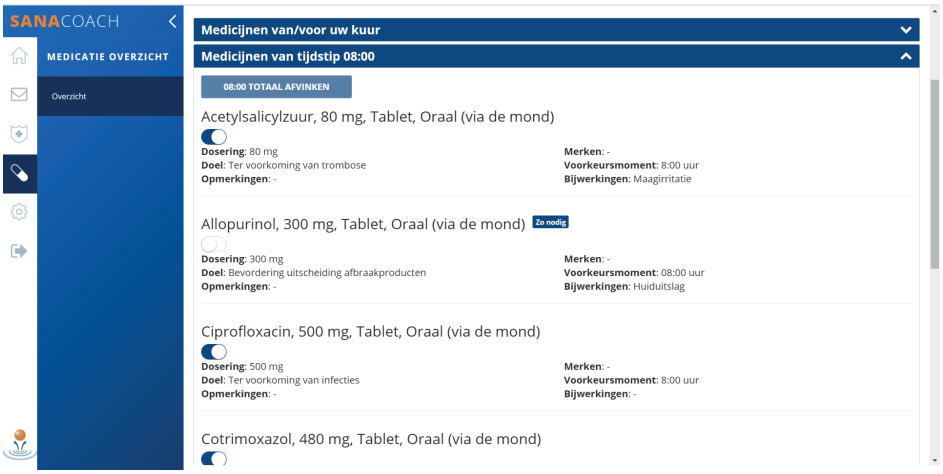

Figure 5.6: Medication registration page.

Module 2: Outpatient visit preparation. The patient is requested to complete a short questionnaire 1 week before each visit, including a blank space to inform the healthcare provider what the patient would like to discuss (Figure 5.7). This questionnaire was based on the most important items determined during discussion of the symptom questionnaire with patients and healthcare providers. The patient and healthcare provider can evaluate short-term well-being and decide what may (not) be discussed during the consultation. This may individualize the consultation and put the patient more in the lead.

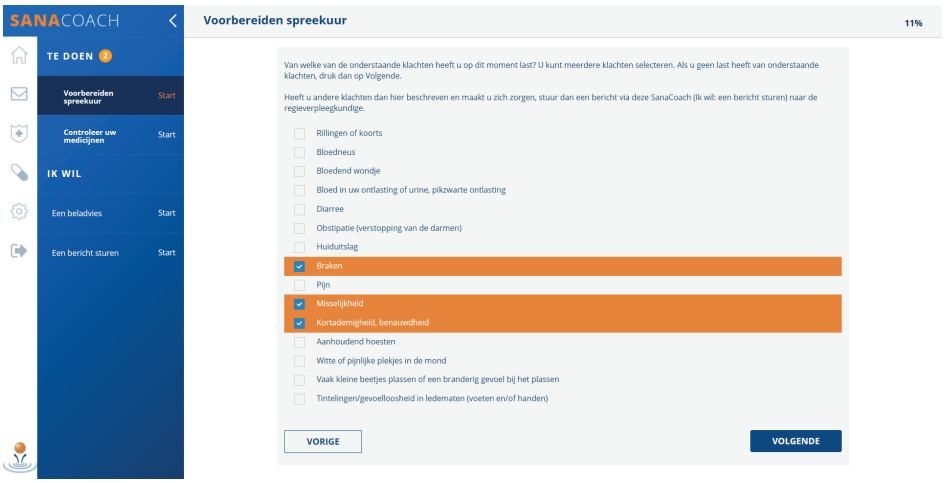

Figure 5.7: Outpatient visit preparation questionnaire (not showing blank space).

Module 3: Periodic assessment. The patient is requested to complete a more elaborate periodic questionnaire, including PROMS and PREMS (Figure 5.8 and 5.9). This questionnaire was based on the MM outcome set that included, amongst other aspects, validated questionnaires assessing quality of life (EORTC QLQ-30 (39) and EQ-5D-5L (40)) and therapy adherence (MARS-5 (41)). The frequency may vary based on local preferences. The patient and healthcare provider can evaluate long-term well-being, aiming to comply with personal treatment goals. Besides intra-individual evaluation, aggregated patient data may be benchmarked for quality assessment and improvement.

Module 4: Ad hoc complaint. It allows a patient to report a complaint or side effect at any time (Figure 5.10). An algorithm with thresholds (settings according to local protocol) provides the patient with advice or notifies the patient to (immediately) contact the healthcare provider.

Module 5: Messaging service. It enables patients and healthcare providers to ask and reply to questions at a moment of convenience. A disclaimer indicates the usual time

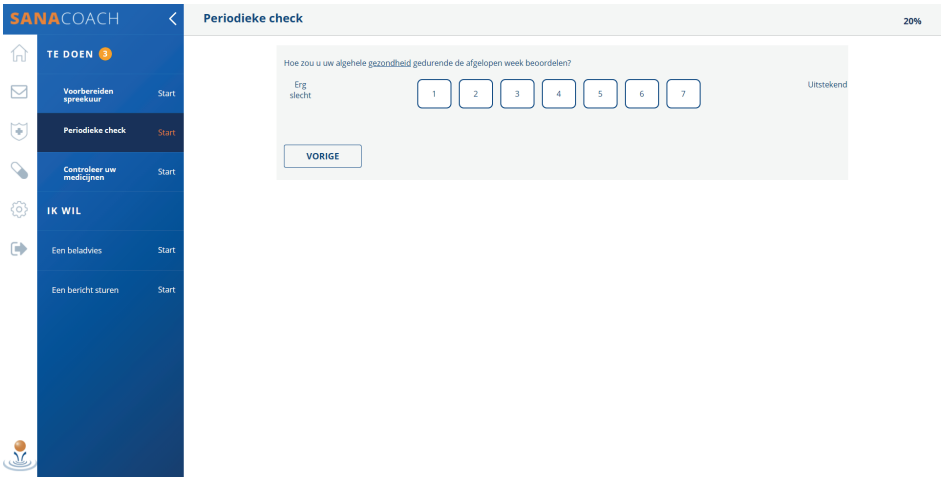

Figure 5.8: Periodic assessment, one question example.

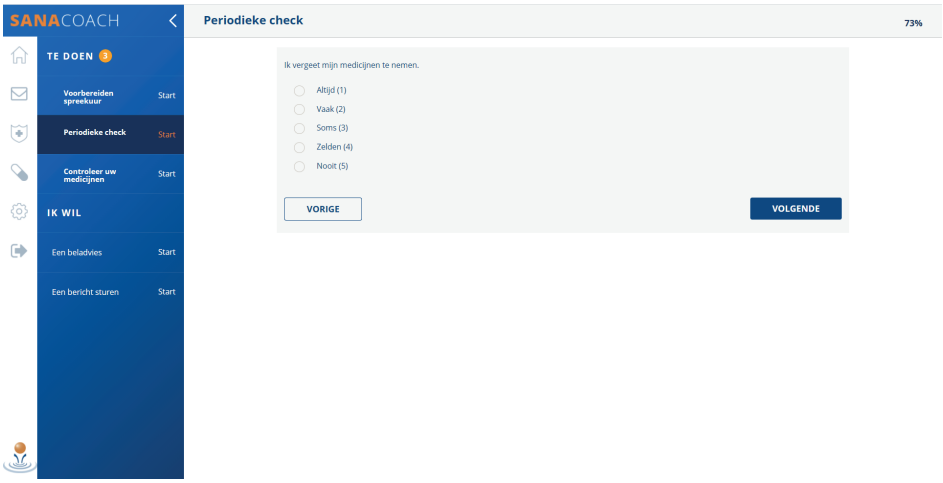

Figure 5.9: Periodic assessment, one question example.

to a reply from the healthcare professional (in our clinic < 24 h during weekdays) and advises patients to directly contact the clinic for emergency situations.

Module 6: Alerts. It notifies the patient to (immediately) contact the healthcare provider, based on thresholds for the periodic check and visit questionnaire items (Figure 5.11). It also generates an alert for the healthcare providers, appearing in the messaging service inbox with a red icon.

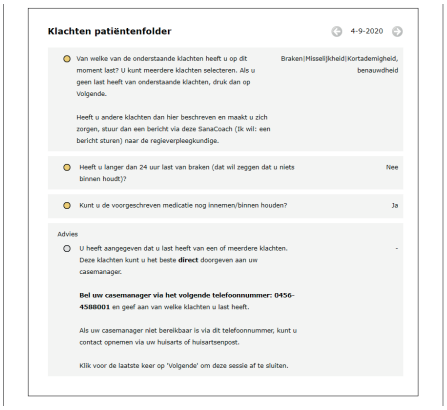

Figure 5.10: Ad hoc complaint form completed, followed by advice.

Figure 5.11: Healthcare providers' alert list, including one active alert.

Module 7: Information. It provides a patient with information about the disease, therapy or general information (e.g., with treatment booklets or information about the clinic).

Module 8: Personal care plan. The patient and healthcare provider can summarize a personal care plan, including treatment goals.

Pilot study characteristics

In the pilot study, 20 patients, two hematologists, four nurse practitioners and one pharmacist were included. Two patients died early, which was unrelated to the use of the MM E-coach. Their data were incomplete and could not be evaluated. The median age of the remaining 18 patients was 63 years (range: 47 to 84 years). Fifteen patients

were male, and three patients were female. All patients received a second or later line of anti-myeloma therapy.

Pilot study usability and usage

The median SUS score by patients at t=1 was 60. At t=1, 83% of patients indicated being willing to continue using the MM E-coach. All 18 patients completed the first outpatient visit preparation questionnaire. The periodic PRO questionnaire completion percentages were 94% at t=0 and 72% at t=1. Fifteen patients (83%) used the messaging service, generating 101 messages (nearly seven messages per patient). The healthcare providers responded with 85 messages, mostly by nurse practitioners. Five patients used the ad hoc complaint module once. One patient was advised to immediately contact the healthcare provider by the alert module. The patients registered 47% of the expected medication intake.

Six healthcare providers completed the evaluation questionnaire. All agreed that the MM E-coach helped them performing their daily clinical work and provided insight into the well-being of patients. All thought the MM E-coach would fit into future healthcare. While the other five participants agreed, one participant disagreed that using the MM E-coach was more efficient than usual care.

Pilot study qualitative evaluation

A summary of the evaluation is provided in Table S1, and some highlights are described here. The patients appreciated the medication overview and the messaging service, with comments such as "It is easy to see whether I have taken my medication"; "I appreciate the daily medication overview"; and "Contacting is flexible and accessible." However, they also experienced various practical, technical and flexibility problems, with comments such as "I would like a function that reminds me when I have forgotten to take my medication"; "I would like to register taking multiple medications at one time instead of registering each medication separately"; and "I have to log in every time and would prefer it to be automatically."

The healthcare professionals also appreciated the messaging service and acknowledged the added value of the outpatient clinic preparation module, with comments such as "An accessible way getting into contact with patients" and "The module visualizes highlights and works properly." They also indicated several practical and technical problems, with comments such as "It takes a lot of time to enter the medication in the MM E-coach, it should feed automatically" and "The questionnaire outcomes are not so clear, I recommend a dashboard functionality."

List of requirements

Following the evaluation of the outcomes with the development team, a list formulated with 16 additional improvements to make the MM E-coach suitable for use in standard clinical practice (Table 5.3). Most concerned the medication module.

Table 5.3: List of requirements. Abbreviations: EHR, electronic health record; PRO, patient reported outcome.

Module	User	Requirement
Medication	Patient	Enable registering medication at a later moment.
Medication	Patient	Introduce optional push message alert, as reminder for medication.
Medication	Patient	Optimize medication registration, including: - early registration (when taken earlier) - late registration (when taken but not registered)
Medication	Both	Solve bugs in medication overview and add user-friendly functionalities.
Medication	Both	View medication in a separate tab.
Medication	Both	Automated medication feed from EHR.
Medication	Both	Add additional medication information.
Medication	Both	Distinguish standard and 'as needed' medication more clearly.
Medication	Professional	Optimize medication adjustments.
Medication	Professional	Change search engine when adding new medication, making it more intuitive.
Messaging	Both	Change the message order.
Alerts	Professional	Optimize alert triggers.
Periodic assessment	Both	Create a dashboard to view PROs.
Visit preparation	Professional	Automated appointment feed from EHR with questionnaire trigger.
-	Professional	Add functionality 'Burden of disease registry.'
-	Patient	Several changes to the user manual for patients.

Discussion

In this study, we developed a multi-modality e-health application for patients with MM and their healthcare providers—the MM E-coach. The MM E-coach was developed together with the intended end users and several relevant stakeholders. The MM E-coach consists of eight modules, with a medication module that aims to make medication management more patient-centered. We assessed the MM E-coach for usage, usability and experiences and formulated additional requirements before actual use in practice. The patients acknowledged the medication overview and the messaging service as an added value to usual care. The healthcare providers acknowledged the outpatient clinic preparation module and being able to act early on patient reported symptoms or side

effects. All study participants provided useful recommendations to improve the MM E-coach.

An important aspect of the MM E-coach is the addition of a medication module, originating from participation of the pharmacy in the care pathway. We aimed to 'provide personalized medication overview and support,' as this reflected a need from the development team. This need aligns with observations from a study with patients receiving immunomodulatory drugs (IMIDs). Here, 25% of patients with MM rated the IMID dosing schedule as complicated and 17% of patients were not able to name the IMID correctly.[6] While many stand-alone mobile applications exist for medication management,[21,22] the integration of a medication module into an e-health application is novel. The medication module was supported by an integrated care approach, for example, by symptom and side effect reporting and low-threshold contact with the nurse practitioner. The patients in our study indeed acknowledged receiving medication overview and support. They also provided several recommendations to improve the medication module.

In addition to addressing the abovementioned need, the impact of the MM E-coach on therapy adherence may be interesting. Knowledge about therapy adherence in MM is limited and has mostly been studied in patients receiving IMIDs. Adherence seems to be high, although varying from 62% to 100% and using inconsistent measurement methods across studies.[6,42-46] Using the MM E-coach may, on the one hand, increase medication adherence, as patients are more actively involved with medication use. Professionals may then adjust medication prescriptions in line with patients' wishes and reported side effects. On the other hand, by empowering patients regarding knowledge of medication and awareness of side effects, using the MM E-coach may result in more autonomous medication use by patients, less aligning with professionals' prescriptions. In our pilot study, the adherence according to the self-registration of patients was only 47%. However, this may have been due to imperfections in the application. Indeed, many evaluation issues and several recommendations for improvement regarded the medication module. Following subsequent improvements, the MM E-coach is currently being evaluated in a randomized controlled trial (EudraCT 2020-005267-31), including evaluation of subjective and objective medication adherence.

A second important aspect of the MM E-coach was the participation of various stakeholders at different levels during the development process, as depicted in the participation matrix in Figure 2. Arnstein divided participation into eight levels, and nowadays, it is usually divided into five levels: informing, consultation, advising, partnership and control.[33,47] Patients and professionals were included in our development team as the intended end users of the application. The professionals primarily controlled the de-

velopment process and the participation of patients varied, up to a partnership role in the pilot study. The active participation is also called 'co-creation.'[32] This 'collaborative knowledge generation by academics working alongside other stakeholders' is believed to result in significant societal impact, as opposed to classic knowledge translation research.[48] Additionally, the emphasis on patient participation in healthcare innovation aligns with the increased participation of patients in healthcare decision-making.[49,50] Sharing decisions may improve the appropriateness and subsequently the value of care for patients.[51,52]

However, co-creation is a wide construct and may still depict variable levels of participation.[27] The motive for participation may also vary, for example, being collaborative or activist.[53] Therefore, it is important to address stakeholder participation levels in healthcare innovations. We believe end users need to participate actively, as the successfulness of innovation depends on their participation.[28] However, leaving individuals other than researchers in control of the research process or when stakeholders participate at higher levels than needed, scientific independence may be at stake.[48] Here, science and quality improvement seem to touch upon each other. On the one hand, thorough scientific evaluation of healthcare innovation is needed. On the other hand, scientists should be aware of stakeholder participation and the clinical impact of their project.

Therefore, we provide several recommendations to consider when starting a healthcare innovation project, based on our experience and in addition to existing frameworks.[28] First, innovation could be inspired by (aggregated) PROs or supportive care needs.[54] Healthcare providers are increasingly collecting these outcomes, and they may provide a rational basis for innovation. Second, patients should participate throughout the innovation project, individually (acting as an end user) or collectively at the project design level by means of local patient panels or patient associations. The degree of stakeholder participation should be determined for each design step and might differ from consultation to a full co-creative role (partnership).[32] By using a participation matrix, participation can be negotiated, evaluated and improved.[33] Clinical impact and scientific integrity may both be addressed through a dialogue between researchers and stakeholders. Third, an effect evaluation should measure the impact of a healthcare innovation on medical outcomes, PROs and the congruence of healthcare delivery with the patients' needs. This may help to build scientific evidence for patient participation in healthcare innovation.

Methodological reflection

A strength of this study is the contextual, iterative development process, integrating an e-health application in a revised MM care pathway. The main goal of this method

is to close the gap between development and implementation, aiming to reach more clinical or societal impact of a healthcare innovation.[26,27,29] However, we did not use business modeling beforehand, as some e-health design approaches recommend.[27,28,55,56] This may further increase the chance of widespread implementation and subsequent societal impact. Following the pilot study, a business case is being discussed with the developer and healthcare insurance representatives.

In the pilot study, only patients receiving second or later lines of therapy were included. We considered them experienced with our care delivery and therefore capable of providing feedback on the application. However, the impact of MM diagnosis and earlier lines of therapy may differ from the impact of receiving later lines of therapy. Therefore, the care needs of these patient groups may differ and separate evaluation of the usability and usage of the MM E-coach is needed.

Future perspectives

The MM care pathway may differ between hospitals and they may use various electronic health records. We are currently evaluating an implementation support method to align with different care pathways and electronic health records. Efforts need to be made to standardize links between applications and electronic health records.

As technology, MM treatment, MM care delivery and society continuously change; supportive tools, such as the MM E-coach, need to be continuously evaluated and further developed. Furthermore, a digital application may not be suitable for every patient. Incidentally, patients do not have Internet access or may not be equipped to utilize and navigate on mobile devices.[13,57] Possible future steps may be evaluating and adapting the MM E-coach among patients with low digital (health) skills in other MM care situations, such as palliative care and in treatment care pathways for other (hemato-) oncologic diseases.

Conclusions

We developed a multi-modality e-health application, the MM E-coach, which has the potential to support patients and caregivers during MM treatment. Amongst the modalities is a novel medication module. Following adjustments in line with the recommendations in this study, continuous development is required to keep the MM E-coach in line with MM care demands. A randomized clinical trial is currently being conducted to evaluate the clinical efficacy of implementation of the MM E-coach in the multidisciplinary MM care pathway.

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Appendices

Table S1: Summary of qualitative evaluation. Sentences between " " indicate quotations, the other sentences are derived from minutes or notes.

	Patient	Healthcare provider
1. Medication module	"Useful to see wheter I've taken my medication." "Useful to have a day overview." "Useful information about the medication." "Other medication besides for MM needs to be in there." "Medication should be directly in the e-coach when the hematologist prescribes it." "I would like a medication intake reminder." "My medication is not always entered correct." "Medication registration does not always work." "I would like be able to register >24u after medication intake." "MedApp is more flexible." "Sometimes I cannot register all medication at one moment and have to perform this for each medication separately."	To enter medication manually is not safe. The workflow now needs to be aligned to the manual input of the medication. Manual input of the medication is time consuming. The medication buttons do not show fields that you would intuitively expect. A week overview would be handy.
2. Outpatient visit preparation	-	It provides insight into patients' performance status and neuropathy well. It works well, especially the blank space to inform us about important things that a patient would like to discuss.
3. Periodic assessment	-	The current display is not clear; we suggest a dashboard.
4. Ad hoc complaint	-	-
5. Messaging service	"Getting into contact is flexible and accessible." "I appreciate contacting my hematologist directly."	Quick signaling of problems. Accessible getting into contact. Easy to refer a patient without the need to find a moment for a phone call. Messages are depicted chronological instead of sorted by message.
6. Alerts	-	A urinary tract infection was noted and timely intervened. A patient was admitted on our request for dyspnea following a notification. Patient was timely provided with supportive medication for a side effect.
7. Information	-	Maybe information movies would add to the app.
8. Personal care plan	-	-

Table S1: Summary of qualitative evaluation. Sentences between " " indicate quotations, the other sentences are derived from minutes or notes. (continued)

	Patient	Healthcare provider
General	"Both on my iPad and my phone it works fine."	"This is not easy to work with for every person." "I have to login every time again, it does not remember me." "The app crashes sometimes." Patients may like to switch modules on or off depending on their wishes.

CHAPTER 6

6

General Discussion

Outline

In this chapter I repeat the study aim and research questions, followed by a short summary of the main results of the conducted studies. Then, I discuss several aspects of the thesis, comparing to recent literature. Subsequently, I reflect on the strengths and limitations of the thesis. Finally, I provide conclusions and recommendations.

In this thesis I aimed to contribute to sustainable implementation of patient-centered innovations in cancer care, by means of a critical assessment of current patient-centered innovations from a practice driven viewpoint. The projects were chosen based on relevance and actuality. Two projects about cancer care decision-making focused on patient centeredness in multidisciplinary teams (MDTs) and on shared decision-making (SDM). Two other projects regarded patient empowerment by electronic health applications, focusing on electronic patient portals (EPPs) and a multi-modality e-health application. The research questions were:

- What are the needs of MDT members for improvement of patient-centeredness in oncological MDT meetings and which strategies do they recommend to improve patient-centeredness in complex oncological MDT decision-making?
- What is the perception of SDM by patients with a hematologic malignancy and their physicians and what are possible areas for quality improvement regarding SDM in hematologic oncology?
- What are the wishes, expectations and thoughts of patients with a hematologic malignancy and their physicians with regard to an electronic patient portal?
- What is the optimal design of a multi-modality e-health application for patients with multiple myeloma (MM) and their health care providers, aligning with the MM care pathway?

Summary of the main findings

In **chapter 2**, we explored twenty-four cancer multidisciplinary team (MDT) members' perspectives on the need to improve patient-centeredness in complex decision-making, and subsequently, the strategies to enhance it. They voiced the need for additional information (patient-centered information, patients' needs and preferences, individualized medical information) during the MDT meeting, to be more patient-centered in the decision-making conversation with the patient following the meeting, and for more information following the meeting to support patient-centeredness. The most prominent strategies, mostly originating from the needs, were those aimed at collecting and using

patient-centered information, and to facilitate the decision-making conversation with the patient following the MDT meeting.

In **chapter 3** we explored to what extent elderly patients with a hematologic malignancy and their treating hematologists perceive shared decision-making (SDM), when they were recently involved in a preference sensitive decision. We also assessed which decision-making process steps and patient or professional characteristics influence the perceived level of SDM. Using questionnaires, we found that SDM perception of patients and hematologists seemed satisfactory, although the items regarding preference elicitation and deliberation were scored significantly lower than the other items. These items fit into the third step of SDM, 'preference talk', where the professional takes an explorative stance and tries to learn about the patient's preferences. Additionally, SDM was perceived less and decisional conflict more with/by patients above 75 years, patients discussing non-curative treatment and patients who encountered a hematologist in training.

In **chapter 4**, we explored wishes, expectations and thoughts of patients with a hematologic malignancy and their physicians with regard to the electronic patient portal, by using a questionnaire, based on insights from literature and a focus group discussion. Patients were interested in many different types of access to information and portal functionalities. However, their opinions varied about the provision of access to the portal to other people, the role of the physician, possibilities for communication via the portal and timing of access. Patients frequently expressed to be open about the potential of the patient portal to orchestrate their care. The physicians acknowledged the relevance of the electronic patient portal, but had some worries about the patients' autonomous information handling, organizational and technical issues. Most physicians appreciated their supporting role towards the patient.

In **chapter 5**, we developed a multi-modality e-health application, following an iterative 'action-based' methodology. Key end-users and relevant stakeholders participated in the development process. First, the care pathway was evaluated, the focus of development was determined and a solution ideated during recurring multidisciplinary meetings. Second, a prototype was assessed for content, interface, comprehensibility, functionality/navigation and usefulness for practice, and was then improved. Third, a subsequent prototype was evaluated during a pilot study with patients and healthcare professionals on usability, usage and end-user experiences. The multi-modality application consisted of a newly developed medication module, patient reported outcomes (PRO) questionnaire assessments, a messaging service, alerts, information provision and a personal care plan. The median system usability score was 60 on a scale of 0-100, slightly below

the score that is associated with good user-friendliness. Patients appreciated the medication overview, healthcare professionals the outpatient clinic preparation module and both appreciated the messaging service. Subsequently, additional requirements for improvement were formulated and mostly revolved around flexibility of functionalities and look and feel of the application.

Discussion of the study findings

In this section I will discuss several findings in this thesis, in relation to the decision making continuum, using the appropriate information and the implementation of interventions.

Decision making continuum

In the first part of this thesis, we focused on SDM and the MDT as important steps in cancer care decision-making. In both approaches, decision-making revolved around patients' values, preferences and 'non-medical' aspects, such as psychosocial information. Indeed, treatment preferences may differ between patients and their healthcare providers[1] and preferences may differ between patients.[2] Furthermore, many physical, psychological, social and relational issues may impact treatment-related decision-making.[3, 4] This confirms the importance of these patient-centered approaches.

These approaches focus primarily on interactions of the patient with healthcare providers, such as the conversation between the physician and the patient. This implies a one-point event of SDM. However, the cancer care decision-making process not only takes place during but also outside the clinical encounter.[5, 6] The patient seeks for information, interacts with loved ones and fulfills a role in society. The patient may wish to discuss information with healthcare providers, but also with family, fellow patients or other important people in his or her life.[7] In addition, patients' goals or preferences may vary over time.[8, 9] Moreover, the same applies to a healthcare professional, who interacts with colleagues and prepares a consultation, for example by self-study or during an MDTM. Therefore, in practice, cancer care decision-making is a continuous process involving various decisional moments, different healthcare providers and relatives.[5, 10]

This requires additional considerations with regard to our findings. Instead of focusing on SDM and the MDT as key decisional moments, patient-centered innovations could address or keep in mind the decision-making continuum. In **chapter 2**, we focused on the MDT as a starting point to improve patient-centeredness, resulting in several strategies aiming to 'connect' the patient decision-making process with the MDTM. Al-

ternatively, looking from a service perspective,[10] the MDT may be considered as one of the contributions to the patient's decision-making journey. This may imply a reconsideration of the goal of a MDT discussion: what do the patient and the physician want to ask the MDT, to inform their decision-making process? The patient and physician could then provide the MDT with the relevant information to answer this question. The MDT could provide the patient and the physician with the information or advice that would help them making shared decisions. We did not investigate this particular matter in this thesis. Nevertheless, these considerations may emphasize the recommended strategies aiming to optimize information transfer from and to the MDT meeting. Another option, in line with these considerations, could be patient attendance, although the professionals in our study opposed to this strategy. Others have evaluated patient attendance during breast or gynecological cancer MDTMs. The great majority (86%) of patients had the opportunity to express their opinion during the MTDM, however only 61% reported having been involved in the treatment decision made in the MDTM.[11] It seems that the implementation of this strategy is variable and may only be feasible for a (yet to be determined) selection of patients.[11, 12]

In **chapter 3**, we explicitly focused on one preference sensitive decision, resulting in a recommendation to focus on preference talk, for example by supporting patients with decision aids. Indeed, a decision aid may prepare patients and their family before clinical encounters and provide additional information and considerations following encounters. However, decision aids usually do not provide 'longitudinal' decision support for patients and healthcare providers, possibly requiring iterative agreement upon decisional roles, information needs and treatment preferences. In other words, supportive tools may need to support patients with the decision-making process, instead of only supporting one decision. Here, amongst others, the role of e-health may be interesting, as greater perceived e-health literacy is positively associated with SDM perception.[13] Furthermore, electronic patient portal implementation is positively associated with psycho-behavioral outcomes, such as patient knowledge, self-efficacy and decision-making.[14] The continuous decision-making process may be supported with e-health tools. For example, the patient may inform the physician before a clinical encounter by filling out a patient reported outcome measure (PROM) questionnaire in an e-health application. Patients and healthcare providers may communicate between consultations using digital services. Patients may determine their treatment goals at home and communicate them to their physicians, for example by providing access to their personal health records. This might reflect the supportive role of e-health to empower patients with regard to decision-making. However, the aforementioned associations may also reflect the willingness and/or capability of a group of patients with adequate (digital)

health skills to engage in their care, including using e-health. Future research may investigate the possible causal relationship between e-health and SDM uptake.

Using the appropriate information

Reconsidering how to support patients with decision-making may also require a reconsideration of the information that we use to make a decision. Nowadays, patients suffering from cancer are being offered treatments, based on results from clinical trials. These trials are powered on medical outcomes, usually progression free or overall survival. When they meet efficacy outcomes and when they are considered safe, mostly based on grade 3-5 adverse events, they are often approved by regulatory agencies and recommended in clinical practice guidelines. This method of proving treatment efficacy is called 'Evidence Based Medicine' (EBM) and we consider it as the optimal base for medical acting for already more than 30 years, predominantly based on medical information.[15]

However, this limited interpretation does not consider all EBM principles, including integrating scientific information with the experience of the clinician and the values of the patient.[16] As most patients would not be eligible for clinical trials, the results of clinical trials may not reflect real-world effectiveness.[17] Until recently, real-world evaluation of the effectiveness of care interventions on patient outcomes was not regular practice. Furthermore, survival data do not reflect the only outcome information patients would like to consider for decision-making. For example, first, elderly patients receiving hematopoietic stem cell transplantation have additional information needs, tailored to their situation, such as information about treatment burden, side effects and supportive care.[7] Second, tyrosine kinase treatment was more often stopped or dose adjustments were made in patients with chronic myeloid leukemia in a real world observation, in comparison to the pivotal clinical trials where the treatment indications are based on.[18] Third, recent studies confirm the ongoing limited availability and quality of psychosocial information, patient views and input of nurse specialists on MDTMs,[19, 20] while patients often experience great impact on their lives from treatment.[21] Finally, information needs and decision-making preferences vary among patients and may depend on patient characteristics such as educational level, gender or age.[2, 22] Considering this, we may use the wrong data – or use the data wrong - to support decision-making. First efforts are now being made to monitor the use and real world effectiveness of expensive medicines in hematology in the Netherlands.[23, 24] Furthermore, PROMS, that have ideally been co-created together with patients are being implemented in practice and clinical trials.[25]

Implementation of interventions

Considering the effort that is required to innovate patient-centered care delivery, the successful implementation of interventions is important. However, the implementation of the patient-centered interventions investigated in this thesis has recently been delayed or unsuccessful.[26-28] Many factors at different ecological levels are known to influence successful implementation.[28-32] Roughly, they may regard the innovation in question, the individual patient or healthcare professional, the healthcare organization and the healthcare system. In this thesis we mostly addressed the innovation in question and the individual patient or healthcare professional, often revolving around the individual participation of the most important stakeholders. I discuss additional implementation considerations with regard to the findings in this thesis about patient-centeredness in the MDT, SDM and e-health. Subsequently I discuss the role of collective stakeholder participation in research design.

The MDT professionals in **chapter 2** mostly recommended strategies transferring patient-centered actions 'outside' the MDT. This aligns with the finding that, despite an open attitude towards psychosocial aspects and patient preferences, MDT professionals may not be convinced that the MDTM is the best place to discuss this type of information.[31] This may result from the fact that in the early days the MDT was established primarily for organizational reasons and it was seen as a key development in the improvement of (medical) outcomes for patients.[33] More attention for patient-centeredness would therefore require acknowledgement of other outcomes and patient preferences, as discussed earlier. In the mean time, the strategies we reported may overcome the healthcare professional and organizational barriers to implement patient-centeredness in or around the MDT meeting. However, successful implementation of these strategies may also require confirmation by patients. In general, the implementation of patient-centeredness in the MDT may first require 're-conceptualization' of the aims and goals of cancer care, as the MDT could then serve as a means to reach these aims and goals.

Although the results in **chapter 3** pointed out that patients with a hematologic malignancy and their physicians perceive SDM satisfactorily, recent studies identified (shared) decision-making needs among patients with other types of cancer and their relatives.[34-36] Our results may indicate that these needs are not present within the studied population, however it is also known that SDM perception does not necessarily equal actual performed SDM behavior and a ceiling effect is often seen.[37] If the results would instead reflect skepticism or misinterpretation of the meaning of SDM, this may require SDM implementation strategies addressing patients and healthcare providers, as these may overcome skepticism and may help solidifying new SDM behaviors.[32] Although in the mean time some healthcare system factors have been addressed by legal and

reimbursement regulations, allowing to perform a double-length consultation,[38, 39] more information is still needed to address the patient and healthcare professional related factors. As our results pointed out, further exploration should especially pay attention to the preference talk phase of SDM, as room for improvement appeared most likely for that particular phase in SDM.

Several strategies are already available for e-health development and design, including addressing implementation issues.[40, 41] **Chapter 4 and 5** revealed that patients with a hematologic malignancy are interested in e-health innovations, but preferences vary (e.g. for functionalities or usage). Although healthcare providers were positive towards these innovations, they may also have initial skepticism. This emphasizes developing and evaluating e-health applications together with all relevant stakeholders, aiming to add value and align e-health with daily activities or workflow. This also includes taking into account limited (e-) health literacy.

This thesis addressed collective participation of stakeholders to a limited extent. The research topics were determined and the initial protocols were designed from an academic perspective. Due to my double role as investigator and practicing hematologist, I provided the research design with viewpoints from clinical practice of a hematologist, but not from the other stakeholders. Collective stakeholder participation, in terms of determining the research topics and protocol, may however be regarded as a means of addressing healthcare organization or system implementation factors: Stakeholders may participate in partnership or control in determining the research agenda and thus prioritizing relevant research projects from a societal perspective. However, this may require additional considerations, as scientific integrity may be under pressure when stakeholders participate in an improper way.[42] For example, first, it is well known that financial incentives may impact the delivery or uptake of care by healthcare providers and patients.[43, 44] Second, sponsorship of drug and device studies by the manufacturing company has been shown to relate to favorable efficacy results.[45] And finally the Dutch research agenda does not only reflect potential societal impact as the correlation between research volume and disease burden or healthcare costs is low.[46] The impact of collective stakeholder participation in research therefore needs further elucidation, also with regard to financial aspects.

Strengths and limitations

In this section I will reflect on the mixed methods study design, individual stakeholder participation, the study setting and on health literacy throughout this thesis.

Mixed methods study design

Strength in this thesis was using different methods to critically assess patient-centered innovations, tailored to the research question.[47] Depending on existing knowledge from literature, the research question and our resources, we applied qualitative, quantitative and a parallel or sequential combination of research methods: In **chapter 2**, we used interviews. In **chapter 3 and 4** we used questionnaires, in chapter 4 also based on a focus group interview. In **chapter 5** we mixed questionnaires and qualitative methods. The generally spoken explorative research questions were mostly assessed with qualitative methods, such as interviews and focus groups, trying to gain in-depth insights and understanding of a topic.[48] With regard to the general aim of this thesis, this helps understanding the underlying motivation of participants for a patient-centered innovation: *Why* does the innovation matter and *how* does it add value to the current delivery of care. Additionally we used quantitative questionnaire methods to determine the focus for further research or innovation from a population perspective: *what* are the possible areas for further exploration or for quality improvement? Using both methods combines both aspects: Exploring from a broad perspective, while going into depth when needed.

Individual stakeholder participation

Individual stakeholder participation varied between the studies in this thesis and involved, amongst others: Students, quality of care employees, information technology specialists, managers, secretaries and several healthcare professionals, such as physicians, pharmacists and nurse practitioners. Furthermore, patients participated during the studies, for example when the results were member checked and/or by the nature of the studies, that intended to learn about patients' needs and perceptions. Strength of this thesis was using 'practice-driven' approaches, including participation of these stakeholders, which may overcome several implementation barriers.[49, 50] For example, knowing about the healthcare professionals' needs for patient-centeredness in **chapter 2** may overcome their reluctance when strategies are proposed that match these needs. Comparably, the implementation of e-health applications may profit from participatory design.

The most extensive example of individual stakeholder participation in this thesis is the iterative participatory application development process in **chapter 5**. This may also be referred to as a 'co-creative' approach. Co-creation builds on the concept of collaboration between academics alongside other stakeholders and aims to close the gap between research and practice, thereby generating more clinical impact from research.[51, 52] The ladder of participation may be applied to determine and evaluate the level of (meaningful) participation for each involved stakeholder: informing, consultation, advising, partnership and control.[53, 54] The use of a participation matrix and participation evaluation may

help to optimize research design, improve transferability of results and optimize care delivery outcome and societal impact.[53] Therefore it is important to identify all involved stakeholders beforehand.[40, 51] In **chapter 5**, the healthcare professionals were in control of the research project, patients' participation varied from informing to partnership and the remaining stakeholders participated at lower levels. This resulted in an application that aligned with the care pathway and in several recommendations to optimize the application for clinical implementation. In the remaining chapters a participation evaluation was not part of the research project and could have optimized individual stakeholder participation.

Study setting

The aim of critical assessment of current patient-centered innovations subsequently resulted in various study settings, which can be looked upon as both strength and limitation. The MDT study regarded various types of cancer care teams, while the other studies focused on hematological malignancies. The e-health application study only regarded patients with MM. The studies were variably performed in an academic hospital, a non-academic hospital or both. The study results therefore regard diverse settings, which may impact the transferability of the results. Some considerations are given: First, the MDT improvement strategies may require an assessment of the local MDT situation and the most applicable strategies could be selected. Second, before implementing tools that support SDM, the local decision-making culture may need to be addressed to identify tools that best align. Third, the design of a patient portal may require identification of local information technology availability. Finally, the implementation of the MM e-health application modules and content may need to be adapted to applicable guidelines or the local context. In conclusion, our study results may be used to inform clinicians and policy makers, followed by subsequent transferability judgment before actual implementation.

Health literacy

Limited health literacy is prevalent in almost 25% of the Dutch population, also among higher educated people.[55] People with limited health literacy less frequently use e-health applications.[56] A limitation of this thesis is not addressing (digital) health literacy. For example by using questionnaires in **chapter 3 and 4** we may have excluded patients who cannot read or write sufficiently from our data collection. Additionally, patients with (very) limited digital health skills were excluded from the e-health application study and the usage evaluation did not include possible determinants of low usage, such as limited digital health skills. Furthermore, the investigated patient-centered healthcare innovations mostly comprised more patient participation, which may discourage patients with low confidence, motivation and social skills – also attributes of health literacy.[56]

The applicability of our results to patients with limited health literacy may therefore be limited. Future initiatives may consider including patients with limited health literacy in qualitative studies by purposive sampling methods; Design questionnaires with simple language, videos or pictograms; And may include patients with limited health literacy in e-health development teams.

Conclusion

The multidisciplinary team and the conversations between patients and physicians play an important role in the (continuous) process of cancer treatment decision-making. With this thesis I contributed to a better understanding of the needs and perceptions of multidisciplinary team and shared decision-making by patients and healthcare professionals, contributing to a patient-centered decision-making process. The empowerment of society due to the rise of digitalization requires evidence-based patient-directed cancer care innovations. I provided deeper insight into empowering patients with hematologic cancer by using electronic health innovations. The studies in this thesis have been small steps to overcome implementation barriers on the path towards a partnership between patients and physicians, optimizing healthcare delivery from a patient-centered perspective.

Recommendations for practice and policy

The findings of this thesis lead to the following recommendations:

- MDTs may reflect on their functioning, identify local needs for patient-centeredness, compare their setting to our study setting and consider implementing some of the recommended strategies in their care. Although some strategies were quite specific and may require local adaptations, the underlying aim should include the transfer of patient-centered information between the patient and the MDT meeting.
- Hematologists that wish to practice SDM may focus on the aspect of 'preference talk', as essential part of SDM: taking an explorative stance by active listening and trying to learn about the patient's preferences towards medical options. Awareness may be required when facing a situation including a patient receiving treatment with palliative intention, the most elderly patients or hematologists in training. Hematologists may look for training programs and decision aids from the broad field of oncology, although their value requires further assessment in hematologic oncology.
- The currently available – mostly 'one size fits all' – electronic patient portals may not be tailored to the needs of hematology patients. Hematologists in practice should

be aware of this and may discuss the optimal contribution of the available electronic patient portal to the individual situation of their patients.
- The participants in our studies provided us with a great variation of thoughts, opinions, needs, considerations and recommendations. Continuously involving stakeholders in patient-centered healthcare innovation will increase the chance of successful implementation. When clinicians and local policymakers face (digital) innovations that seem advanced and ready to use in practice, successful implementation may still require involving the most important stakeholders.

Recommendations for research

Further exploration of the role of the cancer MDT with regard to patient centeredness and decision-making may include:
- Identifying the needs and expectations of patients with regard to the MDT. What do they think the role of the MDT should be with regard to their situation and decision-making process? How do they want to be involved with the MDT process: By attendance of the meeting itself, by information transfers or otherwise?
- Relating the needs and expectations of patients to our findings with the professionals to enhance patient-centeredness on MDTs. Does this reveal additional barriers to implementation of patient-centeredness? Can this identify common needs and expectations? Which strategies would fit with these common findings?
- Evaluating the implementation of strategies that aim to improve patient-centeredness on MDTs. Do they result in increased use or consideration of patient-centered information? Do they impact the SDM process or attributes of decision-making process?

Further exploration of the shared decision-making process of patients with hematologic cancer and their physicians may focus on:
- The actuality and relevance of our findings in relation to the new insights into the SDM process. Is the perception of SDM still satisfactory when we consider a decision-making continuum, involving other participants and information besides the clinical encounter between the patient and physician?
- Exploring the perspectives of patients, relatives and healthcare providers with regard to preference elicitation. What are their needs for information or tools to support preference elicitation? How would this contribute to their decision-making process?
- Subsequently, identifying strategies to improve preference elicitation. Are decision aids that are currently available adequately set up for this task? Do we need new

tools? Do decision aids or new tools require parallel strategies to optimize their intended use?
- Exploring the role of e-health with regard to the previous two research topics. (To what extent) May e-health fulfill a supportive role in (shared) decision-making?

In future patient-centered (e-) health innovation projects in cancer care, the application of participatory e-health design and implementation approaches may improve their clinical value and chance on successful implementation. Points of interest may include:
- What is the preferred participation level of the relevant stakeholders?
- What is the added value of an innovation for the stakeholders?
- (how) Does the end product meet the intended requirements for the stakeholders?
- (how) Do the end product and the process in which it is embedded address patients with limited (digital) health skills?
- How do participation levels of relevant stakeholders impact implementation success chances?

Such approaches may also apply to other healthcare (treatment) innovations and the clinical trials in which they are evaluated and research questions may include:
- How does collective stakeholder participation contribute to the healthcare innovation research agenda?
- Which benefits and drawbacks are relevant for the most relevant stakeholders, including patients?
- Which effect evaluations contribute to (shared) decision-making and to what extent?

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CHAPTER 7

7

Summary

Summary

In **chapter 1** the concept of patient-centeredness is introduced as an important feature of consistent, high-quality health care. It is defined as a biopsychosocial approach that aims to deliver care that is respectful, individualized and empowering. It implies the individual participation of the patient and is built on a relationship of mutual trust, sensitivity, empathy and shared knowledge. It closely relates to patient empowerment and patient participation. Together these concepts resemble an ideological shift from paternalistic health care to a participation-based healthcare, which is also seen in cancer care. Patient-centered participation-based cancer care requires the development and implementation of patient-directed interventions with the most relevant stakeholders, including a scientific evaluation of the efficacy and effectiveness. Although patient-centered care innovation is quickly progressing, a rigorous scientific evaluation by clinical trials may not be part of all innovation projects. This may lead to new standards of care without robust scientific evidence. In these circumstances a participatory innovation design is highly relevant for uptake and implementation of patient-centered care innovations. Therefore, this thesis aimed to contribute to sustainable implementation of patient-centered innovations in cancer care, by means of a critical assessment of current patient-centered innovations from a practice driven viewpoint. Four empirical studies were chosen based on relevance and actuality and regarded cancer care treatment decision-making and patient empowerment by electronic health applications.

Patient-centeredness on cancer multidisciplinary teams

Patient-centeredness is essential in complex oncological multidisciplinary team (MDT) decision-making. Improvement seems to be needed, while there is a lack of knowledge about healthcare providers' needs for improvement. In **chapter 2**, we explored MDT members' perspectives on the need to improve patient-centeredness in complex decision-making, and subsequently, the strategies to enhance it. Twenty-four professionals participated in semi-structured interviews. They attended one of five MDTs (gastrointestinal, gynecological, urological, head and neck, and hematological cancer) in a Dutch academic hospital. Data were analyzed with a combination of inductive and deductive content analysis. The participants voiced the need for additional information during the MDT meeting, such as patient-centered information, patients' needs and preferences, and individualized medical information. Furthermore they wished to be more patient-centered in the decision-making conversation with the patient following the meeting, and to have more information following the meeting to support patient-centeredness. The most prominent strategies were those aimed at collecting and using patient-centered information, and to facilitate the decision-making conversation with the patient following the MDT meeting. In conclusion, these findings highlighted the

need to improve patient-centeredness in oncological MDTs and provided a comprehensive overview of strategies for improvement, supported by MDT members. These strategies emphasized involvement of patients throughout the continuous cancer care decision-making process and may be implemented by other oncological MDTs, taking in mind the local needs.

Shared decision-making in hematologic oncology

While knowledge about shared decision-making (SDM) experiences from patients in solid oncology is abundant, it is limited in hematologic oncology. In **chapter 3** we explored to what extent elderly patients with a hematologic malignancy and their treating hematologists perceived SDM, when they were recently involved in a preference sensitive decision. We also assessed which decision-making process steps and which patient or professional characteristics influenced the perceived level of SDM. We collected patient data with a questionnaire including the 9-item Shared Decision Making Questionnaire (SDM-Q-9, scale range 0-100, with 0 indicating no SDM and 100 perfect SDM, no cut-off defined) and the Decisional Conflict Scale (DCS, range 0-100, with 0 indicating no decisional conflict and 100 maximal decisional conflict; <25 is associated with implementing decisions, >37.5 with decisional delay of feeling unsure about implementation). The hematologists received a questionnaire including the SDM-Q-Doc and the Provider Decision Process Assessment Instrument (PDPAI). Scores were calculated and differences were analyzed with non-parametric tests. Patients and physicians evaluated SDM with median SDM-Q-9 and SDM-Q-Doc scores of 84 (IQR 63-98) and 82 (IQR 73-89). The median DCS score was 27 (IQR 16-38) and PDPAI score 19 (IQR 6-31). Patients and physicians scored the questions regarding preference elicitation and deliberation significantly lower than the other questions. Additionally, patients above 75 years, those discussing non-curative treatment and those who encountered a hematologist in training experienced less SDM and more decisional conflict. Patient and physician scores correlated moderately. In conclusion, it seemed that patients and hematologists perceived SDM to be satisfactory in general, but preference talk needs more attention. Patient age, treatment intention and education level of the hematologist may impact SDM perception.

Electronic patient portals in hematologic oncology

Electronic patient portals are increasingly being implemented, also in (hematologic) oncology. However, portal usage is low and depends on user and provider engagement. In **chapter 4**, we explored wishes, expectations and thoughts of patients with a hematologic malignancy and their physicians with regard to the electronic patient portal. Based on insights from literature and a focus group discussion we built a 44-item questionnaire. This questionnaire was spread amongst patients with a hematologic malignancy at an

outpatient clinic that was not yet exposed to patient portal facilities. Haematologists completed a questionnaire based on insights from literature. Patients were interested in access to many different types information and portal functionalities. However, their opinions varied about the provision of access to the portal to other people, the role of the physician, possibilities for communication via the portal and timing of access.

Patients frequently expressed to be open about the potential of the patient portal to orchestrate their care. The physicians acknowledged the relevance of the electronic patient portal, but had some worries about the patients' autonomous information handling, organizational and technical issues. Most physicians appreciated their supporting role towards the patient. In conclusion, patients and physicians appreciated the electronic patient portal. Both groups need to be involved in further portal development to improve engagement by meeting patients' wishes, taking into account organizational and professional issues and managing expectations for both parties. To fit various patient profiles, portal design should be flexible and individualized.

Development of a multi-modality e-health application in multiple myeloma care

Patients with multiple myeloma (MM) increasingly face complicated treatment regimens. E-health may support patients and healthcare providers in enhancing a patient-centered healthcare approach. In **chapter 5**, we described the development of a multi-modality e-health application, assessment of the application for usability and end-user experiences and subsequently formulation of additional requirements for improvement. The application was developed following the design thinking approach. Key end-users participated and relevant stakeholders were consulted in the development process. First, the care pathway was evaluated, the focus of development was determined and a solution ideated during recurring multidisciplinary meetings. Second, a prototype was tested and improved. Third, a subsequent prototype was evaluated during a pilot study with patients and healthcare professionals on usability, usage and experiences. The multi-modality application, 'MM E-coach', consisted of a newly developed medication module, patient reported outcomes questionnaire assessments, a messaging service, alerts, information provision and a personal care plan. The median system usability score was 60 on a scale of 0-100, slightly below the score that is associated with good user-friendliness. Patients appreciated the medication overview, healthcare professionals the outpatient clinic preparation module and both appreciated the messaging service. Recommendations for improvement mostly revolved around flexibility of functionalities and look and feel of the application. In conclusion, the MM E-coach has the potential to provide patient-centered care by supporting patients and caregivers during MM treatment and is a promising application to be implemented in the MM care pathway.

Discussion and recommendations

In **chapter 6,** the main findings of this thesis were summarized and discussed in light of the decision making continuum, using the appropriate information and the implementation of interventions. Subsequently, the main strengths and limitations were discussed. This thesis contributed to a better understanding of the needs and perceptions of multidisciplinary team decision-making and shared decision-making by patients and healthcare professionals, in turn contributing to a patient-centered decision-making process. It provided deeper insight into empowering patients with hematologic cancer by using electronic health innovations. The studies in this thesis have been small steps to overcome implementation barriers on the path towards a partnership between patients and physicians, optimizing healthcare delivery from a patient-centered perspective. Using our findings, clinicians may implement patient-centered decision-making and e-health innovations, taking in mind transferability to the local situation. We recommend clinicians and local policymakers to involve the most important stakeholders when developing and implementing an (digital) innovation that seems advanced and ready to use in practice. We provided several points of interest for further research on patient-centered cancer care innovations. Finally, moving beyond the topic of patient-centered innovations only, the development of any future healthcare innovation may be critically evaluated with regard to stakeholder participation, including patients. This might facilitate patient-centered healthcare delivery.

CHAPTER 8

8

Impact

Impact

In this chapter I explain about current and possible implications of the research reported in this thesis on science and on society. Traditionally health care was characterized by paternalism, but already more than 20 years ago a change towards a partnership between patients and physicians was recognized.[1] Acknowledging this partnership, the delivery of healthcare became more 'patient-centered'. Patient-centeredness is a biopsychosocial approach and attitude that aims to deliver care that is respectful, individualized and empowering. It implies the individual participation of the patient and is built on a relationship of mutual trust, sensitivity, empathy and shared knowledge.[2] Probably resulting from the change to a more patient-centered healthcare delivery, but also building on the 'digital revolution' from the last decades, many patient-centered (digital) healthcare innovations take place. Usually, many stakeholders are involved in these innovations, besides the patients: Academic researchers, policymakers, healthcare professionals and commercial company representatives are amongst them. In this quickly moving field, influenced by the many stakeholders, a scientific evaluation may not be part of all patient-centered innovation projects, possibly leading to new standards of care without robust scientific evidence. Cancer care is one of the medical fields where many of these innovations take place. We aimed to contribute to sustainable implementation of patient-centered innovations in cancer care, by means of a critical assessment of several patient-centered innovation projects from a practice driven viewpoint. The projects were chosen based on relevance and actuality and regarded cancer care treatment decision-making and patient empowerment by electronic health applications. The impact of the results is described on the patients, healthcare professionals, policymakers and academia.

Patients

The burden of cancer is heavy for patients and their relatives and cancer treatment decisions may have significant impact on their lives. Understandably, patients often wish to (be empowered to) participate in decision-making about cancer treatment. However an important moment in decision-making occurs in cancer multidisciplinary team meetings (MDTs), without the patients' presence. We explored strategies to make these meetings more patient-centered. We communicated the results to cancer patient representatives at a symposium, empowering them as a group to use this information in their activities. Implementation of the recommended strategies resulting from the study in practice may contribute to more patient participation in cancer treatment decision-making. We also contributed to a better understanding of shared decision-making (SDM) perception in patients suffering from hematological cancer. SDM is a model to engage patients in the process of health care decisions. Importantly, our results pointed out that

the decision-making step 'preference talk', where the professional takes an explorative stance and tries to learn about the patient's preferences, requires more attention. In the future, patients may profit from the next steps that could be taken to implement SDM in the hematology practice, for example by using tools that support this model and specifically by focusing on preference talk. Finally, two projects addressed electronic health (e-health) innovations. Currently, numerous e-health applications are being implemented in cancer care. However often development and/or implementation of these applications limitedly occurs with participation of patients. This may result in low adoption of these applications by patients and most importantly, they will therefore not contribute to patients' wellbeing. Serving as a best practice example, our study may contribute to a sustainable implementation and therefore societal impact of e-health innovations. Furthermore, following further development of the multimodality application that this thesis reported on, patients may profit from its application in multiple myeloma care practice.

Healthcare professionals

Healthcare professionals have participated throughout all research projects in this thesis. In general their participation raised awareness for the investigated patient-centered innovations and concepts. This has lead to several discussions about current and future care delivery amongst them. Similar to the patients, the healthcare professionals are key stakeholders in the studied patient-centered innovations and their participation matters when successful implementation is desired.[3]

During the writing of this thesis I have performed several activities, enabling me to share the expertise gained from conducting the studies in this thesis: First, by participation in a professional association committee about SDM (*Werkgroep Samen Beslissen*, FMS), which amongst others helps with SDM implementation in clinical practice and medical education. Second, being co-author of an informative manuscript about SDM legislation in the Dutch setting. Third, supporting a SDM training study for oncologists and participation in guideline development for redesigning the MDT in the Isala hospital. Finally participating in the Innovation committee (*Commissie Zorgvernieuwing en Innovatie*) of the Dutch Hematology Association.

Policymakers

Policymakers create the frameworks in which healthcare acts in practice, thereby also setting the stage for patient-centered innovations. This requires considering the tradeoff between costs and benefits of healthcare. In the Netherlands, about 6-7% of the total healthcare expenses are for cancer care, mostly due to hospital care.[4] Furthermore, the relative expenses of healthcare compared to the gross domestic product have

doubled over the past 20 years and healthcare expenses nowadays exceed 25% of the total government expenses.[5] Therefore, policymakers need to consider the added value and costs of patient-centered innovations. Although we can learn from unsuccessful projects, patient-centered innovations are ideally developed in a way that health impact is high and implementation is successful. This would optimize the effort and money put into it. The studies in this thesis may inform policymakers about possible determinants of successful implementation of patient-centered healthcare innovations and may serve as best practice example. Furthermore, as the policy for patient-centered care is still in its infancy, currently being limited to one law and reimbursement regulation about shared decision-making,[6, 7] the findings in this thesis may inform engaged professionals and policymakers to optimize the regulations.

Academia

The results from this thesis contribute to a deeper understanding of the studied patient-centered innovations or models. Results are available through publication in peer-reviewed journals and at (inter) national conferences. The insights that have been obtained in this thesis have been or are currently being used in various research projects: One project aims to refine and implement an 'Integrated Oncology Decision-making Model' (IODM) to further improve personalized treatment decision-making for cancer patients, partially building upon our findings. Informed by the findings in this thesis, I have contributed to a grant award for a decision aid for chronic lymphocytic leukemia and a grant application for a decision aid for multiple myeloma. Following the pilot study of the e-health application for patients with multiple myeloma, the application is currently being evaluated in a randomized clinical trial.

Traditional academic driven research implicates 'top-down' knowledge transition. A collaborative knowledge generation by academics working alongside other stakeholders is believed to result in significant societal impact, as opposed to traditional knowledge translation research.[8] The participatory methods used in this thesis may inform other researchers about collaborative research approaches, serving as a best practice example. The increased use of collaborative approaches may result in more effective application of research.

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APPENDICES

A

Appendices

Nederlandse samenvatting

Introductie

In **hoofdstuk 1**, de introductie, beschrijf ik het concept 'patiëntgerichtheid' als een belangrijk onderdeel van kwalitatief goede en consistente gezondheidszorg. Patiëntgerichtheid wordt gedefinieerd als een benadering van zorg waarin niet alleen aandacht is voor biomedische aspecten, maar ook voor psychologische en sociale factoren. Hierbij wordt respectvolle en geïndividualiseerde zorg gegeven en het steunt op wederzijds vertrouwen, gevoeligheid, empathisch vermogen en gedeelde kennis. Patiëntgerichtheid impliceert individuele patiënt participatie en stelt de patiënt in staat om invloed te hebben op zijn of haar gezondheid door beter te worden in het beheersen en beheren van de dingen die hij of zij belangrijk vindt. Dit wordt ook wel '*patient empowerment*' genoemd.

Tezamen belichamen patiëntgerichtheid en *patient empowerment* een ideologische verschuiving van paternalistische naar participatieve gezondheidszorg. Deze verschuiving vindt ook plaats in de oncologische zorg, ofwel de zorg voor patiënten met kanker. Om deze verschuiving te faciliteren is de ontwikkeling en implementatie van patiëntgerichte interventies nodig met participatie van de belangrijkste belanghebbenden. De ontwikkeling van deze innovaties gaat snel, maar een gedegen wetenschappelijke evaluatie wordt niet altijd gedaan en niet altijd participeren de belangrijkste belanghebbenden aan de ontwikkeling. Hierdoor kunnen nieuwe zorgstandaarden ontstaan die niet (optimaal) ondersteund worden door wetenschappelijk bewijs en/of een beperkte maatschappelijke impact hebben.

Het doel van dit proefschrift is bij te dragen aan een duurzame implementatie van patiëntgerichte innovaties in oncologische zorg door middel van kritisch onderzoek van actuele patiëntgerichte innovaties, gezien vanuit een praktijkgestuurd perspectief. Op basis van relevantie en actualiteit zijn vier empirische studies gekozen die de besluitvorming en *empowerment* door gebruik van digitale applicaties bij patiënten met kanker onderzochten.

Patiëntgerichtheid bij multidisciplinaire oncologieteams

Patiëntgerichtheid is belangrijk bij complexe besluitvorming tijdens oncologisch multidisciplinair team overleg (MDO). Meer patiëntgerichtheid bij MDO's lijkt wenselijk, maar er is weinig kennis over de behoefte om dit te verbeteren bij zorgverleners. In **hoofdstuk 2** beschrijf ik ons onderzoek naar hun behoeften en vervolgens hun suggesties voor verbetering. Vierentwintig zorgverleners namen deel aan semigestructureerde interviews.

Zij behoorden tot één van de volgende vijf oncologische MDO's van een academisch ziekenhuis: Maag/darm, gynaecologie, urologie, hoofd/hals en hematologie. De zorgverleners hadden behoefte aan meer informatie tijdens het MDO, zoals patiëntgerichte informatie, wensen en voorkeuren van de patiënt en geïndividualiseerde medische informatie. Daarnaast wilden zij zich meer patiëntgericht kunnen opstellen in het gesprek met de patiënt na afloop van het MDO en hadden behoefte aan informatie om daarbij te helpen. De meest in het oog springende verbeteringsvoorstellen waren gericht op het verzamelen en gebruiken van patiëntgerichte informatie en op het ondersteunen in het besluitvormende gesprek met de patiënt na het MDO. Concluderend onderstrepen deze bevindingen de behoefte aan meer patiëntgerichtheid bij oncologische MDO's en geeft de studie een overzicht van verbeteringsvoorstellen, met draagvlak bij de zorgverleners. Het benadrukt de betrokkenheid van patiënten tijdens het gehele besluitvormingsproces. De oplossingen kunnen door andere oncologische MDO's worden gebruikt, al dan niet na aanpassing aan hun eigen behoeften en situatie.

Samen beslissen bij hematologie

Oncologie houdt zich bezig met de zorg voor patiënten met kanker. De zorg voor kanker van de bloedvormende organen en lymfeklieren is een specifiek vakgebied, te weten hematologie. Een steeds meer toegepast model om samen met patiënten te besluiten over diagnostiek of behandeling is 'Samen beslissen', ofwel *Shared decision-making (SDM)*. Hoewel er veel informatie is over Samen beslissen bij kanker is dit beperkt bij hematologie. In **hoofdstuk 3** beschrijf ik hoe Samen beslissen is ervaren door oudere patiënten met hematologische kanker en door hun artsen, nadat ze recentelijk een voorkeursgevoelig besluit hadden genomen. Dit is een besluit waarbij er meerdere gelijkwaardige (behandel-) keuzes zijn en/of waarbij de afwegingen tussen de voor en tegens van een behandeling noemenswaardig verschillen tussen patiënten. Ook beschrijf ik dit voor de verschillende stappen die herkend worden in het proces van Samen beslissen. Verder beschrijf ik de invloed van enkele kenmerken van de dokter en patiënt op de gerapporteerde ervaring van Samen beslissen. Patiënten kregen vragenlijsten die Samen beslissen meten (SDM-Q-9, score van 0 tot 100, waarbij 0 geen en 100 maximaal 'Samen beslissen' aangeeft) en Keuzespijt (DCS, score van 0 tot 100, waarbij 0 geen en 100 maximaal Keuzespijt aangeeft). Artsen kregen vergelijkbare vragenlijsten. De mediane (middelste) score van patiënten en artsen was respectievelijk 84 en 82 voor Samen beslissen en 27 en 19 voor Keuzespijt. Dit is een vrij goede score in vergelijking met onderzoeken bij andere soorten kanker. De vragen over het verhelderen van de voorkeur en overwegingen van de patiënt werden door patiënt en arts relatief laag gescoord. Verder scoorden zij minder Samen beslissen en meer Keuzespijt bij patiënten ouder dan 75 jaar, bij patiënten wier behandeling niet op genezing was gericht, en wanneer de arts een hematoloog in opleiding was.

Concluderend lijkt het dat patiënten en hematologen Samen beslissen in het algemeen als voldoende ervaren, maar dat het onderdeel 'Voorkeur bespreken' meer aandacht behoeft. Factoren van invloed op deze ervaring zijn de leeftijd van de patiënt, of de besproken behandeling op genezing gericht is en de opleidingservaring van de arts.

Elektronische patiënten portalen bij hematologie

Via een elektronisch patiënten portaal kunnen patiënten hun medische gegevens raadplegen en er zijn vaak nog andere functies aan het portaal gekoppeld, zoals het maken van een afspraak of het aanvragen van een herhaalrecept. Deze portalen worden in toenemende mate geïmplementeerd in ziekenhuizen, zo ook bij oncologie en hematologie. Het gebruik is echter beperkt en afhankelijk van de betrokkenheid van gebruikers en aanbieders. In **hoofdstuk 4** beschrijf ik de wensen, verwachtingen en overwegingen van patiënten met hematologische kanker en van hun artsen met betrekking tot een portaal. Dit onderzochten we bij patiënten via een vragenlijst met 44 items, samengesteld op basis van literatuur onderzoek en een focusgroep discussie. De vragenlijst werd verstrekt op een polikliniek waar nog geen portaal beschikbaar was. Ook de hematologen kregen een vragenlijst, samengesteld op basis van literatuur onderzoek. Bijna alle patiënten toonden interesse in het verkrijgen van toegang tot verschillende soorten informatie en functies van een portaal. De meningen waren verdeeld over de toegang voor andere mensen, de rol van de arts, de mogelijkheden voor communicatie en het moment waarop informatie toegankelijk zou moeten zijn. De patiënten stonden open voor de potentie van een portaal om hen te helpen hun zorg te organiseren. De artsen zagen het belang van een portaal, maar hadden zorgen over de manier waarop patiënten zouden omgaan met de informatie en over organisatorische en technische kwesties. De meeste artsen hechtten waarde aan hun ondersteunende rol aan patiënten, rondom het gebruik van een portaal. Concluderend waren zowel artsen als patiënten positief over een portaal. Het is belangrijk dat beiden betrokken worden bij de verdere ontwikkeling van een portaal, zodat rekening gehouden wordt met hun wensen en met praktische en organisatorische aandachtspunten. Ook kan dit helpen om reële verwachtingen te scheppen. Het verdient aanbeveling een flexibel en geïndividualiseerd portaal te ontwikkelen, zodat goed kan worden aangesloten bij de verschillende type patiënten.

Ontwikkeling van een multifunctionele e-health applicatie bij multipel myeloom.

Multipel myeloom, ook wel de ziekte van Kahler, is een hematologische kanker van bloedcellen die niet te genezen is. Patiënten met deze ziekte krijgen vaak behandelingen met ingewikkelde schema's, met als doel de ziekte tot rust te brengen en daarmee het leven te verlengen of de kwaliteit van leven te behouden of verbeteren. Elektronische

gezondheidszorg, ook wel *e-health* genoemd, kan patiënten en zorgverleners ondersteunen om deze zorg op een meer patiëntgerichte manier in te richten. In **hoofdstuk 5** beschrijf ik de ontwikkeling van een multifunctionele *e-health* applicatie, de beoordeling van deze applicatie op gebruiksvriendelijkheid en de geformuleerde vereisten om de applicatie verder te verbeteren. De applicatie werd ontwikkeld door middel van de *design thinking* methode. Belangrijke eindgebruikers van de applicatie participeerden in de ontwikkeling en andere belanghebbenden werden geraadpleegd. In het proces werd eerst het ideale zorgpad vastgesteld en werd nagedacht over een verbetering met een applicatie. Dit gebeurde tijdens terugkerende multidisciplinaire bijeenkomsten. Daarna werd een prototype getest en verbeterd. De multifunctionele applicatie, genaamd de 'MM E-coach' bestond uit zes functies: 1. Een nieuw ontwikkelde medicatie module. 2. Vragenlijsten met patiënt gerapporteerde uitkomst items. 3. Een berichtendienst. 4. Alarmnotificaties. 5. Informatievoorziening. 6 Een persoonlijk zorgplan. Uiteindelijk werd een volgend prototype gebruikt om een *pilot studie* (een kleine teststudie) uit te voeren met twintig patiënten en vier zorgverleners. Hierbij werden bruikbaarheid, daadwerkelijk gebruik en gebruikerservaringen bekeken.

De mediane (middelste) bruikbaarheidscore was 60 op een schaal van 0-100, net onder de grens die een goede bruikbaarheid aangeeft. Patiënten hechtten vooral waarde aan het medicatie overzicht, de zorgverleners aan de spreekuurvoorbereiding vragenlijst. Beide groepen hechtten waarde aan de berichtendienst. De aanbevelingen voor verbetering betreffen met name de flexibiliteit van functies, het gebruiksgemak en de informatieweergave. Concluderend heeft de MM E-coach de potentie om patiëntgerichte zorg te ondersteunen bij de behandeling van multipel myeloom en is de applicatie veelbelovend om in het multipel myeloom zorgpad te implementeren.

Discussie en aanbevelingen

Tot slot vat ik in **hoofdstuk 6** de belangrijkste bevindingen uit dit proefschrift samen en bespreek dit in de context van het continuüm van besluitvorming, het gebruik van de juiste informatie en de implementatie van interventies. Vervolgens bespreek ik de belangrijkste sterkte- en verbeterpunten.

Dit proefschrift beoogt bij te dragen aan een beter begrip van de behoeften en ervaringen van patiënten en zorgverleners bij MDO besluitvorming en gezamenlijke besluitvorming in de spreekkamer. Dit kan vervolgens bijdragen aan een patiëntgericht besluitvormingsproces. Het proefschrift beoogt inzicht te geven in het *empoweren* van patiënten met hematologische kanker door gebruik van *e-health* innovaties. De studies in dit proefschrift zijn stapjes om vanuit een patiëntgericht perspectief de implementatie van interventies te verbeteren. En, om zo uiteindelijk te komen tot een partnerschap

tussen patiënten en zorgverleners. Zorgverleners kunnen hiermee patiëntgerichte besluitvorming en *e-health*-innovatie implementeren in hun dagelijkse praktijk. Ik beveel zorgverleners en lokale beleidsmakers aan om bij de ontwikkeling en implementatie van (digitale) innovaties de belangrijkste belanghebbenden te betrekken, ook als deze innovaties al 'klaar voor gebruik' lijken.

Ten slotte geef ik aanbevelingen voor verder onderzoek met betrekking tot patiëntgerichte innovaties. Naast andere aandachtspunten geef ik ter overweging om alle toekomstige gezondheidszorg-innovatie kritisch te toetsen op het aspect van participatie van de belangrijkste belanghebbenden met als ultieme doel een meer patiëntgerichte gezondheidszorg.

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Curriculum Vitae

Paul Geerts was born on January 5th 1986 in Oirschot, the Netherlands. After completing secondary school at the Sint Willibrord Gymnasium in Deurne in 2004, he studied Medicine at Maastricht University. During the bachelor he worked as a student-assistant at the Medical Microbiology department of Academisch Ziekenhuis Maastricht. Following obtaining his master's degree in Medicine in 2010, Paul worked one year at the Intensive Care unit of the Maxima Medical Center in Veldhoven. At this hospital, he started his Internal Medicine residency in 2011, which he continued from 2015 at the Maastricht University Medical Center, including a hematology fellowship. During this second part of the residency he started performing the research projects described in this thesis: "Optimizing implementation of patient-centered innovations: Learning from cancer care practice", supervised by prof. dr. G.M.J. Bos, prof. dr. T. van der Weijden and dr. A. Moser at CAPHRI and GROW Schools at Maastricht University. He continued the research following obtaining his degree as Internist-hematologist in 2017 and worked as Internist-hematologist at Deventer Ziekenhuis, Maastricht University Medical Center and currently at Isala Klinieken in Zwolle. Performing the research, he collaborated with colleagues from Maastricht University Medical Center, Zuyderland Hospital in Sittard and Isala Klinieken in Zwolle.